

**BIRTH DEFECTS: STRATEGIES FOR PREVENTION
AND ENSURING QUALITY OF LIFE**

HEARING

BEFORE THE

**SUBCOMMITTEE ON CHILDREN AND
FAMILIES**

OF THE

**COMMITTEE ON HEALTH, EDUCATION,
LABOR, AND PENSIONS
UNITED STATES SENATE**

ONE HUNDRED SEVENTH CONGRESS

SECOND SESSION

ON

**EXAMINING PUBLIC HEALTH ISSUES RELATED TO BIRTH DEFECTS, FO-
CUSING ON STRATEGIES FOR PREVENTION AND ENSURING QUALITY
OF LIFE**

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BIRTH DEFECTS: STRATEGIES FOR PREVENTION AND ENSURING QUALITY OF LIFE

FRIDAY, JULY 26, 2002

U.S. SENATE,
SUBCOMMITTEE ON CHILDREN AND FAMILIES, OF THE
COMMITTEE ON HEALTH, EDUCATION, LABOR, AND PENSIONS,
Washington, D.C.

The subcommittee met, pursuant to notice, at 9:40 a.m., in room SD-430, Dirksen Senate Office Building, Hon. Christopher J. Dodd (chairman of the subcommittee) presiding.

Present: Senators Dodd and Reed.

OPENING STATEMENT OF HON. CHRISTOPHER J. DODD, A U.S. SENATOR FROM THE STATE OF CONNECTICUT

Senator DODD. The subcommittee will come to order.

Thank you all for being here this morning. Let me just announce ahead of time that I think we are going to have one or perhaps two votes at 10 a.m., which will disrupt the hearing a little bit; but my hope would be to complete your work with us, Dr. Cordero, and since I do not have to vote immediately—I can vote after the vote starts—so we will have about 40 minutes or so. And then I will come back right after the vote, and we will continue the hearing. So just to announce ahead of time that we may have some disruption of the orderly flow of events.

But I am very grateful to all of you for joining us, those of you who are in the audience today as well as those who will be testifying, and family members and friends who have come out for this hearing of the Senate Committee on Health, Education, Labor, and Pensions, and the subcommittee which I am very proud to chair, the Subcommittee on Children and Families, which I have been proud to be associated with during my entire service here in the United States Senate for more than 20 years.

The title of today's hearing is "Birth Defects: Strategies for Prevention and Ensuring Quality of Life." Today the Subcommittee on Children will examine two very crucial questions—first, how do we best prevent birth defects, and second, how do we best support those born with birth defects and the families and loved ones who work to assure their care.

We should begin initially with an examination of the problems presented by birth defects. Birth defects are the leading cause of infant mortality in the United States and affect more than 150,000 infants born each year. In many cases, children with birth defects face a lifetime of disability. They are the leading cause of death in

the first year of life. Sadly, the parents of one out of every 28 babies receive the terrifying news that their child has a birth defect.

Both genetic and environmental factors can cause the more than 4,000 known birth defects. However, the causes of about 60 percent of birth defects are currently unknown.

We have a chart here on my left which will highlight some of the points I am about to make. Each and every day in the United States, more than 400 children are born with a birth defect. Tragically, in the same day, 17 infants will die due to a birth defect. Another 78 infants will lose their lives before they reach their first birthday because of a critical birth defect.

The wonderful pictures that surround the dais today show children—Nicholas Liguori, of Granby, CT, whom I just met and who said, “Hello, Senator Dodd”—I appreciate that, Nicholas; I told him I have a brother named Nicholas as well, so it is a great name—Nicholas is with us today and is the son of Fred Liguori, whom we will hear from shortly on the second panel. You are also looking at a picture of Gregory Pote, carrying the Olympic torch. We are proud to have you with us, Gregory. Greg is the nephew of another witness, Hal Pote, who will also testify on our second panel.

These are children who are, thankfully, very much with us. It is because of people like Greg and Nicholas that we are here today to talk about this issue. So the question is not only how do we best prevent birth defects, but also how do we best support those born with birth defects and the loved ones who work so hard to provide for their care.

I know that every parent here with us today will agree that there is no greater gift for a parent than that received upon the birth of a child. As we also know, with such a great gift comes great responsibility. However, for parents of a child born with a severe birth defect, such a great gift brings with it even more responsibility.

Every parent wants the very best for their child. Parents of children with birth defects are clearly no different. The blessing that comes with the birth of a child is clearly no less joyous for parents of a special needs child. However, it is only reasonable to accept that parents of a special needs child may require more assistance in order to ensure that their children receive the supportive services that they require and deserve.

I believe that as policymakers here in the United States Congress, we have responsibilities as well. Our responsibility should lead us to enact effective, helpful systems of care that not only prevent birth defects but also provide aid to those with birth defects so they can achieve all that their abilities allow.

Thankfully, we have made progress. Since 1960, the number of infants dying due to birth defects has been cut by more than half, which is great news. We now know that there exist some simple measures that can greatly decrease the chances of birth defects. We must work to ensure that all women of childbearing age are aware that there are certain, often very easy steps that will help to ensure a safe and healthy pregnancy.

For example, we know that a modest 400 microgram daily dose of the B vitamin folic acid could prevent 50 to 70 percent of all cases of spina bifida and other neural tube defects.

While encouraging as these numbers may be, we also know that about half of all pregnancies are unplanned and that in order to be effective, women must be taking the required dose of folic acid before they get pregnant. And while studies indicate that the message stressing the critical importance of folic acid is currently being heard, we all know that behaviors do not change overnight. I believe that if we continue our educational efforts, the desired changes in behavior will occur, as evidenced by the fact that the number of women who smoke during pregnancy has dropped approximately 30 percent since 1989 alone. However, we must continue to work to spread the lifesaving messages that truly prevent birth defects.

Efforts to prevent birth defects are tremendously worthy. In fact, they should be strengthened. And while the importance of birth defect prevention cannot be overstated, the fact remains that there is no one action that will prevent all birth defects.

While progress has been made both with regard to birth defect prevention and efforts to better the lives of those living with birth defects, this is not to say that more cannot be done. In fact, Congress can and should do more.

The Birth Defects Prevention Act of 1998 authorized the Centers for Disease Control and Prevention to conduct programs aimed at the prevention of birth defects through surveillance, research, and education. With the authority given by the BDPA, the National Center on Birth Defects and Developmental Disabilities at CDC provides funding to 28 States to develop, implement, and/or expand community-based birth defects tracking systems, programs to prevent birth defects, and activities to improve health services for children with birth defects.

However, the BDPA's authorization ends this year. In fact, I look forward to working with my colleagues, both Democrats and Republicans, Senator Bond in particular, to reauthorize this important legislation and maintain our commitment to preventing birth defects and ensuring the quality of life for those living with birth defects.

I am also encouraged by the efforts underway to create a National Spina Bifida Program. I believe that such a program could greatly improve our efforts to prevent the incidence and morbidity of spina bifida and other neural tube defects. A National Spina Bifida Program would also have the effect of greatly improving the quality of life of the more than 70,000 people presently living with this often severely disabling birth defect.

Thankfully, advances over the years in medical treatment such as the development of in utero surgery have allowed children with spina bifida to become adults living with spina bifida. I believe that a National Spina Bifida Program would provide vital resources to help these individuals lead full and rewarding lives.

It is my hope that the discussion we are going to have this morning will provide us with an outline that will lead us to advances in both prevention and the development of helpful systems of care for those living with birth defects.

So it is with great optimism that we begin today's hearing. Again, I want to thank all of our witnesses, particularly the fami-

lies who have come down with Nicholas and Greg to be part of this program today to shed some light on these important issues.

I see that my colleague from Rhode Island has joined us, and I thank him very much for being here and will turn to him for any opening comments or thoughts that he might have.

Senator Reed?

**OPENING STATEMENT OF HON. JACK REED, A U.S. SENATOR
FROM THE STATE OF RHODE ISLAND**

Senator REED. Well, Mr. Chairman, you said it so well that I cannot add very much at all.

I want to welcome Dr. Cordero. Obviously, this is a topic of great concern. We have made progress over the last several years, but we can do much more.

I would note that your interest in children goes way back; it is no longer theoretical. Mine is strictly theoretical, so I want to just commend you for holding the hearing, and let us get on with the witnesses.

Senator DODD. Since you have asked, Grace's pictures are right here.

[Laughter.]

Senator REED. Usually I do not have to ask.

Senator DODD. She was born a little more than 10 months ago and brought great joy. I often say that when I reach into my wallet to take out the pictures, there is a 50-50 chance that my AARP card will also drop out.

[Laughter.]

So I am an older father.

Let me introduce our first witness—and I thank my colleague from Rhode Island for his comments.

This morning, we are going to hear from two panels, as I mentioned at the outset. Our first witness is Dr. José Cordero, Director of the National Center on Birth Defects and Developmental Disabilities at the Centers for Disease Control and Prevention.

Throughout his very distinguished career, Dr. Cordero has been a strong and very effective leader in the fight against birth defects. He is a pediatrician and joined the CDC in 1979, first working in the Division on Birth Defects and Developmental Disabilities, and later serving as deputy director of the National Immunization Program.

Since the National Center opened last year, Dr. Cordero has undertaken the critical work of saving the lives of infants through the prevention of birth defects and developmental disabilities.

He is also a recognized leader in developing effective policies to support those who are born with birth defects.

I thank you, Dr. Cordero, not only for your presence here today but for many, many years of commitment to this issue. You truly honor us with your presence, and we are anxious to hear what ideas, thoughts, and advice you can give this Congress.

STATEMENT OF DR. JOSÉ F. CORDERO, DIRECTOR, NATIONAL CENTER ON BIRTH DEFECTS AND DEVELOPMENTAL DISABILITIES, CENTERS FOR DISEASE CONTROL AND PREVENTION, U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES, ATLANTA, GA

Dr. CORDERO. Thank you. Good morning, Mr. Chairman, Senator Reed.

I am José Cordero, Assistant Surgeon General and Director of the National Center on Birth Defects and Developmental Disabilities.

Thank you for the opportunity to be here today to discuss public health issues related to birth defects prevention and ensuring quality of life for individuals who have a birth defect.

Mr. Chairman, as you mentioned, more than 150,000 infants are born with a birth defect each year in the United States. Birth defects are the leading cause of infant mortality in the U.S. Babies who do survive often experience lifelong disability. In addition to experiencing physical impairments, 7 percent of children with a birth defect also have a serious developmental disability such as mental retardation, hearing loss, or vision impairment.

The challenges that confront children over the course of their lives, including access to medical care and preventive services, the development of secondary conditions, and social isolation are critical public health issues.

With the establishment of the National Center on Birth Defects and Developmental Disabilities in 2001, efforts related to birth defects, developmental disabilities, and the health of people with disabilities have been given new visibility.

Although the Center is fairly new, CDC's commitment to these issues is not. Since 1968, CDC has made birth defects monitoring, research, and prevention a priority. In 1985, we initiated a similar program for developmental disabilities, and in 1988, we established our disability prevention program and dedicated ourselves to promoting wellness for the 54 million Americans who have a disability.

When it comes to the prevention of birth defects and developmental disabilities, we have already seen a great many public health successes. We have virtually eliminated the mental retardation, hearing loss and vision impairments associated with congenital rubella syndrome, as well as mental retardation from Hib meningitis, which I must say when I was a pediatrician was a very, very common cause of mental retardation.

We have seen drugs which caused devastating birth defects, such as thalidomide, denied entry to the United States market or now tightly controlled.

Another emerging success story is the result of research which shows that the B vitamin folic acid prevents serious birth defects including spina bifida and anencephaly.

