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OVERSIGHT ON DISEASE CLUSTERS AND ENVIRONMENTAL HEALTH

HEARING

BEFORE THE

COMMITTEE ON ENVIRONMENT AND PUBLIC WORKS UNITED STATES SENATE

ONE HUNDRED TWELFTH CONGRESS

FIRST SESSION

MARCH 29, 2011

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ONE HUNDRED TWELFTH CONGRESS
FIRST SESSION

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OVERSIGHT ON DISEASE CLUSTERS AND ENVIRONMENTAL HEALTH

TUESDAY, MARCH 29, 2011

U.S. SENATE,
COMMITTEE ON ENVIRONMENT AND PUBLIC WORKS,
Washington, DC.

The committee met, pursuant to notice, at 10 a.m. in room 406, Dirksen Senate Office Building, Hon. Barbara Boxer (chairman of the committee) presiding.

Present: Senators Boxer, Crapo, Lautenberg, Whitehouse, Johanns and Boozman.

STATEMENT OF HON. BARBARA BOXER, U.S. SENATOR FROM THE STATE OF CALIFORNIA

Senator BOXER. The Committee will come to order. I would like to begin by thanking our witnesses for coming here today. You traveled long distances and we are very appreciative of that.

In particular, I want to welcome Trevor Schaefer, a brave young man, who has overcome so much in his life already. I met him when he was much younger. He beat cancer that he got when he was just a child and he is inspiring a lot of people to make sure that others don't have to go through the same thing.

Trevor has come out of his experience with great purpose. He has decided to devote his life to helping children who also face the frightening reality of having to beat cancer. Trevor and our other distinguished witnesses are here to testify on a very important issue, the need to better protect our families and our communities from dangerous diseases that occur in clusters.

I would like to also recognize the two other witnesses from my State of California: Ms. Erin Brockovich, who I think needs no further introduction. We all know of her work. Dr. Gina Solomon, who has done a tremendous amount of work on cancer clusters.

Without a doubt, our country has made great strides in addressing devastating diseases that were once commonplace. Our Nation invested in drinking water treatment plants and waste water treatment facilities, and these facilities are now essential parts of our public health infrastructure.

Despite these great advances, we still have more work to do to address diseases such as cancer and birth defects that take the lives of our children and our family members. According to the Environmental Protection Agency, from 1975 to 2007, rates of childhood cancer have increased by more than 20 percent. I want to say that again. According to the EPA, from 1975 to 2007, rates of childhood cancer have increased by more than 20 percent. So consider

this hearing an alarm bell. The country needs to pay attention to a statistic like this.

According to the National Cancer Institute, leukemia is the most common form of childhood cancer, accounting for 20 percent of the incidences. The greatest number of childhood cancers occurs during infancy, the first year of life. Our youngest and our most vulnerable in our society should not have to shoulder such a devastating burden.

When the same disease suddenly impacts an entire family or an entire neighborhood or an entire community, people are rightly concerned that a common factor is the cause. Scientists don't always know the exact cause of the cancer, but we know that when we look at cancer, they usually find it is genetics or environmental causes.

Just last year, the President's Cancer Panel said that "It is particularly concerned to find that the true burden of environmentally induced cancer has been grossly underestimated." Let me repeat that. "The true burden of environmentally induced cancer has been grossly underestimated."

I would ask unanimous consent to enter into the record this report from the President's Panel.

Without objection, I will do that.

[The referenced information was not available at time of print.]

Senator BOXER. The Panel urged the Federal Government "to remove the carcinogens and other toxins from our food, our water, our air that needlessly increase health care costs, cripple our Nation's productivity, and devastate American lives."

Clearly, efforts to address diseases such as childhood cancer and birth defects deserve focused, coordinated and effective action at every level of government so that we respond in the most effective manner when a cluster occurs. That is why I introduced, along with Senator Crapo, S. 76, the Strengthening Protections for Children and Communities from Disease Clusters Act. S. 76 is designed to increase coordination, transparency, accountability when Federal agencies work to invest and address potential disease clusters. It is designed to give people and communities a seat at the table to better understand such investigations.

If we learned anything from the battle about chromium VI, we learned that the community was just at sea and didn't know where to turn. They had to turn to an attorney and his able assistant to find out that things were going on in the community that were mimicking their own experiences.

This bill by itself is not going to end disease clusters. We know that. But it is an important step in helping our communities effectively investigate and address devastating diseases that still impact our families, our neighborhoods and our society.

The critical importance of our bill can be stated in a simple way. If by working together we can establish the cause of a disease cluster, we can then take steps to end the problem and not waste precious time when so much is at stake, the very health of our families. That is the simple truth about our bill.

Now I am delighted to call on my co-sponsor, Senator Crapo.

STATEMENT OF HON. MIKE CRAPO, U.S. SENATOR FROM THE STATE OF IDAHO

Senator CRAPO. Well, thank you very much, Madam Chairman. I appreciate working with you on this legislation and I appreciate your calling this oversight hearing on disease clusters and environmental health.

This is an important issue, as you have indicated, and I really am glad that our committee is looking into it.

I want to thank our witnesses for coming today, Erin Brockovich, Dr. Belzer and Dr. Solomon. We appreciate your making the time to be here and appreciate the information and testimony that you are going to provide.

I want to extend a special welcome to Trevor Schaefer who, as the Chairman has indicated, is from Idaho and he himself has an incredible history that helps us to address this issue. Trevor is the Founder of Trevor's Trek Foundation and we in Idaho are proud that he is there doing this great work.

When he was just 13 years old, Trevor was diagnosed with brain cancer. With the love and support of his family, and I want to point out that his mother, Charlie Smith, is also here today.

Senator BOXER. Stand up, Charlie, if you would. Would you stand for a second?

Senator CRAPO. Charlie, thank you for being with us.

Trevor relocated from McCall, Idaho to undergo surgery, radiation, and chemotherapy. After surviving and recovering from his grueling ordeal, Trevor decided that he wanted to help children with cancer. So in 2007, along with his mother, Charlie, he founded Trevor's Trek Foundation.

Through raising awareness and research funds, to providing mentoring services for young cancer survivors, the Foundation is a shining example of how the selfless actions of an individual can make a real difference in the lives of those in need.

As if Trevor's work at the Foundation isn't enough, Trevor is also a volunteer with the Make-A-Wish Foundation in Idaho, and he has helped the Comprehensive Cancer Alliance for Idaho to create the Childhood Cancer Strategic Plan. He is also a Youth Ambassador for the National Disease Cluster Alliance and has organized the first childhood cancer awareness walk in Idaho.

You can see that he is very committed. All of these things have been achieved by a young man who just graduated from Boise State University in 2008.

I am very happy that you could join us today, Trevor, and thank you for coming and we look forward to your testimony. We are very appreciative of the incredibly hard work you have put into these kinds of issues.

Madam Chairman, let me just say briefly that I appreciate the opportunity for this committee to take a closer look at the issue of disease clusters. While we have heard quite a bit about them through books and movies such as Erin Brockovich and such as Jonathan Harr's A Civil Action and others, we have not had a recent detailed discussion about them here in Congress, but we should. Thanks to the effort of people like Trevor and Charlie and Erin and our other witnesses, we will.

Today's hearing begins that discussion and I look forward to hearing from our experts about the scientific research behind the causes of disease clusters, the coordinated response between Federal, State and local governments, and any other information that may be helpful to us.

Thank you again, Madam Chairman. That concludes my statement.

Senator BOXER. Thank you so much.

I was remiss. I wanted to introduce another Californian who is sitting next to Trevor's mom, Charlie. This is a woman who brought this particular issue to my attention. She has worked with the family and is an advocate for the family and is an author.

Susan Rosser, will you stand up? I am so proud that you are here and we are very proud of you in California.

Now it is a pleasure to call on Senator Lautenberg.

STATEMENT OF HON. FRANK R. LAUTENBERG, U.S. SENATOR FROM THE STATE OF NEW JERSEY

Senator LAUTENBERG. Thanks very much, Madam Chairman.

Many of us in this room are parents, grandparents, and we spend our lives trying to protect our children and keep them safe.

Trevor, my hat is off to you for the work that you have done. You are a living example of what happens when one has courage and determination, and we thank you for what you have done.

No parent should ever have to be afraid to send their child into the backyard, to a neighborhood park or to a school because it might make them sick, yet this is the reality facing parents who live in communities where residents are under assault from diseases such as cancer.

For example, in the 1990's a cancer cluster was discovered in Toms River in New Jersey where children were being diagnosed with leukemia and brain cancer at alarmingly high rates. Toms River is the home of two Superfund sites and a number of industrial facilities. An investigation of Toms River by the State and the Centers for Disease Control and Prevention found an association between mothers who drank contaminated water and children who developed leukemia.

Now, science tells us that children are especially vulnerable when they encounter dangerous substances. Studies show as much as 5 percent of childhood cancers, 10 percent of neurobehavioral disorders and 30 percent of childhood asthma cases are associated with hazardous chemicals.

Make no mistake, you don't have to live near a Superfund site to be exposed to potentially harmful chemicals. They are all around us. Testing by the non-profit Environmental Working Group found more than 283 industrial chemicals in newborn babies and more than 400 in adults that they tested. Additional testing by the CDC also found hundreds of industrial chemicals in adults, including six carcinogens.

Studies show that kids whose mothers had high levels of certain chemicals in their blood are more likely to have behavioral and health problems. That is why we have to create stronger and more regulation of chemicals that could harm our children, an issue that we ought to be tackling on several fronts.

I will soon introduce an updated version of my Safe Chemicals Act, which would require that chemical manufacturers prove that their products are safe before those substances end up in our bodies. I received helpful feedback on the bill last year and I will incorporate ideas that further improve the bill.

I am committed to working with colleagues from both parties to modernize the Toxic Substances Control Act in a way that protects public health and works for businesses. But the need is too urgent to wait while our children continue to be exposed to untested chemicals. I am going to be working with Chairman Boxer to mark up a bill in the coming months.

We also must pay close attention to what is happening in communities where disease clusters are present, and kids face the greatest risk. Now, I am proud to cosponsor Chairman Boxer's legislation to make it easier for State and Federal agencies to work together to investigate disease clusters and educate communities about them.

The bottom line is that we have to do more to protect our children and grandchildren from conditions and substances that could damage their health and shorten their lives.

So I look forward to hearing from today's witnesses about how we can create a healthier environment for everyone, and particularly our children.

I thank you very much, Madam Chair.

Senator BOXER. Thank you very much, Senator.

We are going to call on two Senators that are coming now in a moment. I want to ask unanimous consent to place in the record support for the Boxer-Crapo bill from the Children's Environmental Health Network, the Breast Cancer Fund, the Sierra Club, the Center for Health, Environment and Justice in Virginia, the National Disease Clusters Alliance. I want to make sure we get that done.

[The referenced information was not available at time of print.]

Senator BOXER. I also want to put in the record the disease clusters in California that were identified by the NRDC and the National Disease Clusters Alliance, eight sites where they found these clusters. So we will put those in the record.

[The referenced information was not available at time of print.]

Senator BOXER. Senator Johanns, you are up next.

STATEMENT OF HON. MIKE JOHANNS, U.S. SENATOR FROM THE STATE OF NEBRASKA

Senator JOHANNS. Madam Chair, thank you for the opportunity, but I have been called to the floor in about 15 or 20 minutes to speak, so I am going to pass. If I have anything, I will offer it in written form. Again, thanks for the opportunity.

Senator BOXER. Thank you so much, Senator.

Senator Whitehouse.

STATEMENT OF HON. SHELDON WHITEHOUSE, U.S. SENATOR FROM THE STATE OF RHODE ISLAND

Senator WHITEHOUSE. I will follow the good Senator's example so that we can get on to the witnesses. But I wanted in particular to welcome Ms. Brockovich. We were together years ago on the Chil-

dren's Health Environmental Coalition, which is a wonderful organization in the Chairman's home State, and I am delighted to welcome her here to Washington.

So thank you, Madam Chair, and I appreciate the way you and Senator Crapo have worked together on this.

Senator BOXER. Thank you so much.

Well, we will get right to our witnesses. Our first witness, Trevor Schaefer, Youth Ambassador and founder of Trevor's Trek Foundation, has been such an inspiration to me personally and so many people and inspired me to work with Senator Crapo on this legislation. So we are honored to have you.

Trevor, you have 5 minutes, but if you go over a couple of minutes, that is fine. Go ahead.

STATEMENT OF TREVOR SCHAEFER, YOUTH AMBASSADOR AND FOUNDER, TREVOR'S TREK FOUNDATION

Mr. SCHAEFER. Thank you, Chair Boxer.

I would also like to thank Ranking Member James Inhofe and my great Senator, Mike Crapo for taking on the issue of childhood cancer and cancer clusters, and what they mean to our public health.

I would also like to thank all of the Senators on the Environment and Public Works Committee for allowing me to address some of these issues today. I am so very proud to be able to State that I am here today as a witness for both the majority and minority committee Members.

Most of you do not know me other than I am associated with S. 76, also known as Trevor's Law. My hope is that by the end of my testimony, you will not only know me, but you will remember me as the voice of every child in this great Nation.

As you have been told, I was diagnosed with brain cancer at the age of 13. Until that time, I was thriving in McCall, a small town nestled on the banks of a glacial lake in the beautiful mountains of Idaho. I really had a fairytale life in paradise. But the carefree days of my childhood changed abruptly and dramatically after my cancer diagnosis.

Like a snap of the fingers, I was robbed of my childhood and my innocence. I was thrown into the antiseptic world of hospitals in 8-hour brain surgery, followed by 14 grueling months of radiation and chemotherapy treatment. Unfortunately, I was not the only kid in my town with this pernicious disease.

In the same year that I was diagnosed, there were four other cases of brain cancer diagnosed. Over a 10-year period, there was an abnormally high number of cancer cases diagnosed there before and after I became ill. What happened in my town continually repeats itself throughout our Nation year in and year out.

According to the CDC, 46 children per day, two classrooms full, are being diagnosed with cancers unrelated to genetic or family history. As Trevor's Law states, cancer is the second leading cause of death among children, exceeded only by accidents.

Many of us young cancer survivors will forever face chronic health challenges resulting from the heroic medical measures used to save our lives. Children who have had cancer often experience confusion and embarrassment as they try to return to a so-called

normal life and are dealing with the physical side effects related to their cancer and treatment. I can attest to that.

Several years ago when cancer struck me, I fought so hard for my life. I fought through the countless number of needle pricks, the blood transfusions, nausea, vomiting, and physical therapy, so I could live to see the sunrise and the snowfall. I am so grateful to be alive.

Still, the aftermath from the cancer treatments that I have endured have affected me in many disturbing ways. Every morning, I wake up with a ringing in my ear which never stops. I have trouble with my memory and I may never be able to have children of my own. How ironic that I fought so hard to save my own life, yet now I may never be able to give life.

Senators, I am considered one of the success stories. Although there has been a significant increase in the cure rate of childhood cancer, children still are getting sick at an increasingly steady rate. In small towns throughout our country, possible cancer clusters exist. Parents are trying to get authorities to investigate these clusters and to discern what caused the disease patterns. Scientists and health activists say that the government's current response to disease clusters ranges from piecemeal to non-existent. Some people are told that their small populations render them statistically insignificant.

There is nothing insignificant about even one child diagnosed with cancer and then dying of that cancer without ever knowing why. Trevor's Law seeks to rectify that by allowing people in small communities to have their voices heard and their concerns validated about the environmental impacts on their children's health.

Environmental toxin exposure is insidious in all instances, yet it affects our children in greater proportion than adults. Children are more vulnerable to chemical toxins than adults because they have faster metabolism and less mature immune systems.

According to Dr. Sandra Steingraber, we are seeing more brain tumors in 4 year olds, ovarian cancer in adolescent girls, and testicular cancer in adolescent boys. These cancers are rising rapidly and, of course, children do not drink, smoke or hold stressful jobs. We therefore cannot really evoke lifestyle explanations.

There are no good familial links that we know of. We are beginning to recognize that not only prenatal life, but adolescent life is a time of great vulnerability to cancer-causing chemicals when the connection between health and the environment becomes even more important.

Toxins migrate right through geographical boundaries and property lines. Cancer spares no ethnic group, no socioeconomic group, nor any geographical area. In its wake, we are left with the burden of extreme personal and social loss.

I would also like to stress that cancer does not only attack the victim. It greatly impacts every member of the family. Siblings often experience concern, fear, jealousy, guilt, resentment and feelings of abandonment which can last long term. Relationships between family members can become tense. There can be stress on a marriage and oftentimes a family breaks up.

I vowed that if I survived, I would dedicate my life to helping other children with cancer who otherwise would never be heard. I

truly believe that I have been given a second chance at life to convey to you the urgency and importance of addressing the proliferation of childhood cancer clusters and the methods of reporting them. For the children, I strongly encourage your support for Trevor's Law.

In closing, I would ask you to consider how much your child or grandchild's life and well being are worth to you. While you are doing that, please close your eyes for a brief moment and imagine a world without children.

Thank you.

[The prepared statement of Mr. Schaefer follows:]

Trevor Schaefer's Testimony
U.S. Senate, EPW Committee
Oversight Hearing on Cancer Clusters
And Children's Health
March 29, 2011

I want to thank Chair Barbara Boxer, Ranking Member James Inhofe, and my senator, Mike Crapo, for taking on the subject of childhood cancer and cancer clusters and what they mean to our public health. I would like to thank *all* of the senators on the Environment and Public Works Committee for the care you give in debating the environmental and health dilemmas a modern world creates and for allowing me to address some of those issues today. And-- I am so *very* proud to be able to state that I am here today as a witness for **both** the Majority and Minority committee members.

Most of you don't know me other than that I am associated with **S.76**, also known as **Trevor's Law**. By the end of my testimony my hope is that you will not only know *me,* but that you will remember me as the voice of every child in this great nation.

(As you have been told) I am a twenty-one-year-old brain cancer survivor. In November of 2002 at the age of thirteen, I was diagnosed with a highly malignant *Medullablastoma*. What a word! I could barely

pronounce it correctly, let alone get my mind around what it meant to my future.

Until that time, you see, I was living and thriving in McCall, a small town located on a lake nestled in the beautiful mountains of Idaho. I was enjoying a fairy tale life in paradise: boating with friends and family in the summer, snowboarding in the winter and playing football for my seventh grade football team. But the carefree days of my childhood changed abruptly and dramatically after my cancer diagnosis. My entire world came crumbling down around me. Cancer was an alien word to me, one that was synonymous with invasion and death. I had to suddenly face the realization that there was a chance I might never see my friends, my family or my home, again.

Like a snap of the fingers I was robbed of my childhood and my innocence. The antiseptic world of hospitals became my life as I went through invasive tests then endured an eight hour surgery to remove a golf ball sized tumor from the base of my brain. While I recuperated I could not even stand. I barely had the strength to open my eyes. How could it be that a mere two months prior to this I was struggling for a touchdown, and now I was struggling to stay alive? Soon after leaving the hospital I entered an even more terrifying life: I began fourteen grueling months of radiation and chemotherapy treatment.

Unfortunately I wasn't the only kid with this pernicious disease in my town. In the same year of my diagnosis there were four other brain

cancers in our tiny resort community with a year-round permanent population of 1,700 residents. Over a ten year period there was an abnormally high number of cancer cases diagnosed there prior to, and after, my diagnosis. My mother was alerted to, and alarmed by, these numbers and took this information to the Cancer Data Registry. She expressed her fears that perhaps our beautiful little town was the wrong kind of paradise. Her fears were responded to in a patronizing fashion, the official telling her that even if her data proved true, our town was too small to warrant a cancer cluster study: We were not ***statistically significant.***

Just as she never let me give up my fight for life, she refused to give up the fight for the truth. That encounter at the Tumor Registry started both of us on the course that has led to *this* day in *this* room to consider the overall issue of childhood cancer clusters and how best to respond to those who believe they might be part of one. Some of those issues could be resolved through **S.76** which, among other things, will provide the most effective means of coordinating agencies and ensuring outreach to, and involvement of, community members.

What happened in my community continually repeats itself throughout this *entire* country, year in and year out. It impacts many of your neighborhoods and many of your neighbors. Nationally the statistics for childhood cancer are alarming. According to the CDC, *forty-six children per day* (***two classrooms-full***) are being diagnosed with cancers *unrelated* to genetics or family history. The National

Cancer Institute states that there are over 12,500 children diagnosed with cancer each year. As **S. 76** states, "cancer is the second leading cause of death among children, exceeded only by accidents."

According to Dr. Sandra Steingraber, Childhood cancers are "swiftly rising cancers... pediatric leukemia, brain tumors amongst four-year-olds, ovarian cancer amongst adolescent girls, testicular cancer amongst adolescent boys. These cancers are rising rapidly and of course **children don't smoke, drink or hold stressful jobs**. We therefore can't really evoke lifestyle explanations. There are no good familial links that we know of. We are beginning to recognize that not only pre-natal life but adolescent life is a time of great vulnerability to cancer causing chemicals, when the connection between health and the environment becomes even more important." (Steingraber interview by Rita Dixit-Kubiak, *Seacoast Spirit*, Vol. I, No.5).

The emotional and monetary costs of childhood cancer and cancer clusters continue to mount, unraveling the very fabric of our society thread by thread. Many of us young cancer survivors will forever face chronic health challenges resulting from the heroic medical measures used to save our lives. According to Kevin Oeffinger of New York's Memorial Sloan-Kettering Cancer Center, childhood cancer patients' "health problems, which include heart disease, lung scarring, strokes and second cancers, can be caused both by their original tumors as well as the harsh treatments used to cure them." In fact, more than 73% of

patients cured of pediatric cancer will develop chronic illness within thirty years of the diagnosis. (*New England Journal of Medicine*).

Senators, nothing is quite so lonely as being a child with cancer. Lying in a hospital bed and sitting in a chemo chair getting chemotherapy treatments and blood transfusions while other kids are outside playing ball and riding bikes isn't exactly the childhood I, or any of us, had in mind. Out growth and social advancement may be stunted, but in other ways we are forced to become mature beyond our years: learning to be patient and resilient, and becoming courageous warriors fighting our own battles without any armor.

Children who have had cancer often experience confusion and embarrassment as they try to return to a so-called *normal* life and are dealing with the physical side effects related to their diagnosis and treatment. I can attest to that. During my chemotherapy treatments I developed neuropathy, more commonly known as Foot-Drop. I walked with a decided limp and felt as though I could fall over at any moment. During the time of my treatment and this side-effect, I was changing schools. I was cautioned to think twice about going someplace new: *the kids would laugh at you because you walk funny.* Don't think that wasn't always in the back of my mind *every* hour I spent in school while I had this condition.

Although it has been almost nine years since my diagnosis of brain cancer, I am constantly reminded of this bully who tried with a

vicious determination to take my life. Every morning I still wake up with a distinct ringing in my ear which I have with me every second of every day, a residual effect from my brain tumor, only one of many. Before brain cancer I could have appeared before you and delivered this entire testimony from memory. The residual cognitive effects of chemotherapy make it difficult for me to do that.

Several years ago when cancer struck me I fought so hard for my life. I endured the countless needle pricks, blood transfusions, nausea, vomiting and physical therapy so I could live to see the sunrise and the snowfall. I am so grateful to be alive. Still, the aftermath from the cancer treatments that I received have affected me in a way where I may never be able to have children of my own. How ironic that I battled so hard to save my own life, succeeded, yet now I may never be able to give life.

The emotional side effects from cancer can be devastating to a once active and vibrant child. We can feel a range of emotions that include fear, depression, anxiety and symptoms similar to Post Traumatic Stress Disorder. We may also feel lost or isolated because we no longer have stability or a sense of control over our lives. Lack of interest and poor self-esteem can last long after our final treatment is over.

I would also like to stress that childhood cancer doesn't only attack the victim, it greatly impacts every member of the family.

Siblings often experience concern, fear, jealousy, guilt, resentment and feelings of abandonment which can last long-term. Relationships between family members can become tense; there can be stress on a marriage, and frequently a family breaks up.

So many times at my treatment appointments, I would see a parent alone with several children, one of whom was the sick member of the family. My mother and I sometimes talked to these parents. Most of them had heartbreaking stories to tell of families going bankrupt, having to sell their house, or a mother losing her job because she had to stay home with her sick child. One time we learned from a frazzled mother sitting near us that her husband had just left her a few weeks before. She'd lost her job and couldn't afford a babysitter for the rambunctious two-year- old in her arms who was *autistic*. She had no choice but to bring him along to the clinic while her older, six-year-old son lay on the couch next to her shivering under a blanket while awaiting his turn for treatment for advanced bone cancer.

Coping with a life-threatening disease like cancer is an ambiguous and unpredictable process. Although there has been a significant increase in the cure rate of childhood cancer, there needs to be more focus and research on what causes this disease and other catastrophic and chronic illnesses in children. There is an increasingly vast body of evidence showing that some chronic conditions such as birth defects, developmental disorders among children, and cancers are linked to the

ubiquitous toxins that are dumped into the food children eat, the water they drink, and the air that they breath.

In small towns throughout our nation possible cancer clusters exist. Parents are trying to get authorities to investigate these clusters and to discern what caused the disease patterns. Scientist and health activists say the government's current response to disease clusters ranges from *piecemeal to non-existent.* **S. 76** allows people in small communities to have their voices heard and their concerns validated about the environmental impact on their children. It would have been a different story for my mom all those years ago had this legislation been in place. This is true for so many communities throughout the nation.

Take **Clyde, Ohio**, for instance, where twelve-year-old Tanner was diagnosed with Leukemia in 2008. Tanner is one of *thirty-five* kids who have been diagnosed with cancer since 1996. His older sister, Tyler, is a cancer survivor and she is only seventeen. The cancer rate in this cluster is almost *six times the normal rate* for children in this part of Ohio.

And then we have **Sierra Vista, Arizona**, where *eleven* children were diagnosed with Leukemia in a five year period. Linus was a toddler at the time of his diagnosis. Jessica was also two years old-- and the list goes on.

In a community just outside Boise, Taylor was diagnosed with Hodgkin's Lymphoma at age eight, and Gracie was diagnosed with kidney cancer at age two. Zach, at age thirteen, has been fighting Leukemia since he was eleven years old, and Paige was diagnosed with thyroid cancer at the age of fourteen.

And then there's my little friend Bradley who lives near my home. He is seven years old and has battled Neuroblastoma (a rare cancer of the nervous system) since he was three years old. His body is intersected with surgery scars resembling a road map. Bradley has been an amazing fighter and an inspiration to all who meet him. Lately, however, you can see that some of the spunk has gone out of his personality. He's become more aware that his little brother is bigger and taller than he is. And just a few months ago he was diagnosed with an old person's affliction—*cataracts* in both eyes. One day a few weeks back, Bradley's teacher found a note that he had scribbled. She gave it to his grandma. She shared it with us. In it, Bradley asked what it was like in heaven and said that he was afraid to die because he did not want dirt in his eyes.

From these few examples alone you can see why it is that I have been inspired to help develop and propose legislation like **S.76**. Introduced in the spirit of amity *not* enmity by **both** Chair Boxer and Senator Crapo, this truly **bi-partisan bill** is especially encouraging to a neophyte to the political system like me. Despite our charged political

climate, **Trevor's Law** is proof that party affiliation need not prevent senators from putting children's health above politics.

What I especially like about **S.76** is that it could help pinpoint the causes of predatory disease at its earliest stage by bringing together agencies with the relevant expertise needed to investigate and report disease clusters in a timely manner. Through this multi-agency system, the burden could be lifted off the health community which for now shoulders the arduous responsibility as the repository of cancer information. And it will also make the investigative process transparent and inclusive. No longer will those who reside in fear in small communities be told that they have no place at the table, that they don't count because they are *statistically insignificant.* There is *nothing insignificant* about even one child becoming part of a cancer cluster then dying of that cancer without ever knowing why.

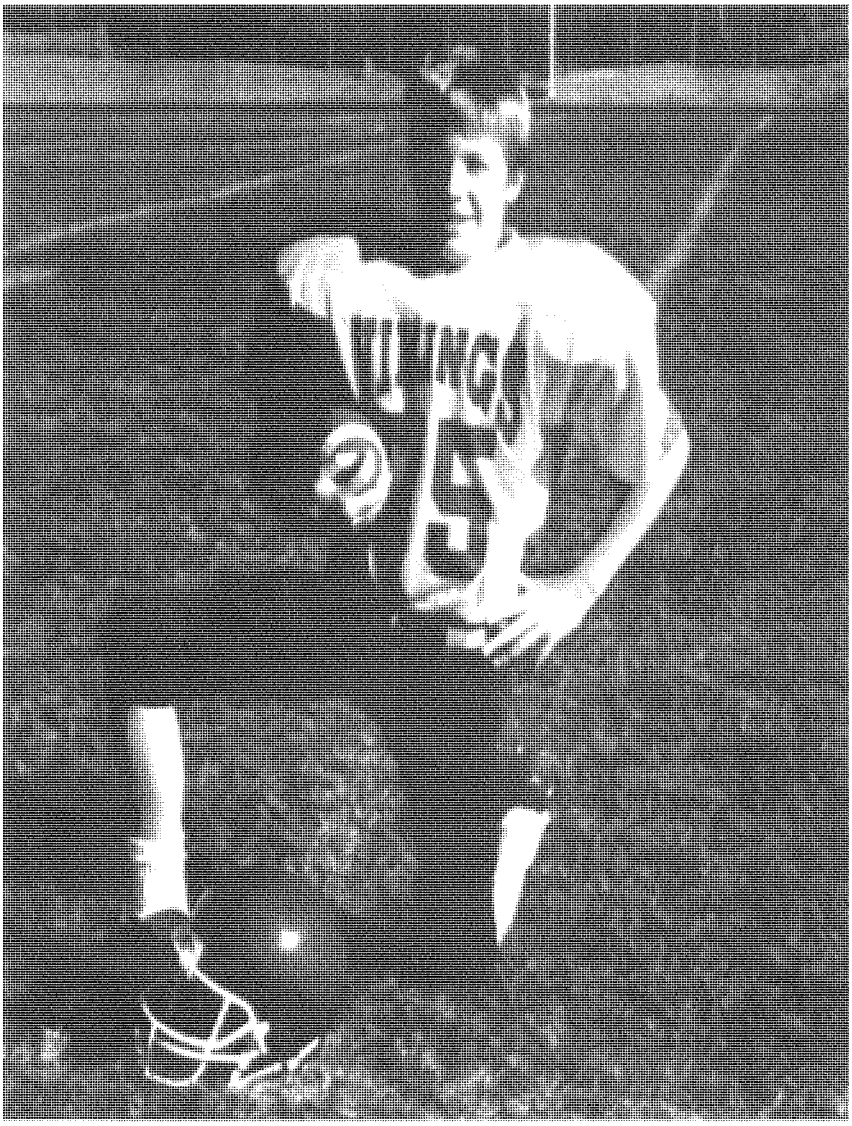
Environmental toxin exposure is insidious in all instances, yet it affects our children in greater proportion than adults. Let me reiterate, children are **more vulnerable** to chemical toxins than adults because they have faster metabolisms and less mature immune systems.