In 1992, the U.S. Public Health Service issued a recommendation that all women of childbearing age should consume 400 micrograms of folic acid to reduce their risk for these birth defects. CDC and the National Council on Folic Acid, a coalition of non-profit organizations, took action to provide women with information about folic acid. The members of the National Council, the Spina

Bifida Association of America, and the March of Dimes will also be testifying here today.

In 1996, the Food and Drug Administration also responded to this compelling scientific information and required all enriched cereal grain products to be fortified with folic acid by January 1998. The results of these public health information and fortification efforts are beginning to bear fruit.

Data published last week from 24 population-based State birth defects surveillance programs indicate that the prevalence of spina bifida has decreased 31 percent from 1995, before fortification, to 1999, after fortification.

These results are extremely encouraging as are the data emerging from other CDC-supported projects, suggesting that folic acid may also prevent or might have a role in preventing other birth defects.

Epidemiologic research like this is the foundation of our efforts to identify new causes of birth defects and developmental disabilities. For example, CDC supports Centers for Birth Defects Research and Prevention in seven States. These Centers are undertaking the National Birth Defects Prevention Study, one of the largest studies ever conducted on the causes of birth defects. This study will provide the Nation with a continuing source of information on potential causes of birth defects. CDC is also supporting similar research programs for developmental disabilities.

We are very optimistic about our ability to use science to identify new causes of birth defects and developmental disabilities and the ability of the public health community to translate the science into action.

However, until all causes of birth defects are identified, and prevention strategies are implemented, some children will still be affected. Many of these children will share the experience of tens of millions of other Americans who are living with a disability.

Great health disparities currently exist among people with disabilities. For that reason, CDC is supporting research related to health promotion and wellness among people with disabilities. One promising research project involves a community-based wellness program known as Living Well. This program has been shown to reduce disabilities due to secondary conditions by 37 percent and to reduce physician visits by 45 percent. We are expanding this program to a number of States.

Finally, CDC recognizes the importance of ensuring that people with disabilities have access to the specific types of medical treatment and care that are required as a result of their disability but also access to preventive health services. For example, CDC is working to ensure that women who use wheelchairs have access to mammograms and cervical cancer screening.

However, there are many challenges ahead of us. We can take great pride in the fact that individuals with disabilities are living longer. But the health care system is not adequately prepared to deal with the consequences of our success. Most physicians have little experience providing care to adults with spina bifida, cerebral palsy, Down syndrome, or other similar conditions.

Young people who have grown up with spina bifida or other birth defects often experience serious medical complications during their

teenage years and need assistance dealing with both physical and social challenges associated with their disability.

It is clear that there is a need to educate health care providers on the issue of disabilities across the lifespan. We have a long way to go, but we are already moving forward. I think we can and will do much more in the future.

I appreciate the opportunity to share with you this information on CDC's activities to prevent birth defects and developmental disabilities and promote quality of life for people with disabilities. It is our goal to ensure optimal health and wellness, beginning before birth and continuing throughout the lifespan. To achieve this goal, we undertake epidemiologic and prevention research, implement tracking and monitoring programs, and partner with organizations who share our mission.

I hope you find this overview useful, and I will be very happy to answer any questions that you may have.

Thank you.

[The prepared statement of José Cordero, M.D. follows:]

PREPARED STATEMENT OF JOSÉ CORDERO, M.D., M.P.H.

I am Dr. José Cordero, Director of the National Center on Birth Defects and Developmental Disabilities at the Centers for Disease Control and Prevention (CDC). I am a pediatrician and geneticist, with 29 years of public health experience related to birth defects, developmental disabilities and children's health.

I am very pleased to be here today to discuss the extremely important public health issues related to birth defects prevention and ensuring quality of life for individuals who have a birth defect. More than 150,000 infants are born with a birth defect each year. Many of these babies do not survive, and birth defects are the leading cause of infant mortality in the United States. For those babies that do survive, they often experience lifelong disability. In addition to physical impairments, birth defects are closely linked with a variety of cognitive and developmental disabilities—7 percent of children with a birth defect also have a serious developmental disability. The challenges that confront these children over the course of their lives, including access to medical care and preventive health services, the development of secondary conditions and social isolation, are critical public health issues.

With the establishment of the National Center on Birth Defects and Developmental Disabilities (NCBDDD) in April 2001, CDC has been given increased visibility for its efforts in these areas. However, while the organizational structure for NCBDDD is relatively new, CDC's commitment to these important issues is not. Since 1968, with the development of the Metropolitan Atlanta Congenital Defects Program, CDC has made birth defects monitoring, research and prevention a priority. In 1985, we initiated a similar program for developmental disabilities. Over the years, efforts in these two areas were focused on two primary goals—the prevention of birth defects and developmental disabilities for which causes have already been identified and the identification of causes for those which have not. However, we also recognized that the public health community's responsibility does not stop with prevention. We cannot afford to ignore the public health needs of the 54 million Americans who have disabilities. As a result, in 1998, we established our disability prevention program and dedicated ourselves to a prevention research, monitoring and intervention program aimed at identifying and implementing strategies that will eliminate challenges to optimal health and development and promote wellness for all Americans, including those who have a disability.

PREVENTION WORKS

When it comes to the prevention of birth defects and developmental disabilities, we have already seen a great many public health successes. Through immunization, we have virtually eliminated the mental retardation, hearing and vision impairments associated with congenital rubella syndrome, as well as mental retardation from Hib meningitis. We have seen drugs which caused devastating birth defects, such as thalidomide, denied entry to the United States market or tightly controlled. Removing lead from gasoline has meant that far fewer children have blood lead levels that might adversely affect their intelligence, behavior and development. These

successes have been achieved through close coordination and collaboration between Federal agencies—including CDC, the National Institutes for Health, the Food and Drug Administration, Health Resources and Services Administration—and with the private sector.

More recently, we have seen the results of many years of prevention research pay off when we learned that increasing consumption of the B vitamin folic acid resulted in significant reductions in the rates of neural tube defects—a category of common birth defects which include spina bifida and anencephaly. In 1992, the United States Public Health Service issued a recommendation that all women of childbearing age consume 400 micrograms of folic acid to reduce their risk for these serious birth defects.

As a result of this recommendation, CDC immediately began *The National Folic Acid Campaign* to provide women with information about folic acid. It is especially important for women to know that in order to prevent these birth defects, folic acid must be taken before conception and during early pregnancy. Educational materials have been developed stressing the use of folic acid prior to conception and these materials are provided to State and local campaigns. The National Council on Folic Acid, a coalition of non-profit organizations, has been established to assist in this effort. Two key members of the National Council, the Spina Bifida Association of America and the March of Dimes, will also be testifying here today. In 1996, the Food and Drug Administration also responded to this compelling scientific information regarding folic acid and authorized manufacturers of enriched cereal grain products to fortify these products with folic acid. All such products were required to be fortified by January 1998.

We may be beginning to see the results of these public health education and fortification efforts. Data published just last week from 24 population-based State birth defects surveillance programs supported by CDC indicate that the prevalence of spina bifida decreased 31 percent from 1995 (pre-fortification) to 1999 (post-mandatory fortification). Additionally, the 1999 data from the National Health and Nutrition Examination Survey (NHANES) on folate blood concentrations reveal substantial increases among women of childbearing age. The trend in 1999 already exceeds the Healthy People 2010 goal to increase the median red blood cell folate level to 220 ng/mL among nonpregnant women 15–44. Further research, which includes not only measuring rates of birth defects but also includes measuring women's folic acid intake, is needed to confirm that these downward trends are a result of the fortification and public health education. However, these results are extremely encouraging, as are the data emerging from other CDC-supported projects that suggest that folic acid may also play a role in preventing other birth defects, such as imperforate anus and abdominal wall defects known as omphalocele.

RESEARCH HOLDS NEW PROMISE

Epidemiologic research is the cornerstone for our efforts to identify new causes of birth defects and developmental disabilities. Translating these epidemiologic findings into effective public health strategies through applied research represents the next step to making prevention a reality. CDC has underway a broad range of research, including both epidemiologic and applied, that will be providing the foundation for our next prevention success stories.

CDC's Centers for Birth Defects Research and Prevention, first established in 1996 and formalized with the passage of the Birth Defects Prevention Act of 1998 (Public Health Law 105–168), serve as a cornerstone for these efforts. The Centers were established in 7 states with nationally recognized expertise in birth defects surveillance and research. CDC supports and coordinates the overall activities of the Centers, and participates as an eight study site in the National Birth Defects Prevention Study (NBDPS). This study—one of the largest ever conducted on the causes of birth defects—is a key part of the program of research for the Centers. The study will provide the Nation with a continuing source of information on potential causes of birth defects and will serve as a mechanism for identifying new substances in our environment that are harmful to developing babies. In addition to participating in the NBDPS, each individual Center is undertaking its own center-specific research agenda on issues including nutritional, environmental and behavioral factors associated with birth defects, financial and other costs of birth defects, and birth defect prevention research.

CDC is also supporting similar research programs for developmental disabilities. The Children's Health Act of 2000 mandated the creation of centers for excellence in autism and developmental disabilities epidemiology, and in 2001, CDC established CADDRE—Centers for Autism and Developmental Disabilities Research and Epidemiology. This collaborative network of four centers plus CDC will collect and

analyze information on the incidence, correlates, and causes of autism and related developmental disabilities.

Our collaborations on research to identify causes for birth defects and developmental disabilities are not limited to institutions in the United States. CDC has initiated a very important collaboration with Denmark to help improve our understanding of the potential causes of cerebral palsy—a condition which affects 10,000 babies born in the United States each year. As part of this collaboration, we will be undertaking a case-control study of the relationship between infection in pregnancy and cerebral palsy, using cases identified in the Danish Cerebral Palsy Register and archived newborn blood samples. Denmark has a unique combination of national public health data systems that is not found elsewhere in the U.S. or abroad. These unique Danish data systems can all be linked by a universal personal identifier. Thus, they provide much important information (such as health, medical, and sociodemographic information) to carry out epidemiologic studies of reproductive and developmental outcomes. Also, because these data systems contain information on large numbers of individuals over long periods of time, studies can be made with an unusually high level of statistical power. For reasons like these, such collaborations are invaluable in providing timely and relevant information that can be put to immediate use in the development of prevention strategies.

Other prevention-oriented research currently supported by the CDC includes Legacy for Children and Project Choices. Legacy for Children is a program consisting of randomized, controlled, longitudinal research projects being implemented at the University of Miami and the University of California at Los Angeles. These projects examine the potential for improvement in child developmental outcomes through interventions designed to influence parenting behavior. The early years of life—especially from birth to age five—are crucial for cognitive and social/emotional development. Parents play a critical role in their children's development and are responsible for their children's environment. Children develop within the context of their family and their development is affected by the nature of the relationship with their parents. Previous early intervention efforts have typically included early education for children in child care centers and social or mental health services for the parents in their role as adults, with only marginal attention devoted to parenting behavior. The interventions initiated by CDC focus on parenting behaviors and the relationship of the parent with his or her own child. Results from these projects will be available over the next few years and will help determine what are the critical components of early intervention programs for children at-risk for developmental delay.

Drinking alcohol during pregnancy poses a serious threat to the health of the unborn child. While overall alcohol use during pregnancy has been declining since 1995, rates of frequent drinking and binge drinking remain high and thus continue to pose a risk for many women. Interventions aimed at reducing alcohol consumption must begin before pregnancy because birth defects associated with prenatal exposure to alcohol can occur in the first 3 to 8 weeks of pregnancy, before a woman even knows that she is pregnant.

In an effort to reduce the number of children born with alcohol-related birth defects, CDC is working to develop and test interventions to identify women at high risk for an alcohol-exposed pregnancy and help them to reduce their alcohol intake and postpone pregnancy until they stop or limit their drinking. Project Choices is the centerpiece of CDC's research efforts aimed at preventing alcohol consumption during pregnancy. CDC has demonstrated that women in certain community-based settings (such as alcohol and drug treatment centers, jails, and primary care centers serving low income populations) have a sevenfold higher risk for an alcohol-exposed pregnancy. However, information on how best to reduce this risk was lacking. To address this data gap, CDC initiated Project CHOICES: a multi-site collaborative study involving three universities (Nova Southeastern University, University of Texas at Houston, and Virginia Commonwealth University). Results from the first phase of the study found that two-thirds of all women who were at risk prior to the intervention were no longer at risk at the time of the 6-month follow-up visit. The intervention is now being tested more rigorously through a randomized clinical trial.

MONITORING OUR PROGRESS AND MEASURING OUR SUCCESS

As more causes for birth defects and developmental disabilities are identified, and prevention strategies are implemented, it will become even more important for the public health community to have good information regarding the number of cases of birth defects and developmental disabilities. Only by having such information will we be able to ensure that our programs are having their desired effect and make any needed adjustments and improvements. In addition, monitoring rates of birth defects and developmental disabilities over time also enables us to determine wheth-

er rates are varying over time or in different geographic regions. Such variations in rates may provide clues to additional causes or possible need for concern.

CDC is working toward the establishment of comprehensive monitoring and tracking programs to accomplish these objectives, and currently CDC:

- Conducts model surveillance programs to monitor the prevalence of birth defects and developmental disabilities in the metropolitan Atlanta area.
- Provides financial and technical support for State-based birth defects surveillance through cooperative agreements with 35 states, as well as through a collaborative effort of State programs known as the National Birth Defects Prevention Network that collects and disseminates State-based birth defects surveillance data.
- Supports the Fetal Alcohol Syndrome Surveillance Network (FASSNet) in five states.
- Supports the Autism and Developmental Disabilities Monitoring Network (ADDM) in four states.
- Funds 30 State-based Early Hearing Detection and Intervention (EHDI) tracking programs.
- Continually monitors folate in women through the NHANES.
- Works with States to improve the timeliness and quality of reporting of birth defects through the vital statistics systems.

ENSURING HEALTH, WELLNESS AND QUALITY OF LIFE COMPLETES THE PICTURE

While we are very optimistic about our ability to use science to identify new causes of birth defects and developmental disabilities and the ability of the public health community to translate this science into public health action, we know that our prevention efforts will never be 100 percent successful. For example, we estimate that folic acid has the potential to prevent 50–70 percent of all neural tube defects. There are still other causes of neural tube defects that remain unknown. Until the causes of all birth defects are identified and prevention strategies are implemented, close to 3 percent of all babies will still be born with a birth defect. Most of these children will share the experience of tens of millions of other Americans who are living with a disability. For that reason, CDC has also placed a high priority on research focused on promoting health and wellness among people with disabilities.

Working with universities and other research organizations, CDC conducts research to develop a better understanding of the varied and unique health conditions of people with disabilities. CDC seeks to identify health risks and protective factors and to measure and develop effective health promotion activities to prevent the secondary conditions related to living with a disability. CDC is currently funding 11 projects in academic settings that develop new methods for promoting health and wellness among people with disability. One particularly promising research project will be rigorously testing a community-based wellness program, known as “Living Well,” which has previously been shown to reduce disability due to secondary conditions by 37 percent and reduced physicians visits by 45 percent over 6 months. This empirically grounded health promotion intervention, delivered by community-based consumer-controlled independent living centers, offers a model for both improving health and independence of adults with physical disabilities, as well as containing medical services costs within a managed-care context. The new study will evaluate the model with a larger, more representative sample and a more rigorous design. Additional data on costs and preferences will be developed to conduct a cost-effectiveness assessment. The researchers will also look at how adults with physical disabilities can maintain and improve their health after participating in a health promotion program to further enhance cost-effectiveness.

In addition, CDC is working with State health departments to improve their capacity for implementing programs to address the public health needs of people with disabilities. Currently, CDC is supporting such activities through cooperative agreements with 16 states. Specific programmatic efforts include improving State surveillance activities, conducting health promotion interventions, developing and monitoring policies affecting people with disabilities, and facilitating partnerships between State- and research- or service-based agencies. These programmatic efforts do not focus on specific types of disabilities, but rather they address common issues in a variety of cross-cutting disability domains including communication, learning, mobility, and personal care/home management.

Finally, CDC recognizes the importance of working with the health care delivery system to ensure that people with disabilities have access not only to the specific types of medical treatment and care that are required as a result of their disability, but also access to important preventive health services. For example, CDC has worked to ensure that women with a mobility impairment who use a wheelchair

have access to mammograms through the Breast Cancer Early Detection Program. To ensure this, CDC works with State programs to purchase special equipment. In addition, CDC is working to ensure that people with disabilities have access to information that will help them reduce health risk behaviors such as tobacco use and sedentary lifestyles.

However, there are major challenges that remain ahead of us. While we can take great pride in the advancements that have been made in increasing the life expectancy of individuals with disabilities, we also must recognize that the health care system is not adequately prepared to deal with the consequences of our success. The life expectancy of an individual with Down Syndrome has increased from 1 year to 49 years since the late 1960's. Just several decades ago, very few children with spina bifida survived at all. Because these changes have occurred over a relatively short period of time, most physicians have had no experience dealing with an adult with these types of conditions. In 1994, SBAA and United Cerebral Palsy sponsored a symposium entitled "Preventing Secondary Conditions Associated with Spina Bifida or Cerebral Palsy." Then, as now, one of the major issues of concern to people with spina bifida and cerebral palsy, their families and their health care providers was the issue of transition from pediatric care. The need is particularly acute in teenage years. These are difficult years for any young person, but for a young person with a disability, such as spina bifida, they can be even more challenging. For example, teenagers with spina bifida often experience serious medical complications. In addition, these teenagers often need assistance in dealing with both physical and social challenges associated with catheterization, skin care, and cleanliness. Social, educational, and vocational support are also essential to ensuring full participation as an adult.

It is clear that, in addition to developing programs that address the public health needs of people with disabilities, there is a need to educate healthcare providers on the issue of disability across the lifespan. Addressing these issues will also provide an opportunity to begin to prepare our public health and health care systems for the challenges presented by the aging of the American population. I look forward to working toward future successes in these areas, and recognize that achieving them will require broad-based partnerships and collaborations with research, public health, medical and voluntary organizations. We have a long way to go, but we are already moving forward. I think we can and will do much more in the future.

I appreciate this opportunity to share with you this information on CDC's activities to prevent birth defects and developmental disabilities and ensure quality of life for individuals who have experienced disability. Our goal is to ensure optimal health and wellness—beginning before birth and continuing throughout the lifespan. To achieve this goal, we undertake epidemiologic and prevention research, implement tracking and monitoring programs, and partner with health care and voluntary organizations who share our mission. I hope you found this overview useful, and I will be happy to answer any questions that you may have.

Thank you.

Senator DODD. Thank you very much, Dr. Cordero, for your work. Of course, the work of the National Center is tremendous, and we are very grateful for the efforts that have been made and the initiatives that have been undertaken.

I have a number of questions. Just picking up on one of the last points you made about the need to educate health care providers and the problem that exists out there with the lack of understanding among the physician or health care provider population, what specific recommendations would you make? We are going to be re-authorizing legislation here, and if there are some things we could recommend as part of our efforts that could help close that gap, I would think that that would be one of the critical things we could try to achieve.

Dr. CORDERO. Yes, Senator. There are two areas that we are actually approaching at CDC. One is that we have entered into a collaborative agreement with the American Academy of Pediatrics to educate physicians about the challenges in the first 18 years of life of working with individuals with disabilities, particularly spina bifida and others.

Second is that CDC is developing, in collaboration with the National Institutes of Health and the AHRQ, to look at a consensus on what are the specific activities that can be done to help individuals with spina bifida. This consensus conference will address issues of medical care, issues of functional limitations, and also social and activities of daily life. I think that will identify both what are the research gaps and what are the things that we can implement currently to help individuals with spina bifida.

Senator DODD. When do you anticipate those recommendations?

Dr. CORDERO. The meeting is scheduled for April or May of 2003.

Senator DODD. The reauthorization expires this year, so any thoughts you have ahead of time would be helpful if we are going to reauthorize before the expiration. I do not want to have to get to this in the next Congress. We could end up losing a year or so. It is going to be tough this fall with so much on the agenda, but this will be very important to get reauthorization. I anticipate wide support for us, so if you could give us some ideas specifically on how we can do that, it would be helpful early on.

Dr. CORDERO. Right. We will be happy to provide more specifics in writing for you.

Senator DODD. Would you, please? That would be very, very helpful to us. And I can see heads nodding in the audience, so I am sure we will get some additional suggestions on this.

What I will do is ask a couple more questions and then turn to my colleague from Rhode Island. As I announced ahead of time, Jack, we will then break to go over and vote, but we will at least finish with Dr. Cordero. So I will watch the clock, and I may have to submit some additional questions to you in writing.

I wonder if you could give us some idea as to why these numbers continue—they are still large numbers. We know that we have done a lot with folic acid, yet the numbers still seem high in the case of spina bifida among certain communities. I wonder if you could shed some light on that.

Second—and I will ask both questions and then turn to my colleague—what has the CDC identified as some of the environmental causes of birth defects, and what is the National Center doing to provide information about these causes so that people have a better level of education about what to avoid and what to be careful about?

Dr. CORDERO. Let me answer the first one about the numbers in the case of spina bifida. Actually, I think we have made great progress, as I mentioned, with the over 30 percent decline in spina bifida comparing before and after fortification.

We have made some progress in educating women and families about the use of folic acid, but we realize that we still have challenges in reaching some communities, particularly the Hispanic community. We are actually working to develop a more aggressive campaign to educate women in Hispanic communities about the use of folic acid. We have actually started a project in Miami and San Antonio on how we can be sure to reach the Hispanic community, with messages but also working with physicians and the communities in those areas to be sure the message gets out and that it is translated into action.

Senator DODD. That is important. What about the environmental issues?

Dr. CORDERO. CDC is also working with the Center for Environmental Health and the National Institute for Environmental Health Sciences in actually funding a number of projects and centers looking at the area of birth defects and developmental disabilities.

As I mentioned, we are funding seven Centers for Birth Defects Research and Prevention, and these centers are actually conducting the largest study, one of the largest ever, and there, we are hoping to identify new causes of birth defects, including environmental areas.

In terms of what we can recommend today, I think the important things are, one, that women begin to take folic acid—

Senator DODD. When they are of childbearing age.

Dr. CORDERO [continuing]. Of childbearing age, yes—and also, that they actually stop using alcoholic beverages before pregnancy begins, quit smoking, and also, that they review with their doctor what kinds of exposures they have in the workplace to ensure that they are not exposed to chemicals and other things that could be a problem for them during pregnancy.

Senator DODD. Are there lists of these things, for instance, chemicals or substances in the workplace—there are known lists of these materials, aren't there, that women who are pregnant or are thinking about getting pregnant should not be around?

Dr. CORDERO. Yes. Actually, one of the challenges that most women have when they seek information is finding one place where they can get all the information. And actually, one of our fundings for this year is a center that would provide information. This is a center in California which would be able to answer women's questions about what are the kinds of exposures, so if they have specific questions, they can be answered. I think that that is something that hopefully, we can expand in the future.