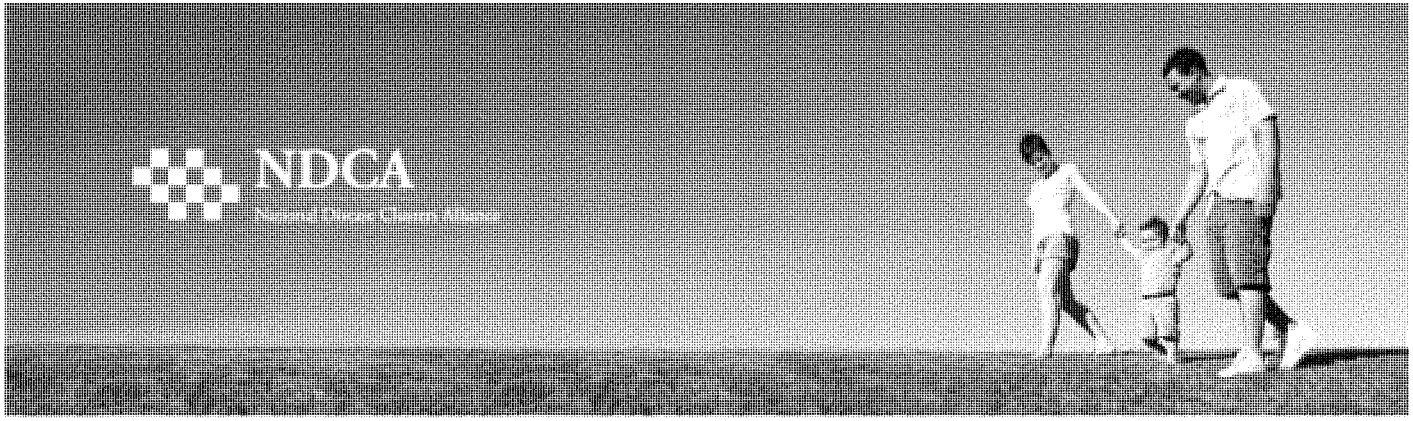
Toxins don't respect geographical boundaries or property lines. Cancer eschews all boundaries, too. This disease spares no ethnic group, no socio-economic group nor any geographical area. In its wake we are left with the burden of enormous personal and social loss.

I made a promise to myself that if I survived I would dedicate my time in this world to helping other children with cancer so they would not have to suffer the way I did. Senators, I was spared. I truly believe I have been given a second chance at life to convey to you the urgency and importance of a need to address the growing dilemma of childhood cancer clusters. On behalf of all the children with cancer who are suffering now and for those who may one day suffer, I strongly encourage your support for **Trevor's Law.**

In closing, I would ask you to consider how much your child or grandchild's life and well-being are worth? And while you're doing that, please close your eyes for a brief moment and picture a world without children.

Thank you.





Putting Children Above Politics

Trevor's Law, U.S. Senate Hearing

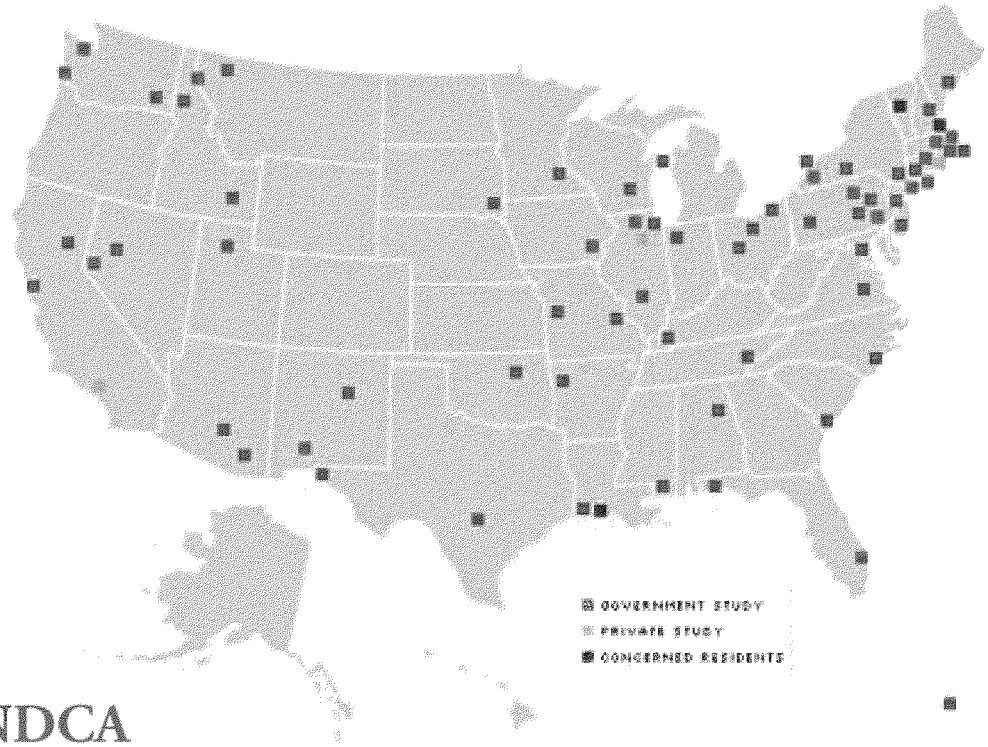
March 29, 2011

Meet some
of our
children

harmed by
disease
clusters

and chronic
disease

Disease Clusters and Hotspots



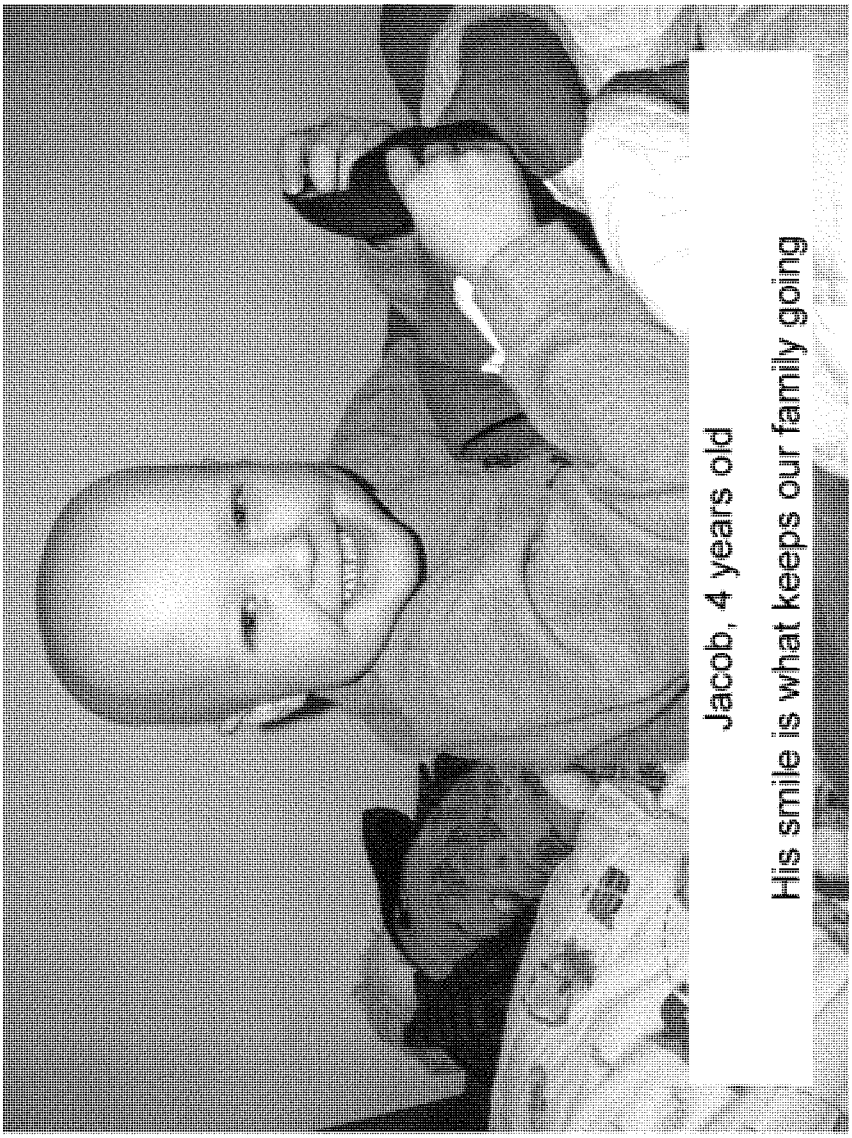
NDCA
National Disease Clusters Alliance

In memory

Stephanie

Fallon NV

Rumi

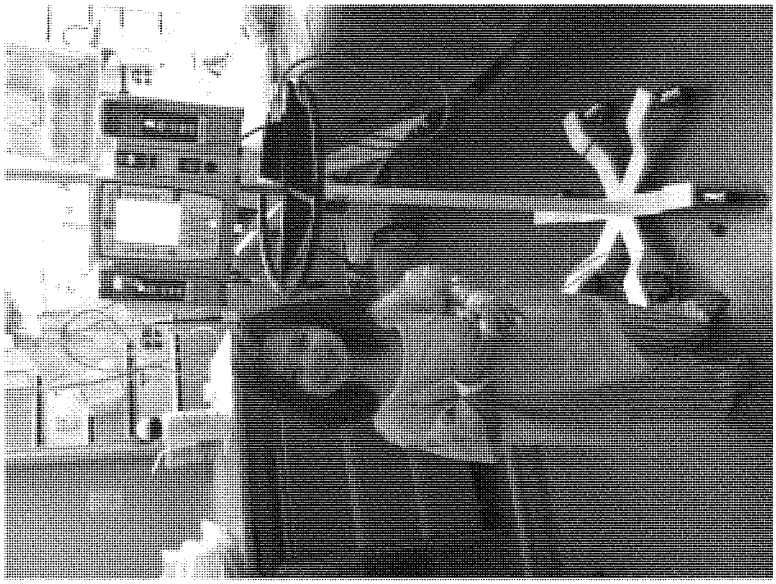

Jacob, 4 years old
His smile is what keeps our family going

In memory

Nikki

18 years old

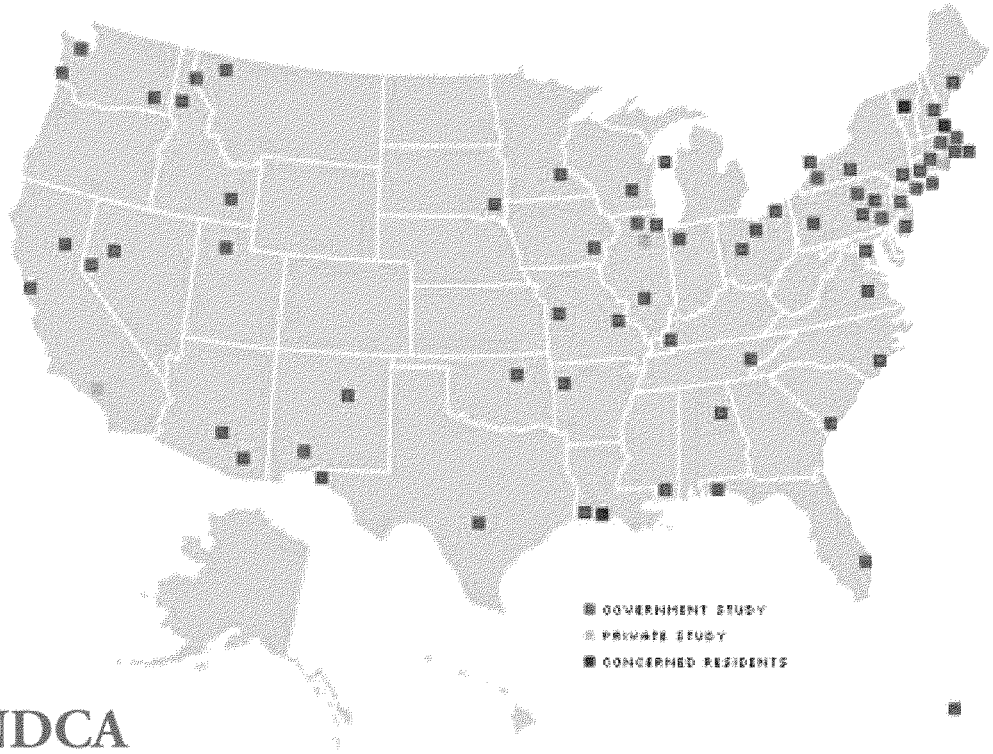
Morgan



Kids can't fight cancer alone!

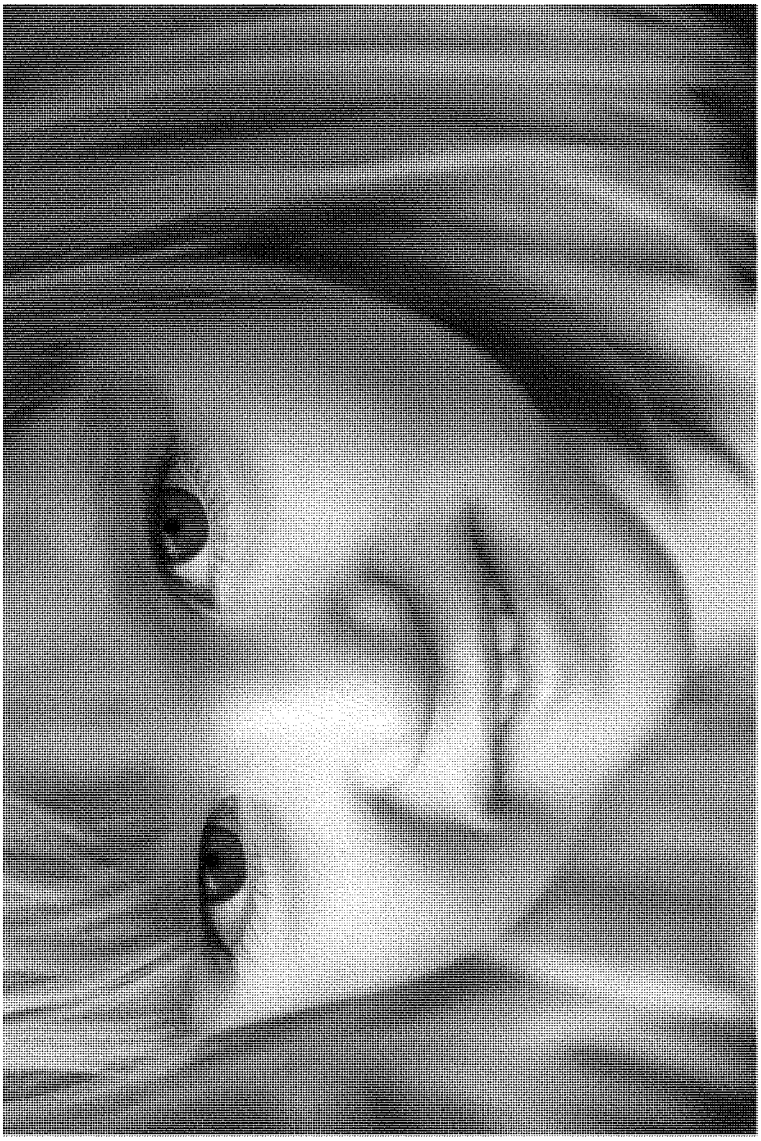
Mason

Disease Clusters and Hotspots



NDCA
National Disease Clusters Alliance

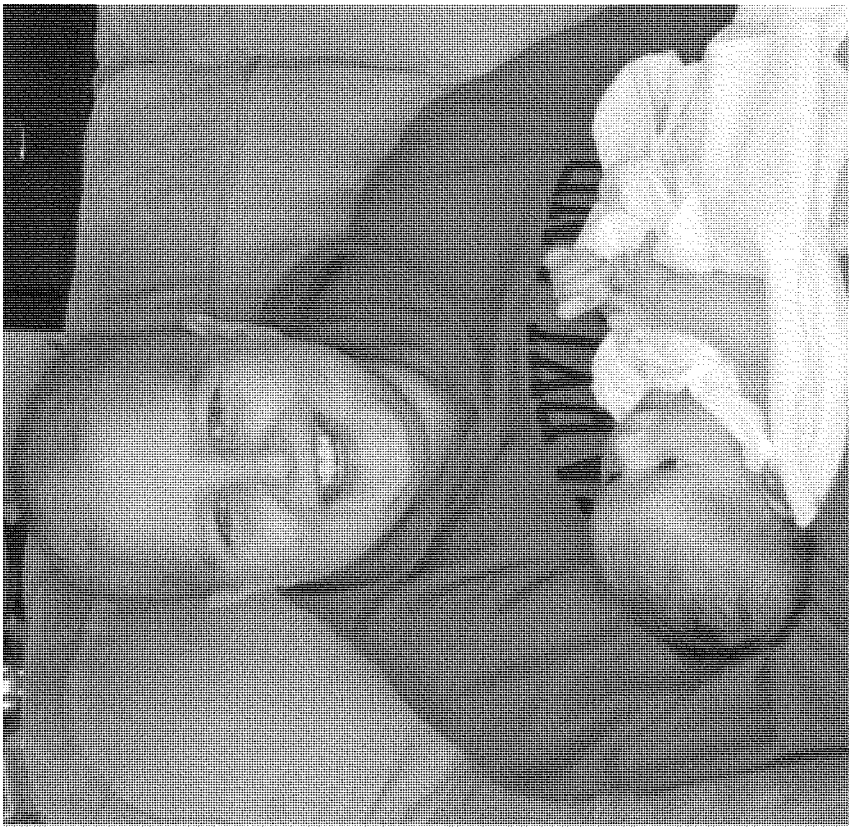
In memory: Julee



Madelyn

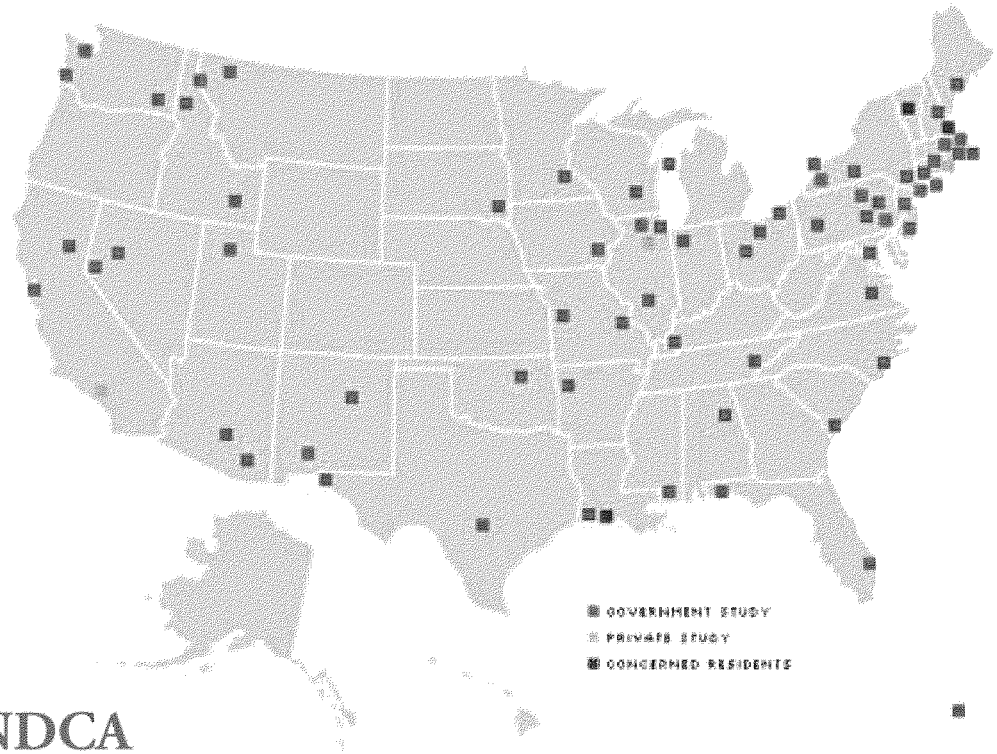
Madelyn

Levi

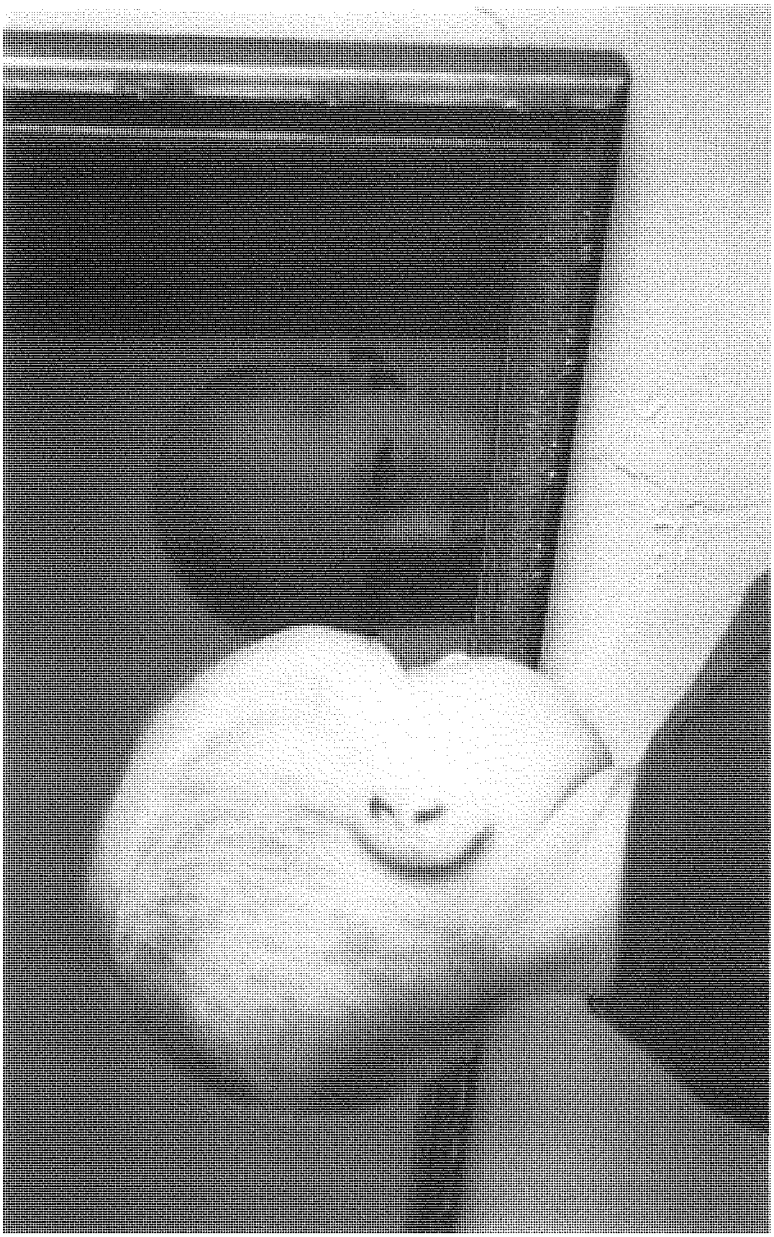


Joey

Disease Clusters and Hotspots



NDCA
National Disease Clusters Alliance

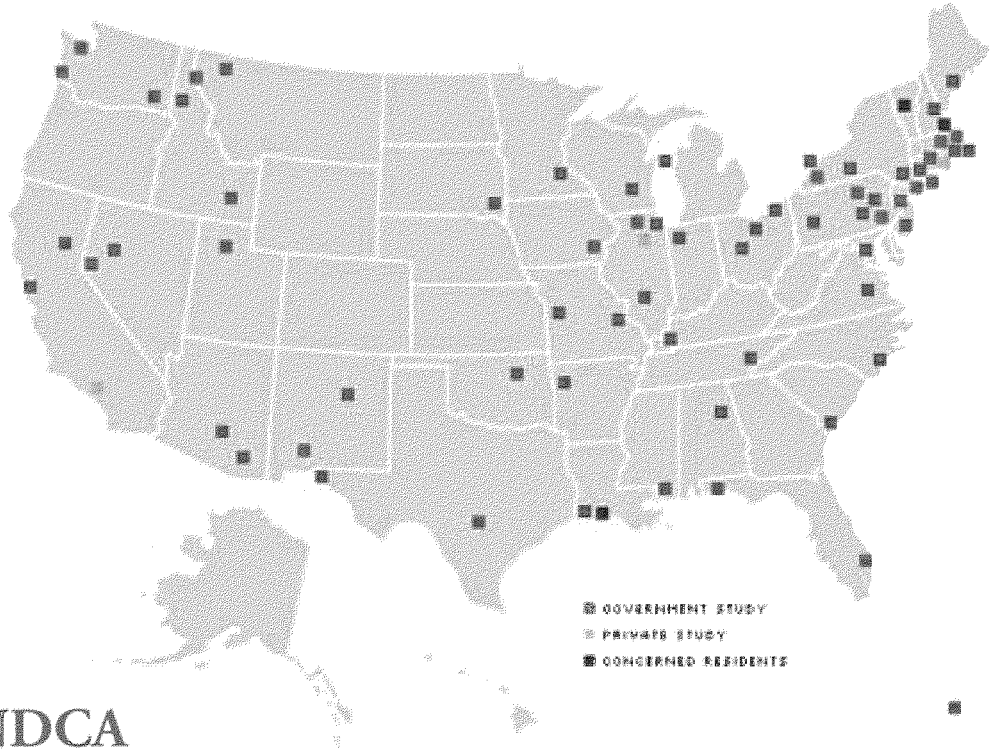


Linus

Evan wants to be a chemist

Amina, Downs syndrome and leukemia

Disease Clusters and Hotspots



NDCA
National Disease Clusters Alliance

In memory

Adam

Fallon NV

RESPONSES BY TREVOR SCHAEFER TO ADDITIONAL QUESTIONS FROM SENATOR INHOFE

Question 1a. In your opinion, if we in Congress had to take away the most important message of your testimony, what goals of yours would you find most essential to be written into law?

Question 1b. Would you support potential changes to S. 76 that create a stronger and more thorough registry for disease clusters, improve coordination among agencies with the relevant expertise to investigate and report disease clusters in a timely manner, ensure small communities a place at the table, and didn't shift primary authority in this process to EPA? In other words, is it your goal to have EPA in the lead role, or would you be supportive of allowing another agency, such as the Agency for Toxic Substances and Disease Registry, to be in charge?

Response. I believe that questions 1 and 2 must be answered together, since our goals are one in the same with the ideas put forth in question 2.

We want the Senate to accept that we need a more efficient, standardized method for collection of potential cancer cluster data with a quicker response time. In that way, we will be able to keep cluster cases small and less costly to eradicate both environmentally and medically. Fewer lost business days, fewer lost jobs, and less costly medical care. All around, this would be cost-effective.

We want improved coordination among agencies with the relevant expertise to investigate and report disease clusters in a timely manner. Waiting until a brush fire becomes a raging inferno only makes putting out the fire more costly in lives taken and the future well-being of the affected community.

We have championed the concept of bringing smaller communities into the mix, offering them a place at the table. I grew up in a small town, McCall, Idaho. I swam in a lake that was a probable source of toxins. I came down with brain cancer in 2002 at the age of thirteen. That year there were four others like me. We were told by the Idaho Tumor Registry that we were too statistically insignificant to warrant a cancer cluster study. That is just wrong. And short-sighted. Since my diagnosis, there continues to be a plague of cancers and other diseases in young people in many small communities in Idaho. What we've seen in Idaho repeats itself countless times across this great nation. If some agency had listened to our citizens and come into McCall early on, I might have been spared a life-time of residual illness, pain and suffering, as would have others. Small communities must be heard.

And most important, we have never advocated that Trevor's Law can only work with the EPA in the lead role, and to that end we would welcome the ATSDR in a co-lead joint committee with the EPA. When we first met with Senator Boxer 3 years ago to present our concept for a new piece of legislation, we told her our goal finally was to standardize reporting at all levels of government and give our children and small communities a voice. She looked at the EPA as a possible place for our ideas to take root and find a home. Since S. 76 was written into its present form as a truly bi-partisan bill with the full support of Senator Crapo, and since it has passed out of committee awaiting a vote in the US Senate, we have spoken to Senator Boxer again. She assured us that she is completely committed to a bi-partisan solution as to where the legislation will be administered. If you feel that you can support S. 76 by making this change, then let's get it done.

We at Trevor's Trek Foundation understand that the economy and getting it back on its feet is the No. 1 priority of both houses of Congress. As it should be. We are patient. We would rather you approach this bill when it has the best chances of support by both sides of the aisle. If that means delaying the vote, so be it. But we also know that every day that another child comes down with cancer from possible exposure to toxins in his or her environment and we do nothing, we edge ever closer to being derelict with our future. As I said in my address to the EPW committee: "Imagine a world without children."

Senator BOXER. Thank you.

Erin Brockovich, who is such a fighter for people who did nothing wrong and suffered, and I am welcoming you and Trevor. You touched our hearts deeply and I thank you.

STATEMENT OF ERIN BROCKOVICH, PRESIDENT, BROCKOVICH RESEARCH AND CONSULTING

Ms. BROCKOVICH. Chair Boxer and distinguished Members of this committee, thank you for the opportunity to testify today.

My name is Erin Brockovich. As an environmental and consumer advocate, I respond to requests for help in groundwater contamina-

tion complaints in all 50 States. I currently work on investigations in California, Texas, Florida, Michigan, New York, New Jersey, Alabama, Louisiana, Illinois, Mississippi, and Missouri. I am also a proud mother of three wonderful children, two of whom are presently serving their country as soldiers in the U.S. Army, one currently deployed in Afghanistan.

Each month, I receive over 40,000 visitors to my website, thousands of whom report issues ranging from environmental pollution, cancer and disease, worker injury and illness, and more. These people make up whole communities that are witnessing first-hand the harmful effects that exposures to chemicals such as hexavalent chromium have had on them. These communities, both large and small and in every corner of the United States, are sending out an SOS.

From small farming towns like Cameron, MO to small desert towns like Midland, TX, to the forgotten town of Leadwood, MO, where the lead mining tails are so large that children think that they are hills and they play on them. In passing as the children wave, it is startling to see the palms of their hand gray, soaked in lead dust.

Unfortunately yet again in Hinkley, CA, this has becoming an all too common occurrence. It would appear that most of these communities are under siege by one form of pollution or another. Protecting the health of our families and our children should be top priorities for us all. Yet the system for investigating, responding and reporting these concerns is inadequate. This is why I strongly support S. 76, the Strengthening Protection for Children and Communities from Disease Cluster Act, also known as Trevor's Law in honor of this brave young man, Trevor Schaefer.

Trevor's Law will bolster Federal efforts to assist communities that are impacted by potential disease clusters and will identify sources of environmental pollutants and toxic substances suspected of causing developmental, reproductive, neurotoxic and numerous cancerous and other adverse health effects.

According to the CDC in 2011, one in three people will develop cancer in his or her lifetimes, one in three. As an advocate for the past 20 years, I have reached an undeniable conclusion there are simply too many cancers in this country and not enough answers.

That is what these communities who reach out to me are trying to do, get answers to the most basic questions. Why is my child, who was perfectly healthy, now sick with leukemia? Why does my daughter have a brain tumor at the age of 10? Why is the same thing happening to my neighbors' kids? Hundreds of mothers and fathers ask me these questions every week.

Today, I would like to share with you a map over here to my left, that I have put together over the past 6 months of communities that have come to me with concerns of what they believe and they are seeing to be excessive cancers in their neighborhoods and communities. There are 534 dots on this map today, and what makes me sad is I still have hundreds that I have yet to position on the map.

The statistics appear to be alarming. These are mothers reporting to me six children on the same block with leukemia. These are mothers reporting to me 15 children within blocks of one another

who have glioblastomas. In some instances, it is nurses reporting to mothers the large numbers of pediatric cancers they are seeing in certain communities.

This work is being done ad hoc by concerned citizens. We must gather data from the field and act. We must develop national strategies for identifying actionable information. We must take a combined arms approach, if you will, to the battle against disease of our own making.

When I talk about this issue, I think of my son who is fighting a war in Afghanistan. If I were suddenly to find myself in the field of conflict, it would not matter how credentialed I was, environmentalist, Ph.D. or U.S. Senator. I would take my lead from those who had been on the ground. Make no mistakes, I feel as if we are in a war here at home.

In this battle, we look to you as our commander. On that map, those constituents, your troops, they are sending you a message, but we are not listening. While the map is not scientific, it does show first-hand experiences of providing us the data that we need. They are reporting to me for help because they are concerned that the pollution in their towns is what is making them and their children sick.

I will continue to work diligently to gather greater information and report what it is that they are seeing. This map, I believe, begs us all to do so.

We must listen and learn from what these people in the affected communities are telling us. We can't just sit back in the safety of our offices and our own homes and hear these stories and think that isn't possible. The reports say it can't happen.

I am here to tell you today that they do happen and they are happening.

In April 2010, the President's Council declared that the number of cancers caused by toxic chemicals is grossly underestimated and warns that Americans face grievous harm from the largely unregulated chemicals that contaminate our air and water.