Senator DODD. And these health clinics—last Monday, we opened a dental division—we have 11 public health clinics in Connecticut, but they are all over the country, and they are growing, and they are very successful. It seems to me that for the audiences that we are talking about here, those places would be a very good place to start, given the fact that so many people who may not be as well-informed about the problems could start getting that information when they show up at these health clinics.

Dr. CORDERO. I agree, Senator. I think that that is an area that we can look into, how we can expand there.

Senator DODD. Yes. I have about 100 more questions for you, but let me turn to my colleague from Rhode Island, Senator Reed.

Senator REED. Thank you very much, Mr. Chairman.

Thank you, Dr. Cordero. When we were doing the Children's Health Act of 2000, I became aware of and interested in the Fragile X problem. Is CDC doing any work with respect to Fragile X?

Dr. CORDERO. Senator, we have been working with a number of colleagues on Fragile X for a number of years. We actually funded Dr. Stephanie Sherman, who is one of the world experts on Fragile X, to conduct a study looking at two questions—one, what can be done to help individuals with Fragile X, and two, can we begin

screening for Fragile X in the near future. At that time—this was a few years ago—the answer was that it was not yet the time for that. And we are working with colleagues, reviewing those questions, and especially what we can do to identify children with Fragile X early and then, what are the interventions that may actually work.

Let me say that we are about to publish a paper in the Morbidity and Mortality Weekly Report that has actually been looking at the delays in diagnosing Fragile X. I think that that is going to give us some information to then move into additional actions.

Senator REED. Thank you, Doctor.

This line of questioning raises the issue of the impact of genomic research, generic research, on birth defects and to what degree CDC or NIH is pursuing the breakthroughs that we have seen in genomics.

Dr. CORDERO. I think genomics offers a great opportunity for, one, finding more causes of birth defects, especially looking at the genetic environment interactions, which is an area that we had very little opportunity to look at before. We are working very closely with our Office of Genomics at CDC, as well as with the NIH, in exploring areas where we can use the genomics knowledge to actually find causes of birth defects. In fact, several of our centers—a center in Iowa is actually looking at the role of genes in cleft palate, and also the interaction of cleft palate and genes in causing these serious birth defects.

I think it is the future, and we expect and will continue through our Centers on Birth Defects to do more research and fund more research in that area.

Senator REED. I know the Center on Birth Defects is preparing a study about the topic. It seems to me that there are so many different ways to approach the issue, since it is very complicated, but without being overly simplistic, there are some basic public health initiatives—education, good nutrition—and then, there are some more sophisticated issues in terms of genetic predisposition, environmental factors.

Within your study, are you also going to send up here or devise a strategy that would approach the public health problems in terms of the comprehensive way, and let us know how much it would cost, and then lay out a strategy to deal with the more complicated issues of genetics and environmental? Is that something that you are contemplating?

Dr. CORDERO. The answer is yes. Actually, I think that what you are outlining is very much the approach that we are following in terms of addressing both the issues of birth defects and also when we apply genetics into it. For whatever we do—let us take the example of even spina bifida—we actually need to educate the public, we need to educate the health care professionals, and then determine how the intervention actually works and how we insert also the laboratory work that needs to go into it.

I agree, and I think that that is exactly the process that we are following, and as we get more into the genetics of diseases, I think we will have more of that. But the public health effort to educate and track and also conduct more research will be the basis of what we will continue to do.

Senator REED. Thank you very much, Dr. Cordero.
Thank you, Mr. Chairman.

Senator DODD. Thank you, Senator Reed.

I would ask you if you could, just in response to Senator Reed's questions, if you are going to get us some early information in the next month or so where you include this kind of information. As I said, Doctor, you have a very willing and anxious Senator here on this issue. Senator Bond offered the original bill back in 1998, I guess it was—he is going to try to come by this morning, by the way—but we would very much like to get as much of this information as we can so that when we craft the reauthorization legislation, we can accommodate as many of these ideas as possible in that bill.

Dr. CORDERO. We will be very delighted to provide more information in writing.

Senator DODD. And before we race to make the vote, I did not get to the questions on the additional costs. I mean, \$1 million is not an outrageous number when you start talking about the cost of continuum of care. That is a staggering figure. And obviously, these disabilities do not choose people based on economic circumstances and their ability to afford it; they are blind to that. So we need to be talking as well about how we can provide some really meaningful support so that with the wonderful new breakthroughs now medically, people can live very productive lives for a long time, and to enhance their ability to do that and support their caregivers and their families has got to be a critical piece of any discussion in this area. So I would be very interested as well in any ideas you can suggest and give to us on how we can be more supportive of the families out there and the individuals themselves, so they can have lives that are fruitful and productive.

If you would make that a part of your recommendations to us, I would appreciate it.

Dr. CORDERO. We certainly will, and especially the care of individuals with birth defects is a key area that needs to be addressed.

Senator DODD. Yes. Again, I will submit some additional questions to you in order not to hold you up, and we will come right back as soon as the vote is over.

[Questions of Senator Dodd were not available for inclusion at press time, however, copies are retained in the committee file.]

Dr. CORDERO. Thank you.

Senator DODD. The subcommittee will stand in recess for a few minutes.

[Recess.]

Senator DODD. The subcommittee will come to order.

My apologies to all of you for being disrupted with the vote. Let me thank all of you again for being here.

I am going to submit for the record a statement from Senator Bond who will be unable to join us this morning but, as I mentioned a while ago, was the author of the authorization in 1998. So his statement will be included in the record.

[Statement of Senator Bond was not available at press time, however, copies are retained in the committee files:]

Senator DODD. I am pleased now to introduce our second panel of witnesses and thank all of you again for being here.

First, we will hear from Mr. Hal Pote. Mr. Pote is the president of the board of directors of the Spina Bifida Foundation, which is affiliated with the Spina Bifida Association of America, an organization dedicated not only to eradicating spina bifida but one that is admirably working to better the lives of more than 70,000 individuals living with this birth defect.

In addition to his responsibilities at the Foundation, Mr. Pote is a regional bank executive at J.P. Morgan Chase Bank. He is the proud uncle of Greg, whom I met before the hearing and who is with us here today and whose picture is up behind me here, carrying the Olympic torch.

Mr. Pote, we thank you for joining us today. You are very gracious to be here, and I commend you for the wonderful work that you are doing.

Next, we are going to hear from Dr. Nancy Green, who has recently been named the medical director for the March of Dimes, an organization that we are all familiar with for its long record of life-saving work. Since its founding in 1938 by President Franklin Roosevelt, the March of Dimes has proven itself an invaluable national resource to the Nation's public health.

Dr. Green received her M.D. from Columbia University College of Physicians and Surgeons and currently serves as associate professor of pediatrics and cell biology at the Albert Einstein College of Medicine in New York.

We congratulate you on your new position and look forward to you working with this committee in the coming years.

Our final witness is Fred Liguori from Granby, CT. I am pleased to have you here, Fred, coming from our State. Fred and his wife Jill have a son, Nicholas, whom I have already mentioned and talked about, a fine young man.

We also have up here on the dais a picture of Nicholas riding his tractor. He is reading diligently over there with his mother at this particular point. Nicholas has spina bifida, and Mr. Liguori will testify to some of the unique needs that Nicholas has.

I have already discussed some of the costs that can hit a family, and we are anxious to hear your ideas and thoughts, and again, we are very grateful to you, as well as to you, Hal, for being here. I am always impressed when people are willing to come forward in a public setting and talk about these matters. It is not easy to do so, and I am glad that you have brought family along as well so we will get a chance to meet them—so these are not just numbers and statistics and data, but we in the Congress here and our staffs and members who can be here, those who are watching on CSPAN, which is covering this hearing today, can appreciate that this is more than just about data and numbers. It is about real human beings and real needs and what we can do cooperatively to make those burdens lighter, and to see that we maximize the potential of each one of these wonderful God-given gifts of life.

So we thank you for coming today, and we will begin with you, Hal, and move right down the table in the order that I have introduced you.

STATEMENTS OF HAROLD POTE, PRESIDENT, SPINA BIFIDA FOUNDATION, NEW YORK, NY; DR. NANCY S. GREEN, MEDICAL DIRECTOR, MARCH OF DIMES BIRTH DEFECTS FOUNDATION AND ASSISTANT PROFESSOR OF PEDIATRICS, ALBERT EINSTEIN SCHOOL OF MEDICINE, NEW YORK, NY; AND FRED LIGUORI, PARENT, GRANBY, CT

Mr. POTE. Thank you, Senator.

Mr. Chairman and Senator Reed, you are very gracious with your remarks. I want both of you to know how pleased we are to have this opportunity to be here today, so thank you very much for that.

I am here representing the Spina Bifida Association of America, the Spina Bifida Foundation, and our whole spina bifida family, and I respectfully request that my testimony be included in the record.

As you mentioned in your opening remarks, Senator Dodd, spina bifida is a neural tube defect that results from the spine failing to close properly. More important, it is the most common birth defect in the United States that results in permanent disability, and as you mentioned a minute ago, there are currently 70,000 families in our country who have been affected by spina bifida.

Our Association is a national voluntary health agency working on behalf of all of these folks and their families through education, advocacy, research and service. We are about 30 years old, and today we have 60 chapters and serve 100 communities around the country.

As you mentioned, Senator, my personal passion for this issue comes about through my relationship with my nephew, Greg, who is here today. He is a terrific kid, and I love him deeply, but he has been dealt a tough hand. He has had several major surgeries; he has another one scheduled for next month. On the other hand, as you can see from that photograph, he is clearly the most famous member of our family, and while that was very early in the morning, Senators, I am sure that both of you saw him on television when he was carrying the torch.

[Laughter.]

While prevention of spina bifida is a critical public health issue, and we are fully committed to the range of activities that can reduce the incidence of spina bifida, in the interest of time, I will focus my remarks on three other important issues, and my written testimony will deal with prevention. And Dr. Green, I am pleased to say, in her role here representing the March of Dimes, will be focusing on prevention in greater detail.

The three issues are the following. First, quality of life. As a result of this neural tube defect, most babies and children with it suffer from a very broad range of challenges, including physical, psychological, and educational challenges. These include paralysis, developmental delay, numerous surgeries, and living with a shunt in an attempt to ameliorate their condition.

After decades of poor prognoses and short life expectancy, due to recent breakthroughs in research and treatment, more children with spina bifida are becoming adults with spina bifida, and that is the very good news. This then provides a new range of chal-

lenges including education, job training, independent living, and health care, now prolonged for secondary conditions.

Even if we are successful in preventing the majority of spina bifida cases in the future through folic acid and supplementation of grain, our Nation must still take the steps to ensure that the thousands of individuals living with spina bifida today can live full and healthy lives.

To that end, improved secondary prevention interventions and treatment therapies must be identified, developed, and delivered to those in need. Dr. Cordero referenced some of the things that we are working on in conjunction with his organization, AHRQ, and others.

Secondary conditions associated with spina bifida—and by the way, these secondary conditions are more complicated for a person with spina bifida than they are for anyone with any other birth defect—can include neurological disorders, paralysis, bladder and bowel control difficulties, learning difficulties, depression, social and sexual issues, latex allergy, obesity, and skin breakdown.

For example, our children with learning disabilities may have difficulty paying attention, expressing or understanding language, and grasping reading and math. So a response there—early intervention with children who have experienced learning problems can help them considerably prepare for school.

With appropriate, affordable, and high-quality medical, physical, and emotional care, most people born with spina bifida will live a long and productive life. Ensuring access to the full range of necessary and appropriate services is essential to improve the quality of life for those born with spina bifida.