I was born and raised in a very simple, beautiful lifestyle in Kansas. I happened to be raised by a very strong Republican and military man who actually worked for industry and the U.S. Government as an engineer. He is the very person that taught me the value of clean water, good land, good health and the respect of one another.

It always amuses me when someone believes I have a certain party's affiliation. I find it disturbing for those who assume the environmental activist is anti-business. I always thought growing up that caring for the environment and public health was a conservative thing to do. I have later learned it is just the right thing to do.

We all need to come together on this issue, Republicans, Democrats, Independents, businesses and communities. We need government, business, and affected communities to joint as one for the betterment of the whole, and begin to clean up our messes.

We should ask no more of ourselves than we ask of our children. We need to work together to find solutions and learn what I believe my children and countless other children who serve our country are teaching us. We must protect, nurture and defend what we love

and cherish the most, our families, our health, our land, our water and our very environment.

Chair Boxer and Senators here today, I thank you for the opportunity to share this map with you and be a part of this presentation, and I do thank you for your tireless efforts to help make our environment a better place to live.

[The prepared statement of Ms. Brockovich follows:]

Testimony of

Erin Brockovich

President
Brockovich Research & Consulting

Before the

United States Senate
Committee on Environment and Public Works

On

"Oversight Hearing on Disease Clusters and Environmental Health"

Tuesday, March 29, 2011

Chairman Boxer and distinguished members of the committee: Thank you for the opportunity to testify today on the issues of disease clusters and environmental health.

My name is Erin Brockovich, and I am the President of Brockovich Research and Consulting. As an environmental advocate I respond to requests for help in groundwater contamination complaints in all fifty states. I am currently working on investigations in California, Texas, Florida, Michigan, New York, New Jersey, Alabama, Louisiana, Illinois, Mississippi and Missouri. I am also the proud mother of three children, two who are presently serving their country as soldiers in the United States Army; my son Matthew with the Tenth Mountain Division, Fort Drum, New York has deployed to Afghanistan.

Each month I receive 45-60,000 visitors to my website of which thousands contact me personally reporting issues ranging from environmental pollution, cancer and other diseases resulting from contamination of their property and environment, worker injuries and illnesses; and more. These inquiries come from 140 countries. These people make up whole communities that are witnessing first-hand the harmful health effects exposure to toxic chemicals such as hexavalent chromium has on them and their families. Recently, my colleagues at Environmental Working Group detailed the widespread chromium-6 pollution in our drinking water – an issue that this committee explored earlier this year.

In April 2010, the President's Cancer Panel declared that the number of cancers caused by toxic chemicals is "grossly underestimated" and warned that Americans face "grievous harm" from largely unregulated chemicals that contaminate air, water and food (President's Cancer Panel 2010).

These communities – both large and small and in every corner of the United States – are sending out an SOS. From Cameron, Missouri to Midland, Texas to Champaign, Illinois and unfortunately yet again in Hinkley, California, communities beleaguered by contamination need their elected leaders to listen, and to take action. Approximately 40 million Americans are on private domestic well water; a group of citizens that has fallen off the grid, unaccounted for, when it comes to understanding what might be poisoning

them.

Protecting the health of our children should be a top priority, yet the system for investigating and responding to these concerns is inadequate. That is why I strongly support S. 76, "The Strengthening Protections for Children and Communities from Disease Clusters Act," also known as Trevor's Law for this brave young man Trevor Schaefer.

Trevor's Law will bolster federal efforts to assist communities that are impacted by potential disease clusters and will identify sources of environmental pollutants and toxic substances suspected to cause developmental, reproductive, neurotoxic, carcinogenic and other adverse health effects.

In the United States, 1 in 3 people will develop cancer in his or her lifetime (CDC 2011). As an advocate for the past twenty years I have reached an undeniable conclusion: there are simply too many cancers in this country and not enough answers. And that's all these communities are trying to do – get answers to the most basic questions: why is my son, who was perfectly healthy just months ago, now sick with leukemia? Why does my daughter have two brain tumors at the age of six? And why is the same thing happening to my neighbors' kids? Mothers and fathers ask me these questions by the hundred every week.

Part of the puzzle that has been missing is that there is not an agency on the ground going door-to-door talking to and identifying residents who may be affected by contamination in their area. As a result, people have no faith in the federal government to investigate what's making people sick in their communities, and that is why they turn to me. But I cannot take the place of a disease registry or an official reporting program. Trevor's Law, S.76, however, takes steps to address this problem by strengthening federal coordination with state and local authorities in investigating the potential causes of a disease cluster. This bill will empower communities to work with these agencies and therefore facilitate investigation and response.

I am not here to play scientist, nor am I here to sling accusations or assign blame. This is not a partisan issue. Gathering the information necessary to take action protective of human health is a long and daunting task, and when it comes to the health of our children, we cannot afford to jump to conclusions. But it's time for us to stop turning away from these communities. How many childhood brain cancers is enough for us to start getting serious about investigating the potential causes of these illnesses? We need to be listening to community members' concerns when they raise their hand and say something is not right in their neighborhood.

You, members of this Committee, carry the voice and the will of those who elected you to serve this country. I can tell you those voices are crying out for help. Some of your constituents are fearful, others are frustrated; they all need your help to stay united as a community that is trying to find answers.

This process needs to be transparent; I cannot stress that enough. Not only does transparency ensure accountability but it also enables a healthy flow of communication between all involved parties, which is crucial in an investigation of a public health issue that in some cases may be linked to industrial pollution.

Trevor's Law requires the Environmental Protection Agency (EPA) to establish and regularly update a publicly accessible online database that provides communities important information on investigations, associated illnesses and pollutants. This database would foster transparency.

Another important factor to take into account is that just because people are exposed in one neighborhood or one town does not mean they live there forever. One of PG&E's favorite arguments about the cancer rate in Hinkley, California is that it isn't higher than should be expected. What they fail to mention – though I do every chance I get – is that there are people who are sick that were exposed to chromium-6 in Hinkley that may have since moved out of Hinkley. If you believe the environment where you live is harming you wouldn't you move if you have the resources to do so? I urge all of you and the agencies to explore all tools, including social media, to ensure that all people affected are contacted and brought into the response process – not just those that are still there.

Better Coordination, Transparency and Accountability is Needed

For my nearly two decades as a consumer advocate I have met and spoken with tens of thousands of Americans who have suffered the consequences when big companies pollute the water or the air in their communities. And what you and I have known for many years, Chairman Boxer, and what you've worked tirelessly on for your nearly 20 years as a Senator, is that the government needs to help these people.

Because of my work and because the government agencies that should be doing it have dropped the ball, in recent years I have become a kind of reporting agency for suspected disease clusters around the country. Thousands of Americans contact me every month asking for help and telling me about unexplained diseases in their neighborhood or on their streets. I've started to put together a map. This is not a scientific sampling but simply a map of people who are reaching out to me for help because they are concerned that environmental pollution in their community has made them sick. I believe this simple map demonstrates we need to do a better job of listening and responding to these communities including the ones I haven't heard from. (Appendix A)

This is the issue of our time – whether it is pollution in our water, our air or products we use every day. The government must play a stronger, better role in helping all Americans. I understand this might not be a popular position in some circles but most of my life has been about taking unpopular stands against big polluters so I'm okay with that. Madam Chairman, Senator Crapo, I believe that your legislation "The Strengthening Protection for Children and Communities from Disease Clusters Act" will help Americans that desperately need it. And the bipartisan nature of Trevor's Law will send a very valuable message that clean air and clean water and healthy communities are

not political issues – they are human issues. American issues. I will also remind the public that it was a Republican President – President Nixon – that created the Environmental Protection Agency.

We need better coordination among all government agencies and I have major concerns about the Agency for Toxic Substances and Disease Registry's (ATSDR) efforts to identify and deal with disease clusters. Because ATSDR doesn't effectively respond to citizens' concerns they turn to anyone who will listen, including to me, to report the strange clusters or high numbers of disease in their neighborhoods and towns. Better coordination among federal agencies that bring different expertise to the table including the Environmental Protection Agency (EPA), ATSDR, Department of Health and Human Services (HHS) and National Institute of Environmental Health Sciences (NIEHS) is necessary and appropriately addressed in S. 76.

It's also important that the federal government doesn't just come in, run some tests and leave. Make no mistake – the federal government must play a key role in identifying and responding to disease clusters because federal agencies have the research, response and enforcement capacity that states and localities often don't. But we can't lose sight of the most important part of any effort to identify and respond to a possible disease cluster – the people themselves.

That's why I'm pleased to see that this legislation requires EPA to establish and operate Regional Disease Cluster Information and Response Centers and Teams that will, among other steps, provide expertise to the public as well as state and local officials and involve the community in investigations through participatory research initiatives. Another important piece of the legislation is the establishment of Community Disease Cluster Advisory Committees to provide oversight over investigations and addressing causes and ensure effective community outreach and involvement. The affected people must and will be a part of these committees. Any response to a potential disease cluster cannot be considered successful and effective if the affected community is marginalized.

Everyone believes, because of a movie, that I am an environmental activist. I do care a great deal about the environment but my real work and my greatest challenge is trying to overcome obstacles that end up jeopardizing public health and safety; and to find ways to prevent them in the first place.

I am an advocate for awareness and a person's right to know. Often times we don't think about or understand what is happening to someone else until it affects us personally. Cancer or some chronic disease has touched all of us. And disease does not recognize our political party affiliation. I am proud to support this bill and am proud that it has bipartisan support.

The time has come for the federal government to step up and provide the expertise and resources only it can.

I commend your leadership Chairman Boxer and Senator Crapo. We must act now to help these communities who are suffering.

Thank you.

Sources:

CDC (Centers for Disease Control and Prevention). 2011. Cancer Clusters.
Available at: http://www.cdc.gov/nceh/clusters/about.htm

NDCA (National Disease Clusters Alliance). 2010.
Available at: http://clusteralliance.org/

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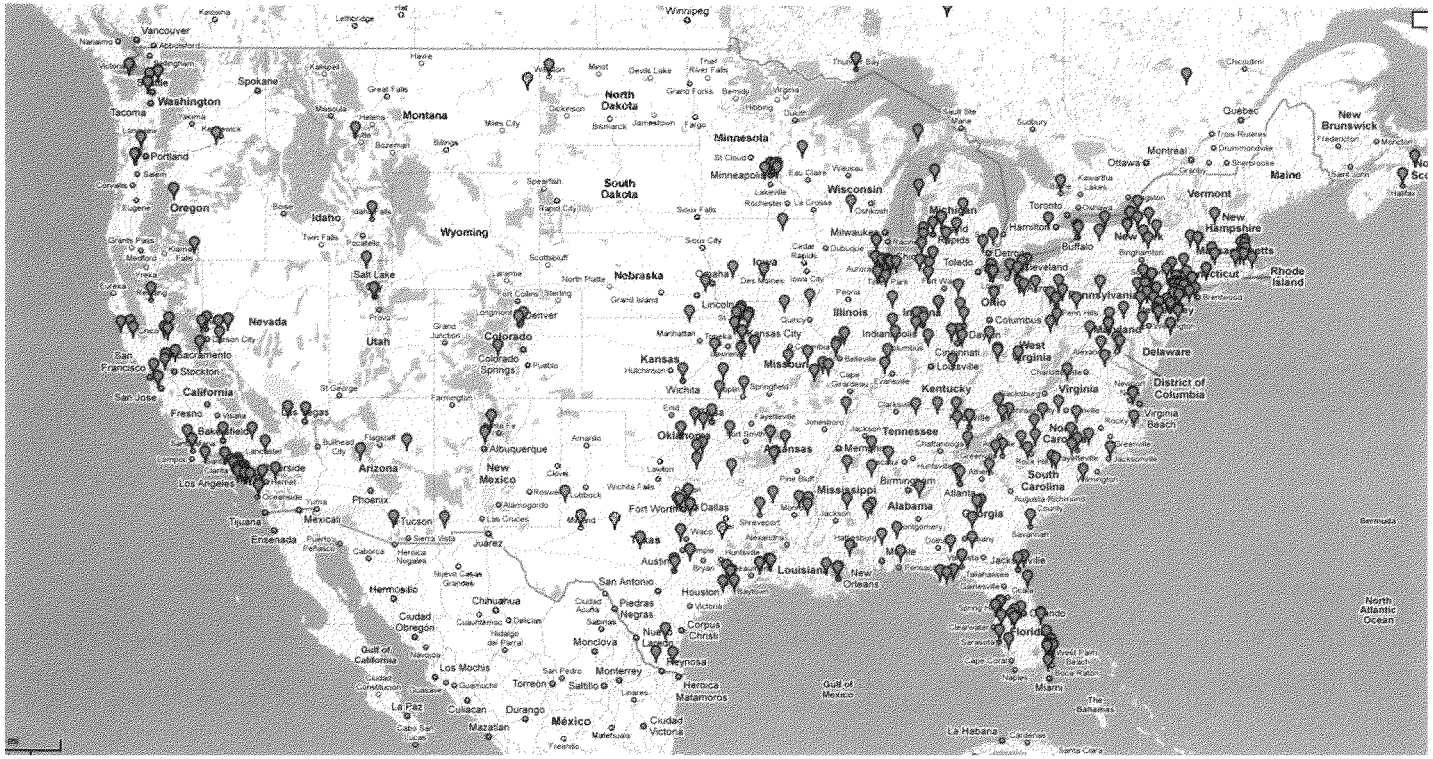
Available at: http://deainfo.nci.nih.gov/advisory/pcp/pcp08-09rpt/PCP_Report_08-09_508.pdf

Appendix A

Map of Concerns About Disease Outbreaks Reported to Erin Brockovich


Vancouver
Winnipeg
Washington
Spokane
Montana
North Dakota
Minnesota
Portland
Oregon
Idaho
Wyoming
South Dakota
Wisconsin
Michigan
Toronto
Ottawa
Montreal
Québec
New Brunswick
Maine
Vermont
New Hampshire
Massachusetts
Rhode Island
Connecticut
New York
Pennsylvania
Salt Lake
Utah
Nebraska
Iowa
Illinois
Ohio
Nevada
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Denver
Kansas
Missouri
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West Virginia
Delaware
District of Columbia
Virginia
California
Sacramento
San Francisco
San Jose
Fresno
Las Vegas
Arizona
Phoenix
Tucson
New Mexico
Albuquerque
Oklahoma
Arkansas
Kentucky
Tennessee
North Carolina
South Carolina
Mississippi
Alabama
Georgia
Texas
Dallas
Fort Worth
Austin
San Antonio
Houston
Louisiana
New Orleans
Florida
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Tijuana
Ensenada
Mexicali
Hermosillo
Chihuahua
Ciudad Obregón
Monclova
Monterrey
Reynosa
Matamoros
Los Mochis
La Paz
Culiacán
Durango
Mazatlán
México
Torreón
Saltillo
Ciudad Victoria
Gulf of California
Gulf of México
La Habana
The Bahamas
Bermuda
North Atlantic Ocean

RESPONSES BY ERIN BROCKOVICH TO ADDITIONAL QUESTIONS FROM SENATOR BOXER

Question 1. Ms. Brockovich, you have spoken about people across the country who have called you asking for help with unexplained diseases in their communities. You've also put together a map showing where these communities are located, and have testified that "this map demonstrates we need to do a better job of listening and responding to these communities."

How do you think the Federal Government could improve its ability to listen and help the types of people and communities who have reached out to you asking for help?

Response. As I said in my testimony, listening to the community when they raise concerns is vital. While I'm sure I'm not the only person who frustrated Americans are reaching out to, it's not just about listening. The government must also improve communication so that the community is involved when decisions are made.

One of the key provisions of S. 76 in this regard is the required coordination between various Federal agencies including the Environmental Protection Agency, the Department of Health and Human Services, the National Institute of Environmental Health Sciences, and the Agency for Toxic Substances and Disease Registry. All of these agencies bring different, needed expertise that the community will benefit from.

I also believe that the Regional Disease Cluster Information and Response Centers and Teams as well as the Community Disease Cluster Advisory Committees will help communities be more involved and allow them to provide invaluable information to government experts.

People across America are crying out for help and S. 76 will help to not only hear those cries, but to effectively help them respond to potential disease clusters by bringing in needed expertise while incorporating and valuing local input.

Question 2. Ms. Brockovich, your testimony emphasizes the importance of ensuring accountability and transparency when government agencies investigate potential disease clusters.

What are the main benefits to the people who are stricken with illness and to other people in their community from increased transparency and accountability?

Response. The main benefit of increased transparency and accountability is increased faith that the Federal Government is listening, investigating and working to solve the issues surrounding potential disease clusters.

In the Strengthening Protections for Children and Communities from Disease Clusters Act, the EPA will be required to establish and regularly update a publicly accessible online data base to provide communities with important information on investigations, associated illnesses, and pollutants. Unfortunately, not everyone in a community, even if they are experiencing health effects, will reach out to others—or the government; ensuring that key information is publicly available the government will be able to bring more people into the process and to positively or negatively identify a disease cluster. By ensuring transparency both the affected community and the government agencies will have access to more information, which will help in identifying and treating disease clusters.

The public information will also allow the community to monitor the work being done by different entities, which fosters accountability. As has been said, sunlight is the best disinfectant.

Question 3. Ms. Brockovich, some people have said that Hinkley, California did not have a disease cluster because the area had no more cancers than one would normally expect in the community.

How do you respond to that argument?

Response. Unfortunately this is an argument I hear much too often, usually from Pacific Gas & Electric (PG&E) who were responsible for the hexavalent chromium pollution and have failed time and again to effectively clean it up. However, part of the reason that Hinkley did not have more cancers than one would normally expect is because authorities are only testing and looking at current residents of Hinkley. If you believe that your environment is harming you and you have the means to do so, wouldn't you move? In this age of where people from different corners of the globe are connected through social media, the Federal Government should leverage these and other tools to more effectively track people when they move away from potential disease cluster sites.

RESPONSES BY ERIN BROCKOVICH TO ADDITIONAL QUESTIONS FROM SENATOR INHOFE

Question 1. Currently the Agency for Toxic Substances and Disease Registry and the Centers for Disease Control investigate disease clusters. Please describe the deficiencies in their programs which makes them unsuitable to do what S. 76 has EPA doing?

Response. Members of Congress, local community groups, and public health advocates have harshly criticized the Agency for Toxic Substances and Disease Registry (ATSDR) for failing to protect the public from toxic exposures, while independent scientists have pointed to the lack of scientific rigor and integrity in the agency's health assessments. They argue that ATSDR often seeks ways to avoid linking local health problems to specific sources of hazardous chemicals rather than actively trying to identify and prove exposures.[1]

S. 76 lays out clear guidelines for conducting investigations, including a description of roles and responsibilities as well as Regional Disease Cluster Information Response Teams, which will ensure that local communities play a more active participatory role in investigations.

We need more transparency and accountability in the process of identifying and investigating potential disease clusters. The plan laid out in S. 76 will require more of both, which will increase the government's ability to better handle the myriad issues surrounding disease clusters.

Question 2. Do you believe that S. 76 will allow EPA to take action to prevent a company from emitting or discharging identified toxic substances? Should S. 76 provide EPA with additional authority to take actions to address an identified or potential disease clusters?

Response. I don't believe that S. 76 will allow EPA to take action to prevent a company from emitting or discharging identified toxic substances beyond the agency's current authority already codified in laws like the Safe Drinking Water Act and the Comprehensive Environmental Response, Compensation, and Liability Act. The legislation strengthens the Federal Government's ability to identify and investigate disease clusters as well as better coordinate among Federal, State, and local agencies and affected communities.

S. 76 is not the appropriate vehicle by which to grant EPA the additional authority to take such actions. Reform of the Toxic Substances Control Act, however, would allow the agency to better address toxic substances that may be associated with disease clusters.

Question 3. Should the primary focus be on cancer clusters and not other diseases, such as asthma?

Response. The focus should be on disease clusters in general, which is how S. 76 is laid out. Unfortunately, we are seeing increases in several diseases including childhood cancer as well as asthma and autism. Illnesses often have affected the physical, mental and financial wellbeing of the impacted people and their families. The agencies pulled together by S. 76 should and will focus on all potential disease clusters.

Question 4. Would areas for investigation be identified by public reporting of concerns? By incidence reporting by the medical community? Do you have any recommendation in this area?

Response. The quick answer is all of the above. As the map I showed at the hearing and Trevor Schaefer's testimony demonstrated, we can't just rely on one source of reporting. Trevor's first doctors did not share the information with the relevant authorities and my map represents people who felt they had nowhere else to turn. People should be able to report potential disease clusters through the petition process outlined in the bill. They should also be confident that if they share information with their doctors, the doctors will share the information with the proper authorities.

There need to be various paths of reporting of concerns to ensure that concern and information about potential disease clusters reaches the Federal agencies tasked with investigating and identifying them. We should ensure more reporting not less.

Question 5. EPA currently regulates the emissions of both toxic substances, and required pollution controls will reduce emissions of many other chemicals. Are you in favor of requiring additional reductions, and additional controls, to address potential disease clusters?

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[1] Report by Majority Staff of Subcommittee on Investigations and Oversight, House Committee on Science and Technology, March 10, 2009.

Response. I am in favor of additional reductions and additional control being part of the potential actions that can be taken by Federal agencies involved in identifying and investigating disease clusters. When pollution and illnesses are widespread as they would be in the case of a disease cluster, immediate action must be taken to reduce exposures.

While there are laws that regulate emissions, releases and exposures of toxic chemicals, hazardous substances and other pollution some of these are too weak to effectively limit exposure to toxic substances. One example is the Toxic Substances Control Act (TSCA), which is so weak, EPA was unable to ban asbestos, one of the most carcinogenic substances on earth. Because of its limited authority under the law, EPA has required testing for only 200 chemicals and banned only 5 in the 35 years since TSCA passed. Under current law the burden rests on EPA to prove a chemical is unsafe (with very little authority or ability to do so) instead of the manufacturer having the burden to prove a chemical is safe.

As you know, there have been efforts to reform TSCA in recent years and one of the core components of that effort is to protect vulnerable populations. There is little doubt that people impacted by disease clusters are vulnerable populations and exposure to harmful pollution must be reduced and controlled.

Question 6. Under S. 76, what do you think would constitute "clearly" describing "the basis for the requested investigation or action" when it comes to a petition by a person for investigation?

Response. The bar should be relatively low when it comes to the basis for the requested investigation. As I pointed out in my testimony, Americans around the country feel that the government is not listening to them. That's why they reach out to me in such numbers that I felt compelled to create the map I presented at the hearing. As Trevor Schaefer made clear, right now determining whether a cluster exists is stacked against the community and potential victims. For those reasons deference should be given to the person filing the petition.

The Strengthening Protections for Children and Communities from Disease Clusters Act also builds strong considerations into the petition process so the agencies aren't forced on wild goose chases while also allowing them to deny or defer a petition. However, it is important that the Americans that haven't been heard for too long be given a voice to alert the Federal Government to potential disease clusters.

Question 7. The definition of membership on Community Disease Cluster Advisory Committees shall include "individuals who are or may be impacted by a suspected or potential disease cluster, and the designee of such an individual who may participate with or in the place of such an individual." Is there anyone in the United States that does not meet that definition? Should attorneys for clients with potential suits against local companies or manufacturers be included in the definition of "designee"?

Response. I disagree that this definition is too broad and that anyone in the United States meets it. In fact in the legislation, there is a ban on members of the committee that may have any direct or indirect conflict of interest, which would probably disqualify not only attorneys for clients with potential suits against local companies or manufacturers but also defense attorneys or paid defense expert witnesses. However, it is important that designees could be included in these committees, especially if the impacted person is not physically capable of participating.

The goal is and should be to ensure that the impacted individuals, State and local government officials and Federal appointees can come together to share information and data and ensure that all affected parties are involved.

Senator BOXER. Thank you so much, Ms. Brockovich.

This map is really unbelievable that people called you. They didn't have another place to go, and you should feel really proud of your record in the past and that America feels comfortable in letting you know this. But that is what we are trying to work on is to make it easier for people to report these to us and therefore we can then take the whole community and bring together State, local, community, individuals and get to the bottom of these disease clusters, some of which are not related to environment and many of them are.

Dr. Belzer, welcome.

STATEMENT OF RICHARD B. BELZER, PRESIDENT, REGULATORY CHECKBOOK

Mr. BELZER. Thank you very much, Chairman Boxer and Members present of the committee. I appreciate the opportunity to testify today. I want to make a friendly correction, Chairman Boxer, to your opening statement. I, too, am a California native, so there is a certain imbalance on this panel. I was raised in Torrance, CA and got my bachelor's and master's degrees at the University of California at Davis. That is a few years ago. Subsequently earned a master's and doctorate from Harvard. I sometimes regret I was not able to move back.

Senator BOXER. Well, that is the thing. We miss you. You have left us for Virginia and we can't forgive you for that.

[Laughter.]

Mr. BELZER. Thank you so much. My parents sometimes feel the same way.

My background is as an analyst, an economist, a risk analyst, and I want to point out that although my 10 years spent as an economist in the Office of Management and Budget normally would make people think of sort of a green eyeshade sort of view of someone like me. I want to point out in particular that I shepherded through OMB's convoluted review process EPA's National Human Exposure Assessment Survey probably almost 20 years ago now. At the time, it was the biggest attempt to get real world representative data on environmental exposure. I am very proud to have shepherded it through. At least 40 papers have been published in peer-reviewed literature because of this project. I am happy to have played a small role in that.

With that small introduction, I want to raise a couple of questions here. My written testimony covers a number of scientific and technical issues, but I wish to focus on four of them right now.

First, how is the term disease defined? Without a clear definition of disease, almost anything could be included within it. We have experience with this problem. The term adverse health effect is used hundreds of times in Federal law, but it is either defined circularly or it is not defined at all. This creates an number of problems for us in attempting to be responsive.

S. 76 does not include a definition of disease either. It uses the term adverse effect, but like existing law, it does not define it.

Second, how is the term disease cluster defined? A good scientific definition would be both sensitive and selective. Sensitivity is needed to ensure that we miss very few real cases, what statisticians call false negatives. Selectivity is needed to minimize the number of random cases that are incorrectly classified as part of a cluster. What statisticians would call false positives.

Now, false negatives are obviously costly. We don't want to miss real cases. But false positives are costly, too. They create significant fear and anxiety. They may lead to the closure of parks, schools and drinking water wells. They depress the market value of people's homes.

This also creates a serious problem for scientists who are investigating or would be investigating petitions alleging a disease cluster. The less sensitive the definition, the greater will be the proportion of investigations that come up dry because there isn't anything

defined. Now, when scientists come up dry, people often are more angry than relieved. Their trust in government is damaged sometimes beyond repair.

The conventional definition, the definition in S. 76, has really good sensitivity, but really poor selectivity. It is very unlikely to miss a real disease cluster. That means it has a low rate of false negatives. However, it is very likely to misclassify a lot of random cases as disease clusters. That means it has a high rate of false positives.

In my written testimony, I show how the conventional definition results in the majority of random cases of disease getting misclassified as disease clusters. In my example, 27 percent of fixed geographical zones have greater than expected numbers of cases, and so they would be legislatively deemed to be disease clusters.

If my data were randomly generated, that means all of my data were false positives. This does not help those who belong to a bona fide disease cluster since ample resources will be spent searching for environmental linkages that do not exist. That takes resources away from trying to understand real disease clusters.

My third concern, how is the term potential cause of a disease cluster defined? The definition in S. 76 is in some respects narrow and in other respects very broad. It is narrow because it focuses on anything subject to regulation by EPA. It is broad because it demands no scientific evidence. A chemical is a potential cause just by being present. No evidence is required that the chemical causes the disease of interest. No evidence is required that any exposure to the chemical actually occurred. No evidence is required of a dose-response relationship.

In short, the problem is the definition does not follow the scientific risk assessment model.

Finally, I am worried about the possibility of subordinating science to law and politics. When Congress attempts to legislate science, science is compromised. That science would be compromised is evident, especially to me, in the way EPA would be directed by its risk assessments in a health-protective way. This is not science and it damages the credibility and integrity of risk assessments. Scientists should never be told what conclusion to reach and invited to conduct research in order to support it.

To be credible, risk must be estimated objectively. This is a core scientific value and responsible scientists will not participate in a system in which core incentive values are compromised.

Thank you again for the opportunity to testify.

[The prepared statement of Mr. Belzer follows:]

Written Testimony of Richard B Belzer

Committee on Environment and Public Works
U. S. Senate

"Oversight Hearing on
Disease Clusters and Environmental Health"

March 29, 2011

Chairman Boxer, Ranking Member Inhofe, and Members of the Committee:

Thank you for the opportunity to testify today on this important subject. I am Richard B. Belzer, president of Regulatory Checkbook, a nonpartisan nonprofit organization based in Virginia. Our mission is to improve the quality of scientific and economic information used for public decision-making. We never take positions on substantive legislation or regulation. I have specific concerns about how well meaning efforts to identify and respond to bona fide disease clusters caused by environmental factors may unwittingly backfire.

MY BACKGROUND

I was raised in Torrance, California, where my parents still reside. I earned Bachelors and Masters degrees in agricultural economics from the University of California at Davis in 1979 and 1980, respectively. In 1982, I earned a Masters in Public Policy from Harvard's John F. Kennedy School of Government, and in 1989 I completed my doctorate from Harvard.

For 10 years, I served as an economist in OMB's Office of Information and Regulatory Affairs. In addition to reviewing draft major regulations, I prepared the final version of OMB 1990 guidance on how to prepare Regulatory Impact Analysis.[1] I contributed

[1] OFFICE OF MANAGEMENT AND BUDGET, *Regulatory Impact Analysis Guidance (Appendix V) in* Regulatory Program of the United States Government, April 1, 1990 -- March 31, 1991. (1990).

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significantly to OMB's 1995 Principles for Risk Analysis,[2] which remain in effect to this day.[3]

On a number of occasions I reviewed proposed epidemiological surveys to ensure they met applicable statistical quality standards.[4] For example, I personally shepherded through the sometimes Byzantine OIRA clearance process EPA's National Human Exposure Assessment Survey (NHEXAS).[5] At the time, this was the largest and most ambitious EPA effort to obtain statistically valid data on environmental exposure. A search of PubMed shows more than 40 peer-reviewed scholarly papers that have been produced from this data set. I am proud to have helped make this happen.

Besides being an economist I am an experienced risk analyst. In 1988 and 2000, I was elected Treasurer of the Society for Risk Analysis, the premier professional association for environmental risk professionals, and in 2003 I earned the Society's Outstanding Service Award. Service to the professions matters to me. In 2008 and 2010, I was elected Secretary/Treasurer of the Society for Benefit Cost Analysis, a new professional association recently established with significant support from the MacArthur Foundation.

Detecting disease clusters is a very difficult epidemiological and statistical problem. Today, I will show you why several provisions in S. 76, the proposed "Strengthening Protections for Children and

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[2] SALLY KATZEN, *Principles for Risk Analysis* (Office of Management and Budget ed., 1995).

[3] SUSAN E. DUDLEY & SHARON L. HAYS, *Updated Principles for Risk Analysis* (Office of Management and Budget and Office of Science Technology Policy ed., 2007).

[4] For a current version of Federal statistical policy related to surveys, see OFFICE OF MANAGEMENT AND BUDGET, *Standards and Guidelines for Statistical Surveys*, Office of Management and Budget (2006), at http://www.whitehouse.gov/sites/default/files/omb/assets/omb/inforeg/statpolicy/standards_stat_surveys.pdf. OMB published Federal information quality standards in 2002. See OFFICE OF MANAGEMENT AND BUDGET, *Guidelines for Ensuring and Maximizing the Quality, Objectivity, Utility, and Integrity of Information Disseminated by Federal Agencies; Notice; Republication*, 67 Federal Register (2002).

[5] U.S. ENVIRONMENTAL PROTECTION AGENCY, *NHEXAS: National Human Exposure Assessment Survey* (2011), at http://www.epa.gov/nerl/research/nhexas/nhexas.htm.