The second topic, which you have referenced already, Senator, is cost. It is in fact estimated—and we do not yet have hard data on this, but that is part of what we are doing—that the lifetime cost of care for individuals with spina bifida very often exceeds \$500,000 and very often exceeds \$1 million, as you mentioned. And Senator, as you pointed out earlier, when you look at that million-dollar cost and then you think back to Dr. Cordero's testimony, the decline in spina bifida incidence is happening in the socioeconomic groups where you would expect to first see it. The challenge is that folks who have greater socioeconomic challenges are also the folks who are not seeing a decline in spina bifida incidence, and they are in fact the folks who are least able to afford these burdens of medical cost and probably least likely to have the private health insurance that can help ameliorate that situation.

Nationally, we think this is a \$750 million per year issue, and we know that the Social Security Administration is paying out \$82 million a year to folks who are affected by spina bifida.

The third issue that I would like to comment on deals with the range of choices available to families when they learn of a diagnosis of a fetus with spina bifida. Historically, that family had two choices—first, to carry full term, to have a beautiful child but a child who would be faced with a lifetime of challenges; and the second option was to terminate the pregnancy voluntarily. There is perhaps now a third option developing from in utero surgery, and through the work being done now at three hospitals, it is very early, and we are now supporting the work being done to go back

and look at the results, but it appears that there is some encouraging evidence coming out that, for example, perhaps 30 to 50 percent of births of folks who have received in utero surgery would result in their not requiring a shunt. So there could be some very exciting things coming out of in utero surgery, but we need support to make sure we understand that and that those best practices can be promulgated to the community of surgeons as well.

I would like to close by first thanking Dr. Cordero for his testimony and for his leadership. There are two specific messages that we would like to leave with this subcommittee.

The first is that the National Center for Birth Defects and Developmental Disabilities is critical for our community. It was a very important step forward when this Center was founded and Dr. Cordero's leadership was established. We would urge that it be funded at a level of \$115 million this coming year. I think that is about \$25 million more than the funding it received last year. We are well aware that this is a budget with lots of challenges, but we would love to see that kind of support.

Then, secondly, as you indicated in your opening comments, Senator, identifying \$3 million of that to support the Center of Excellence for Spina Bifida would be something that would also be very important to us as well.

So in closing, let me again thank you on behalf of our community and for the 70,000 families for the leadership that you have shown and the work that your subcommittee is doing, and thank you for the opportunity to be here.

Senator DODD. Thank you very much for very fine testimony. I look forward to working with you some more on this.

[The prepared statement of Mr. Pote follows:]

PREPARED STATEMENT OF HAROLD POTE

INTRODUCTION

Mr. Chairman, and Members of the Subcommittee, on behalf of the Spina Bifida Association of America (SBAA) and the Spina Bifida Foundation, thank you for the opportunity to come before you today to discuss issues related to Spina Bifida, the nation's most common, permanently disabling birth defect.

I am honored to be here today to discuss with you the importance of preventing Spina Bifida and improving the lives of the more than 70,000 individuals and their families who are affected by this condition. I respectfully request that my testimony be included in the Congressional Record.

While in my day job I currently serve as the head of the Regional Banking Group at JP MorganChase, I also serve as the President of the Spina Bifida Foundation Board, a cause that is near and dear to my heart. SBAA is the national voluntary health agency working on behalf of people with Spina Bifida and their families through education, advocacy, research and service. The Association was founded in 1973 to address the needs of the Spina Bifida community and today serves as the representative of 60 chapters serving more than 100 communities nationwide.

My personal interest and passion which drives my involvement with these organizations stems from the fact that my family is one of the 70,000 affected by Spina Bifida. My nephew Gregory Pote—who is here today in the audience—was born with Spina Bifida 16 years ago. One of my proudest moments as Greg's uncle was the morning that our family awoke before the crack of dawn and gathered together on the side of a street in Philadelphia to watch Greg carry the Olympic torch earlier this year. To date, Greg has already had more than 20 surgeries. Double digit numbers for surgeries unfortunately are not unusual for children living with this condition. I am here today to outline what Congress can do to prevent Spina Bifida and help improve the quality of life for Greg and the other individuals and their families that live with this birth defect.

BACKGROUND

Spina Bifida is a neural tube defect (NTD) and occurs when the spinal cord fails to close properly during the early stages of pregnancy. This happens within the first few weeks of pregnancy and most often before the mother knows that she is pregnant. Over the course of the pregnancy—as the fetus grows—the spinal cord is exposed to the amniotic fluid which increasingly becomes toxic. It is believed that the exposure of the spinal cord to the toxic amniotic fluid erodes the spine and results in Spina Bifida. There are varying forms of Spina Bifida occurring from mild—with little or no noticeable disability—to severe—with limited movement and function. Unfortunately, the most severe form of Spina Bifida occurs in 96 percent of children born with this birth defect.

The result of this neural tube defect is that most children with it suffer from a host of physical, psychological, and educational challenges—including paralysis, developmental delay, numerous surgeries, and living with a shunt in their skulls which seeks to ameliorate their condition by helping to relieve cranial pressure associated with spinal fluid that does not flow properly. It is wonderful to report that after decades of poor prognoses and short life expectancy, children with Spina Bifida are now living long enough to become adults with Spina Bifida. These gains in longevity principally are due to breakthroughs in research, combined with improvements in health care and treatment. However, with this extended life expectancy, our Nation and people with Spina Bifida now face new challenges—education, job training, independent living, health care for secondary conditions, aging concerns, among others.

PREVENTION

While the exact cause of Spina Bifida is unknown, over the last decade, medical research has confirmed a link between a woman's folate level before pregnancy and the occurrence of Spina Bifida. Sixty million women are at risk of having a child born with Spina Bifida and each year approximately 4,000 pregnancies in this country are affected by Spina Bifida, resulting in 2,500 births. Recent studies have shown that if all women of childbearing age were to consume 0.4 mg of folic acid prior to becoming pregnant and throughout the first trimester of pregnancy, the incidence of Spina Bifida could be reduced by up to 75 percent. There are few public health challenges that our Nation can tackle and conquer by three-fourths in such a straightforward fashion. However, we must still be concerned with addressing the 25 percent of Spina Bifida cases that cannot be prevented by folic acid consumption as well as ensuring that all women of child-bearing age consume adequate amounts of folic acid.

Progress has been made in convincing women of the importance of consuming folic acid supplements and maintaining diets rich in folic acid. Since 1968, the Centers for Disease Control and Prevention (CDC) has led the Nation in monitoring birth defects and developmental disabilities, linking these health outcomes with maternal and/or environmental factors that increase risk, and identifying effective means of reducing such risks. While the CDC has a long-standing history of addressing birth defects and developmental disabilities, in 2000—as you know—the National Center on Birth Defects and Developmental Disabilities (NCBDDD) was established at the agency as created by the Children's Health Act of 2000. NCBDDD's mission is to improve the health of children by preventing birth defects and developmental disabilities. Mr. Chairman we thank you and other members of the subcommittee and the full Health, Education, Labor, and Pensions (HELP) Committee for your assistance in creating the NCBDDD.

Former CDC Director Jeff Koplan stated last year that the Center's folic acid prevention campaign has reduced neural tube defect births by 20 percent. This public health success should be celebrated, but it is only half of the equation as approximately 2,500 babies are born each year with Spina Bifida. This public education campaign must be enhanced and broadened to reach segments of the population that have yet to heed this call to ensure that as many cases of Spina Bifida can be prevented as possible.

However, even if we are successful in preventing the majority of Spina Bifida cases in the future, our Nation must still take steps to ensure that the thousands of individuals living with Spina Bifida can live full and healthy lives. To ensure the highest quality of life possible, prevention interventions and treatment therapies must be identified, developed, and delivered to those in need. As I mentioned earlier, major medical advances have permitted babies born with Spina Bifida to have a normal life expectancy and live independent and fulfilling lives. Despite these gains, individuals and families affected by Spina Bifida face many challenges—physical, emotional, and financial.

CHALLENGES OF SPINA BIFIDA

Secondary conditions associated with Spina Bifida include full or partial paralysis, neurological disorders, bladder and bowel control difficulties, learning disabilities, depression, latex allergy, obesity, skin breakdown and social and sexual issues. Spina Bifida children with learning disabilities may have difficulty with paying attention, expressing or understanding language, and grasping reading and math. Early intervention with children who experience learning problems can help considerably to prepare them for school. With appropriate, affordable, and high-quality medical, physical, and emotional care, most people born with Spina Bifida likely will have a normal or near normal life expectancy. Ensuring access to these services is essential to improving the quality of life for those born with this birth defect.

Julie Yindra, an active volunteer with the Spina Bifida Association of America from North Carolina is with us in the audience today. As an adult with Spina Bifida, Julie believes strongly that the key to being able to be independent, self-sufficient and productive is education. Because of that, Julie is close to completing a PhD in Higher Education and working at Greensboro College to increase access for students with disabilities.

It is important to note that the lifetime costs associated with a typical case of Spina Bifida—including medical care, special education, therapy services, and loss of earnings—are as much as \$1,000,000. The total societal cost of Spina Bifida exceeds \$750 million per year with just the Social Security Administration payments to individuals with Spina Bifida exceeding \$82 million per year. Moreover, tens of millions of dollars are spent on medical care covered by the Medicaid and Medicare Programs. I believe strongly that our Nation must do more to help reduce the emotional, financial, and physical toll of Spina Bifida on the individuals and families affected.

IN-UTERO SURGERY TO ADDRESS SPINA BIFIDA

SBAA seeks to support individuals and families affected by Spina Bifida, maximize the prevention of Spina Bifida, and ensure that as many Spina Bifida pregnancies go to term as possible. When families recently diagnosed with a Spina Bifida pregnancy contact SBAA, the organization puts them in touch with another family who has a child with the condition so they can learn of the joys and challenges of having a child with the birth defect. Unfortunately, traditionally when families have faced a Spina Bifida diagnosis they have had two difficult options. The first is to continue the pregnancy with the expectation of multiple surgeries for the child after birth, uncertain life expectancy, and many physical and developmental challenges and complications. The second, unfortunately, is to voluntarily terminate the pregnancy. Fortunately, now there may be a third option.

Since the late 1990's, doctors at three U.S. hospitals—Children's Hospital of Philadelphia, Vanderbilt University Medical Center in Nashville, and the University of California at San Francisco—have been operating before birth on fetuses diagnosed with Spina Bifida. Last year, the University of North Carolina, became the fourth hospital in the Nation to perform these operations. By closing the lesion early in pregnancy, these doctors believe they can minimize the damage created by fluid leaking from the spine, as well as by the spinal cord's contact with amniotic fluid. Surgeons have found that closing the hole in the spine in this fashion before birth may correct breathing problems in 15 percent of the children receiving the procedure and may reduce the need for a shunt to drain brain fluid buildup by between 33 percent and 50 percent. Given the potential for this surgery in the secondary prevention of conditions associated with Spina Bifida, we must do a better job of studying this procedure, educating health care providers and families about this surgery, and making information about it available to more families facing a Spina Bifida pregnancy. It is our hope that with improved quality-of-life for individuals and families affected for Spina Bifida available through this surgery as well as interventions through a National Spina Bifida Program, the stigma and fear associated with a Spina Bifida birth will decrease significantly. In turn, the number of Spina Bifida pregnancies continued to term likely will increase.

THE NEED FOR A NATIONAL SPINA BIFIDA PROGRAM

SBAA and the Spina Bifida Foundation are working hard to ensure that our Nation is taking all the steps possible to prevent Spina Bifida and diminish suffering for those currently living with it. To that end, we currently advocate that the CDC receive \$3 million in fiscal year (FY) 2003 to develop and implement a National Spina Bifida Program to promote quality-of-life programs which support people with Spina Bifida so they can live fulfilling and productive lives.