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Communities From Disease Clusters Act,"[6] have the practical effect of supplanting science with law. I will explain why S. 76 structures the programs it would create in ways that pose a grave risk to the integrity of science. Combined, these elements make it very unlikely that people who actually are part of a disease cluster will be made better off.

BROAD GOALS + INDETERMINATE MEASURES OF SUCCESS = FUTURE CONFLICT

The Federal government has ample experience with statutes that have worthy, broadly worded goals. S. 76 is no different. Indeed, its stated goals are so expansive that we can be sure that they will never be achieved. This is clear from just the first of these goals:

> [T]o protect and assist pregnant women, infants, children, and other individuals who have been, are, or could be harmed by, and become part of, a disease cluster;...[7]

No one in America is excluded from this goal.[8] Moreover, there is no way to measure EPA's performance. The Agency will not be able to quantify the outcomes it achieves, so it will have to measure success in terms of outputs. This means "success" will be measured by the numbers of Response Centers and Teams EPA establishes, the numbers of investigations these Teams perform, the number of pages of guidance EPA issues, and potentially the number of meetings EPA holds with stakeholders.

Open-ended goals combined with indeterminate measures of success often result in significant future conflict. We are seeing this now in the case of EPA's efforts to regulate carbon dioxide and other greenhouse gases using the broadly worded language of the Clean Air Act of 1970.[9]

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[6] "Strengthening Protections for Children and Communities From Disease Clusters Act". S. 76. U.S. Senate, 112th Congress, 1st Session. (Boxer and Crapo, 2011).

[7] S. 76, Section 4(1).

[8] Indeed, the text does not limit its applicability to U.S. citizens or residents. Everyone on Earth could qualify.

[9] U.S. ENVIRONMENTAL PROTECTION AGENCY, *Endangerment and Cause or Contribute Findings for Greenhouse Gases Under Section 202(a) of the Clean Air Act; Final Rule*, 74 Federal Register 66496 (2009).

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WHAT IS "DISEASE"?

One way to head down a slippery legislative slope is to be ambiguous about the target. S. 76 would provide a statutory definition for a number of important terms, including "disease cluster" and "potential causes of a disease cluster," but notably absent is any definition of "disease." If we are ambiguous about what would be joined together in a "cluster," or vague about what it is that "potential causes" would presumably cause, we will have abandoned all hope of clarity in the endeavor.

Federal law and regulation often use the term "adverse effect" as a synonym for disease. A recent research paper sponsored by the Society for Risk Analysis reported that the term "adverse effect" appears over 300 times in federal laws, but that "the federal statutes themselves give little or no definition or guidance regarding the precise meanings or intended interpretations." Implementing regulations do not add clarity, either:

> Though some statutes purport to define these terms, the definitions are often circular and of little value because they include the term being defined as part of its definition. The statutes generally do not speak to the scientific methods to be used to calculate adverse effects. Agency regulations and judicial interpretations add some clarity, but still leave basic questions of meaning and methodology unaddressed.[10]

The pattern of circularity in Federal law would not be disturbed by S. 76. The term "adverse health effect" is used in a crucial place,[11] but it is not defined. Indeed, as I will point out below, the definition of "potential causes of a disease cluster" cross-references a definition of "environmental pollutants or toxic substances" that relies exclusively on existing statutes with circular or absent definitions of adversity.

In Federal regulatory practice, the practical definition of an "adverse health effect" is remarkably broad. Frank disease is always included, of course, but a wide variety of phenomena at the other end

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[10] KELSEY STANSELL & MARK MARVELLI, *'Adverse Effects' and Similar Terms in U.S. Law: A Report Prepared by the Duke Center for Environmental Solutions for the Dose Response Specialty Group of the Society for Risk Analysis (SRA)* p. 3 (Duke University Center for Environmental Solutions 2005).

[11] S. 76, Section 5(7)(H).

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of the spectrum also have been deemed "adverse." Examples include such things as precursors (e.g., hyperplasia), biomarkers of disease (e.g. molecular signatures), biomarkers of exposure (e.g., serum or urine detects of a chemical or its metabolites), and so-called "key events."[12] Exposure below the threshold of an adverse effect (e.g., below the Reference Dose) cannot have adverse effects, but EPA considers them adverse because an organism exposed below the threshold for adversity may have a diminished capacity to compensate for other, unrelated exposures. Each of EPA's working definitions has scientific content but it is controlled by the explicit or implicit application of substantial policy judgments.[13]

These definitions increasingly extend to phenomena that are quite minor. For example, in the 2008 revision to the National Ambient Air Quality Standards for ozone, EPA deemed short-lived, reversible, single-digit percentage reductions in forced expiratory volume observed in a handful of test subjects to be an adverse effect worthy of prevention through national standards.[14]

Meanwhile, toxicologists and epidemiologists have been unable to come up with a scientific definition of "adverse." Ironically,

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[12] EPA defines a "key event" as "an empirically observable precursor step that is itself a necessary element of the mode of action or is a biologically based marker for such an element." The first instance I am aware of in which this terminology was used is EPA's 2002 external review draft risk assessment (since rescinded) for perchlorate. See S. 76; S. 76; U.S. ENVIRONMENTAL PROTECTION AGENCY OFFICE OF RESEARCH AND DEVELOPMENT NATIONAL CENTER FOR ENVIRONMENTAL ASSESSMENT, *Perchlorate Environmental Contamination: Toxicological Review and Risk Characterization (NCEA-1-05-3), External Review Draft* Section 5(7)(H) (U.S. EPA Office of Research and Development 2002).

[13] For example, EPA defines the Reference Dose (RfD) as "[a]n estimate (with uncertainty spanning perhaps an order of magnitude) of a daily oral exposure to the human population (including sensitive subgroups) that is likely to be without an appreciable risk of deleterious effects during a lifetime. It can be derived from a NOAEL, LOAEL, or benchmark dose, with uncertainty factors generally applied to reflect limitations of the data used." Each of the underlined terms has no scientific definition, but rather reflect the personal regulatory policy judgments of Agency scientists. See EPA, IRIS Glossary ("Reference Dose") (http://www.epa.gov/iris/help_gloss.htm#r).

[14] U.S. ENVIRONMENTAL PROTECTION AGENCY, *National Ambient Air Quality Standards for Ozone; Final Rule*, 73 Federal Register (2008).

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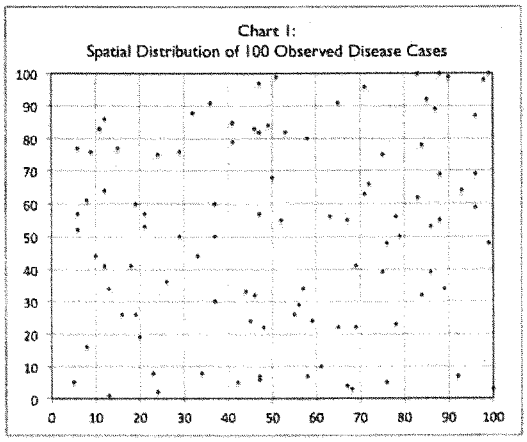
economics alone among the sciences provides objective scientific definitions for both the adversity and severity of a health effect, but no federal agency uses it.[15]

THE DEFINITION OF "DISEASE CLUSTER"

Chart 1 plots the spatial dispersion of 100 disease cases. The area is divided into 100 equal sized blocks. You may see what appear to be disease clusters within certain blocks, and the absence of disease in others. Blocks with a disproportionate number of cases may host a disease cluster.



In **Chart 2**, I have replaced the data points with the number of points in each block. Because there are 100 blocks and 100 cases, if there are no disease clusters the expected number of cases in each block is exactly one. I have highlighted these blocks in light green with cross-hatching (for visibility in B&W). For every other block, the number of cases differs from the expected value.

[15] An adverse health effect is any health effect that an individual is willing to pay to avoid. The severity of such an effect is the magnitude of the individual's willingness to pay.

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Chart 2:
Blocks with Expected Number of Cases

	0	10	20	30	40	50	60	70	80	90	100
100	0	0	0	1	1	1	1	1	3	3	
90	0	2	0	1	4	2	0	0	1	1	
80	2	1	2	0	1	0	0	1	1	0	
70	1	2	0	1	0	1	0	2	2	2	
60	2	0	3	1	1	1	2	2	2	1	
50	0	3	0	1	0	0	1	1	0	1	
40	0	1	1	1	2	1	0	1	3	0	
30	0	2	0	0	2	3	2	1	0	0	
20	1	0	1	0	0	0	1	0	0	0	
10	1	1	2	1	3	1	2	1	0	2	
0											

In **Chart 3**, I have highlighted in solid red (black in B&W) one block that contains <u>four</u> times the expected number of cases. It would be logical to look at this particular block as a possible disease cluster.

Chart 3:
Blocks with 4x Expected Number of Cases

	0	10	20	30	40	50	60	70	80	90	100
100	0	0	0	1	1	1	1	1	3	3	
90	0	2	0	1	4	2	0	0	1	1	
80	2	1	2	0	1	0	0	1	1	0	
70	1	2	0	1	0	1	0	2	2	2	
60	2	0	3	1	1	1	2	2	2	1	
50	0	3	0	1	0	0	1	1	0	1	
40	0	1	1	1	2	1	0	1	3	0	
30	0	2	0	0	2	3	2	1	0	0	
20	1	0	1	0	0	0	1	0	0	0	
10	1	1	2	1	3	1	2	1	0	2	
0											

But there are seven additional blocks each with <u>three</u> times the expected number of cases. In **Chart 4**, they are shown in orange (//// diagonal gray stripes in B&W). It also would be logical to consider them as possible disease clusters. Notice that there are two pairs of adjacent blocks, each having 3 times the expected number of cases. It

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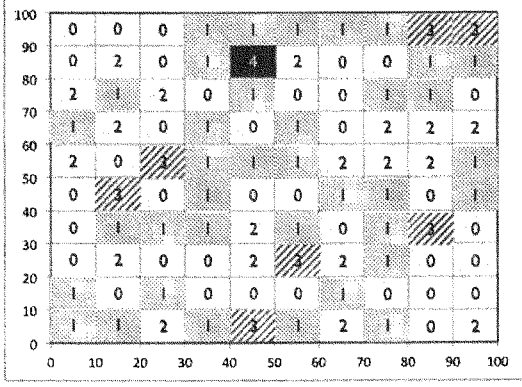
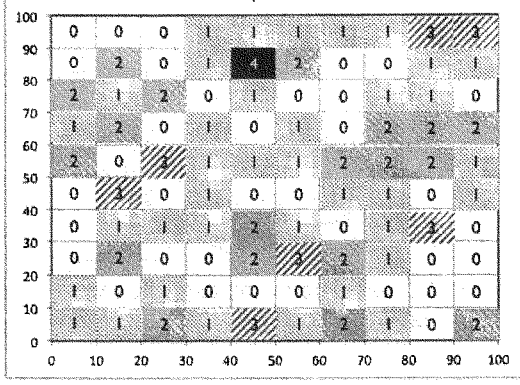
is possible that they represent disease clusters spanning more than one block.

Chart 4:
Blocks with 3-4x Expected Number of Cases



There are 19 more blocks with two times the expected number of cases. In **Chart 5**, I've highlighted them in yellow (\\\\ diagonal gray stripes in B&W). Though perhaps less likely, it is not unreasonable to think that a disease cluster could be found in one or more of them.

Chart 5:
Blocks with 2-4x Expected Number of Cases



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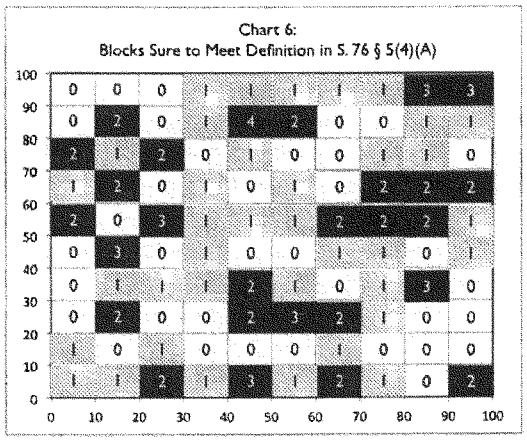

Therefore, each of these 27 blocks would be eligible for investigation and regulatory management as a potential disease cluster simply by virtue of geographical proximity. To make this visual, in **Chart 6** I have highlighted them all in solid red (black in B&W).

In sum, 27 of the 100 blocks have greater than the expected number of disease cases. They all meet the first half of the definition of "disease cluster" in S. 76:

> *§ 5(4) DISEASE CLUSTER.—The term "disease cluster" means—*
>
> > *(A) the occurrence of a greater-than-expected number of cases of a particular disease within a group of individuals, a geographical area, or a period of time;...*

I have not attempted to take into account the extent to which cases would qualify as "disease clusters" under the other two dimensions in the definition: "periods of time" and "groups of individuals." Time can be subdivided, and individuals can be grouped, in a seemingly infinite number of ways. Thus, it is highly likely that many more than the 27 cases I have identified as belonging to potential "disease clusters" would meet the first half of the proposed statutory definition.

The second half of the definition in S. 76 would provide essentially unlimited discretion to the EPA Administrator to deem other relationships as "disease clusters":

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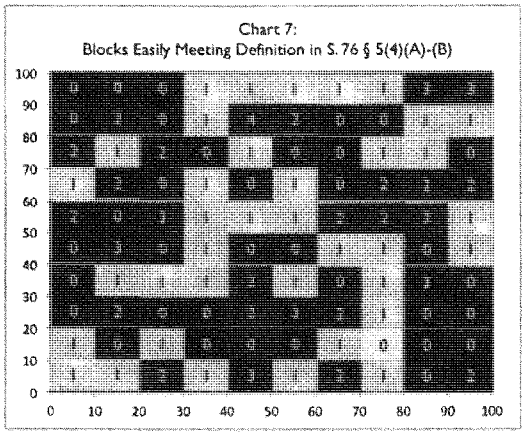
§5(4) DISEASE CLUSTER.—The term "disease cluster" means—

...

(B) the occurrence of a particular disease in such number of cases, or meeting such other criteria, as the Administrator, in consultation with the Administrator of the Agency for Toxic Substances and Disease Registry and the Director, may determine.

To see how this could work in practice, consider the easy situation in which the biomarker of interest is not the presence of something but rather its absence. In that scenario, there are 36 blocks in which the number of "cases" is zero. It would be entirely reasonable for the Administrator to exercise her discretion to deem these cases "disease clusters," too.

In **Chart 7**, I have highlighted in red (black in B&W) all of the blocks that easily meet the full, two-part definition of "disease cluster" in S. 76. Sixty-three of 100 blocks qualify. Under the proposed statutory definition, "disease clusters" could be the norm rather than the exception.



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DEFINITION OF "POTENTIAL CAUSE OF A DISEASE CLUSTER"

Disease has many etiologies, some of which may have environmental origin. What proportion does have environmental origin depends on the definition of "environmental." Typically, this term is widely used as a synonym for such things as chemical exposure. However, the environment is much larger than that. It also could be used to encompass disease allegedly associated with climate change, as EPA has done in its 2009 Endangerment Finding. The term also could be used to apply to catastrophic events such as the recent earthquake and tsunami that devastated much of northeast Japan.

S. 76 would establish a definition that is narrow and specific in certain respects, but quite broad in others.[16] The definition is narrow and specific insofar as it is limited to "environmental pollutants and toxic substances," a term defined to include substances regulated under various statutes EPA implements. The definition is broad insofar as it is not limited to these substances, however. It reaches "any other form of environmental pollution or toxic substance that is a known or potential cause of an adverse health effect."[17]

It is difficult to imagine what is not included within this expansive definition.[18] Indeed, alleged health effects from climate change are obviously included by virtue of EPA's Endangerment Finding and the embedded cross reference to the Clean Air Act. But the indirect effects of earthquakes, tsunamis, and presumably meteorite impacts also would be included. Are influenza and foodborne illness covered? They appear to be within "any other form of an environmental pollutant or toxic substance," albeit not one explicitly listed or currently regulated by EPA. What about transportation risks? Probably not, but they could be covered if there were indirect adverse health effects potentially related to environmental pollutants or toxic

[16] S. 76, Section 5(7).

[17] S. 76, Section 5(7)(H).

[18] The proposed definition also defines "sources of ... pollutants and substances" by reference to existing environmental statutes. Thus, any entity defined as a "source" under an existing statute or regulation would be presumptively a "source" for a "potential cause of a disease cluster." It is both expansive (any regulated source qualifies) and narrow (only regulated sources qualify).

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substances.[19] There is empirical evidence suggesting that the annual changeover from Standard to Daylight Savings Time causes a statistically significant short-term increased incidence of acute myocardial infarction (heart attack).[20] Presumably, these health effects could not constitute a "disease cluster," but only because they are the consequence of a legislative act and thus are not within the ambit of an "environmental pollutant or toxic substance."

The insertion of the adjective "potential" before "cause" widens the definition without bound. Strictly speaking, a "potential" cause is present unless it is scientifically or technically infeasible, and as noted above, under some established regulatory definitions of adversity, even technical infeasibility is not necessarily a bar. If exposures below the threshold for an adverse effect are nonetheless adverse because they reduce the margin of safety, there is no such thing as a de minimis effect.

Interestingly, the definition of a "potential causes of a disease cluster" in S. 76 appears to exclude the three most important actual causes of disease: genetics, behavior, and aging. A fair reading of the definition in S. 76 is that none of these dominant factors qualify as "potential causes." Only potential environmental causes matter, and among environmental causes, the ones that matter most are those that are most heavily regulated by EPA.

CONSTRAINING SCIENCE TO FIT A STATUTORY PARADIGM SUBORDINATES SCIENCE TO LAW AND POLITICS

It is strange to define "disease clusters" and their potential causes in ways that have no scientific content. As long as the number of cases is greater than expected, they would be deemed by statute as a "disease cluster." Every chemical present is a "potential cause of a

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[19] Were a truck to crash on the Capital Beltway, deaths and injuries from impact would be exempt because they are not health effects. But if the truck spilled hazardous materials that might cause health effects, the exemption is no longer obvious.

[20] IMRE JANSZKY & RICKARD LJUNG, *Shifts to and from Daylight Saving Time and Incidence of Myocardial Infarction*, 359 New England Journal of Medicine 1966 (2008). The reported incidence ratio (1.05) is greater than the percentage increase in incidence of mortality said to be caused by ozone (0.3% for 10-ppb O_3). See MICHELLE L. BELL, et al., *The Exposure-Response Curve for Ozone and Risk of Mortality and the Adequacy of Current Ozone Regulations*, 114 Environmental Health Perspectives (2006).

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disease cluster" regardless of whether exposure occurred, how much exposure occurred, or for how long it occurred. These definitions abandon what we have learned about risk from decades of research. They covert scientific inquiry in the search for knowledge into potentially corrupt political and legal calculations.

The first such calculation would be the preparation by EPA of implementing guidance.[21] By law, those with strong policy views about risk management would have preferential input into the practice of risk assessment.[22] EPA would be required to publish implementing guidance that subordinates science to predetermined policy judgments.[23] No research adhering to these guidelines would meet minimum scientific standards for objectivity, so no responsible scientist would agree to adhere to them.

Another predictable consequence of this statutory structure would be the creation of new, and arguably unlimited, civil liability. Any manufacturer, importer, distributor, retailer, or user of a chemical discovered (or even merely suspected) of being co-located in space or time to a "disease cluster" would be presumptively responsible for any "disease cluster" to which it might be linked, however remotely or spuriously. There is no escape from being a "potential cause of a disease cluster" because the absence of causality can never be proved. And, as noted above, the definition of "disease cluster" is so broad that it is reasonable to expect that, in the limit, every instance of disease would be part of at least one cluster and every source of a Federally regulated pollutant would be a potential cause.

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[21] S. 76, Section 6.

[22] For example, Section 6(a)(2) would require EPA to ensure that a specific advisory group, the Children's Health Protection Advisory Committee, has "a prominent role on behalf of the Agency in developing and updating guidelines." In practice, this is approximately equal to delegating rulemaking authority to persons who are not officers of the United States Government.

[23] For example, Section 6(b)(4) would require EPA to ensure that its risk assessments were biased "in a health-protective way"—that is, to overstate the strength of association, causality, and the likely magnitude of risk.

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POLITICIZED IMPLEMENTATION THROUGH REGIONAL RESPONSE CENTERS AND TEAMS

Any program honestly intending to identify disease clusters has to grapple with what to do with this information once it is obtained. The model that S. 76 would set up consists of myriad Regional Disease Cluster Information and Response Centers and Regional Disease Cluster Information and Response Teams.[24] From the outset, these Centers and Teams would be corrupted by politics, both of the conventional sort and of the internal, bureaucratic variety. They also would be large targets for rentseeking by individuals (serving on Response Teams) and universities (which would house Response Centers and Teams pursuant to EPA grants and cooperative agreements).

Indeed, financial corruption is virtually assured. Just to ensure that their appropriations are sustained, Response Centers and Teams must identify large numbers of disease clusters. If they fail to do so, budget constraints would lead Congress to seriously consider reducing or eliminating their appropriations. By identifying large numbers of disease clusters, however, Response Centers and Teams could build politically resilient constituencies to lobby for sustained funding, and probably to increase it.[25]

What would the Response Centers and Teams do? Apparently, their activities would be statutorily unbounded. The EPA Administrator would be delegated the authority to decide, and any activities would be permissible so long as they "are consistent with achieving the goals of this Act." As noted above, the goals of S. 76 are unbounded; there is no measurable standard by which the public could conclude that the bill's goals had been met.

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[24] S. 76, Section 7(a).

[25] S. 76 forbids persons with a "direct or indirect conflict of interest" from participating on a Response Team. See Section 7(b)(1)(B). "Conflict of interest" is not defined, however, but it has to exclude those with the greatest financial conflict—persons who actually work for a Response Center or on a Response Team. Moreover, persons who have been identified as belonging to a disease cluster, and their designees and advocates, would be presumed not to have conflicts of interest. However, it is almost certain that a conflict of interest would be discovered for any person directly or indirectly related to, affiliated with, or owning stock in, an entity that is a "potential cause of a disease cluster."

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One thing the Response Teams will have an incentive to do is encourage the submission of petitions seeking investigation into a potential disease cluster.[26] One of the few areas in which S. 76 denies EPA discretion concerns whether to respond to these petitions. Written responses must be provided within 60 days.[27] For the Response Centers and Teams, the more petitions that are submitted, the greater is the pressure on EPA to deem petitions worthy of investigation, and thus the greater is the apparent demand for their services.

INVITING CAUSATION BY ASSOCIATION, OR LESS

A database of actual disease clusters would be extremely valuable. Unfortunately, the database that S. 76 would direct EPA to establish would not be limited to scientifically validated disease clusters. Rather, it would extend to every legislatively deemed disease cluster and every legislatively deemed potential cause.[28]

The predictable consequence of a database of this design is public misinformation and unwarranted alarm. The public would be encouraged to misinterpret legislative definitions as scientific and to misconstrue association with causation, something that science consistently teaches against. Even the mere suspicion of a relationship between "disease" and a purported "source" appears to be sufficient for memorialization in this database.

IS THERE A GOVERNMENT FAILURE FOR WHICH THIS IS A SOLUTION?

Welfare economics teaches that markets are always imperfect to some degree, and that government intervention may be needed if the magnitude of these imperfections is severe enough and if supplanting market with government allocation results in net social benefits. These principles have been enshrined in Executive branch policy and practice for at least 17 years.[29] An integral part of this policy and practice is the

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[26] S. 76, Sections 7(b)(3)(C) [describing the petition process] and 7(b)(3)(B)(ii) [describing Response Teams' activities related to responding to petitions].

[27] S. 76, Section 7(b)(3)(C)(iv).

[28] S. 76, Section 7(b)(6)(a)(ii)(I)-(IV).

[29] WILLIAM J. CLINTON, *Executive Order 12866--Regulatory Planning and Review*, 58 Federal Register 51735 (1993); OFFICE OF MANAGEMENT AND BUDGET, *Circular A-4: Regulatory Analysis* (2003), at http://www.whitehouse.gov/OMB/circulars/a004/a-4.pdf.

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recognition that public institutions (i.e., governments) also are susceptible to imperfection and failure.[30]

Superficially, S. 76 is targeted on a presumptive market failure: individual cases of disease are assumed to be linked to a common environmental source of anthropogenic origin. Looked at more closely, however, S. 76 is targeted on a presumptive government failure. Federal responsibility for disease epidemiology generally is assigned to the Centers for Disease Control and Prevention (CDC), and responsibility for environmental epidemiological research is assigned to the National Institute of Environmental Health Sciences (NIEHS). S. 76 would largely supplant the programs operated by CDC and NIEHS with a new (and much larger) program within EPA, a regulatory agency of enormous scope and scale. At least with respect to disease clusters, S. 76 would make CDC and NIEHS bureaucratically subordinate to EPA, leaving them only minor consultative roles in areas where they have greater scientific and technical expertise.

Before agreeing to such a radical change, Congress might want to investigate the extent to which CDC and NIEHS have failed to address disease clusters in a scientifically credible manner. No evidence of failure is provided in the findings section of the bill.

RESOURCE ALLOCATION UNDER SCARCITY

In 1848, philosopher Thomas Carlyle ridiculed economics as "the dismal science," a pejorative term that seems to have stood the test of time. Today, economics still has a reputation among some for being dismal, but that's because it insists on identifying and quantifying tradeoffs that many noneconomists prefer to ignore. In a world of scarce resources—that is, the world in which we all live—every decision to commit resources for one purpose requires that they be taken away from the pursuit of another. This is the meaning of the term "opportunity cost": the real "cost" of any expenditure of funds is not mere dollars; rather, it is the value of those things that we must

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[30] Executive Order 12866 states, "Each agency shall identify the problem that it intends to address (including, where applicable, the failures of private markets or public institutions that warrant new agency action) as well as assess the significance of that problem" (emphasis added). OMB Circular A-4 says to agencies, "You should show that a government intervention is likely to do more good than harm."

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sacrifice in order to obtain the benefits we hope to gain from the expenditure.

Although presumably unintended, S. 76 would address the legitimate issue of disease clusters with a combination of selection bias, statistical bias, and the politicization of science. Selection bias would arise because only environmental causes of disease clusters matter, and among environmental causes only the subset potentially attributable to chemicals matters. We can predict that this selection bias will result in massive resource misallocation. Is cancer an important health effect? Absolutely. What about Alzheimer's Disease? Diabetes? Yes, of course. But under the scheme that S. 76 would establish, learning the etiology of disease clusters only matters if there may be a way to link it to a regulated chemical.

Statistical bias is assured because S. 76 would encourage (if not direct) EPA to bias its risk assessments with specific risk management conclusions. In 1983, when the National Research Council first offered guidance on managing the process of risk assessment in the Federal government, it strongly counseled against this approach:

> We recommend that regulatory agencies take steps to establish and maintain a clear conceptual distinction between assessment of risks and consideration of risk management alternatives; that is, the scientific findings and policy judgments embodied in risk assessments should be explicitly distinguished from the political, economic, and technical considerations that influence the design and choice of regulatory strategies.[31]

Over the past 28 years, fidelity to this advice has been sparing. It has long been the practice of EPA staff to infuse risk assessments with policy judgment, and to decline to "explicitly distinguish" where science ends and policy judgment begins.[32]

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[31] NATIONAL RESEARCH COUNCIL, Risk Assessment in the Federal Government: Managing the Process p. 7 (National Academies Press. 1983). See, esp., the non sequitur on p.13: "[S]ince EPA is a health and environmental protective agency, EPA's policy is that risk assessments should not knowingly underestimate or grossly overestimate risks."

[32] U.S. ENVIRONMENTAL PROTECTION AGENCY OFFICE OF THE SCIENCE ADVISOR, *An Examination of EPA Risk Assessment Principles and Practices; Staff Paper, EPA/100/B-04/001* (2004), at http://www.epa.gov/osainter/pdfs/ratf-final.pdf.

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Finally, science is inherently politicized when its role is limited to the support of pre-determined political purposes. These purposes are self-evident in the findings, the definitions, and the way Response Centers and Teams would be organized and function. That is not to say that the political purposes of the bill are necessarily invalid or inappropriate. The issue here is that science is a method of learning; it has its own philosophy, its own institutionalized practices, conceits, and foibles. But it also enjoys a certain credibility and respect gained from widespread belief that it is apolitical. This would be compromised, if not lost, because of the way S. 76 treats science as an instrument for achieving certain political goals rather than for creating knowledge that informs decision-making.

For EPA, the definition of "disease cluster" is so broad that there is no politically credible way for the Agency to set priorities scientifically. Facing a demand that it order the investigation of nearly everything, the Agency would face a stark choice: either designate nearly every claim as a "disease cluster" or focus resources intensively to find true positives. If it does the former, it can make more petitioners superficially happy by acknowledging their distress, but it also can be assured that almost every legislatively deemed "disease cluster" is a false positive of no genuine environmental interest. If it does the latter, however, it is more likely to detect true positives, but be widely criticized for callously neglecting those whose illnesses are real but whose evidence supporting environmental causation is weak.

For this reason alone, I can predict that if enacted S. 76 would not—indeed, it could not—achieve its stated goals. Sadly, I can also predict that substantial public and private resources will be misallocated based on political rather than scientific concerns. Members of Congress can expect to be deluged with appeals that they intervene on behalf of specific constituents. Many will do so, and because S. 76 is written in a way that maximizes EPA's discretion, the Administrator may be unable to resist the pressure to exercise her discretion in politically sensitive ways.[33]

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[33] The Administrator would be subject to both conventional political pressure and internal political pressure from the leaders of her Response Teams, who would report directly to the Administrator. See An Examination of EPA Risk Assessment Principles and Practices; Staff Paper, EPA/100/B-04/001.

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Aside from politics, the strongest factor in resource allocation decisions under S. 76 would be chance. Although surely it was not intended, S. 76 maximizes the role of chance by making the definition of a "disease cluster" so broad that virtually any phenomenon can fit within its bounds. Meanwhile, the definition of a "potential cause of a disease cluster" is so narrow that it resembles the famous story of the drunkard searching in vain under a lamppost for his keys not because he lost them nearby, but because that's where the light is. In combination, these features of S. 76 make it likely that few of the people it is intended to help would actually benefit from it.

To prove this, I wish to note that the data that I used for my eight charts were actually produced by the random number generator in Microsoft Excel. There are, in fact, no disease clusters in my data. Nonetheless, 27 of 100 blocks have greater than the expected number of cases, thus making them legislatively deemed "disease clusters" under the first prong of the definition. Another 36 of 100 blocks easily could be deemed "disease clusters" under the second prong. With creativity, few of the remaining 37 "cases" in my randomly generated sample of 100 would escape designation as part of a "disease cluster." Untold resources would be devoted trying to tease out environmental linkages that do not exist. The people most harmed by this will be those who really are members of a bona fide disease cluster.

Thank you again for the opportunity to testify today. I am happy to address any questions you might have.

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RESPONSES BY RICHARD B. BELZER TO ADDITIONAL QUESTIONS FROM SENATOR INHOFE

Question 1. Would S. 76 give the EPA Administrator limitless discretionary authority over what could be labeled a "disease cluster" and what the "potential causes of a disease cluster" could be?

Response. S. 76 would establish by statute an exceptionally broad definition of "disease cluster" and give the EPA Administrator unlimited discretion to expand it. The proposed statutory definition has no scientific content, and the Administrator would not be required to base any expansion of the definition on science.

In contrast, S. 76 would narrowly define "potential cause of a disease cluster" based on EPA's portfolio of legal authorities and give the EPA Administrator considerable discretion to expand the depth of the definition, if not its breadth. The bill would give her the authority to include environmental pollutants and toxic substances if they appear "in any other form," such as in occupational settings, consumer products, and food. The proposed statutory definition has no scientific content, and the Administrator would not be required to base any expansion of the definition on science.

In circumstances where one of these statutory definitions yielded foolish results, the Administrator would have no authority to waive it.

The statutory definition of "disease cluster" would be exceptionally broad and nonscientific. § 5(4)(A) uses a highly inclusive statistical rule: the occurrence of a "greater-than-expected" number of cases within (a) any group of individuals, (b) any geographic area, or (c) any period of time, would be deemed by law to be a "disease cluster." A single case could constitute a "cluster" if the expected number in any group of individuals, geographic area, or period of time is less than one. Moreover, a greater-than-expected number of cases is a common phenomenon. The modifier "any" permits individuals to be grouped an infinite number of ways. With mildly creative interpretation, no case of disease would escape inclusion within at least one statutorily defined "disease cluster."

The EPA Administrator would have no discretion to overrule the statutory definition of "disease cluster." Nothing in S. 76 allows the EPA Administrator to determine that cases meeting the definition in subparagraph (A) do not merit designation as a "disease cluster," such as for scientific reasons. She could not use new scientific knowledge, no matter how persuasive, to withdraw or rescind a statutorily-defined designation. For example, even proof beyond a reasonable doubt that an observed greater-than-average number of cases is a spurious cluster would be insufficient to overcome the statutory designation because the statutory definition allows no exemptions.

The EPA Administrator would have unlimited discretion to expand the definition of "disease cluster." § 5(4)(B) would allow the EPA Administrator to establish an unlimited number of supplementary criteria defining "disease cluster." Cases need only "meet[] such other criteria, as the Administrator . . . may determine." She also could establish a lower numeric threshold than "greater-than-expected." Incidence need only to be as great as "such number of cases . . . as the Administrator . . . may determine." To be concrete, she would be permitted to endorse a famous folk superstition and decide that any collection of three events constitutes a "disease cluster."

"Potential causes of a disease cluster" would be limited to what EPA regulates, but only in part. The definition in § 5(7)(A)-(G) is limited to pollutants, chemicals, and substances regulated by EPA under existing statutory authorities. Thus, "disease clusters" are presumed to have only environmental origins, and among environmental origins, only those which are regulated by EPA matter.

While the domain is limited to pollutants and substances that EPA regulates, this is true only in part. The catch-all provision in clause (H) includes any other form of environmental pollution or toxic substance that is a known or potential cause of an adverse health effect, including a developmental, reproductive, neurotoxic, or carcinogenic effect (emphasis added).

The boundaries of this text are difficult to plot, but some idea of its unstated breadth can be seen by walking through a couple examples. Benzene is clearly a "potential cause" because it is a regulated pollutant in air, water, and soil, and a regulated constituent in motor gasoline. Clause (H) would enable EPA to expand the domain of "potential cause" to include side-stream and second-hand tobacco smoke, neither of which it otherwise regulates, because both contain benzene in "[an]other "form." Similarly, EPA could decide that fine Bordeaux is a "potential cause of a disease cluster." It contains ethanol in "[an]other form," which EPA regulates under the Clean Air Act. Charting the boundaries of this text ex ante may be impossible because the array of "other forms" cannot be measured. EPA regulates formalde-

hyde, and formaldehyde is present at part-per-billion levels in human breath. Could people be deemed "potential causes of a disease cluster" because they exhale? Much like the Clean Air Act defines air pollutant capaciously ("any air pollution agent or combination of such agents, including any physical, chemical, biological, radioactive (including source material, special nuclear material, and byproduct material) substance or matter which is emitted into or otherwise enters the ambient air" [42 U.S.C. § 7602(g)]), S. 76 specifies no limit to the potential breadth of the "any other form" provision. The only things clearly excluded from the definition are the three most important actual causes of disease—genetics, behavior, and aging. EPA-regulated substances may be involved at cellular levels, but they are exempt because genetics, behavior, and aging are not environmental phenomena.

One of the more troubling aspects of the proposed definition is the adjective "potential" preceding "cause." As I noted in my testimony, only technical feasibility could logically preclude something from being a "potential" cause. Even technical infeasibility is not necessarily a bar under some established regulatory definitions of adverse effect. For example, EPA sometimes considers exposures below the threshold for biological effect to be nonetheless adverse because they may reduce a person's ability to withstand challenges from otherwise non-adverse exposures to other substances. (In this model, everything is adverse because it contains potential risk.)

Question 2. Would S. 76 grant the EPA Administrator an unlimited scope of delegable authorities to Regional Response Centers and Teams?

Response. S. 76 would require the EPA Administrator to delegate certain authorities to Regional Response Centers and Teams. It also would allow her considerable discretion to delegate other authorities. Some authorities could not be delegated. Credibly ascertaining the scope of Response Team authority requires resolving a pair of key uncertainties—what is meant by the mandatory delegated authorities to (1) "investigate suspected or potential disease clusters, environmental pollutants or toxic substances associated with those disease clusters, and potential causes of disease clusters" and (2) "address the potential causes of disease clusters."

The EPA Administrator would be required to delegate certain authorities. § 7(b)(3)(B) would require the EPA Administrator to delegate to Regional Response Centers and Teams authorities that range from promotional ("making guidelines, protocols, data, and other relevant information and expertise available to State and local officials and the public") to investigative ("investigating suspected or potential disease clusters, environmental pollutants or toxic substances associated with those disease clusters, and potential causes of disease clusters") to remedial ("addressing the potential causes of disease clusters").

The scope of these mandatory authorities, particularly the investigative and remedial, is not clear. With respect to the investigative authorities, for example, S. 76 would not explicitly authorize Response Teams to seek subpoenas, issue unilateral orders, or enter private property and collect data without permission. S. 76 also would not explicitly authorize Response Teams to require that persons suspected of being part of a disease cluster involuntarily provide biological or other data. On the other hand, the bill does not forbid Response Teams from undertaking any of these activities, and a plausible case could be made that they "are consistent with achieving the goals of the Act."

Similarly, S. 76 is unclear concerning the scope of the Response Teams' mandatory remedial authorities. A general principle of statutory construction is to assume that a text has practical meaning. Without any authority at all, however, the requirement to "address[] the potential causes of disease clusters" would be an empty one. Thus, the questions unresolved by the text of the bill are (1) what does it mean to "address" a "potential cause of a disease cluster"? and (2) what actions would exceed Response Teams' delegated authority?

It should be noted that the definition of a "potential cause of a disease cluster" implies the identification of a person, firm, or other entity that is a source of a regulated pollutant, chemical, or substance (though "source of a potential cause of a disease cluster" is not defined in the bill). These identifications require no particular scientific evidence, as S. 76 includes no scientific standards for causation. Moreover, the data base EPA would be directed to establish and maintain would not be constrained by scientific standards. It would include every phenomenon the EPA Administrator deemed to be a "disease," and every legislatively or administratively deemed "disease cluster" and "potential cause of a disease cluster."

The EPA Administrator would not be able to delegate certain S. 76 authorities to Response Teams. Several new authorities could not be delegated, including (a) the authority to establish additional criteria for defining "disease clusters"; (b) the authority to "establish criteria for the consideration of petitions" seeking an investigation of a potential disease cluster; (c) the responsibility for acting on such peti-

tions; and (d) the responsibility of compiling and regularly updating the data-base of disease cluster reports and related information.

S. 76 would authorize the EPA Administrator to direct Response Teams to take investigative and remedial actions based on her own judgment ("that the Administrator determines should be investigated or addressed") or because she is dissatisfied, for whatever reason, with the efforts of State and local governments ("that the Administrator determines State and local officials need assistance in investigating or addressing"). Thus, S. 76 would authorize the EPA Administrator to overrule the judgment of State and local government officials with respect to matters that, with rare exception, are not Federal in scale or scope and for which Federal authorities do not have presumptively superior knowledge or insight.

The EPA Administrator may be able to delegate certain S. 76 authorities to Response Teams. § 7(b)(3)(A) directs the EPA Administrator to "establish the scope of activities for Response Teams to ensure that the activities are consistent with achieving the goals of the Act." Nothing in the bill would prohibit her from re-delegating authorities delegated to her by other statutes. For example, the EPA Administrator has certain authorities to seek subpoenas, issue unilateral orders, and enter property to collect data without permission. If she determined that these authorities were needed to "ensure that the activities [of Response Teams] are consistent with achieving the goals of the Act" and re-delegation was not otherwise prohibited, she might be able to authorize Response Teams to undertake them.

It appears that the EPA Administrator could not delegate to Response Teams the authority to decide on their own which investigations to undertake. Among the Response Teams' mandatory directives is to "respond[] rapidly to a petition" by "investigat[ing] suspected or potential disease clusters . . ." and "address[ing] the potential causes of disease clusters . . ." However, Response Teams do not appear to gain any explicit authority to commence these activities absent prior authorization by the Administrator. Still, nothing in S. 76 forbids Response Teams from undertaking these activities prior to or in anticipation of such a decision, nor does the text forbid the Administrator from delegating the authority to conduct provisional investigations prior to making a decision whether to investigate formally.

The EPA Administrator also might be able to delegate to Response Teams the authority to review petitions seeking Federal investigation. Because Response Teams would be incentivized to maximize false positives, they would be conflicted in conducting such reviews. S. 76 forbids direct or indirect conflicts of interest in the selection of Response Team members (§ 7(b)(1)(B)), in the selection of Community Disease Cluster Advisory Committee members (§ 7(c)(3)), and in the procedures for peer review of guidelines for environmental investigations of disease clusters (§ 6(b)(5)), though what constitutes a direct or indirect conflict of interest is not stated. But there is no prohibition against a Response Team reviewing a petition on which it is demonstrably conflicted. This could happen, for example, if one or more Team members had assisted in preparing the petition, which they are implicitly encouraged to do via the provision of technical assistance (see § § 6(B)(3)(iv) and 7(c)(4)).

Question 3. In your opinion, are CDC and NIEHS the more appropriate agencies to deal with disease clusters than EPA? If this work is not properly being done by those organizations, wouldn't it be more appropriate to work on any deficiencies within their framework rather than shift so much authority to EPA?

Response. I regret that I cannot comment on which agency would be "more appropriate" to define and investigate potential disease clusters. Such a judgment lies beyond my technical expertise in risk analysis. What I can say with near certainty, however, is that S. 76 would fail to achieve its stated purposes irrespective of whether its authorities were delegated to EPA, CDC, NIEHS, or another agency.

Failure is assured because S. 76 would subordinate science to politics, and thereby undermine the scientific integrity of every disease cluster investigation. Critical terms defined in S. 76 lack scientific merit, and the absence of a scientific definition for "disease"—even though everything in the bill hinges on it—likely would result in science becoming functionally irrelevant to the program from the outset.

If there are scientific deficiencies in existing CDC and NIEHS programs, they have not been identified. In my testimony, I asked: Is there a government failure for which S. 76 is a reasonable solution? The question was not rhetorical; answering it is an essential prerequisite for rational policymaking in this area.

S. 76 appears to be founded on several crucial assumptions: (1) existing programs operated by CDC and NIEHS have failed scientifically; (2) these institutional failures cannot be remedied, but their programs should not be reduced or terminated; (3) existing CDC and NIEHS programs would be enhanced if a large new program were established under EPA's auspices; and (4) a large new program operated by

EPA would likely succeed scientifically where existing programs operated by CDC and NIEHS have not.

I am aware of no credible evidence supporting any of these assumptions. In addition, no credible evidence was presented at the March 29 hearing. Rather, among proponents of the bill, there appears to be a desire to abandon science because it has not succeeded in reaching what they regard as obvious conclusions.

I encouraged Congress to take a step back, and first make a persuasive case of government failure:

Before agreeing to such a radical change, Congress might want to investigate the extent to which CDC and NIEHS have failed to address disease clusters in a scientifically credible manner.

I stand by that advice.

Question 4. In your testimony you mention that under S. 76, "substantial public and private resources will be misallocated based on political rather than scientific concerns." Do you think that if this or similar legislation were passed it could actually harm the ability of the Federal Government to better understand and address disease clusters due to this misallocation of resources?

Response. If S. 76 or a similar bill were enacted into law, the ability of the Federal Government to better understand and address bona fide disease clusters cannot escape being severely damaged, if not ruined. This damage would result because resources would be reallocated from investigating whether scientifically plausible phenomena are actually disease clusters to hunting down culprits for legislatively deemed disease clusters. The principle victims would be those who belong to real disease clusters. Few resources would be available to investigate their cases because the vast majority of effort would be spent pursuing wild goose chases. S. 76 also would require EPA to produce intentionally misleading risk assessments, thereby destroying the Agency's scientific credibility.

S. 76 would ensure that public and private resources are allocated based on political rather than scientific considerations. The bill invites mischief by lacking either a scientific definition of "disease" or a requirement that EPA define the term scientifically. EPA currently defines as "adverse effects" an increasing wide swath of phenomena, including things that are reversible, transient, or even unobservable. Thus, the EPA Administrator should be expected to define "disease" very broadly. Whatever definition she promulgated, it would be virtually impossible to challenge.

S. 76 would require scarce public resources to be diverted to wild good chases. Government epidemiologists would be so overwhelmed investigating statutory disease clusters that they would not be able to focus on investigating those clusters with the greatest likelihood of being scientifically genuine. Indeed, S. 76 would define the term "disease cluster" in a way that maximizes such "false positives." Because the apparent success of each Response Center and Team would depend on the number of "disease clusters" identified and purported to be associated with one or more "potential causes," each Center and Team would be highly motivated to identify as many false positives as possible. Because politics would govern every material aspect of this new program, Response Centers and Teams inevitably would become rentseeking political actors rather than disinterested scientific investigators.

Fostering wild goose chases misallocates private resources. Entities regulated by EPA because of a legal connection to an enumerated pollutant or substance would be implicitly targeted as a source of a "potential cause of a disease cluster." (Indeed, it seems likely that the definition of a "potential cause" would morph from pollutants or substances enumerated § 5(7) to a "potential source of a potential cause.") For every wild goose chase taken on by government epidemiologists or a Response Team, it would be imprudent for a "potential source of a potential cause" not to attempt to refute such linkages. That is, they would have little choice but to reallocate scarce resources from productive purposes. Though it isn't one of the stated purposes in § 3, it is nevertheless likely that investigations would unleash considerable personal injury litigation of inherently dubious merit.

S. 76 likely would destroy the credibility of EPA risk assessment. Perhaps the most important place where S. 76 would lead to egregious public and private resource misallocation is in §§ 6(c)(4) and 7(b)(3)(C)(iii). These provisions, which appear innocuous on their face, would direct EPA to intentionally exaggerate the alleged relationship between a "disease cluster" and a "potential cause," and by extension, to a "potential source of a potential cause." If EPA were directed to produce and disseminate purposefully biased risk assessments for this program, the scientific integrity of all future Agency risk assessment would be suspect.

At the end of my testimony, I mentioned that my data base of 100 disease cases was produced by the random number generator in Microsoft Excel®. By definition, random cases of disease cannot be part of a "disease cluster." Thus, the EPA Admin-

istrator would be statutorily required to treat at least 63 of my 100 random cases as belonging to one of at least 27 imaginary disease clusters. All resources devoted to identify systemic "causes" for imaginary disease clusters would be wasted. As I testified:

Untold resources would be devoted trying to tease out environmental linkages that do not exist. The people most harmed by this will be those who really are members of a bona fide disease cluster.

Identifying disease clusters is a scientifically complex task. S. 94 would solve the problem of scientific complexity, but it would do so by removing science from the task.

Senator BOXER. Thank you, and I look forward to responding to your critique.

Dr. Gina Solomon, we welcome you, senior scientist at the NRDC.

STATEMENT OF GINA SOLOMON, SENIOR SCIENTIST, NATURAL RESOURCES DEFENSE COUNCIL

Dr. SOLOMON. Thank you, Chairman Boxer and Members of the committee, Senator Crapo.

Good morning. My name is Gina Solomon. I am a practicing physician. I am also a senior scientist at the Natural Resources Defense Council, and I am the director of the Occupational and Environmental Medicine Residency Program at the University of California at San Francisco.

Most health professionals at some point in their career encounter a disease cluster. A disease cluster is a mysterious excess of one or more illnesses such as cancers, birth defects or neurological disease in a particular workplace or particular community over a period of time.

These disease clusters are frightening for communities and often frustrating for scientists because at least in the past, there were limited tools for understanding and solving them.

But disease clusters also hold the potential, especially with the new scientific tools of today and that are emerging as we move forward, these disease clusters may unlock some of the mysteries of chronic disease, including birth defects and cancer.

When I was a clinical fellow at Harvard in the mid–1990's, I learned about a cancer cluster in nearby Woburn, MA. Twelve children in that very small town got leukemia over a period of just a few years and most of them lived on just one street in a certain section of town.

That cluster, like many, was not discovered by a State or Federal Agency or scientists. It was actually discovered by community members who recognized each other when they were sitting waiting in the waiting room at the Dana-Farber Cancer Institute. Ultimately, this cluster was confirmed by scientists and it provided a very key clue because it was the first time that the chemical trichloroethylene or TCE was linked with cancer in humans. An abundance of science since that time has multiply confirmed that link. So that cluster provided a clue that helped science move forward.

This Senate Committee held a hearing, a field hearing in April 2001 in the town of Fallon, NV where within 2 years 11 children were diagnosed with leukemia. Scientists published a paper calculating that a cluster of this magnitude would occur in the United States by pure chance about once every 22,000 years. Like Woburn,

that cluster in Fallon provided clues. Testing in the community revealed that almost 80 percent of community members had urinary tungsten levels above the 90th percentile of people nationwide. Tungsten was not previously thought to be carcinogenic, but it had never really been studied.

This same metal then showed up at high levels in Sierra Vista, AZ, another community affected by a childhood leukemia cluster. Those two findings triggered a much-needed study by the National Toxicology Program which is ongoing today and which may advance the science and help protect public health.

Although it is really difficult to conclusively prove what caused any specific disease cluster, what I want to say today to you is that we can gather invaluable clues and hints from these tragic events, and those can then help us solve the mystery of chronic disease.

Historically, disease clusters have revealed the link between cancer and asbestos, between peripheral neuropathy and hexane, between testicular toxicity and male infertility and DBCP, and between liver cancers and vinyl chloride, just to name a few examples.

All of these chemicals are now well known to be dangerous to humans and one of them, the pesticide DBCP, has actually been banned. All of the other chemicals I mentioned fall under the purview of the Toxic Substances Control Act and they are actually still in widespread use today.

My colleagues and I just released an issue paper documenting 42 disease clusters in 13 States that have been confirmed by investigations, by State or Federal investigations. This issue paper is attached to my written testimony. We found examples such as brain cancer in children and adults at the Acreage in West Palm Beach, FL, which was brought to the attention of this very committee by Senator Bill Nelson a year ago; birth defects in Kettleman City, CA, including 20 babies born over less than 2 years with birth defects and four children with birth defects so severe that they have since died in a town of only 1,500 people.

There are numerous other examples, including the well-known cluster of male breast cancer, as well as childhood cancer and birth defects, at Camp Lejeune, NC, where more than 60 Marines who lived on that base have been diagnosed with male breast cancer. This is an extraordinary and alarming finding. It is almost impossible that that could occur by chance alone and it deserves urgent attention.

Some of the much-needed tools to solve disease clusters are found in S. 76, the legislation known to many as Trevor's Law. This legislation would direct and fund Federal Agencies to swiftly assist State and local officials to investigate community concerns about disease clusters and their causes, but it would also create consistent science-based guidelines for a systematic and team approach to investigating disease clusters.

These guidelines would be developed in collaboration between EPA, the Centers for Disease Control, the National Institute of Environmental Health Sciences, and the National Institutes of Health. They would address these issues of statistical significance that are often so difficult in disease clusters.

This bill would also set up local advisory committees to improve outreach and involvement of community members. This is essential to build trust within the community, but also to learn from the community because it is often community members who have pointed out the critical clues to unlocking these clusters.

The other thing that S. 76 would do is encourage deployment of powerful new scientific tools like toxicogenomics, toxicity pathway screening, and even analytical chemistry techniques that can screen for hundreds or even thousands of chemicals in people.

So I am thinking today of the residents of all of the many dozens of communities across the country that are affected by confirmed disease clusters and the hundreds of communities where residents are self-identifying clusters and looking for help. These people have suffered through illness and uncertainty, through hope and loss, and they fought for answers, and in most cases have not received them.

But it is not too late for these communities and others like them. We now have the scientific tools and there is an opportunity to improve and systematize our approach to disease clusters so these communities get the support they need and the answers they seek.

Thank you.

[The prepared statement of Dr. Solomon follows:]

Testimony of

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OVERSIGHT HEARING ON DISEASE CLUSTERS AND ENVIRONMENTAL HEALTH

Submitted in writing to the
Committee on Environment and Public Works
United States Senate

March 29, 2011

Testimony of Gina Solomon, M.D., M.P.H. March 29, 2011

Thank you for the opportunity to submit written testimony to this Committee. I am Gina Solomon, a Senior Scientist at the Natural Resources Defense Council (NRDC) and an Associate Clinical Professor of Medicine at the University of California, San Francisco (UCSF) where I am also the Director of the UCSF Occupational and Environmental Medicine Residency Program. NRDC is a national, nonprofit, public interest organization dedicated to protecting human health and the environment, with over 1.2 million members and online activists in all 50 states. I am a practicing physician and am Board certified in both internal medicine and occupational and environmental medicine, and I have done research and education for over a decade on the links between disease and the environment.

Scientists estimate that of the 30 years added to our average life expectancy since 1900, 25 are attributable to public health programs -- primarily programs such as drinking water disinfection, sewage treatment, better nutrition, safer handling of food, and improved tracking of disease. Tracking of disease is fundamental to saving lives because it allows agencies to identify populations at risk and rapidly respond to outbreaks, clusters, and emerging threats. Investigation of disease and exposure allows scientists to establish relationships between hazards and disease, thereby guiding prevention strategies.

Since the conquest of old scourges such as smallpox, plague, polio, and leprosy, our national public health system has begun to stagnate. Our public health system needs to better address current threats such as chronic disease and environmental health. Currently the Centers for Disease Control and Prevention (CDC) tracks and rapidly responds to outbreaks of fifty acute infectious diseases. This is a fantastic tracking system, but there is no parallel for most chronic non-infectious diseases.

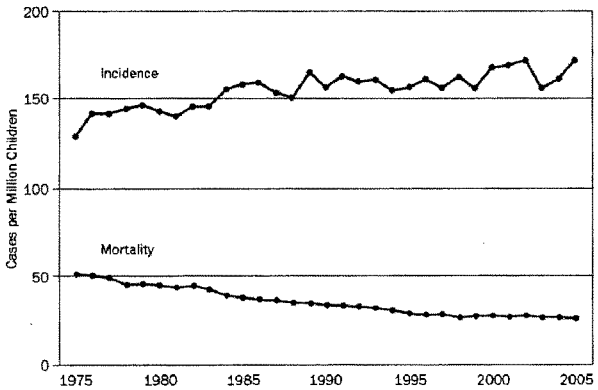
Chronic disease is responsible for four out of five deaths in the U.S. today, and the suffering of 133 million people per year in the United States. Asthma, developmental diseases such as birth defects or neurobehavioral disorders, degenerative neurological diseases such as Parkinson's and Alzheimer's, diabetes, and cancer are all chronic diseases. According to the U.S. Centers for Disease Control and Prevention (CDC), almost half of all Americans are living with chronic disease, which now accounts for 75% of U.S. health care costs.[1] Many chronic diseases are on the rise, and many are preventable. There is also increasing evidence that many of these illnesses may be linked to exposures in our environment.

Numerous chronic diseases and cancers are on the rise, including:

- Leukemia, brain cancer, and other childhood cancers, which have increased by more than 20% since 1975, even though – thanks to improved medical treatment – deaths have decreased (see Figure 1 below).[2]
- Breast cancer rates went up by 40% between 1973 and 1998.[3] While breast cancer rates have declined a bit recently, a woman's lifetime risk of breast cancer is now one in eight, up from one in ten in 1973.

- Asthma, which approximately doubled in prevalence between 1980 and 1995 and remains at the elevated rate.[4]
- Cryptorchidism (undescended testes) which has increased 200% during the 1970's and 1980's.[5]
- Autism, the diagnosis of which has increased by more than 10-fold over the last 15 years.[6]

FIGURE 1 **Cancer Incidence and Mortality for Children Under 20**



Cancer is the second most common cause of death for Americans under the age of 20. The incidence of childhood cancer increased more than 20% between 1975 and 1990. Since 1990, the incidence has remained roughly at this elevated rate. Although improved treatment options have led to a decline in the percentage of children who die from cancer, the percentage of children who are diagnosed with leukemia, brain, and other cancers has increased.

Source: U.S. EPA. America's Children and the Environment. *www.epa.gov/envirohealth/children*
Data: National Cancer Institute, Surveillance, Epidemiology and End Results Program

These nationwide statistics are alarming but can disguise the specific suffering experienced by individuals and communities. When I was a Clinical Fellow at Harvard in the mid-1990's, I learned of a major investigation into a childhood leukemia cluster in Woburn, Massachusetts. Twelve children in that small community developed leukemia over a period of ten years – an extraordinarily high rate of this rare disease. Did the state cancer registry identify this cluster of childhood leukemia, and link it to contamination of the water supply with the chemicals trichloroethylene and perchloroethylene? No. This cluster was discovered by mothers sitting with their children in the waiting room at the Dana Farber Cancer Center and recognizing other families from their neighborhood. Only later was this cluster confirmed and investigated by scientists at Harvard and state agencies.

This Senate Committee held a field hearing in April of 2001 in the town of Fallon, Nevada, where from 1999 to 2001, 11 children were diagnosed with leukemia. Scientists calculated that a cluster of this magnitude would be expected to occur in the United States by chance about once every 22,000 years.[7] The area had significant local environmental contamination with elevated levels of radioactivity, tungsten and arsenic in the water supply or in the community. The Fallon case came more than a decade after the Woburn case. This time, surely the public health system identified the problem?

Unfortunately, no. Nevada didn't even have a cancer registry at that time. Again, it was families in the town that first brought the problem to public attention.

In the summer of 2001, the Senate EPW committee again held a field hearing, this time on Long Island New York, to investigate the elevated rates of breast cancer in that area.[8] At that hearing, Senator Reid stated that "The time is long overdue for the Federal Government to craft an orderly approach for rapidly and effectively responding to the needs of communities for support and guidance in identifying and addressing disease clusters." (Transcript p.6) A full decade later, the time is even more overdue, and I am encouraged by Senators Boxer and Crapo's efforts to remedy this problem.

The last time I appeared before this committee, one year ago on March 17, 2010 at a hearing on children's health and the environment, Senator Bill Nelson came to the hearing to plead for help in the investigation into the causes of a childhood brain cancer cluster at The Acreage in Palm Beach County, Florida.

Although all of these high-profile cancer clusters were ultimately investigated, and various environmental problems were identified in most of the communities, the exact causes of all of these clusters were never fully understood. Disease clusters can be frustrating in that way. Scientists and researchers often have a hard time getting to the bottom of what's going on. Worse still, the well-known cancer clusters I have listed above are just the tip of the iceberg.

My colleagues and I just released an issue paper documenting 42 disease clusters in 13 states.[9] It is attached as part of my testimony. We documented confirmed clusters of:

- Testicular cancer in Prairie Grove, Arkansas, including three cases in 14 year-old boys, in a town of only 2,500 people.
- Birth defects in Kettleman City, California, including twenty babies born over less than two years with birth defects, and four children born with birth defects so severe that they have since died, in this town of only 1,500 people.
- Amyotrophic Lateral Sclerosis (Lou Gehrig's disease) – a very rare disease - in Herculaneum, Missouri, a town affected by a major lead smelter and decades of pollution.
- Multiple sclerosis (MS) in Wellington, Ohio, where residents are three-times more likely to develop MS than in the rest of the country, a disease whose causes are unknown but are thought to involve a combination of genetic and environmental causes.
- Polycythemia Vera, a rare and severe blood disorder, with four cases occurring on one road in Eastern Pennsylvania.
- Male breast cancer, childhood cancer, and birth defects in Camp Lejeune, North Carolina. More than 60 men who lived on that base have been diagnosed with breast cancer – an extraordinary finding, and one which deserves urgent attention.

Environmental Causes of Cancer

Although it is difficult to conclusively prove what caused any specific disease cluster, we can gather invaluable clues and hints from these tragic events. The Woburn cluster, for example, provided a key clue linking trichloroethylene (TCE) with cancer in humans – something that has since been confirmed in multiple studies. The cluster in Fallon, Nevada also provided important scientific clues. Biological sampling in Fallon revealed community-wide exposure to tungsten with almost 80% of the participants having urinary tungsten levels above the 90th percentile in the National Health and Nutrition Examination Survey (NHANES), and the median tungsten levels were almost 10-fold higher than the 1999 NHANES median level for tungsten. Tungsten was not previously thought to be carcinogenic, but had never been adequately studied. This same metal subsequently showed up at elevated levels in Sierra Vista, Arizona, another community affected by a childhood leukemia cluster. This tungsten is now undergoing testing by the National Toxicology Program to better understand its potential health effects.[10] Other disease clusters have revealed the cancer-causing properties of asbestos, the profound peripheral neuropathy caused by exposure to n-hexane, the complete wipe-out of sperm production from the pesticide DBCP (dibromochloropropane), and the liver cancers caused by vinyl chloride. All of these chemicals are now well-known to be human health hazards, and one of them – the pesticide DBCP – has been banned. The other chemicals, which fall under the purview of the Toxic Substances Control Act (TSCA), are still in widespread use today.

There is good reason to believe that only a small fraction of the links between the environment and disease has been revealed to date. Although there has been much focus on the genetic causes of disease, the scientific consensus has shifted to the position that most diseases are primarily caused by a combination of genetic and environmental factors. For example, a study of nearly 45,000 twins published in the New England Journal of Medicine evaluated the relative importance of genetic and environmental factors in cancer.[11] If the cancers were primarily genetic, identical twins (which share the same genome) would have more similar cancer patterns than fraternal twins (which only share the genetics of any siblings). The bottom line of this important study was that the vast majority of cancers are environmental rather than genetic. Statistically significant genetic effects were only seen for three cancers -- prostate, colorectal, and breast. In the case of breast cancer, less than one-third of the risk was due to inherited factors (potential range 4-41%); that means that about 70% of the remaining risk of breast cancer is due to environmental factors. For other cancers, the environmental component was even larger. The same principle is true for most other diseases, where environment is turning out to be more important than genetics.

Yet people keep citing a 30 year old paper from a British statistician that estimated that only 2 percent of cancers are environmental, and 4 percent are occupational.[12] That number was largely based on cancers from asbestos, and does not reflect the myriad other environmental causes of cancer and other diseases, nor does it reflect the knowledge from newer studies such as the New England Journal of Medicine twin study cited above.

If you ask me to tell you exactly what percent of cancers, birth defects, or neurological disorders are due to environmental factors, it would be difficult. That's because there's a

lot of work that still needs to be done to identify the list of specific environmental causes of cancer that go beyond the British statistician's narrow estimate and that add up to the 70 percent or more from the New England Journal of Medicine. Some of these factors are well-known (such as cigarette smoke), others are partially understood (such as the lists of carcinogens that occur naturally or that are in manmade substances), and others have yet to be discovered. In addition, because of the interactions between chemicals, as well as between chemicals and genes, the sum of causes will add up to more than 100 percent.[13] The big problem is that the rates of some cancers – including childhood cancers – and other diseases, are rising, so we don't have the luxury of a lot of time. People are getting sick and suffering, so we need to move quickly and use whatever clues we can to understand what's going on.

The President's Cancer Panel released a landmark report in April 2010 entitled, "*Reducing Environmental Cancer Risk: What we can do now*".[14] The report included the following statements:

> *Approximately 41 percent of Americans will be diagnosed with cancer at some point in their lives, and about 21 percent will die from cancer. The incidence of some cancers, including some most common among children, is increasing for unexplained reasons... A growing body of research documents myriad established and suspected environmental factors linked to genetic, immune, and endocrine dysfunction that can lead to cancer and other diseases.*
>
> *Action is possible at several levels: conducting scientific research to enhance our understanding and by extension, our ability to prevent and respond to environmental carcinogens; enforcing existing policies and regulations that protect workers and the public; implementing policy and regulatory changes that support public health and reduce the burden of cancer; and taking personal action.*"

Learning lessons from the disease clusters in communities around the country allows for the possibility of some good emerging from something that is otherwise very bad. I'm sure that every parent of a child with cancer would do whatever they can to help – not only their own child – but also help prevent other parents and children from having to go through such an ordeal by identifying causes and preventing future disease.