A national program works on two critical levels—to reduce and prevent Spina Bifida incidence and morbidity and to improve quality-of-life for those living with Spina Bifida. A National Spina Bifida Program would ensure that what is known by scientists is practiced and experience by the 70,000 individuals and families affected by Spina Bifida. For example, such an initiative would help individuals with Spina Bifida and their families learn how to treat and prevent the secondary health problems which range from learning disabilities and depression to severe allergies and skin problems that make life difficult for these individuals. All of these problems can be treated or prevented, but only if those affected by Spina Bifida are properly educated and taught what they need to do to keep themselves healthy.

A National Spina Bifida Program offers young families hope and help through a plan to educate the public of the importance of taking a vitamin with folic acid and the maintenance of a healthy diet that includes foods fortified with folic acid. As SBAA works collaboratively with CDC and the March of Dimes to increase awareness of the benefits of folic acid for those at risk of having a baby with neural tube defects (those who have Spina Bifida themselves or those who have already conceived a baby with Spina Bifida) these activities need to be expanded to reach the broader population in need of these public health education, health promotion, and disease prevention messages. Such efforts should include reaching out to at-risk populations (e.g. Hispanic-Latino communities), health professionals, and community outreach in this critical public health education and awareness effort.

Second, a National Spina Bifida program offers benefits to those who suffer from Spina Bifida and their families by working to improve the outlook for a life challenged by this complicated birth defect, identifying valuable therapies from in utero throughout the lifespan and making them available and accessible to those in need. These secondary prevention activities represent a tangible quality-of-life difference to the 70,000 citizens in the U.S. with Spina Bifida. Focusing on living well with Spina Bifida, the initiatives as part of the secondary prevention program should be designed to create and implement strategies to improve the quality-of-life. These quality-of-life efforts would center on reaching the general population with Spina Bifida, advancing treatment of Spina Bifida and its related conditions, and working with adolescents living with Spina Bifida to address their specific academic, psychosocial, and vocational needs. In addition, we envision that a National Spina Bifida Program would create and implement a comprehensive program to assist teens with Spina Bifida in the development of life skills for independence, self-reliance, and success in the world.

Initiating a National Spina Bifida Program will help ensure that our Nation mounts a comprehensive effort to prevent and reduce suffering from Spina Bifida. SBAA and the Spina Bifida Foundation stand ready to work with you and your colleagues to reduce suffering and improve the quality of life for the 70,000 individuals and their families who live day in and day out with this birth defect. Again, I thank you for your calling this important hearing and for your support and leadership for establishing a National Spina Bifida Program. I would be happy to answer any questions you and your colleagues may have. Thank you.

Senator DODD. Dr. Green, thank you for being here.

Dr. GREEN. Thank you for the opportunity to speak this morning, Mr. Chairman, Senator Reed.

I am Dr. Nancy Green, medical director of the March of Dimes Birth Defects Foundation, and I am pleased to have the opportunity to speak this morning on behalf of our 3 million volunteers and 1,600 staff of the March of Dimes. I want to thank others for their comments about the March of Dimes, including our work not only on prevention but also treatment of neural tube defects and other important and serious birth defects.

As you know, the March of Dimes works to improve the health of mothers, infants, and children by preventing birth defects and infant mortality.

The Foundation is a unique partnership of scientists, clinicians, parents, volunteers, business and community leaders throughout the Nation. We also have a chapter structure in all 50 States as well as the District of Columbia and Puerto Rico.

The statistics that were discussing this morning on birth defects are very troubling, obviously, to all of us. It is a serious health

problem facing our Nation. We take a two-pronged approach to this problem. One is research to identify causes and improve prevention tools and treatment tools, and access to health care for women and infants so they can best benefit from existing and emerging medical knowledge.

So I want to support your efforts and those of several Federal agencies to prevent birth defects and to improve the quality of life for those born with birth defects. In addition, I want to use my time to urge Congress to reauthorize the Birth Defects Prevention Act of 1998 as a way of ensuring that this important work continues.

The March of Dimes defines birth defects as an abnormality of structure, function, or body metabolism presenting at birth or in early childhood that results in physical or mental disability, or is fatal.

The entire research budget of the March of Dimes supports basic and clinical research, the ultimate aim of which is to assure that every baby born is healthy. The research funded by the Foundation addresses basic biologic processes that underlie development and also examines clinical aspects of pregnancy.

Research currently funded includes studies of developmental biology and genetics and those important processes leading to healthy birth outcomes. When these steps go awry, normal birth is abrogated, with consequences of miscarriage, stillbirth, or live births of infants with birth defects.

So all research that is supported by the March of Dimes deals with prevention of birth defects. In 2001, the Foundation's research budget was \$39.7 million. In the history of our grant program, awards have been made to more than 1,200 universities including Yale, Brown, Harvard, Columbia, Stanford, University of California, and other fine institutions throughout the Nation. The average award in 2001 was \$72,000.

As a private foundation, the March of Dimes can respond relatively quickly to new directions or promises in research to accelerate the pace of scientific discovery. Previous March of Dimes research included identification of fetal alcohol syndrome, which we heard about this morning, thus establishing the association between birth defects and alcohol use. Fetal alcohol syndrome is the most common preventable birth defect in the United States, affecting about 4,000 infants every year.

More recently, the Foundation has been funding professional and public educational outreach efforts to reach women and teach them about healthy behaviors during pregnancy to help prevent serious birth defects such as fetal alcohol syndrome.

The March of Dimes has also funded research on fetal surgery, as you heard about just now, for successful interventions for congenital diaphragmatic hernia, as well as early but promising studies on spina bifida.

In addition, the March of Dimes has funded research on Fragile X, including Steve Warren, who identified the Fragile X gene. This is the most common form of inherited mental retardation and has generated three important outcomes for Fragile X. One, it has increased the understanding in the medical community that some forms of mental retardation, including some common forms of men-

tal retardation, are inherited. This leads to the ability to refer affected families for genetic counseling. Second, the work on Fragile X has launched a major research effort to identify additional genes and disorders causing mental retardation. And third, the work on Fragile X has resulted in early screening possibilities for this and related disorders and to begin to determine the impact of early interventions from that early screening for affected children to determine whether their intellectual development can in fact be augmented.

So we are very proud of our research program, and our volunteers and staff vigorously support that program.

In addition, we support Federally-funded research related to birth defects. As you know, the March of Dimes was a vigorous advocate for two recent legislative efforts on birth defects prevention—the Birth Defect Prevention Act of 1998 and the Children’s Health Act of 2000, through which the Center that Dr. Cordero represents so ably was created.

In addition, the March of Dimes has been reaching out to Congress for approval on these important measures. As you know, in 1998, Congress passed the Birth Defects Prevention Act with broad bipartisan support. This has allowed for, as I mentioned, creation of this National Center on Birth Defects and Developmental Disabilities.

As you know, the Prevention Act of 1998 authorized allocations through fiscal year 2002. We understand that Senator Bond will be introducing the Prevention Act of 2002, and we urge you to support this throughout Congress to maintain Federal commitment to preventing birth defects and ensuring the quality of life for those living with birth defects. And we are privileged to be working closely with the Center on their efforts in this regard.

To help find the causes of birth defects, Dr. Cordero mentioned the funding of the Centers for Birth Defects Research and Prevention. Four months ago, the March of Dimes testified before the House Appropriations Committee and submitted a written statement to the Senate Appropriations Committee requesting an increase in the budget of these centers so they can expand and intensify their research pertaining to genetic and environmental causes of birth defects.

These seven regional centers and the eighth site at CDC are participating in the National Birth Defects Prevention Study, the largest such study ever conducted. I think this research holds a lot of great promise for finding etiologies of birth defects and appropriate prevention.

The Birth Defects Center also supports the development, implementation, and expansion of State birth defects tracking systems, programs to prevent birth defects, and activities to improve access to health services for children with birth defects. March of Dimes chapters around the country work closely with these State-based birth defects surveillance programs.

Finally, the ultimate goal of tracking and research is the development and implementation of effective programs to prevent birth defects and developmental disabilities. One such example of this success has been in the national folic acid campaign, led by the March of Dimes and, as Dr. Cordero mentioned already this morning, with

the CDC and many partner organizations including, of course, the Spina Bifida Association. As you heard, we know that this campaign is getting results both through outreach to professionals and to the public, women of childbearing age, as you know so well, as well as grain fortification. So we are cautiously optimistic that this trend will continue and that there will continue to be a decrease in the number of children born with spina bifida and related neural tube defects, and we continue our work on folic acid.

In addition to our support of the National Center, the March of Dimes works collaboratively with other Federal agencies. For instance, we have been a very outspoken advocate for the doubling of the NIH research budget. We also work closely with HRSA and CMMS on initiatives to treat children with birth defects and other special health care needs.

Improving access to newborn screening is one of the Foundation's highest advocacy priorities here in Washington as well as in every State capital. This year, the March of Dimes asked the Appropriations Committee to allocate \$25 million for implementation of the newborn screening program authorized in Title XXVI of the Children's Health Act of 2000. If adequately funded, this program would make it possible for States to develop, evaluate, and acquire innovative testing technologies and improve the screening, counseling and special services for those at risk, these newborns and children.

In conclusion, on behalf of the March of Dimes, I want to thank you, Mr. Chairman, Senator Reed, for holding this hearing today. The March of Dimes volunteers and staff around the country are ready to work with you and other members of this committee to support public policies and provide the resources necessary to prevent birth defects and ensure that those who are born with birth defects enjoy the best life possible.

Thank you for your attention.

Senator DODD. Thank you, Dr. Green, very much.

[The prepared statement of Nancy Green, M.D. follows:]

PREPARED STATEMENT OF NANCY GREEN, M.D.

INTRODUCTION

Good morning, Mr. Chairman. I am Dr. Nancy Green, medical director of the March of Dimes Birth Defects Foundation. I am pleased to have the opportunity to testify this morning on behalf of the over 3 million volunteers and 1600 staff of the March of Dimes, and share with you the Foundation's views on "Birth Defects: Strategies for Prevention and Ensuring Quality of Life."

As you know, the March of Dimes is a national voluntary health agency founded in 1938 by President Franklin D. Roosevelt to find a scientific prevention of the threat of polio to the public. Today, the Foundation works to improve the health of mothers, infants and children by preventing birth defects and infant mortality through research, community services, education and advocacy. The March of Dimes is a unique partnership of scientists, clinicians, parents, members of the business community, and other volunteers in every state, the District of Columbia and Puerto Rico.

The statistics on birth defects are very disturbing and illustrate a serious health problem facing our nation. Of the four million babies born each year in the United States, approximately 150,000, or 34 percent of all live births, have at least one serious birth defect. Severe birth defects often require lifelong medical treatment. Because many conditions cannot be fully corrected, birth defects are a major cause of childhood and adult disability. Birth defects are also the leading cause of infant mortality. The March of Dimes believes a two-pronged approach to prevention and treatment of birth defects is required: research to identify causes and improve pre-

vention tools, and access to health care so women and infants can benefit from existing medical knowledge. I am grateful for the invitation to come before this subcommittee to share the March of Dimes agenda for prevention and treatment. I am here today to support your efforts and those of several Federal agencies to prevent birth defects and to improve the quality of life for those born with birth defects. In addition, I want to use my time with you to urge Congress to reauthorize the Birth Defects Prevention Act of 1998 as a way of ensuring that this important work continues.