Difficulties Identifying Environmental Carcinogens

Most of the chemicals in use today are not tested for their potential to cause cancer or other diseases. Of the approximately 85,000 chemicals on the market today, an estimated 62,000 were 'grandfathered' in without any testing requirements under the Toxic Substances Control Act (TSCA). In the case of new chemicals, most have not been tested for toxicity, since the EPA cannot require testing without specific reasons, so the vast majority of chemicals that are introduced onto the market have not been tested in the laboratory.

For generations, there has been world-wide consensus that it is unethical to intentionally dose humans with toxic chemicals, if the exposures may be harmful. So the advancement of the science of human disease relies on so-called "observational studies" – studies of people who are sick with a given disease, compared with those who are not; studies of people who are more highly exposed to certain contaminants, compared with those who are not. These studies are difficult, often expensive, and they take time. Sometimes they get mired in uncertainty because there are simply not enough people in a given group to generate statistically significant findings; sometimes there are simply too many things going on at once, and it's not possible to tease apart all the potential factors; sometimes nothing turns up in the testing because we aren't testing for the right thing.

When you think about it, it's amazing that any environmental carcinogens at all have been identified from observational studies. Those that have are usually due to one of the following three factors:

1) Workers or communities who have been exposed to high doses of a few chemicals for years, and have experienced elevated rates of disease (such as diesel exhaust, trichloroethylene, benzene, and methylene chloride);
2) The disease is very rare (such as mesothelioma and asbestos, angiosarcoma and vinyl chloride, clear cell carcinoma and diethylstilbesterol);
3) The chemical is very potent (such as tobacco smoke, radiation, 2-naphthylamine, and dioxin).

Even if uncertainties remain in the analysis of the clusters, they contribute valuable information to better understand and prevent cancer. And that new scientific information is invaluable for protecting public health and preventing future disease.

Solutions and Recommendations

Fortunately, there are some tools that can help improve the science of cluster investigations, and that can also help engage communities in coming to a better understanding of the causes of disease clusters.

First, there are new scientific tools, including the rapidly advancing science of biomonitoring that allows detection of numerous chemicals in the human body; rapid improvements in toxicogenomics and metabolomics, that allow researchers to discern the effects of chemicals on the genes and metabolic systems within the body; and improvements in screening of chemicals that will help improve detection of hazards before they come on the market, and will allow further evaluation of agents of possible concern in clusters.

Second, there is the potential for greatly improved coordination between agencies. To date, cluster investigations have frequently been conducted by county or state health departments with limited assistance, or by the Agency for Toxic Substances and Disease Registry (ATSDR) which is expert at some aspects of this work but not others. Bringing agencies such as the EPA into the collaboration will be important to allow all areas of expertise to be brought to bear on the problem. Also, having a set of guidelines for cluster

investigations will help to assure that all communities that truly need assistance will get the attention they need, and will help to focus the federal efforts where they will be most useful.

Third, there is an opportunity to bring community resources into these investigations in a more formal way. As I noted above, the people who detected the problem in Woburn, Massachusetts were the parents of children with leukemia. The people who identified the testicular toxicity of DBCP were workers who realized that none of them had been able to father children. In case after case, the clues to help solve these mysteries have resided in the knowledge and experience of the affected communities. So the creation of formal Community Advisory Committees will be critical to gathering better information and to better communication and resolution of these difficult problems.

Disease clusters demonstrate the need for:

1. Directing and funding federal agencies to swiftly assist state and local officials, and investigate community concerns about potential disease clusters and their causes. Good cluster investigations require the creation of consistent guidelines for a systematic and integrated approach to investigating disease clusters; improved coordination between various agencies at the federal, state, and local level; and local advisory committees that can help improve the outreach to and involvement of community members.
2. Reducing or eliminating known toxic releases into air, water, soil and food through strong science-based environmental controls and tough enforcement of those requirements; and
3. Requiring chemical manufacturers to ensure the safety of their products. Comprehensive chemical policy reform includes testing of all untested chemicals in commerce, requiring manufacturers to prove safety, and the use of an approach that protects children and other vulnerable populations from cumulative risks.

I am thinking of the residents of Woburn, MA, Fallon, NV, Tallevast, FL, Dickson, TN, Midlothion, TX, Camp Lejeune, NC, Prairie Grove, AK, Midland, MI, Kettleman City and Carlsbad, CA, Millsboro, DE, Amelia, LA, Herculaneum, MO, Libby MT, Clyde, OH, Wilkes-Barre, PA, and many dozens of other towns across the country. These people have suffered through illness and uncertainty, hope and disappointment. They have fought for answers, and in most cases, have not received them. It's not too late for these communities and others like them. There's still an opportunity to improve and systematize our approach to these disease clusters so these communities get the attention they need and maybe also the answers they seek.

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[1] http://www.cdc.gov/nccdphp/publications/index.htm

[2] Tracey J. Woodruff, et al., America's Children and the Environment, (Washington, DC: U.S. Environmental Protection Agency, 2008).

[3] Holly L. Howe, et al., "Annual Report to the Nation on the Status of Cancer (1973 through 1998), Featuring Cancers with Recent Increasing Trends," Journal of the National Cancer Institute, 93, no. 11 (June 2001): 824–42.

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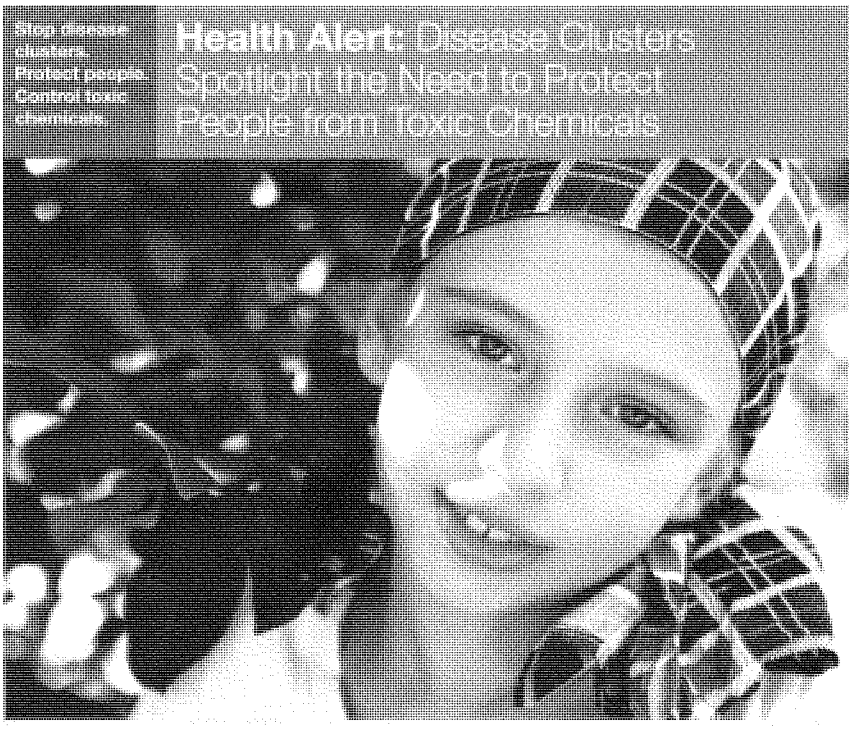

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NRDC
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NDCA
National Disease Clusters Alliance
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About NRDC
The Natural Resources Defense Council (NRDC) is an international nonprofit environmental organization with more than 1.3 million members and online activists. Since 1970, our lawyers, scientists, and other environmental specialists have worked to protect the world's natural resources, public health, and the environment. NRDC has offices in New York City, Washington D.C., Los Angeles, San Francisco, Chicago, Livingston, Montana, and Beijing. Visit us at www.nrdc.org.

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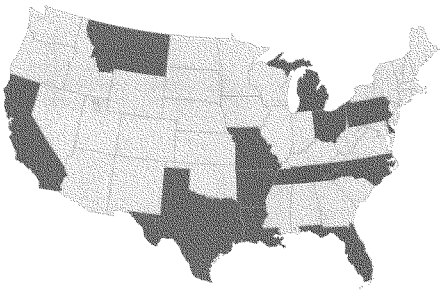
Stop disease clusters. Protect people. Control toxic chemicals.

Health Alert: Cancer Clusters, Disease, and the need to Protect People from Toxic Chemicals

An unusually large number of people sickened by a disease in a certain place and time is known as a 'disease cluster'. Clusters of cancer, birth defects, and other chronic illnesses have sometimes been linked to chemicals or other toxic pollutants in local communities, although these links can be controversial. There is a need for better documentation and investigation of disease clusters to identify and address possible causes. Meanwhile, toxic chemicals should be identified and controlled through reform of the Toxic Substances Control Act, so these chemicals don't pollute communities and sicken people.



Due to a lack of resources, the limited statistical power in doing investigations of small communities or rare diseases, and a lack of knowledge about exposures, it has been difficult for state and federal agencies to shed light on most disease clusters and their causes. There is a need for better documentation and investigation of disease clusters and their causes. Senators Barbara Boxer (D-CA) and Michael Crapo (R-ID), have introduced legislation that would address at least some of these problems, by ensuring that the Environmental Protection Agency and other federal agencies can, and will, provide the resources necessary for investigations and other support, where state-level expertise or resources are not available.

In the United States, the Toxic Substances Control Act (TSCA) is the primary law that ensures the safety of industrial chemicals used in commercial and consumer products by regulating their use, from manufacturing to eventual disposal. Unfortunately, because of major flaws in the law the regulation of toxic chemicals in the United States has been a failure. As a result, dangerous chemicals, including those known to cause cancer, birth defects, and learning and developmental disabilities are still used widely with few, if any, restrictions. These include many of the chemicals which have been linked to some disease clusters, including TCE, dioxins, and asbestos. Better testing and regulation of the thousands of toxic chemicals

that can come into our homes, our workplaces and our schools is critical for reducing the cancer and other chronic illnesses and disease that affect our communities.

An issue paper about disease clusters in particular states was developed by the Natural Resources Defense Council and the National Disease Cluster Alliance to inform people about disease clusters affecting communities across the country. All of these disease clusters have been confirmed or are currently undergoing an official investigation, though in most cases the cause of the cluster is unknown.

The disease clusters spotlighted in the factsheet series illustrate the need for:

1. Directing and funding federal agencies to swiftly assist state and local officials, and investigate community concerns about potential disease clusters and their causes;

2. Reducing or eliminating toxic releases into air, water, soil and food through stronger environmental controls and tough enforcement of those requirements; and

3. Requiring chemical manufacturers to ensure the safety of their products.

Methods

Thirteen states, Texas, California, Michigan, North Carolina, Pennsylvania, Florida, Ohio, Delaware, Louisiana, Montana, Tennessee, Missouri, and Arkansas, were chosen for analysis based on the occurrence of known clusters in the state, geographic diversity, or community concerns about a disease cluster in their area. From May 2010 to July 2010, clusters in each state were identified by searching the websites Google, Proquest, Pubmed, and Web of Science using the name of the state and the words "cluster", "cancer cluster", or "birth defects cluster" as search terms.

The criteria for inclusion in the search were:

1. The clusters occurred after 1976, when TSCA legislation was initially passed and was intended to regulate toxic chemicals.

2. The cluster was confirmed or is currently being investigated by a federal, state or local government agency. Clusters were also included if they were identified by academic researchers and published in a peer-reviewed journal. Sources for each of the described clusters are available on NRDC's website.

When possible, contaminants discussed in investigations and news reports are identified, though in most cases no definitive cause for the cluster has been identified. In addition, industries, hazardous waste sites, or other locations which were identified by community members as being of concern are also referenced in the cluster description.

All the fact sheets were externally peer-reviewed by scientists and community members in the National Disease Clusters Alliance.

Stop disease clusters.
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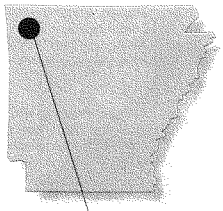
Disease Clusters in **Arkansas**

An unusually large number of people sickened by a disease in a certain place and time is known as a 'disease cluster'. Clusters of cancer, birth defects, and other chronic illnesses have sometimes been linked to chemicals or other toxic pollutants in local communities, although these links can be controversial. There is a need for better documentation and investigation of disease clusters to identify and address possible causes. Meanwhile, toxic chemicals should be identified and controlled through reform of the Toxic Substances Control Act, so these chemicals don't pollute communities and sicken people.

Investigations of disease clusters are complex, expensive, and often inconclusive, partly due to limitations in scientific tools for investigating cause-and-effect in small populations. Preventing pollution is the best way to avoid creating additional disease clusters. Strategies for prevention include: (1) Directing and funding federal agencies to swiftly assist state and local officials, and investigate community concerns about potential disease clusters and their causes; (2) Reducing or eliminating toxic releases into air, water, soil and food through stronger environmental controls and tough enforcement of those requirements; and (3) Requiring chemical manufacturers to ensure the safety of their products.

Arkansas has suffered from at least one confirmed disease cluster. Although environmental contaminants are implicated, experts have been unable to pinpoint an exact cause. Regardless of the cause, disease clusters can devastate communities with anxiety and emotional and financial difficulties including high medical costs and lowered property values, as well as the tremendous burden of the disease itself.



LOCATION:
PRAIRIE GROVE, WASHINGTON COUNTY
DISEASE:
Testicular cancer

LOCATION: **Prairie Grove, Washington County**
DISEASE: **Testicular cancer**
In 2001, the Arkansas Department of Health identified a cluster of testicular cancer from 1997 to 2001; three of the cases were in 14-year-old boys. Though no cause was identified, the town of 2,500 people lies near a now-closed nuclear reactor, a low-level radioactive landfill, a poultry plant, and a manufacturer of poultry feed containing arsenic. Local residents were concerned that the poultry factories were contributing to the high rates of cancer and other health problems because arsenic-contaminated chicken manure was used as fertilizer and spread on fields beside schools and homes in Prairie Grove. In 2004, residents sued one of the poultry farms and the poultry feed manufacturer for spreading the contaminated manure throughout Prairie Grove. However, the court did not rule in favor of the residents and the true cause of the cluster has never been determined.

Stop disease clusters. Protect people. Control toxic chemicals.

Disease Clusters in **California**

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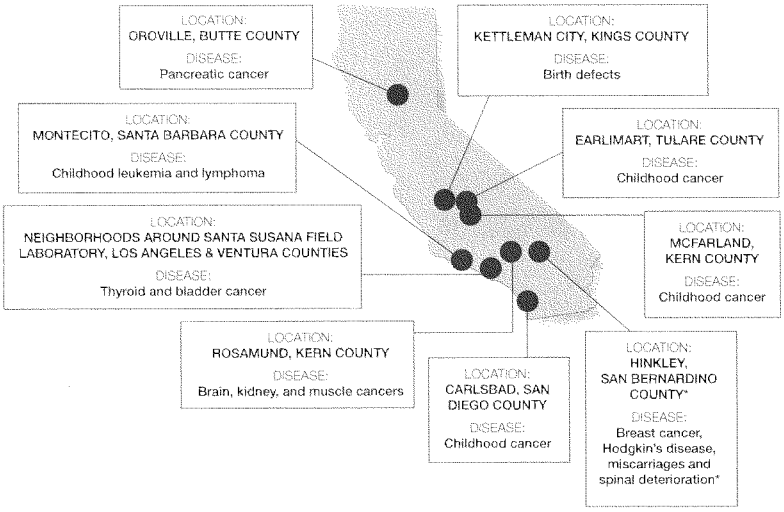
California has suffered from at least eight confirmed disease clusters. Most have afflicted children with cancers or birth defects. Although environmental contaminants are implicated, experts have been unable to pinpoint an exact cause. Regardless of the cause, disease clusters can devastate communities with anxiety and emotional and financial difficulties, including high medical costs and lowered property values, as well as the tremendous burden of the disease itself.



LOCATION: **Carlsbad, San Diego County**
San Diego County health officials are currently investigating a possible childhood cancer cluster in Carlsbad. A community group, Carlsbad Cancer Connection, has identified homes built on pesticide-contaminated farmland and a nearby power plant as being potentially related to the cancer cluster.

LOCATION: **Earlimart, Tulare County**
The California Department of Health Services (DHS) concluded there was a cluster of childhood cancer cases diagnosed between 1986 and 1989 in Earlimart. All of the Earlimart children with cancer were from families of farm workers.

LOCATION: **Kettleman City, Kings County**
The California Department of Public Health identified a birth defects cluster in Kettleman City from 2007 to 2010. Children were born with cleft palates and other severe birth defects such as facial deformities, heart and brain problems, and limb defects. Four of those children have since died. Many residents blame the hazardous waste disposal facility, the largest in the western United States, that is just 3.5 miles southwest of town.

LOCATION: **McFarland, Kern County**
DHS confirmed that McFarland has suffered from a childhood cancer rate three to four times higher than normal. Prior to 1990, there was significant under reporting of the amount of restricted pesticide use, which may have included known cancer-causing compounds. This under reporting has stymied efforts to pinpoint environmental causes of this disease cluster.

LOCATION: **Montecito, Santa Barbara County**
DHS confirmed a cluster of childhood leukemia and lymphoma in Montecito from 1981 to 1988 at a rate 5 times higher than would be expected during an eight-year period in a city of its size. DHS has been unable to pinpoint a specific environmental cause. Community members were concerned about possible health effects from electromagnetic fields (EMF) levels coming from the transformer station near the elementary school and DHS did find elevated EMF at the school.

LOCATION: **Oroville, Butte County**
DISEASE: **Pancreatic cancer**
Oroville had a cluster of pancreatic cancers from 2004 to 2005, confirmed by researchers at the California Cancer Registry. A chemical explosion and fire that occurred in 1987 at the Koppers wood treatment facility in town has been investigated as a possible cause, as well as other Koppers facilities that have historically contaminated residential wells with pentachlorophenol and other toxic chemicals.

LOCATION: **Rosamund, Kern County**
The Kern County Health Department and DHS identified a cluster of childhood cancer in Rosamond. During the years 1975 to 1984, eight cases of childhood cancer occurred in Rosamond. Four of those cases were medulloblastoma (a rare type of brain cancer); two were rhabdomyosarcomas (a rare muscular cancer), one Hodgkin's lymphoma, and a Wilm's tumor (childhood kidney cancer). Although DHS identified several locations in Rosamond that were contaminated with dioxins, furans, and other chemicals that cause cancer, they did not identify how the children could have been in contact with these chemicals.

LOCATION: **Neighborhoods around Santa Susana Field Laboratory, Los Angeles & Ventura Counties**
A 1991 study by DHS confirmed a cluster of bladder cancers in areas in Los Angeles County closest to the Santa Susana Field Laboratory (SSFL) in nearby Ventura County. Additionally, a study performed by researchers at the University of Michigan found that risk of thyroid cancer was linked to distance from SSFL, a notorious source of widespread radioactive and chemical contamination. Currently, the California Department of Toxic Substances Control is overseeing an investigation and cleanup of contaminated soil and groundwater at the site.

★ LOCATION: **Hinkley**
DISEASE: **Breast cancer, Hodgkin's disease, miscarriages and spinal deterioration**
In the case made famous by the film, Erin Brockovich, community members won a $333 million settlement from Pacific Gas & Electric (PG&E) in 1996. Hexavalent chromium leached from PG&E ponds into the town's drinking water supply and community members experienced health effects, such as breast cancer, Hodgkin's disease, miscarriages and spinal deterioration. Although the California Cancer Registry has completed three studies and concluded that cancer rates were not elevated from 1988 to 2008, other state officials have noted that the population is too small for a cancer survey to yield meaningful results. This case is an example of why disease clusters are difficult to prove.

Stop disease clusters.
Protect people.
Control toxic chemicals.

Disease Clusters in **Delaware**

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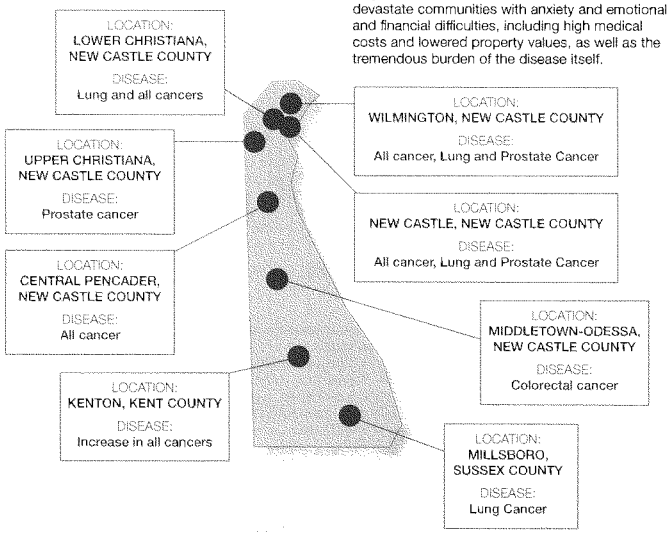
Investigations of disease clusters are complex, expensive, and often inconclusive, partly due to limitations in scientific tools for investigating cause-and-effect in small populations. Preventing pollution is the best way to avoid creating additional disease clusters. Strategies for prevention include: (1) Directing and funding federal agencies to swiftly assist state and local officials, and investigate community concerns about potential disease clusters and their causes; (2) Reducing or eliminating toxic releases into air, water, soil and food through stronger environmental controls and tough enforcement of those requirements; and (3) Requiring chemical manufacturers to ensure the safety of their products.

In 2008, the Delaware Department of Health and Social Services published a unique report which identified eight cancer clusters in the state. This was the result of a sub-county level analysis of cancer registry data from the years 2000 through 2004. The analysis was limited to four types of cancer and all cancer cases only. This process is unique in that Delaware is required to release publicly the information from its cancer registry and only one of the clusters was brought to the attention of the state by concerned residents. Although environmental contaminants are often suspected and sometimes implicated, in this instance the investigation did not attempt to determine the cause of the disease clusters. Regardless of the cause, disease clusters can devastate communities with anxiety and emotional and financial difficulties, including high medical costs and lowered property values, as well as the tremendous burden of the disease itself.



LOCATION: **Lower Christiana, New Castle County**
DISEASE: **Lung and all cancers**
State officials found that Lower Christiana had higher rates of all cancers and also identified a cluster of lung cancer with rates above the state average from 2000-2004. The state investigation did not include research into possible environmental causes of the cluster.

LOCATION: **Upper Christiana, New Castle County**
DISEASE: **Prostate cancer**
A cluster of prostate cancer in Upper Christiana was confirmed by state officials who found rates of this cancer were 45 percent higher than the state average from 2000 to 2004. State officials did not look for an environmental link to the increase in prostate cancer.

LOCATION: **Central Pencader, New Castle County**
DISEASE: **All cancer**
State officials found that Central Pencader had a higher rate of all types of cancer compared to the state average from 2000 to 2004. State health officials did not investigate any specific environmental link to the increase in cancer rates.

LOCATION: **Middletown-Odessa, New Castle County**
DISEASE: **Colorectal cancer**
State health officials found that there was a cluster of colorectal cancer from 2000 to 2004 in Middletown-Odessa where rates were 45 percent higher than the state average. The state investigation did not include research into possible environmental causes of the cluster.

LOCATION: **Wilmington, New Castle County**
DISEASE: **All cancer, lung and prostate cancer**
State officials reported that from 2000 to 2004 there were elevated rates of all cancer and, in particular, identified a cluster of lung and prostate cancer with rates in the area higher than the state average. The state investigation did not include research into possible environmental causes of the clusters.

LOCATION: **New Castle, New Castle County**
DISEASE: **All cancer, lung and prostate cancer**
From 2000 to 2004, state health officials discovered that New Castle had above average rates of all cancers and specifically identified clusters of lung and prostate cancer with rates higher than the state average. The state investigation did not include research into possible environmental causes of the clusters.

LOCATION: **Kenton, Kent County**
DISEASE: **All cancer**
The state health department found a higher rate of all types of cancer in Kenton from 2000 to 2004. The state investigation did not include research into possible environmental causes of the cluster.

LOCATION: **Millsboro, Sussex County**
DISEASE: **Lung Cancer**
State officials identified a cluster of lung cancer in Millsboro from 2000-2004. The state investigation did not include research into possible environmental causes of the clusters. However, the state investigation into possible disease clusters was prompted by local residents who were concerned about contamination at the nearby coal ash landfill operated by the Indian River Power Plant. Elevated levels of arsenic, chromium, and thallium in groundwater have been reported to be above federal primary drinking water standards. Arsenic is associated with increased risk of lung cancer.

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Disease Clusters in **Florida**

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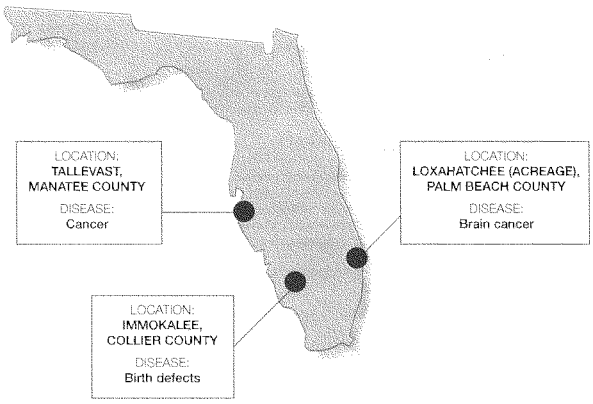
Florida has suffered from at least three confirmed disease clusters, two of which afflicted children. Although environmental contaminants are implicated, experts have been unable to pinpoint an exact cause. Regardless of the cause, disease clusters can devastate communities with anxiety and emotional and financial difficulties, including high medical costs and lowered property values, as well as the tremendous burden of the disease itself.



LOCATION: **Loxahatchee (Acreage), Palm Beach County**
DISEASE: **Brain cancer**
The Florida Department of Health has confirmed a pediatric brain cancer cluster in a rural community called The Acreage. A community group has counted 18 children with brain cancer and 3 children with brain cysts since 1996. Some residents have blamed Pratt & Whitney, the rocket and jet engine company located nearby, which has been responsible for leaks and spills of chemicals, such as solvents and pesticides on its 7,000 acres for the last 30 years.

LOCATION: **Immokalee, Collier County**
DISEASE: **Birth defects**
In 2004, the National Institute of Occupational and Safety and Health and state health officials in North Carolina and Florida identified three women employed by AgMart who gave birth to children with birth defects during a seven week period. All six parents worked on the same tomato fields in North Carolina and Florida. Exposure to pesticides was a suspected cause.
In 2005, the North Carolina Department of Agriculture and Consumer Services alleged that Ag Mart had 369 pesticide violations. These violations included (1) the use of six pesticides classified by the Environmental Protection Agency as among the most dangerous to workers and (2) applying a dangerous pesticide three times more often than allowed by law.

LOCATION: **Tallevast, Manatee County**
DISEASE: **Cancer**
In 2008, the Agency for Toxic Substances and Disease Registry determined that prior long-term use of groundwater for drinking and other household purposes in Tallevast, Florida was a public health hazard. Residents who drank the most highly contaminated groundwater every day for 42 years were more at risk for developing kidney cancer, liver cancer, leukemia, and lymphoma. From 1962 to 1996, the American Beryllium Company manufactured machine parts in the community. During the manufacturing process, cancer-causing solvents such as trichloroethylene were improperly disposed of, resulting in groundwater contamination.

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Disease Clusters in **Louisiana**

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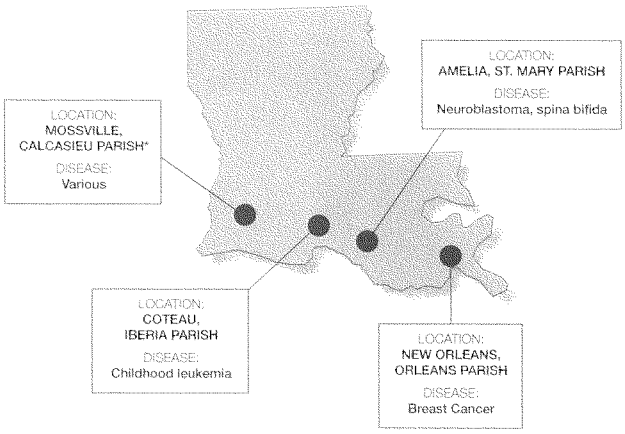
Louisiana has suffered from at least three confirmed disease clusters, two of which afflicted children. Although environmental contaminants are implicated, experts have been unable to pinpoint an exact cause. Regardless of the cause, disease clusters can devastate communities with anxiety and emotional and financial difficulties including high medical costs and lowered property values, as well as the tremendous burden of the disease itself.



LOCATION: **New Orleans, Orleans Parish**
DISEASE: **Breast cancer**
A cluster of breast cancer in an urban census tract at the Agricultural Street Landfill Superfund Site was identified by the Agency for Toxic Substances and Disease Registry (ATSDR) in 2003. The contaminated landfill was in operation between 1909 and 1962 and was the area's main dump for both residential and industrial waste. In 1976, the landfill was covered with a light layer of soil and sand, and redeveloped for residential use. Residents in the area began to discover trash only a few inches below the soil surface and in 1993 the site was designated as a hazardous waste site (Superfund). According to ATSDR, the site and the neighborhood is contaminated with metals, polyaromatic hydrocarbons (PAHs), volatile organic compounds, and pesticides. There is evidence that PAHs can increase the risk of developing breast cancer.

LOCATION: **Amelia, St. Mary Parish**
DISEASE: **Neuroblastoma**
Over the period of 1986 through 1987, a cluster of neuroblastoma, a type of brain cancer, was identified by researchers at Louisiana State University Medical School. City government and state health officials petitioned the Agency for Toxic Substances and Disease Registry to conduct a public health assessment of Marine Shale Processor (MSP) due to regulatory scrutiny and public concern over MSP's operations. In 1994, ATSDR concluded that there was evidence to suggest that adverse health outcomes in the community could be related to environmental exposures. However, there was insufficient data to link a hazardous waste incinerator at MSP to adverse health outcomes in the community. In 2006, MSP and its owner paid the state government a settlement of $7 million for the closure and remediation of the site.

LOCATION: **Coteau, Iberia Parish**
DISEASE: **Childhood leukemia**
State health officials confirmed a cluster of childhood leukemia in the tiny community of Coteau after four children were diagnosed with leukemia. In 2000, the Louisiana Office of Public Health begun conducting a case-control study of 40 children diagnosed with leukemia between 1983 and 1997 in the four-parish area of Lafayette, Vermilion, St. Martin, and Iberia to identify risk factors associated with childhood leukemia in the area. Due to the small size of the study state epidemiologists were not able to make any clear conclusions about environmental factors that may have caused the cluster of leukemia.

* LOCATION: **Mossville, Calcasieu Parish**
DISEASE: **Various**
A health survey by researchers at the University of Texas Medical Branch at Galveston in 1998 found that 91 percent of Mossville residents suffered from health problems, including a high incidence of ear, nose, and throat illnesses, central nervous system disturbances, cardiovascular problems, and increased skin, digestive, immune, and endocrine disorders.

Calcasieu Parish is the site of a large number of companies that produce petroleum-based chemicals, chlorinated hydrocarbon solvents, and other organic chemicals. In 1998, the Agency for Toxic Substances and Disease Registry (ATSDR) tested for dioxin in the blood of 28 Mossville residents and reported elevated levels.

The existence of a cluster was not confirmed by the ATSDR, however they only focused on cancer rates in the community and did not look at other health problems, including those investigated by the University of Texas researchers. The illnesses identified in Mossville are not tracked in any disease surveillance program, highlighting how difficult it is to identify clusters of these types of diseases, since there is no existing information against which to compare.

Stop disease clusters. Protect people. Control toxic chemicals.

Disease Clusters in **Michigan**

An unusually large number of people sickened by a disease in a certain place and time is known as a 'disease cluster'. Clusters of cancer, birth defects, and other chronic illnesses have sometimes been linked to chemicals or other toxic pollutants in local communities, although these links can be controversial. There is a need for better documentation and investigation of disease clusters to identify and address possible causes. Meanwhile, toxic chemicals should be identified and controlled through reform of the Toxic Substances Control Act, so these chemicals don't pollute communities and sicken people.

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Michigan has experienced at least one confirmed disease cluster spanning several different counties, and another is under investigation. Although environmental contaminants are implicated, experts have been unable to pinpoint an exact cause.

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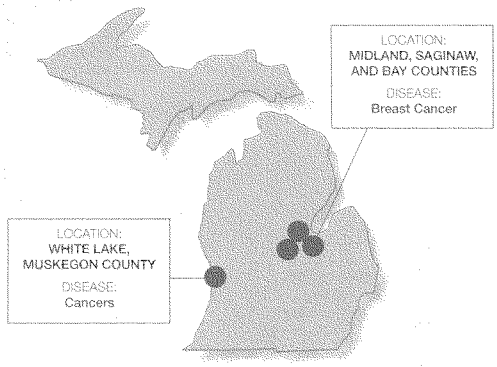


LOCATION: **Midland, Saginaw, and Bay Counties**
DISEASE: **Breast Cancer**
Researchers found a cluster of breast cancer in Midland, Saginaw, and Bay counties between 1985 and 2002. High levels of dioxins and other contaminants in soil and higher-than average body burdens of dioxins in local residents, particularly those who lived in the region prior to 1980, have also been found in the city of Midland and the Tittabawassee and Saginaw River floodplains in Michigan. A 2008 study found increased breast cancer incidence was spatially associated with dioxin contamination. Researchers believed that the source of dioxins in the river came from industrial processes at the Dow Chemical Company Midland plant.

LOCATION: **White Lake, Muskegon County**
DISEASE: **Cancers**
The White Lake area was listed as an area of concern by the Agency for Toxic Substances and Disease Registry in 2008, because 11 sites in the area were categorized as a "public health hazard" or an "indeterminate public health hazard." Seven of these eleven sites are on the EPA's National Priorities List of hazardous waste sites. The Muskegon County Health Department and concerned residents are currently investigating the number of people with cancer. Companies such as Hooker/Occidental Chemical, DuPont and the Whitehall Leather tannery have previously contaminated the White lake area with heavy metals and volatile organic compounds.

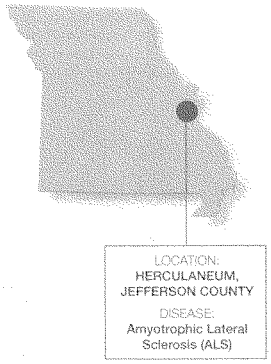
Stop disease clusters. Protect people. Control toxic chemicals.

Disease Clusters in **Missouri**

An unusually large number of people sickened by a disease in a certain place and time is known as a "disease cluster". Clusters of cancer, birth defects, and other chronic illnesses have sometimes been linked to chemicals or other toxic pollutants in local communities, although these links can be controversial. There is a need for better documentation and investigation of disease clusters to identify and address possible causes. Meanwhile, toxic chemicals should be identified and controlled through reform of the Toxic Substances Control Act, so these chemicals don't pollute communities and sicken people.

Investigations of disease clusters are complex, expensive, and often inconclusive, partly due to limitations in scientific tools for investigating cause-and-effect in small populations. Preventing pollution is the best way to avoid creating additional disease clusters. Strategies for prevention include: (1) Directing and funding federal agencies to swiftly assist state and local officials, and investigate community concerns about potential disease clusters and their causes; (2) Reducing or eliminating toxic releases into air, water, soil and food through stronger environmental controls and tough enforcement of those requirements; and (3) Requiring chemical manufacturers to ensure the safety of their products.

Missouri has suffered from at least one confirmed disease cluster. Although environmental contaminants are implicated, experts have been unable to pinpoint an exact cause. Regardless of the cause, disease clusters can devastate communities with anxiety and emotional and financial difficulties including high medical costs and lowered property values, as well as the tremendous burden of the disease itself.



LOCATION: **Herculaneum, Jefferson County**
DISEASE: **Amyotrophic Lateral Sclerosis (ALS)**

In 2007, the Missouri Department of Health and Senior Services (MDHSS) identified a cluster of Amyotrophic Lateral Sclerosis cases, a nervous system disorder also known as Lou Gehrig's disease, around a lead smelter in Herculaneum. The MDHSS stated that the lead contamination in Herculaneum presented "a clear and present risk to public health". MDHSS worked with the Missouri Department of Natural Resources on a settlement that resulted in the purchase of 160 homes by the company that operated the lead smelter due to lead contamination in 2002. The MDHSS reported that the lead smelter also produced pollutants such as zinc, lead, copper, chromium, and cadmium as part of the manufacturing process. Also, slag from the smelter has long been dumped in an enormous pile near the Missouri River.

Stop disease clusters. Protect people. Control toxic chemicals.

Disease Clusters in **Montana**

An unusually large number of people sickened by a disease in a certain place and time is known as a 'disease cluster'. Clusters of cancer, birth defects, and other chronic illnesses have sometimes been linked to chemicals or other toxic pollutants in local communities, although these links can be controversial. There is a need for better documentation and investigation of disease clusters to identify and address possible causes. Meanwhile, toxic chemicals should be identified and controlled through reform of the Toxic Substances Control Act, so these chemicals don't pollute communities and sicken people.

Investigations of disease clusters are complex, expensive, and often inconclusive, partly due to limitations in scientific tools for investigating cause-and-effect in small populations. Preventing pollution is the best way to avoid creating additional disease clusters. Strategies for prevention include: (1) Directing and funding federal agencies to swiftly assist state and local officials, and investigate community concerns about potential disease clusters and their causes; (2) Reducing or eliminating toxic releases into air, water, soil and food through stronger environmental controls and tough enforcement of those requirements; and (3) Requiring chemical manufacturers to ensure the safety of their products.

Montana has suffered from at least one confirmed disease cluster. Although the environmental contaminant that caused this cluster is known, experts researching other disease clusters have generally been unable to pinpoint exact causes. Regardless of the cause, disease clusters can devastate communities with anxiety and emotional and financial difficulties including high medical costs and lowered property values, as well as the tremendous burden of the disease itself.

LOCATION:
LIBBY,
LINCOLN COUNTY
DISEASE:
Respiratory diseases

LOCATION: **Libby, Lincoln County**
DISEASE: **Respiratory diseases**
In 2008, the Agency for Toxic Substances and Disease Registry (ATSDR) identified a cluster of malignant and respiratory diseases from 1979 to 1998 in Libby, Montana. From the 1920's to 1990, vermiculite was mined in and near Libby, Montana and contaminated the entire community and surrounding area. The vermiculite was contaminated with tremolite asbestos, a known carcinogen and cause of non-malignant respiratory illness. Since 1999, the EPA has been working with the community to clean up contamination and reduce exposure.

Stop disease clusters. Protect people. Control toxic chemicals.

Disease Clusters in **North Carolina**

An unusually large number of people sickened by a disease in a certain place and time is known as a 'disease cluster'. Clusters of cancer, birth defects, and other chronic illnesses have sometimes been linked to chemicals or other toxic pollutants in local communities, although these links can be controversial. There is a need for better documentation and investigation of disease clusters to identify and address possible causes. Meanwhile, toxic chemicals should be identified and controlled through reform of the Toxic Substances Control Act, so these chemicals don't pollute communities and sicken people.

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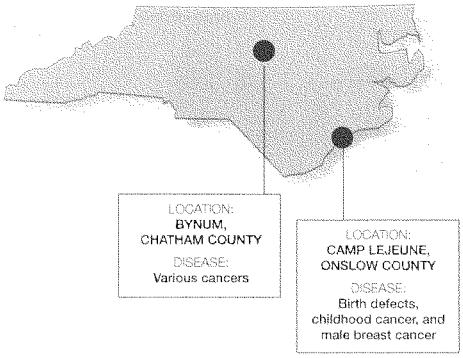
North Carolina has suffered from at least two confirmed disease clusters. Although environmental contaminants are implicated, experts have been unable to pinpoint an exact cause. Regardless of the cause, disease clusters can devastate communities with anxiety and emotional and financial difficulties, including high medical costs and lowered property values, as well as the tremendous burden of the disease itself.



LOCATION: **Bynum, Chatham County**
DISEASE: **Various cancers**
Researchers at The Johns Hopkins University found that Bynum residents had a disproportionately high death rate due to cancer associated with organic contaminants in their drinking water. Results indicated that the percentage of deaths involving cancer increased steadily to a high of 58 percent from 1980 to 1985. From 1947 to 1976, about two-thirds of the residents drank untreated water from the river. Water testing found a variety of pollutants, including carcinogens. Bynum is downstream from significant sources of industrial and agricultural contaminants.

LOCATION: **Camp Lejeune, Onslow County**
DISEASE: **Birth defects, childhood cancer, and male breast cancer**
For nearly 40 years, the groundwater at Camp Lejeune was contaminated with perchloroethylene from an off-base dry cleaner; with trichloroethylene from industrial solvents used on base; and with benzene from fuel tank leaks on the Marine Corps Base. The Agency for Toxic Substances and Disease Registry (ATSDR) is currently conducting a study on various birth defects, childhood leukemia and non-Hodgkin's lymphoma in children born to mothers who lived on base at Camp Lejeune any time during their pregnancies. Newspapers also reported that about 60 men who had lived on the base have been diagnosed with male breast cancer. ATSDR will also be conducting a health survey that will investigate the incidence of cancer and other diseases, including breast cancer, which is expected to begin in the spring of 2011.

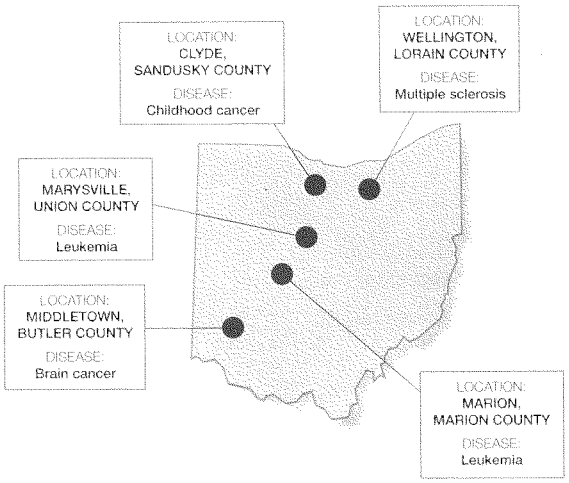
Stop disease clusters. Protect people. Control toxic chemicals.

Disease Clusters in **Ohio**

An unusually large number of people sickened by a disease in a certain place and time is known as a 'disease cluster'. Clusters of cancer, birth defects, and other chronic illnesses have sometimes been linked to chemicals or other toxic pollutants in local communities, although these links can be controversial. There is a need for better documentation and investigation of disease clusters to identify and address possible causes. Meanwhile, toxic chemicals should be identified and controlled through reform of the Toxic Substances Control Act, so these chemicals don't pollute communities and sicken people.

Investigations of disease clusters are complex, expensive, and often inconclusive, partly due to limitations in scientific tools for investigating cause-and-effect in small populations. Preventing pollution is the best way to avoid creating additional disease clusters. Strategies for prevention include: (1) Directing and funding federal agencies to swiftly assist state and local officials, and investigate community concerns about potential disease clusters and their causes; (2) Reducing or eliminating toxic releases into air, water, soil and food through stronger environmental controls and tough enforcement of those requirements; and (3) Requiring chemical manufacturers to ensure the safety of their products.

Ohio has suffered from at least four confirmed disease clusters, two of which afflicted children, and another cluster is currently under investigation. Although environmental contaminants are implicated, experts have been unable to pinpoint an exact cause. Regardless of the cause, disease clusters can devastate communities with anxiety and emotional and financial difficulties, including high medical costs and lowered property values, as well as the tremendous burden of the disease itself.



LOCATION: **Clyde, Sandusky County**
DISEASE: **Childhood cancer**
In 2009, the Ohio Department of Health (ODH) and Sandusky County Health Department confirmed a cancer cluster in the city of Clyde and Green Creek Township area. The analysis found brain and other central nervous system cancers to be the most common cancer types. State and local agencies are continuing to investigate the cause of the higher than expected number of childhood cancer diagnoses in the county.

LOCATION: **Wellington, Lorain County**
DISEASE: **Multiple sclerosis**
A 1998 study by state and local health departments found residents of Wellington were three times more likely to develop multiple sclerosis (MS) than the rest of the country. The Agency for Toxic Substances and Disease Registry found that there had been a release of chemical contaminants in the environment surrounding a former foundry, the LESCO facility, and the still operating Forest City Technologies plant. The LESCO facility was a distributor and formulator of fertilizer and Forest City Technologies manufactures seals and gaskets for the automotive industry. Although the causes of MS are unknown, the disease is believed to be caused by a combination of genetic and environmental factors.

LOCATION: **Marysville, Union County**
DISEASE: **Leukemia**
The ODH has preliminarily concluded that there was a cluster of leukemia cases in this small town. Between 1992 and 2001, eight boys and young men were diagnosed with leukemia, a number that is significantly higher than expected when compared to national rates for a town this size.

LOCATION: **Marion, Marion County**
DISEASE: **Leukemia**
In 1999, the ODH found a cluster of leukemia and esophageal cancer in Marion. River Valley High School was built in the early 1960's on top of an Army depot used for cleaning and repairs of vehicles and heavy machinery. The Ohio EPA discovered several carcinogenic substances at the site at dangerous levels. In 1997, the Army Corp of Engineers began investigating and cleaning up arsenic and lead at the former depot; they expect to complete all clean-up projects in June 2013.

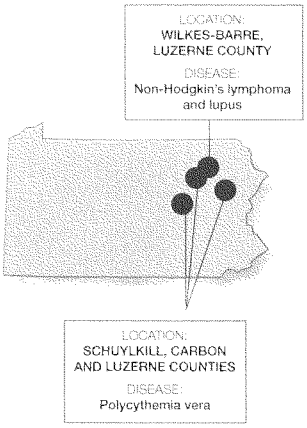
LOCATION: **Middletown, Butler County**
DISEASE: **Brain cancer**
Since 2004, 11 people in Middletown have been diagnosed with glioblastoma, a type of brain cancer. The ODH is investigating this as a potential cancer cluster.

Stop disease clusters.
Protect people.
Control toxic chemicals.

Disease Clusters in **Pennsylvania**

An unusually large number of people sickened by a disease in a certain place and time is known as a 'disease cluster'. Clusters of cancer, birth defects, and other chronic illnesses have sometimes been linked to chemicals or other toxic pollutants in local communities, although these links can be controversial. There is a need for better documentation and investigation of disease clusters to identify and address possible causes. Meanwhile, toxic chemicals should be identified and controlled through reform of the Toxic Substances Control Act, so these chemicals don't pollute communities and sicken people.

Investigations of disease clusters are complex, expensive, and often inconclusive, partly due to limitations in scientific tools for investigating cause-and-effect in small populations. Preventing pollution is the best way to avoid creating additional disease clusters. Strategies for prevention include: (1) Directing and funding federal agencies to swiftly assist state and local officials, and investigate community concerns about potential disease clusters and their causes; (2) Reducing or eliminating toxic releases into air, water, soil and food through stronger environmental controls and tough enforcement of those requirements; and (3) Requiring chemical manufacturers to ensure the safety of their products.



Pennsylvania has suffered from at least two confirmed disease clusters spanning several different counties. Although environmental contaminants are implicated, experts have been unable to pinpoint an exact cause. Regardless of the cause, disease clusters can devastate communities with anxiety and emotional and financial difficulties, including high medical costs and lowered property values, as well as the tremendous burden of the disease itself.

LOCATION: **Wilkes-Barre, Luzerne County**
DISEASE: **Non-Hodgkin's lymphoma and lupus**
In 2004, researchers at Pennsylvania State University found health hazards associated with workplace exposure to trichloroethylene (TCE) at a Wilkes-Barre special education school in the school district's main administrative building. Twelve employees have been diagnosed with non-Hodgkin's lymphoma and lupus. The researchers found TCE exposures were 10,000 times higher than what the Environmental Protection Agency considers an acceptable cancer risk for someone working in the building for at least 10 years. TCE, a probable human carcinogen, was used by the staff to clean the two printing presses.

LOCATION: **Schuylkill, Carbon and Luzerne Counties**
DISEASE: **Polycythemia vera**
In 2008, the Agency for Toxic Substances and Disease Registry confirmed a cluster of polycythemia vera (PV) cases in Schuylkill, Luzerne, and Carbon counties. PV is a rare blood disorder in which the bone marrow makes too many red blood cells. Some residents blame their illness on a nearby coal-fired power plant and a recycling facility that accepted thousands of gallons of paint, sludge, waste oils, used solvents, PCBs, cyanide, pesticides, and many other known or suspected carcinogens.

Stop disease clusters.
Protect people.
Control toxic chemicals.

Disease Clusters in **Tennessee**

An unusually large number of people sickened by a disease in a certain place and time is known as a 'disease cluster'. Clusters of cancer, birth defects, and other chronic illnesses have sometimes been linked to chemicals or other toxic pollutants in local communities, although these links can be controversial. There is a need for better documentation and investigation of disease clusters to identify and address possible causes. Meanwhile, toxic chemicals should be identified and controlled through reform of the Toxic Substances Control Act, so these chemicals don't pollute communities and sicken people.

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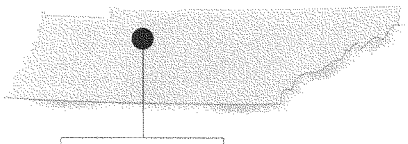
Tennessee has suffered from at least one confirmed disease cluster which afflicted children. Environmental contaminants are implicated in this cluster. Regardless of the cause, disease clusters can devastate communities with anxiety and emotional and financial difficulties, including high medical costs and lowered property values, as well as the tremendous burden of the disease itself.



LOCATION:
DICKSON,
DICKSON COUNTY
DISEASE:
Oral cleft birth defects

LOCATION: **Dickson, Dickson County**
DISEASE: **Oral cleft birth defects**
A cluster of oral cleft (cleft lip and cleft palate) birth defects in Dickson, Tennessee from 1997 to 2000 was identified by the Centers for Disease Control and Prevention. The investigation revealed that in 1997, trichloroethylene (TCE) and toluene were found in a private well, public well, and in the public water supply. Both chemicals have been associated with causing birth defects. Prior to stringent landfill regulations and guidelines, containers of TCE were buried in the Dickson County landfill in Dickson. Additionally, according to the EPA's Toxic Release Inventory in 1997 Quebecor Printing released 1.4 million pounds of toluene into the air in Dickson.

Stop disease clusters.
Protect people.
Control toxic chemicals.

Disease Clusters in **Texas**

An unusually large number of people sickened by a disease in a certain place and time is known as a 'disease cluster'. Clusters of cancer, birth defects, and other chronic illnesses have sometimes been linked to chemicals or other toxic pollutants in local communities, although these links can be controversial. There is a need for better documentation and investigation of disease clusters to identify and address possible causes. Meanwhile, toxic chemicals should be identified and controlled through reform of the Toxic Substances Control Act, so these chemicals don't pollute communities and sicken people.

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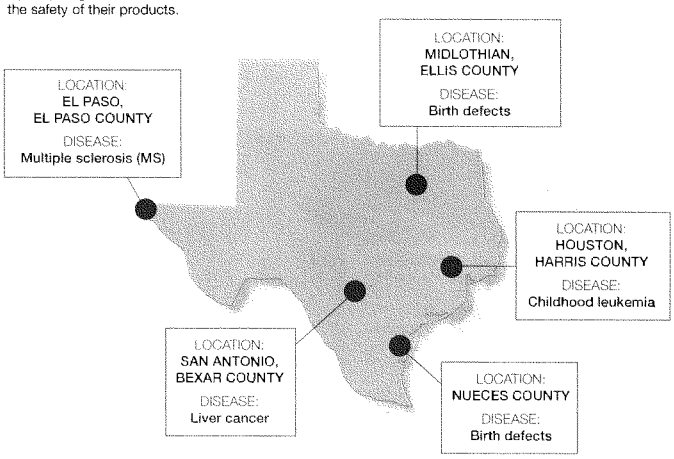
Texas has suffered from at least five disease clusters confirmed by health authorities. Most have afflicted children with cancers or birth defects. Although environmental contaminants are implicated, experts have been unable to pinpoint an exact cause. Regardless of the cause, disease clusters can devastate communities with anxiety and emotional and financial difficulties, including high medical costs and lowered property values, as well as the tremendous burden of the disease itself.



NRDC
The Earth's Best Defense
www.nrdc.org

NDCA
National Disease Clusters Alliance
www.clusteralliance.org

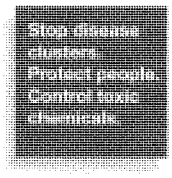
LOCATION: **El Paso, El Paso County**
DISEASE: **Multiple sclerosis (MS)**
In 1996, the Agency for Toxic Substances and Disease Registry (ATSDR) and the Texas Department of State Health Services (TDSHS) found a two-fold increased risk of developing multiple sclerosis (MS) in people who had attended Mesita Elementary School in El Paso. The school is located one mile from an ASARCO smelter facility. Environmental sampling has shown elevated levels of lead, zinc, arsenic, cadmium, and SO_2 in many areas of El Paso. Although the causes of MS are unknown, the disease is believed to be caused by a combination of genetic and environmental factors.

LOCATION: **Houston, Harris County**
DISEASE: **Childhood leukemia**
Researchers from the University of Texas's School of Public Health found that children who live within two miles of the Houston Ship Channel have a 56 percent greater chance of getting leukemia than children living elsewhere. The elevated rates of childhood leukemia were found in census tracts with the highest benzene and 1,3-butadiene levels in the air. The Houston Ship Channel is the largest petrochemical complex in the United States and a Rice University study released in 2006 showed that Houston had the highest air concentration of benzene and 1,3-butadiene in the country. Benzene and 1,3-butadiene are known to be human carcinogens.

LOCATION: **Midlothian, Ellis County**
DISEASE: **Birth defects**
An investigation by TDSHS confirmed a cluster of Downs Syndrome in Ellis County from 1991 to 1994. Residents are concerned about air pollution from three cement plants and one steel-recycling mill and are also documenting birth defects in animals born in the area. The ATSDR is restarting a second health assessment after the first was criticized by academic scientists for using inadequate air monitoring information, discounting evidence showing that some airborne chemicals exceeded federal health standards, and disregarding residents' respiratory complaints. The health assessment is investigating the higher rates of health problems, including leukemia, birth defects and childhood total cancer and the high incidence of respiratory problems in Ellis County when compared to the rest of the state.

LOCATION: **Nueces County**
DISEASE: **Birth defects**
In 2006, the TDSHS found that Nueces County had a birth defect rate that was 84 percent higher than the rest of Texas. A follow-up study explored the relationship between the rate of birth defects and several industrial sites in the county. Researchers were not able to find a direct link to a particular site, but they found that mothers living near refineries and chemical plants had babies with high rates of life-threatening birth defects of the abdominal wall and diaphragm. Living near an old incinerator was linked to other serious birth defects such as narrow anal and intestinal canals or obstructed or narrow urinary tracts. Additionally, researchers found mothers living near a battery plant had higher rates of five different birth defects.

LOCATION: **San Antonio, Bexar County**
DISEASE: **Liver cancer**
Researchers at Southwest Texas State University found a cluster of liver cancer deaths in Bexar County and its adjacent counties using statewide cancer mortality data from 1990 through 1997. About 14 zip codes in San Antonio encompass a plume of polluted groundwater linked to Kelly Air Force Base. Local groups allege that the groundwater was polluted with waste containing benzene, perchloroethylene, and trichloroethylene, all known carcinogens. ATSDR is investigating and has stated that the community may have been exposed to higher levels of contaminants in the past.



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ERRATA for Health Alert: Disease Clusters Spotlight the Need to Protect People from Toxic Chemicals

California

"Rosamund" should be Rosamond.

Michigan

Entry for White Lake, Muskegon County should say:

In Muskegon County, White Lake was listed as an area of concern in 2008 by the Agency for Toxic Substances and Disease Registry. Four hazardous waste sites were identified in the area, and each was categorized as an "Indeterminate Public Health Hazard." Concerned residents and Muskegon County Health Department officials are conducting a study of residential and occupational history in people with cancer in the White Lake area. Companies such as Hooker/Occidental Chemical, DuPont and the Whitehall Leather tannery have previously contaminated White Lake with heavy metals and volatile organic compounds.

RESPONSES BY DR. GINA M. SOLOMON, TO ADDITIONAL QUESTIONS FROM SENATOR BOXER

Question 1. Dr. Solomon, your organization, the Natural Resources Defense Council and the National Disease Cluster Alliance have issued a report on 42 disease clusters in 13 States.

Could you please describe why you put this report together and what the report shows about our nation's capacity to investigate and address disease clusters?

Response. Chronic disease is responsible for four out of five deaths in the U.S. today, and the suffering of 133 million people per year. Asthma, developmental diseases such as birth defects or neurobehavioral disorders, degenerative neurological diseases such as Parkinson's and Alzheimer's, diabetes, and cancer are all chronic diseases. According to the U.S. Centers for Disease Control and Prevention (CDC), almost half of all Americans are living with chronic disease, which now accounts for 70 percent of deaths and 75 percent of U.S. health care costs.[1] Many chronic diseases are on the rise, and many are preventable.

There is also increasing evidence that many of these illnesses may be linked to exposures in our environment. There is an urgent need for information that may help to uncover the causes of this epidemic of chronic disease. Disease clusters may hold clues to this puzzle. Historically, some disease cluster investigations have helped to reveal important causes of cancer and other diseases. Yet many major disease clusters exist in the United States that are never fully investigated.

The Natural Resources Defense Council (NRDC) and the National Disease Cluster Alliance (NDCA) researched and wrote the report entitled "Health Alert: Disease Clusters Spotlight the Need to Protect People from Toxic Chemicals" to demonstrate the widespread presence of disease clusters around the country, and the fact that the causes of most of these clusters are still unknown—often because they have not been fully investigated. The report shows that there are significant improvements needed to our nation's capacity to investigate and address disease clusters. Improvements in our responses to disease clusters may help to uncover some important causes of chronic diseases such as cancer and autism.

Question 2. Dr. Solomon, you have mentioned your time as a Clinical Fellow at Harvard when a cancer cluster was discovered in Woburn, Massachusetts. Can you go into that example in more detail and describe what it tells you about the adequacy of agency efforts to track and investigate disease clusters?

Response. When I was a Clinical Fellow at Harvard in the mid–1990's, I learned of a major investigation into a childhood leukemia cluster in Woburn, Massachusetts. This cluster was quite dramatic—12 children with acute leukemia in one neighborhood of a small town over just a few years—statistically speaking, it is almost impossible for this to have happened by chance. We might hope that the State cancer registry would have identified this cluster of childhood leukemia and linked it to contamination of the water supply.

Unfortunately that was not the case. This cancer cluster was discovered by mothers sitting with their children in the waiting room at the Dana Farber Cancer Center and recognizing other families from their neighborhood. Only later was it confirmed by scientists at Harvard and by the State of Massachusetts. The Woburn case reveals the gaps in the State and Federal monitoring systems for disease clusters. Ultimately, in this case, a fairly thorough investigation was done, but it took a lot of action by the local community to get attention to their very real problem.

Question 3. Dr. Solomon, can you describe some of the current difficulties of investigating disease clusters and whether you think that S. 76, the "Strengthening Protections for Children and Communities from Disease Clusters Act" would help to address some of these difficulties?

Response. There are currently major difficulties investigating disease clusters in three main ways:

(1) There is no system for reporting, tracking, and prioritizing disease clusters for investigation, so communities don't know where to go for help, and agencies refer community complaints around like hot potatoes.

(2) There is no established process or guidelines for investigating disease clusters in a systematic way, so resource-strapped county or State health departments are often struggling to conduct investigations without instructions or Federal support.

(3) Communities are often not adequately involved in the investigation, and don't feel like their voices are heard during the process. So when an investigation is negative or inconclusive, the community often does not trust the result. Early and consistent involvement of community members in the study team is an established ben-

[1] http://www.cdc.gov/nccdphp/publications/index.htm

efit in research studies for many reasons. In case after case, the clues to help solve these cluster mysteries have resided in the knowledge and experience of the affected communities.

S. 76, the "Strengthening Protections for Children and Communities from Disease Clusters Act", would help address these key problems by mandating the creation of a set of guidelines for cluster investigations will help to assure that communities that truly need assistance will get the attention they need, and will help to focus the Federal efforts where they will be most useful. S. 76 would also help improve coordination between agencies. To date, cluster investigations have frequently been conducted by county or State health departments with limited assistance; or on rare occasions by the Agency for Toxic Substances and Disease Registry (ATSDR), which has limited expertise in environmental monitoring. Bringing the EPA into the collaboration will be important to allow all areas of expertise to be brought to bear on the problem. Finally, S. 76 will bring community resources into these investigations in a more formal way through the creation of formal Community Advisory Committees, which will be critical to gathering better information and to better communication and resolution of these difficult problems.

Question 4. Dr. Solomon, your testimony describes a scientific article in the New England Journal of Medicine that examined the potential impact of genetics versus environmental health factors in disease. Could you please describe this study's finding, particularly as it relates to the importance of creating systems to account for and analyze environmental health threats in communities where people are exposed to multiple sources of pollution?

Response. A study of nearly 45,000 twins published in the New England Journal of Medicine evaluated the relative importance of genetic and environmental factors in cancer.[2] If the cancers were primarily genetic, identical twins (which share the same genome) would have more similar cancer patterns than fraternal twins (which only share the genetics of any siblings). The bottom line of this important study was that the vast majority of cancers are environmental rather than genetic. Statistically significant genetic effects were only seen for three cancers—prostate, colorectal, and breast. In the case of breast cancer, less than one-third of the risk was due to inherited factors (potential range 4–41 percent); that means that about 70 percent of the remaining risk of breast cancer is due to environmental factors. For other cancers, the environmental component was even larger. The same principle is true for most other diseases, where environment is turning out to be more important than genetics. As a result of studies like this, the scientific consensus has gradually shifted to the position that most diseases are not just caused by genetics, but rather by a combination of genetic and environmental factors.

However, it's very difficult for scientists to discern exactly what percent of cancers, birth defects, or neurological disorders are due to environmental factors. That's because there's a lot of work that still needs to be done to identify the list of specific environmental causes of cancer that that add up to the 70 percent or more from the New England Journal of Medicine. Some of these factors are well-known (such as cigarette smoke), others are partially understood (such as the lists of carcinogens that occur naturally or that are in manmade substances), and others have yet to be discovered. In addition, because of the interactions between chemicals, as well as between chemicals and genes, the sum of causes will add up to more than 100 percent.[3] The big problem is that the rates of some cancers—including childhood cancers—and other diseases are rising, so we don't have the luxury of a lot of time. People are getting sick and suffering, so we need to move quickly and use whatever clues we can to understand what's going on. One of these clues is disease clusters.

Question 5. Dr. Solomon, can you please describe whether you believe the creation of a tracking system that links disease and pollution sources may benefit public health protections?

Response. I believe that the creation and expansion of a tracking system that links disease and pollution sources will benefit public health. Environmental public health tracking is the ongoing collection, integration, analysis, and interpretation of data about environmental hazards, human exposure, and health effects. In September 2000, the Pew Environmental Health Commission issued the report "America's Environmental Health Gap: Why the Country Needs a Nationwide Health

[2] Lichtenstein P, Holm NV, Verkasalo PK, Iliadou A, Kaprio J, Koskenvuo M, Pukkala E, Skytthe A, Hemminki K. Environmental and heritable factors in the causation of cancer-analyses of cohorts of twins from Sweden, Denmark, and Finland. N Engl J Med. 2000 Jul 13;343(2):78–85.

[3] Clapp RW, Howe GK, Jacobs M. Environmental and Occupational Causes of Cancer Re-visited. Journal of Public Health Policy (2006) 27, 61–76.

Tracking Network."[4] The report, which stated that the existing environmental health system is neither adequate nor well organized, recommended the creation of a "Nationwide Health Tracking Network for disease and exposures." In fiscal year 2002, Congress provided CDC with initial funding to begin developing a nationwide environmental public health tracking network and to develop capacity in environmental health within State and local health departments.