BACKGROUND ON BIRTH DEFECTS

The March of Dimes defines birth defects as an abnormality of structure, function or body metabolism (inborn error of body chemistry) presenting at birth or early childhood that results in physical or mental disability, or is fatal. There are more than 4,000 known birth defects. Both genetic and environmental factors can cause birth defects. In some cases, a child inherits a genetic disease when one parent (who has the disease) passes along a single faulty gene; examples of birth defects caused by dominant inheritance include Marfan syndrome and achondroplasia (a form of dwarfism). More frequently, a child inherits a genetic disease when both parents (who are healthy) pass along the same faulty gene; this is called recessive inheritance. Examples include Tay-Sachs disease and cystic fibrosis. Abnormalities in the number or structure of chromosomes can cause numerous birth defects. Down syndrome, in which a baby is born with an extra chromosome 21, is one of the most common chromosomal abnormalities.

Birth defects also result from environmental factors such as drug or alcohol abuse, infections (such as rubella) or exposure to certain medications (such as the acne drug Accutane) or other chemicals. Often, birth defects appear to be caused by a combination of one or more genes and environmental factors, such as cleft lip/palate, clubfoot and some heart defects.

Birth defects generally are grouped into three major categories: structural/metabolic, congenital infections, and other conditions. When a baby has a structural birth defect, some part of the body is missing or is malformed. Heart defects are the most common type of structural birth defects, affecting one baby in 125. Spina bifida affects one in 2,000 babies. Metabolic disorders are not visible, but can be harmful or even fatal, and affect one in 3,500 babies. PKU (phenylketonuria) is an example of a metabolic disorder, in which affected babies cannot process a part of protein, which builds up in blood and results in brain damage. Fortunately, this disorder is routinely detected with newborn screening tests, so affected babies can be placed on a special diet that prevents mental retardation.

Rubella (German measles) is probably the best known congenital infection that can cause birth defects. If a pregnant woman is infected in the first trimester, her baby has a one-in-four chance of being born with one or more symptoms of congenital rubella syndrome (deafness, mental retardation, heart defects, blindness). Fortunately, because of aggressive immunization programs, this syndrome has been eradicated in the United States and many other countries.

Other causes of birth defects include substance abuse during pregnancy. For example, fetal alcohol syndrome (FAS), which affects one baby in 1,000 (about 4,000 babies per year in the United States) and results in mental and physical birth defects, is common in babies whose mothers are heavy drinkers of alcohol during pregnancy. FAS is the most common preventable birth defect in the United States. Babies of mothers who use cocaine early in pregnancy are also at increased risk of birth defects. Studies suggest that these babies are five times more likely to be born with urinary tract defects than babies of women who do not use cocaine while pregnant.

MARCH OF DIMES RESEARCH ON BIRTH DEFECTS

The entire research budget of the March of Dimes supports basic and clinical research, the ultimate aim of which is assurance that every baby is born healthy. Research supported by the Foundation addresses basic biological processes that underlie development and also examines clinical aspects of pregnancy. Research currently being conducted includes studies of developmental biology and genetics aimed at explaining fundamental steps that lead to healthy birth outcomes. When these steps go awry, normal birth is abrogated with the consequence of a miscarriage, still birth, or live birth of an infant with a birth defect. If we improve our understanding of these normal steps and their occasional aberration, we will be in a better position to devise means of prevention and intervention. Thus, all research that is supported by the March of Dimes deals with the prevention of birth defects.

In 2001, the Foundation's research budget totaled \$39.7 million. In the history of our grant program awards have been made to more than 1,200 institutions, including Yale, University of Connecticut, Washington University, Harvard, Columbia University, Cornell, University of California—Los Angeles, Stanford, University of California—San Francisco, and Johns Hopkins University. The average award in 2001 was \$72,000 per year; the median \$73,000; the range \$48,000–97,000. Typically grants are awarded for 3 years. As a private foundation, the March of Dimes is able to act quickly to fund creative new approaches, accelerating the pace of scientific discovery.

Previous March of Dimes research achievements include identification of fetal alcohol syndrome (FAS), thus establishing the association between the birth defects and alcohol use. More recently, findings from research supported by the Foundation have been used to develop professional and public educational messages that aim to change unhealthy behaviors of pregnant women. The March of Dimes has also supported research to refine fetal surgery techniques, a successful intervention for congenital diaphragmatic hernia and spina bifida. In addition, the March of Dimes supported research on Fragile X, the most common form of inherited mental retardation, which has generated three important outcomes. First, it has increased understanding in the medical community that some forms of mental retardation are genetic in origin, leading to referral of affected families for genetic counseling. Second, it has launched a major research effort to investigate other heritable and potentially preventable forms of mental retardation. And, third, it has resulted in early screening for disorders such as Fragile X and in clinical studies to ascertain the impact of early interventions for affected children to determine whether their intellectual development can be augmented.

FEDERALLY SPONSORED BIRTH DEFECTS RESEARCH AND SERVICES

Although we at the March of Dimes are justifiably proud of the Foundation's research program, the volunteers and staff of the March of Dimes strongly support federally funded research related to birth defects and programs that provide services to those living with birth defects. For example, the March of Dimes was a vigorous advocate for two recent legislative initiatives that focus on birth defects prevention: the Birth Defects Prevention Act of 1998 (P.L. 105–168) and the Children's Health Act of 2000 (P.L. 106–310) through which the CDC National Center on Birth Defects and Developmental Disabilities was created. In addition to Chairman Dodd, Senators Kennedy and Bond who are members of this subcommittee were instrumental in obtaining Congressional approval of these important measures.

BIRTH DEFECTS PREVENTION ACT REAUTHORIZATION

In 1998, Congress passed the Birth Defects Prevention Act with broad bipartisan support. The act, first introduced by Senator Bond, authorized the Centers for Disease Control and Prevention to (1) collect, analyze, and make available data on birth defects; (2) operate regional centers for applied epidemiological research on the prevention of birth defects; and (3) inform and educate the public about the prevention of birth defects. CDC's current birth defects prevention activities described below are made possible by the Birth Defects Prevention Act and conducted under the auspices of the National Center on Birth Defects and Developmental Disabilities.

The Birth Defects Prevention Act authorized these prevention programs, as well as the appropriations that support the National Center on Birth Defects and Developmental Disabilities, through fiscal year 2002. We understand that Senator Bond will be introducing the "Birth Defects Prevention Act of 2002" shortly to revise and extend the Birth Defects Prevention Act. Mr. Chairman, the March of Dimes urges you and the members of the full HELP Committee to complete action on the Senator's bill before the end of this Congress and thereby maintain the Federal commitment to preventing birth defects and ensuring the quality of life for those living with birth defects.

NATIONAL CENTER ON BIRTH DEFECTS AND DEVELOPMENTAL DISABILITIES

Two years after passage of the Birth Defects Prevention Act, Congress took another major step toward preventing birth defects and improving the lives of those born with a birth defect when it created the National Center on Birth Defects and Developmental Disabilities (NCBDDD) as part of the Children's Health Act of 2000. The NCBDD was officially launched in April 2001. The mission of the Center is to improve the health of children and adults by preventing the occurrence of birth defects and developmental disabilities; promoting optimal child development; and promoting health and wellness among children and adults who have a disability.

The Center focuses on identifying the yet unknown causes of birth defects and developmental disabilities through research programs; preventing birth defects and developmental disabilities through public as well as professional education; and promoting wellness for all Americans, including those with a disability. The March of Dimes is privileged to work closely with the Center in carrying out activities to meet these objectives.

To help find the causes of birth defects, NCBDDD currently funds regional "Centers for Birth Defects Research and Prevention" in Arkansas, California, Iowa, Massachusetts, New Jersey, New York, and Texas. Each center is funded at a level of approximately \$900,000 per year. Four months ago, the March of Dimes testified before the House Appropriations Committee and submitted a written statement to the Senate Appropriations Committee requesting an increase of \$6 million in the budgets for these centers so that they can expand and intensify their research pertaining to genetic and environmental causes of birth defects.

These seven regional centers and the eighth site at the CDC are participating in the National Birth Defects Prevention Study, the largest study on the causes of birth defects ever conducted. Now, with information collected on more than 11,000 families, the data are being used in studies designed to help identify the causes of birth defects. For example, work now underway focuses on the effectiveness of various methods for the primary prevention of birth defects, the mechanisms of inducing birth defects by various drugs, the environmental causes of birth defects, the genetic factors that make individuals susceptible to birth defects, and the behavioral causes of birth defects. Moreover other studies examine the costs associated with birth defects. This exciting leading edge research holds great promise and merits an increase in funding.

NCBDDD also supports the development, implementation, and expansion of State birth defects tracking systems, programs to prevent birth defects, and activities to improve access to health services for children with birth defects. March of Dimes chapters around the country work closely with these State-based birth defects surveillance programs.

Finally, the ultimate goal of tracking and research is the development and implementation of effective programs to prevent birth defects and developmental disabilities. One example of a success in this area is the national folic acid education campaign, lead by the March of Dimes, the CDC and its partner organizations, such as the Spina Bifida Association. This is a multi-year national education campaign designed to increase the number of women taking folic acid daily. Each year in the United States, approximately 2,500 babies are born with neural tube defects (NTDs). NTDs are severe birth defects of the brain and spinal cord, including anencephaly and spina bifida. CDC estimates that the annual medical care and surgical costs for persons with spina bifida in the United States exceed \$200 million, and that up to 70 percent of NTDs could be prevented if all women of childbearing age consumed 400 micrograms of folic acid daily, beginning before pregnancy. We know that this campaign is getting results. In fact, a study published in the *Journal of the American Medical Association* in 2001 showed that NTDs in newborns decreased 19 percent between 1995 and 1999 in the wake of this campaign. However, we at the Foundation believe that many more fatal or disabling birth defects could be prevented if more women of childbearing age were to take a multivitamin with folic acid daily.

The Foundation also supports the vital work of the National Center on Health Statistics which offers information essential for these research and programmatic initiatives. Investment in the National Vital Statistics System, a major source of information on birth outcomes and birth defects, would allow CDC to modernize this system using web-based technology that would provide for rapid compilation of data as well as tools to improve the accuracy and completeness of information obtained from physicians and hospitals. These improvements are needed to better detect trends in birth outcomes and to support birth defects registries. Additional resources would also support expansion of the National Survey of Family Growth to provide essential information on factors that affect birth outcomes.

In addition to our support of the National Center on Birth Defects and Developmental Disabilities, the March of Dimes also works collaboratively with agencies that fall within the jurisdiction of this committee. In particular, the Foundation has been an outspoken advocate of doubling the research budget of the National Institutes of Health. With an increase in funding, NIH could expand its research into the causes of birth defects, and also the causes of prematurity. Increased Federal funding would also help accelerate the timetable for implementing a much needed analysis of environmental influences on child health and development that is contemplated by the National Children's Study authorized by this Committee in the Children's Health Act of 2000.

In addition to our work on behalf of a more robust Federal research agenda, the March of Dimes also works closely with Health Resources and Services Administration and the Centers on Medicare and Medicaid Services on initiatives to treat children with birth defects and other special health care needs. Improved access to newborn screening is one of the Foundation's highest advocacy priorities here in Washington and in every State capital. One of the great advances in preventive medicine has been the introduction of newborn screening to identify certain genetic, metabolic, hormonal and/or functional conditions in newborns. As the Chairman knows, such disorders, if left untreated, can cause death, disability, mental retardation and other serious lifelong problems. This year the March of Dimes asked the Appropriations Committee to allocate \$25 million for implementation of the heritable disorders (newborn screening) program authorized in Title XXVI of the Children's Health Act of 2000. If adequately funded, this program would make it possible for states to develop, evaluate, and acquire innovative testing technologies and improve these screening, counseling, testing and special services for at risk newborns and children. On June 14, 2002, a March of Dimes volunteer testified before this subcommittee about the importance of expanding the Federal role to assure that newborn screening programs in every State have access to the technical guidance and financial resources they need to make it possible for every child born in the United States to be screened using State of the art diagnostic and treatment tools.