The CDC National Environmental Public Health Tracking Program has done impressive work with a very small budget, but there are still significant remaining gaps. In particular, the Tracking Program is not designed to discover, or to investigate, disease clusters. So there is a need for a program to provide that information. Tracking diseases such as birth defects, cancer, asthma, autism, and Parkinson's disease is critical to discerning patterns and ultimately to solving many of the mysteries of these diseases. Tracking systems exist in some States, for some of these diseases, but they are fragmented and do not cover all chronic diseases of importance. That's why improved tracking is needed to help protect public health.

RESPONSES BY DR. GINA M. SOLOMON TO ADDITIONAL QUESTIONS FROM SENATOR INHOFE

Question 1. Currently the Agency for Toxics Substances and Disease Registry and the Centers for Disease Control investigate disease clusters. Please describe the deficiencies in their programs which makes them unsuitable to do what S. 76 has EPA doing?

Response. The Agency for Toxic Substances and Disease Registry (ATSDR) is the part of the Centers for Disease Control and Prevention (CDC) that—in theory—is charged with investigating disease clusters. When my research team began investigating disease clusters and compiling the information for our report, we started by contacting ATSDR, assuming that they could provide us with information about disease clusters in all 50 States. In response to our inquiries, ATSDR responded that: (1) Their normal policy is not to investigate disease clusters, and they refer any such inquiries to State health departments; (2) they do not keep any records of reported disease clusters, or even of confirmed disease clusters, and (3) they do not have any established guidelines for investigating disease clusters.

It was disturbing to discover that the Federal agency that was widely believed to be responsible for disease cluster investigations does not appear to view this as a part of its mission, and does not establish guidelines or keep records. In fact, ATSDR does not have any statutory obligations to do any of these things with regard to disease clusters. These deficiencies in ATSDR's program make it essential for a Federal agency to take the lead in investigating disease clusters. S. 76 places that responsibility on EPA.

Question 2. Do you believe that S. 76 will allow EPA to take action to prevent a company from emitting or discharging identified toxic substances? Should S. 76 provide EPA with additional authority to take actions to address an identified or potential disease cluster?

Response. My understanding of S. 76 is that it does not alter EPA's existing regulatory authorities. As such, it would not affect EPA's existing ability to take action to prevent a company from emitting or discharging identified toxic substances. Instead, this legislation would authorize EPA to investigate potential disease clusters and gather information about them. Any action on emissions or discharges would need to be done using other regulatory authorities.

In my opinion, S. 76 is designed to gather information about identified or potential disease clusters and help integrate the activities of EPA and other Federal agencies (and assist State and local authorities) when investigating potential disease clusters. An integrated, coordinated effort would likely make such investigations more effective, efficient, transparent, and accountable. I don't think additional regulatory authority needs to be added to S. 76 in order to make it a valuable law that will help identify and address potential disease clusters.

Question 3. Should the primary focus be on cancer clusters and not other diseases, such as asthma?

Response. Our report on disease clusters in 13 States discovered confirmed clusters of a variety of diseases, including several types of cancer, autism, polycythemia vera, various types of birth defects, multiple sclerosis, and amyotrophic lateral sclerosis (Lou Gehrig's Disease). The point of investigating disease clusters is to learn more about the causes of diseases for which the causes are poorly understood. As

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[4] http://healthyamericans.org/reports/files/healthgap.pdf.

such, it would generally be less fruitful to investigate high rates of asthma—an extremely common disease that is best studied in other ways and for which numerous environmental causes are well-established. In my view, however, it would be unduly narrow to focus exclusively on cancer clusters. A cluster investigation of the birth defect Spina Bifida in Texas helped to uncover the important role of folate in preventing that disease; a cluster investigation of male infertility in Southern California discovered the severe testicular toxicity caused by the pesticide dibromochloropropane (DBCP). When there is an unusually high rate of a rare disease in a specific geographic area over a certain time period, it is a signal of the need for scientific investigation, and it can be an important clue that helps to uncover the causes of serious diseases.

Question 4. Would areas for investigation be identified by public reporting of concerns? By incidence reporting by the medical community? Do you have any recommendations in this area?

Response. S. 76 calls for the establishment of a "systematic, integrated approach that uses the best available science", and requires the establishment of clear guidelines for "disease cluster identification and reporting protocols". Such guidelines would create a process for identifying areas for investigation through a clearly delineated process involving a series of steps to identify and prioritize sites.

My recommendation might be as follows: First, potential disease cluster sites could be identified via various routes, including reports from local physicians or health officers, petitions from community groups, letters from elected officials, or unusual disease rates identified on State or national surveys. Then there would be a preliminary agency review of the site to assess whether there does appear to be an unusually high rate of disease in the identified area. Finally, the site would be prioritized against a set of criteria that would allow the agencies to hone in on sites of greatest public health concern. The selection criteria would need to be developed by the agencies, pursuant to S. 76, and would presumably need to undergo public review and comment.

Question 5. EPA currently regulates the emissions of toxic substances, and required pollution controls will reduce emissions of many other chemicals. Are you in favor of requiring additional reductions, and additional controls, to address potential disease clusters?

Response. I believe that significant disease clusters need to be investigated, and that any additional actions should be determined case-by-case based on the results of the investigations. I do not favor any across-the-board requirements related to pollution reductions or controls related to disease clusters until the investigations have been done. If an investigation of a particular site were to demonstrate the need for additional actions to protect public health, I would favor such actions using EPA's existing statutory authority.

Question 6. Under S. 76, what do you think would constitute "clearly" describing "the basis for the requested investigation or action" when it comes to a petition by a person for investigation?

Response. I may not be the best person to answer this question, as I am a medical doctor, and not a lawyer. However, I read "clearly" as a layperson would: that the petitioner should explain, in as much detail as is reasonable given the circumstances, the basis of their concern, including any statement and supporting evidence regarding particular types of health concerns that the petitioner believes may constitute a disease cluster, concerns about potential sources (if the petitioner has identified any), and the basis for identifying or being concerned about those potential sources. In other words, I interpret "clearly" in this context to be an encouragement for petitioners to provide as much detail as possible about the nature and scope of their concerns, along with whatever supporting evidence (data or information) may exist. Encouraging such clarity seems designed to make the job of identifying, investigating, and prioritizing problems at least somewhat easier and more efficient for EPA and the other Federal, State and local parties involved.

Question 7. The definition for membership on Community Disease Cluster Advisory Committees shall include "individuals who are or may be impacted by a suspected or potential disease cluster, and the designee of such an individual who may participate with or in the place of such an individual." Is there anyone in the United States that does not meet that definition? Should attorneys for clients with potential suits against local companies or manufacturers be included in the definition of "designee"?

Response. Like the previous question, this is not something that my professional expertise really touches upon. However, I suspect that the intended scope was somewhat narrower than the question suggests. In particular, it seems fairly clear to me

that the intent is that these Advisory Committees should include representation from some community members that are impacted by local disease clusters, which appears to me to be a laudable goal. The precise wording seems like a relatively simple matter that can be resolved and clarified, and not something that should unduly hold-up passage of this worthwhile legislation.

Senator BOXER. Thank you very much.

Each of us will have 5 minutes to question, and so I would ask you to keep your answers brief so we can get to all of you.

I just wanted to say to Dr. Belzer, I want to clarify. On page 7 of our bill, we do use a definition of how a disease is defined. It is defined exactly the way the National Institutes of Health define disease, word for word. Then we even add an extra paragraph about the fact that if science improves and there is a better way to do it, we will do that. So I do feel comfortable, but I am happy to work with you if you think there are ways we can make it better.

The other thing is you point out that we force the EPA to look at all the various pollutants, but I want to point out we don't exclude anything like genetics or anything else. We just say they have to include these because if they don't, then we will never know the answer.

So I really think that I appreciate your criticism and I know you are a minority witness today that differs from Trevor, but I just think the important thing is to work with us. Would you be willing to do that if we can tighten this up and you feel better about it? That would be wonderful. OK.

Trevor, you have testified before that your family has had difficulties in the past with the tumor registry. When asking for an investigation, you had problems as a family in looking into this cancer cluster, which is why Senator Crapo and I wrote this bill.

Could you describe the importance that you place on government agencies at all levels meaningfully involving family and community members in a cancer cluster investigation, the importance of including the families themselves?

Mr. SCHAEFER. Thank you for your question, Chair Boxer.

I believe that the citizens and communities want to look to their government for answers. When they have questions about what is in their surrounding environment, they would like somewhere to go to talk to where they are not told they are statistically insignificant, which is what we were told. That even if the data we had proved correct, that our town was too small to warrant a study.

So I think that strengthening the coordination and accountability of Federal, State and local agencies is key to creating that line of communication.

Senator BOXER. Of course, that is what we are doing here. We are bringing together, I think, a more effective way to respond by including the communities so there is no frustration out there and you get the answers.

Ms. Brockovich, your testimony emphasizes the importance of ensuring accountability and transparency when government agencies investigate potential disease clusters. What are the main benefits to the people who are stricken with illness and to other people in their community from increased transparency and accountability as we look at these clusters?

Ms. BROCKOVICH. I think it is clearly important to at a deep level have the community involved, as Trevor has just indicated, what he was just saying. Communities try to reach out to agencies. It can be cancer registries or local agencies, State and/or Federal, and oftentimes they are just treated as a statistic and they aren't heard and they want to be a part of the process.

I think that they are distrusting as a community. They want to look to agencies. They believe that they are the ones that are overseeing them, and then when they find out something has slipped through the cracks, it begins a distrust process. So for them to be part of the process with either the companies, and clearly their agencies, it begins to reestablish trust.

Because a lot of times, when you don't have that, we are not finding out the information that we need to know from them which, when I am in these communities, you have to get to know them, kind of be on the ground with them, and they will begin to provide you with information that will give you more answers so we can begin to find a solution.

So it is very important that they be able to work with you and they don't feel that they have been able to do that.

Senator BOXER. How many people have contacted you for that map that you showed us before? Could somebody hold up that map so Senators who weren't here could look at it? This is a map that Ms. Brockovich put together, calls to her because she is famous and she is known for going after these problems.

I would just say, and this is sort of a rhetorical question, but it is OK, don't you think that this indicates that people are frustrated? It is unbelievable to me that they would call you, someone in the private sector, rather than call the EPA or the NIH. Maybe they are calling them as well. But doesn't this indicate a level of frustration out there that people don't feel they are being heard?

Ms. BROCKOVICH. They don't feel they are being heard, and that is why I started this map, again, over 40,000 emails that I trafficked just on my Web site each month. What happened for me about 8 months ago was that I kept seeing from communities, we are concerned; we are seeing too many cancers; we are hearing of too many cancers.

So that becomes a flag for me, when I have not one community, not 5, not 10, but 20 and 50 and 100 telling me the same thing. So I started to map it. They are frustrated and they want some answers.

As you said earlier, not everything that when we look into it will be related to an environmental issue. In some instances it could clearly be and we may be overseeing it because these people don't just naturally wake up and learn of their friend with cancer and their neighbor, or they get to know each other in the hospital and they don't realize that they are neighbors within the same blocks.

They are very, very frustrated and they are trying to find a way to reach out. They don't wake up and go, wow, we should call CDC and report this; we should call the National Institute of Health and report this. I would have to tell you, 80 percent of the people in their emails to me that have created this map have said, we just don't know where else to go.

Senator BOXER. Well, I think the Boxer-Crapo bill is really trying to address this, and I hope colleagues will jump on as cosponsors and we can get this done quickly through the committee.

Senator Crapo.

Senator CRAPO. Thank you, Madam Chairman.

Trevor, I just wanted to say I found your testimony incredibly informative and compelling, and again I want to thank you for making the effort to come here and be with us.

One of the things that you said in your testimony was you referred to your mother's experience when she went to the local cancer registry in your community to raise concerns about a potential disease cluster, and that she was told that basically your town was too small to warrant an analysis and your case was statistically insignificant.

Could you just comment a little further about that, about what did you do next after you had that experience?

Mr. SCHAEFER. Thank you, Senator Crapo.

What we did is fortunately we were able to take it upon ourselves to get a proper scientist to conduct studies on a personal level to find out some answers and kind of start the ball rolling to see if there were indeed problems in our community.

Senator CRAPO. Did you get assistance from any governmental agencies, whether it be the Federal, the State or the local government in finding that scientist to help you?

Mr. SCHAEFER. We did not, no.

Senator CRAPO. I guess the next question I was going to ask you is you indicated in your testimony that you found that the government's response was piecemeal to non-existent. I guess that is the reality that you ran into. You didn't have formal government direction to turn to where there was a government process in place where coordination was occurring.

Mr. SCHAEFER. Yes, and that is exactly where the statement comes from is from our experience in being told that we were statistically insignificant, absolutely.

Senator CRAPO. Thank you.

Erin, in your testimony, you indicate that the CDC's ATSDR, which I understand is the Agency for Toxic Substance Disease Registry, if I have the acronym correct, you indicate that you think that the ATSDR has serious challenges in identifying and responding to disease clusters. Could you clarify that?

Ms. BROCKOVICH. Well, from just experience of 20 years in being out in the field with these communities, and I talk to them and as they are trying to track whether there are clusters or not, and we inquire of them if ATSDR has been there, 99 percent of the time they have indicated that that agency has made no such effort to come in and find out from the community what is happening.

One thing that I think is really very important that we think might be some flaw in how we are identifying these is these registries and these groups don't come in and watch the movement of where these people are going. Many, many times, if we find out we live in a contaminated community and we are fortunate enough to do so, we move. Now we have lost track of where these people have gone. When people come down with cancer, they report it to the

State in which they reside. They don't report it to the State where they are from.

So we could potentially be missing hundreds, if not thousands of people because we can't track their movements and their geographic location, which I think is very important.

From experience in dealing with these communities, specifically with ATSDR, which is the agencies that are out there to track disease registries, they are not there. They haven't been to the communities and it is frustrating for them, and that is where they feel their voices are not heard.

Senator CRAPO. Thank you.

Dr. Belzer, could you comment a little bit from the scientific perspective of how we deal with this statistical significance issue when you have a small town where we all recognize how you have small numbers. What do you do to deal with this problem?

Mr. BELZER. Trevor's experience is something I am not familiar with it, so I can't comment on that. But the term statistical significance should normally be used only after an analysis has already been done, when data have already been collected. It is not something that should be said of anything or anyone before data have been collected. It is an odd thing to imagine.

I do believe that the terminology, which is normal in classical statistics, is deeply offensive to a lot of people because they understand the term insignificance to mean that they are insignificant. This problem probably could be addressed if the epidemiologists applied a different set of tools. It takes away from some of that. They are also probably superior tools than classical methods for the nature of the problem at hand.

But epidemiology understands all that. I think that is just a case of scientists communicating in their own jargon in ways that nonscientists don't fully understand. They could be far more sensitive about it.

Senator CRAPO. I see my time is expired. Thank you, Madam Chairman.

Senator BOXER. Thank you.

Senator Lautenberg.

Senator LAUTENBERG. Trevor, you said something in your commentary, and we so much appreciate your being here. You said you were glad to be alive. We are all glad that you are alive. I am a professional grandfather. I have 10 grandchildren and I know what I want for them, and so far the conditions that they have run into are relatively mild when compared to cancer.

One of the things that I find so disturbing is that in this place of contemplation and legislation, we often hear sympathy for those who are afflicted with cancer or other threatening-to-life diseases. But somehow or other, we separate the heart from the mind here because we will get into a talk about costs. What is a cost to save a child's life? It doesn't matter what the cost is. There isn't a family in the world who wouldn't dispose of all of their assets to save a grandchild or a child's life.

I have been fortunate enough to be involved in some cancer research. Dr. Solomon, did you ever hear of the Jimmy Fund? It is a prominent Massachusetts situation.

Dr. SOLOMON. Yes.

Senator LAUTENBERG. Was that also in Woburn, MA?

Dr. SOLOMON. That was. Jimmy Anderson was one of the first children diagnosed with leukemia in Woburn. He unfortunately passed away.

Senator LAUTENBERG. Do you know a physician named Landrigan?

Dr. SOLOMON. Yes, Dr. Philip Landrigan from Mount Sinai Hospital.

Senator LAUTENBERG. Yes, a close friend, a good friend of mine. He supports the legislation that I have proposed, and that is to find out whether these chemicals that are being introduced into products, you name the kind of product, as a very important first step. I appreciate the fact that all of you are here to sound the alarm and let people know they are not exempt. No one is exempt.

We do a lot in this committee of ours, Environment Committee led by Senator Boxer, to try and get conditions that will protect children's health. That includes clean air. It includes getting rid of toxins and toxic materials coming out of smokestacks and that kind of thing.

But I wonder, do you see communities rising up and saying that company, XYZ Company, dumped their waste here and they should pay the price that cleanup demands. Do we ever identify, Ms. Brockovich, the companies that say, OK, you have done it; you fouled the air; you fouled the water; you violated our children's health.

Is that ever brought to the attention? Because I think it would be a good idea. I ran a business before I came here, and the regulatory—what did you call your company?

Mr. BELZER. Regulatory Checkbook.

Senator LAUTENBERG. Checkbook. I ran a company called ADP. I have been fortunate enough to be able to respond to the early deaths of my father, 43, my uncle in the same family, 52, my grandfather, 56, all from cancer, all who worked in the silk mills of Paterson, NJ, an industrial city.

So when the chance came along, I was able to help start a cancer research facility and it is supported by, do you know Dr. Jim Holland, by any chance, Dr. Solomon?

Dr. SOLOMON. I know the name, yes.

Senator LAUTENBERG. He did so much on childhood leukemia.

I have several questions that I would like to put to you, but in keeping some time discipline, it is not easy for a Senator. I would ask you this, Dr. Solomon. The investigation into unusually high cancer rates in Toms River, NJ, languished because the New Jersey cancer registry was outdated when the investigation began. Looking at the bill proposed by Senator Boxer, the Disease Cluster bill, wouldn't that have a good effect on situations like this, like the Toms River identity, and evaluate disease clusters more quickly? We have to get ahead of the curve on this and I think it would be a terrific thing to do if we can move it.

Last, if I am forgiven for another minute, I have proposed a piece of legislation which I mentioned here, that we would like to see all chemicals that go into a product, that are then circulated throughout our world, identified as being safe for children's health before it goes into the product, so we then don't have to look at, like we

do with TSCA toxic reform law, which said we should investigate chemicals and see what kind of harm they bring.

We have investigated 200 chemicals out of 80,000. Eighty thousand. It is not a good idea to have EPA searching for those things that are at fault, as opposed to jumping on the bandwagon, getting this done before. I would plead with you, be in touch with your Senators and make sure they understand the problem they have had.

Trevor, you are a soldier in this battle and we want you to keep on fighting. We are proud of you.

Thank you all very much.

Senator BOXER. Senator, thank you for pointing out that the Boxer-Crapo bill deals with the problem after the fact. There is no question about it. Nothing in this bill is going to prevent cancer clusters. We are just saying if one occurs, let's have a way to respond. Let's have a way to tell our communities the best we can what are the probable causes of this first of all, most of all, to protect other people and also to resolve their questions.

But what Senator Lautenberg is talking about is a new way to make sure that before these chemicals are introduced, even more chemicals, that the burden changes so that the company or person or the group that wants to introduce the chemical must prove it is safe before introduction. That is a very different and important move and I, of course, will support you 100 percent. But these are different approaches to the same issue, but they are complementary.

Senator Boozman. Thank you for being here, Senator.

STATEMENT OF HON. JOHN BOOZMAN, U.S. SENATOR FROM THE STATE OF ARKANSAS

Mr. BOOZMAN. Thank you, Madam Chair.

This is certainly a very, very important problem, and I guess it is one that because of the nature of communication being so much easier now and the ability to perhaps keep track of things so much easier, it is something that we can address.

I guess my concern is really two or three things. Again, I believe very strongly that we need to deal with the problem. I am concerned that some of the things that we have in place, the registry program evidently is not doing a good job.

Then also I guess I am concerned that we are talking about it being under EPA, as opposed to, I guess my question would be, why not the CDC or the NIH or the FDA? All of these groups have things that they are involved in in a similar way.

We are talking a lot about cancer, and cancer is a devastating disease. There are lots of neuromuscular diseases, again, that are associated with this sort of thing.

So I would really like for you all to talk about that a little bit. To me, there is no excuse if we have a registry problem, we need to get it fixed. I think that that would help a great deal. We might need to totally revamp that. There are lots of things, diseases now that we need to be following that we are not following. So we can do a much better job of that.

But I do have concerns also about perhaps duplication, and then maybe there is a better way to do this through some of the agen-

cies that are set up really to investigate. Because along with this, you have these clusters, but the cluster might be something there that we are eating not enough of or too much of, besides the environmental concerns that have been raised.

So I appreciate the testimony. I think it is very, very helpful. Your written testimony I got to look at last night, and I do appreciate it. Again, it is something that we very definitely need to work on.

So don't misunderstand. I am committed to helping, but I just want to make sure that we are doing this right and that we don't have more duplication in spending our resources in a way that we really could get very, very aggressive and hold those accountable that are already doing this and get them to do a better job.

Does anybody want to comment? Yes, ma'am.

Ms. BROCKOVICH. I will. You brought up a couple of points that I just wanted to hit upon that I have found interesting in dealing with all of these communities in their reporting to me. There doesn't appear to be any national people's registry where they can report. More often than not, if somebody has cancer, that I have learned from these communities and those with cancer, is their doctors or an agency will actually do the reporting. They don't get to do the reporting, which is why I think they have started to bring information to me.

One phenomenon that I am seeing happening out there in this Facebook work that we live in now is emails coming from people that through Facebook have now found their old high school mates, but they have all been dispersed throughout the United States or in other parts of the world. Once they are stitched back together, they are actually learning that all of them have cancer, similar types of cancer, and were able to pinpoint them back to one location.

So I know there are many agencies out there that are involved, but there isn't one in particular that reports and compiles the data that are coming from the actual people and the actual sources, as this map would kind of indicate.

So they need a specific place to report to, not just CDC, but somewhere they can go and report their actual cancer and indicate where they are from, not necessarily where they currently reside.

So being able to possibly share all the data, because I don't know what exists at CDC or EPA or ATSDR does or doesn't have about certain communities, but to be able to open the doors and share that data between local, State and agencies to see what you have, and then be able to maybe start putting stuff like this on top of it to see what we are missing, because they are not reporting it to your agencies who are supposedly making the reports. The information is getting lost.

Senator BOOZMAN. I agree, and I think again the sharing of data and, as you say, we are in a Facebook age that does make that so much easier.

Ms. Solomon?

Dr. SOLOMON. Yes, your points, Senator, are very important. The problems with tracking diseases in this country are quite serious. The cancer registries have gaps in many States and many diseases that are very important, especially some diseases that appear to be

rising such as Parkinson's disease are really not tracked at all. So that is an important and related issue.

But I also wanted to speak about this issue of duplication, because it is a tricky issue because in my view coordination of resources is very, very important, and making sure that the appropriate expertise is deployed to address these clusters is also very important.

Up until now, the fact that it has really been ATSDR or the States that have responded to clusters means that not all of the necessary resources are at the table, especially some of the environmental sampling approaches.

In addition, when we were involved in researching our report on disease clusters, we contacted the ATSDR, which is housed at CDC, assuming that they would be tracking disease clusters and could tell us where the disease clusters are. They told us that not only do they not track disease clusters and have no information about where they are located, they told us furthermore that they are no longer investigating disease clusters.

So we said, well, if that is the case, who is? They said this is the role of States and local governments. Those entities don't have the knowledge and skills. So that is why legislation like this will bring all of those resources together.

Senator BOOZMAN. Thank you. I don't want to get gaveled on, but I think the point that you make about coordination is a good one.

Again, I guess I just have to work further to see if the CDC is not doing that, should they be the lead agency doing it versus the EPA? Do you see what I am saying?

The other thing, Madam Chair, is, and again, this is something we really need to look at in the sense that we are really concerned about spending money these days because the Federal Government doesn't have it. But this type of thing, improving the registries, getting some of these things under control really would save a tremendous amount of money. So that is I think a point we need to make.

I yield back. Thank you.

Senator BOXER. Well, Senator, thank you so much again for coming, and Michael and I are very hopeful you will join us and I hope you will look at this bill.

I want to answer your one critique, but also mention that I really agree with you on the cost, and I would ask unanimous consent to put into the record this report from Cancer Facts and Figures done by the American Cancer Society. They say about 1,529,000 plus new cancer cases are expected to be diagnosed in 2010. The estimate does not include non-invasive cancer and it also doesn't include skin cancers.

So and then later on they talk about the cost in here and it just is mind-boggling. What are the costs? The NIH estimates overall costs of cancer in 2010 at $263.8 billion. That is $102.8 billion for direct medical costs; $20 billion for indirect morbidity costs, that is lost productivity; and $140 billion for indirect mortality costs, costs of lost productivity due to premature death.

So your point is so well taken. I think if our bill moves forward and we can get to the bottom of this, and let's say we go into a place and we find that, no, there is no connection to the environ-

ment, and they may find it. They found it in several cases in California. All right. We tried. It is really genetic.

If they find out that there is something in the soil or the air or the water that we can fix, now you are going to prevent a lot of these cancers from happening. So I think our bill at the end of the day, it calls for efficiency as we move forward.

Now, I wanted to talk about why EPA. I think it is a fair question. This bill isn't an EPA bill. It says that all the agencies are going to coordinate. The reason we said EPA is if they find it is an environmental issue, it is EPA that has the ability to deal with air, water and soil. The others, CDC, doesn't. They will find out what the cause is, but they can't move to fix it.

So we wanted to give the Agency that could fix the problem, if there is a problem, the lead so that this isn't just an exercise. It actually has follow-through. But if you are concerned about this, if you want this spelled out, but let us work together because I have to say this, and Trevor knows this and he made the point that he is both the minority witness and the majority witness.

In these days when we have so much rancor, I would hope we could come together around this very simple idea. So if there is something really troubling you or bothering you, you want to work with us in a positive way, that would be fine. We want to get this out. We want to move this.

We want to show America that we are now happy to see Erin Brockovich, who is a private—you are an attorney now. Yes? You never did do that. Well, she is an attorney by osmosis then, an advocate, an activist and an advocate for communities, that people are calling her because they are frustrated with our response.

I would also put in the record a little acknowledgment here. The California EPA and the Department of Public Health expressed their appreciation to the U.S. EPA for providing important technical consultation as they looked at causes of birth defects in Kettleman, CA. Now, the jury is out. We don't know whether this is a cancer cluster due to environment or something else. But I think the EPA can be very effective and it is nice to get this comment from my State, so I wanted to put that in the record.

[The referenced information was not available at time of print.]

Senator BOXER. So I guess, and I have to say this was written in December, 2010, so this was before Jerry Brown took over. This was written by Arnold Schwarzenegger. I think it is important. It was a bipartisan thank you.

So Trevor, I would like to give you the last comment of the day from the panel. If there is one thing you could tell Senator Boozman because he missed your testimony. If you could sum up why you support the Boxer-Crapo bill, if you could look him in the eye and tell him what it is, that would be wonderful.

Mr. SCHAEFER. Well, thank you, Senator, for being here. I have known many children who have lost their lives and lost limbs to cancer, and it is heartbreaking to see that. I think that is why we are all here today, to do what we can. As Chair Boxer said, if there is a problem, that we address that.

I would also like to say that the medical community, tumor registry, CDC, are overburdened with data. I think that this would streamline and consolidate the process.

So that is it. Thank you.

Senator BOXER. Thank you very much.

Well, I want to say thank you to this entire panel, all of you. You have just helped us enormously.

Senator BOOZMAN. Madam Chair?

Senator BOXER. Yes, yes, please.

Senator BOOZMAN. Could I just say one thing?

Senator BOXER. Senator, of course.

Senator BOOZMAN. Again, I guess what I was thinking, the British Navy, they had a problem in the old days because their sailors were developing scurvy. So they were able to discover that that was from lack of getting vegetables when they were on board, fruits. So I guess what I would like is a situation where when we have a problem in a cluster, regardless of the disease, that when we go and investigate we investigate and figure out the cause, which if the EPA came out, and again I am not slamming the EPA at all, but you tend to think in terms of your training and whatever. They established that the paint on the boat was good, the decking was good and there was no environmental cause in that way, then we wouldn't have discovered that the people needed to be eating more fruits.

So I guess that is my only concern is where we are going and what agency. I think as Ms. Solomon said, coordinate.

Senator BOXER. Yes, well, this is what I am trying to say. We include every agency. Well, that is the whole point of the bill. If the entire response is coordinated, it includes the EPA, the ATSDR, the NIH, the CDC. Everybody is involved.

In addition, we pull in the State apparatus. We pull in the local, city, county. You are exactly right. You don't send in the EPA. That is not what our bill does. Our bill says we are going to coordinate this response. So everything that you said is what we do.

It is high time we did it because I don't want to see a private citizen getting calls because there is no faith in the government right now, because we are just not coordinated.

So I hope you will take a look at this, and I think you will like what you see. Again, if you want us to make it more clear, we will make it more clear.

I want to thank so much this panel. You have been excellent witnesses, and I look forward to the day that we pass Trevor's Law out of this committee and bring it down to the floor. We have everyone's support and we move it through.

Trevor, you know life takes so many twists and turns, and it is a mystery why. But clearly, your life took a twist and a turn in a way that has given you the power to communicate your story and the empathy and the compassion that you bring to this. Frankly, your common sense side as well is extraordinary.

I just thank you. You could have gone on with your world and put this behind you and said, wow, I dealt with this in my life, but I am closing that chapter.

What you are doing is so enormously helpful and we are so grateful. Your Senator is so proud of you and we thank you.

We stand adjourned.

[Whereupon, at 11:25 a.m. the committee was adjourned.]

[Additional statement submitted for the record follows:]

STATEMENT OF JAMES M. INHOFE, U.S. SENATOR FROM THE STATE OF OKLAHOMA

Thank you, Madam Chair, for scheduling this Oversight Hearing on Disease Clusters and Environmental Health, and in particular children's health.

We can all agree that protecting children's health is of great importance. I agree with the overarching goal of S. 76, cosponsored by Sen. Crapo (R Idaho). It goes as follows: "[protect and assist pregnant women, infants, children, and other individuals who have been, are, or could be harmed by, and become part of, a disease cluster. . ." Who can disagree with that? I have 20 children and grandchildren, and I think they fall into this category.

But general concern for kids and pregnant women is not the end of the matter. As one of our witnesses today, Dr. Richard Belzer, notes in his testimony, "Detecting disease clusters is a very difficult epidemiological and statistical problem." How we actually dig into this issue and decide the best courses of action are obviously up for debate.

At a minimum, we need to ensure the Federal Government, to the extent it's involved in the issue, is relying on the best available science, and doing so in an open and transparent manner.

We should also define, as best we can, science-based limits on what we are searching for and devise appropriate measures to address it once it's found. We need to ensure that we have clear goals and that we have definite measures of what we mean by "success." This is especially important, for, as Dr. Belzer noted, "open-ended goals combined with indeterminate measures of success often result in significant future conflict."

The nation has an existing scientific structure for dealing with disease clusters—I hope we can examine this structure today and determine whether it's adequate or not. At this point, I think it is.

Currently, investigating and addressing cancer and disease clusters is handled at the Federal level by the Center for Disease Control, specifically by the Agency for Toxic Substances and Disease Registry (ATSDR). This is a very capable agency, and I believe it should retain this exclusive authority.

The reason I think this is clear: The ATSDR is an agency with a long history in public health, with the expertise and knowledge necessary to identify and deal with disease clusters. For example, it has an existing infrastructure that facilitates communication between State and local public health departments, as well as local physicians.

It is not a regulatory agency, and I think we should think twice before vesting authority of this kind in a regulatory agency, subject as it is to political pressures, as well as the inherent tendency to issue rules and mandates.

It is vitally important we continue our efforts to identify, treat, and diagnose disease clusters using the best available science. Thank you again for holding this important hearing, and I look forward to hearing from our witnesses.

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