CONCLUSION

On behalf of the March of Dimes, I want to thank you, Mr. Chairman, for holding this hearing today. March of Dimes volunteers and staff around the country stand ready to work with you and the other members of this committee to support public policies and provide the resources necessary to prevent birth defects and ensure that those who are born with birth defects enjoy the best possible quality of life.

Senator DODD. Mr. Liguori, thank you for being here, and thank you, Jill, as well for coming, and Nicholas.

Mr. LIGUORI. Thank you, Mr. Chairman, Senator Reed. Thank you very much for inviting me to testify before you here today. I greatly appreciate this opportunity to help provide you with a parent's perspective on spina bifida.

I respectfully request that my testimony be included in the Congressional Record.

Senator DODD. It will be.

Mr. LIGUORI. I am Fred Liguori from Granby, CT. I have been a pilot for American Airlines for 16 years. I am also a lieutenant colonel in the Massachusetts Air National Guard, where I have flown the A-10 aircraft for the past 21 years. However, my most important role is that of father to my 3½-year-old son, Nicholas, who was born with spina bifida.

As I am mindful of the time today, I will provide you with an abbreviated version of my family's experience with spina bifida. However, I would like to draw your attention to my written testimony, as it contains a longer, more detailed account and information about this all too common birth defect.

When my wife Jill and I decided to start a family, it did not go as expected. After losing two pregnancies, Jill became pregnant for a third time. All went smoothly until an ultrasound exam during the 18th week. As the doctor scanned the baby's back, he stopped and exclaimed, "Your baby has spina bifida."

I asked him what spina bifida was, and he explained that it was an opening of the baby's spine and informed us that babies born with spina bifida may walk as children with the aid of braces and crutches, but normally end up in a wheelchair as an adolescent. They have no control of their bowel or bladder. They need to have a shunt placed in their brain to control the hydrocephalus. And he told us to expect some degree of mental retardation.

After telling us of our options, the doctor asked if we had any questions. My questions were: Am I awake, or is this just a nightmare, and if I am awake, who just hit me in the head with that baseball bat?

By the next day, we began to focus on the decision before us, which we felt should be based on quality of life issues, and unfortunately, the medical professionals painted a very bleak picture. We spent the next few days in the public library and medical libraries. We read sections of textbooks and research papers. We contacted physicians and other health care professionals around the country who were involved with spina bifida children.

Finally, we contacted the Spina Bifida Association of America, SBAA, and asked if we could talk to parents of children with spina bifida. They put us in contact with several families within the State chapter in Connecticut.

After speaking with a number of families, we noticed a big discrepancy between what the medical professionals told us to expect and what the parents thought regarding quality of life of their affected children.

One of the families invited us to meet their 9-year-old daughter, Jaclyn, who was born with spina bifida. We arrived at the house and rang the bell. As the door opened, there was a beautiful, smiling little girl with pink crutches and braces up to her hips welcoming us into their home. In that instant, we knew what kind of quality of life Jaclyn had.

We spent the night talking to Jaclyn about her hobbies and her friends, and we spoke with her parents, Janet and Anthony, about her numerous surgeries and their battle with the school system. We left relieved that our decision was made. Now we needed to get as much information as possible before our son was born. On our way out the door, Janet handed us a copy of "Insights into Spina Bifida," a newsletter published by SBAA.

While reading through "Insights," we came upon an article that concerned in utero surgery on unborn fetuses to reduce the effects of spina bifida. The reasons for doing the surgery as early as possible made sense, and years of animal research yielded some positive results.

After very careful consideration of the risks versus the hoped for rewards for both our unborn son and my wife, we elected to proceed with the fetal surgery at Children's Hospital of Philadelphia, one of the two hospitals performing the surgery at the time.

After the surgery, we were to remain in Philadelphia until the birth of our son. The surgery was performed at 25 weeks gestation. Jill and I spent the next week in the hospital and the next 3 months at the Ronald McDonald House in Philadelphia.

On January 14, 1999, the joy of our life, Nicholas Ferdinand Liguori, was born. Nicholas spent 8 days in neonatal intensive care. We then returned home to Connecticut. Almost immediately, the doctor and therapist visits began. He has been evaluated by a neurosurgeon, an orthopedic surgeon, a urologist, a cardiologist, and a host of other health care professionals.

Today, Nicholas' bladder and bowels do not function properly. He requires two medications daily to allow his bladder to fill at low pressure, to prevent bladder spasms, and to prevent urinary tract

infections. We catheterize Nicholas five times a day to completely empty his bladder, and we are working on a bowel training program to hopefully achieve social continence.

At 3½ years old, Nicholas has attended spina bifida clinics in Connecticut, Pennsylvania, Springfield, MA, and Boston, MA, where he is currently treated. He receives physical therapy, occupational therapy, speech therapy, and developmental therapy—each once per week.

Despite all this, Nicholas has what is considered a “mild” case of spina bifida. He walks on his own without the aid of braces or crutches. Due to the positive changes that occurred in his brain as a result of the fetal surgery, he has not required a shunt. At 3½ years old, Nicholas had his first surgery since birth this past July 5. The little girl sharing his hospital room also had spina bifida, was the same age as Nicholas, and she was recovering from her 23rd surgery.

As parents of a child with spina bifida, we are very grateful to Congress for its assistance and leadership regarding programs for the prevention of spina bifida and improving the quality of life for individuals with spina bifida. The establishment of a National Spina Bifida Program at the Centers for Disease Control and Prevention would provide a crucial necessary next step to help reduce the occurrence of spina bifida and to help those already affected.

A national program would help improve public awareness, which I believe should be considered a top priority. More also needs to be done to improve the quality of life for those living with spina bifida. The number one concern of parents and individuals is that few improvements have been made in the area of bowel and bladder continence, which has devastating emotional and social consequences for the individual.

A national program would also help with the establishment of multidisciplinary care facilities. Spina bifida is a complex defect that cannot be handled by ordinary health care professionals. With clinics established, the health care providers within that facility will become more experienced with the problems affecting spina bifida patients and how those problems interrelate.

In addition, we must have educated professionals within the school system. Educators need to understand the types of learning disabilities associated with spina bifida and develop alternative methods of learning. They also need to teach independent living to those individuals who may not have a support network at home.

Our collective goal should be for the majority of individuals with spina bifida to live long, healthy, independent, and productive lives.

Finally, research into the cause of and a cure for all neural tube defects must be increased. Our job will not be complete until there is no longer a need for a National Spina Bifida Program.

Again, on behalf of my son, my wife, and myself, thank you, Mr. Chairman, for giving me the opportunity to tell our story to you today. It has meant a great deal to us, and we stand ready to be of any assistance to you and your colleagues as you consider issues relating to this all too common birth defect.

Thank you.

Senator DODD. Great job.

[Applause.]

[The prepared statement of Mr. Liguori follows:]

PREPARED STATEMENT OF FRED LIGUORI

Mr. Chairman and Members of the Subcommittee, thank you very much for inviting me to testify before you today. I greatly appreciate this opportunity to help provide you with a parent's perspective on Spina Bifida.

I am Fred Liguori from Granby, Connecticut. I have been a pilot for American Airlines for 16 years. I also am a Lieutenant Colonel in the Massachusetts Air National Guard where I have flown the A-10 aircraft for the past twenty-one years. However, one of my most important roles is that of father to my three-and-a-half year old son, Nicholas, who was born with Spina Bifida.

When my wife, Jill, and I decided to start a family it did not go as expected. After losing two pregnancies Jill became pregnant for a third time. We were excited but apprehensive. Given our past history, Jill was scheduled for routine ultrasound exams at six, twelve, and 18 weeks into the pregnancy. All went smoothly until the eighteenth week. I remember looking at the screen as the technician scanned our baby's head thinking that it didn't look right to me—but what did I know, I'm a pilot not a radiologist. The technician excused herself and returned with the doctor.

As the doctor scanned the baby's back he stopped and exclaimed, "There it is!" He turned to us and said, "Your baby has Spina Bifida." I asked him what Spina Bifida was and he explained that it is an opening of the baby's spine. I then asked, "What does that mean? After our baby is born you sew up his spine and we go home, right?" "Not exactly", he said. "Babies born with Spina Bifida may walk as children with the aid of braces and crutches but normally end up in a wheelchair as an adolescent. They have no control of their bowel or bladder. They need to have a shunt placed into the brain to control the hydrocephalus. In addition, you should expect some degree of mental retardation. Your options are to continue the pregnancy, continue the pregnancy and give the baby up for special needs adoption, or terminate the pregnancy. Do you have any questions?" My questions were: am I awake or is this just a nightmare and, if I am awake, who just hit me in the head with that baseball bat?

Next, the technician handed us a box of tissues and escorted us into a room across the hall. The genetics counselor came in with charts and graphs of "x's" and "y's." Jill and I sat with tears in our eyes just wanting to go home to try to absorb what was happening.

By the next day we began to focus on the decision before us, which we felt should be based on quality of life issues. We knew we had many questions that needed to be answered. What exactly is Spina Bifida?

How does it affect the child? What is the quality of life for children with Spina Bifida? Unfortunately, the medical professionals' responses painted a very bleak picture.

So, we decided to take matters into our own hands and educate ourselves. We spent the next few days in the public library and the medical libraries at UCONN, Yale and UMASS. We read sections of textbooks pertaining to neural tube defects and research papers in medical journals regarding the physical issues and cognitive development of children with Spina Bifida. We contacted physicians and other health care professionals around the country who were involved with Spina Bifida children. Finally, we contacted the Spina Bifida Association of America (SBAA) and asked if we could talk to parents of children with Spina Bifida. They put us in contact with several families within our State chapter in Connecticut.

After speaking with a number of families we noticed a big discrepancy between what the medical professionals and the parents thought about Spina Bifida's quality of life. One of the families we spoke with invited us over to continue our discussion and meet their 9-year-old daughter, Jaclyn, who had Spina Bifida. We arrived at their house and rang the bell. As the door opened, there was a beautiful, smiling little girl with pink crutches and braces to her hips welcoming us into their home.

In that instant we knew what kind of quality of life Jaclyn had. We spent the night talking to Jaclyn about her hobbies and her friends. She was excited to show us her room and her American Doll collection—including the one in the wheelchair. We spoke with her parents, Janet and Anthony, about her numerous surgeries and their battle with their school. We left relieved that our decision was made. Now we needed to get as much information as possible before our son was born. On our way out, Janet handed us a copy of 'Insights,' a newsletter published by SBAA.

A few days later, while reading through 'Insights into Spina Bifida,' we came upon an article that was of great interest to us. It concerned in utero surgery on unborn fetuses to reduce the effects of Spina Bifida. The reasons for doing the surgery as early as possible made sense and years of animal research yielded some positive re-

sults. The article indicated that there were two centers in the country performing fetal surgery for Spina Bifida, Children's Hospital of Philadelphia (CHOP) and Vanderbilt University Hospital. We contacted the surgeons at both centers and traveled to both locations for evaluation and additional information pertaining to the surgery.

After very careful consideration of the risks versus the hoped-for rewards for both our unborn son and for my wife, we elected to proceed with the fetal surgery at CHOP. After the surgery we would remain in Philadelphia until the birth of our son. The surgery was performed October 30, 1998 at 25 weeks gestation. Jill and I spent the next week in the hospital and the next 3 months at the Ronald McDonald House in Philadelphia. On January 14, 1999 the joy of our life, Nicholas Ferdinand Liguori, was born. One chapter was closed and another about to begin.

Nicholas spent 8 days in neonatal intensive care. We then returned home to Connecticut. Almost immediately, the doctor and therapist visits began. We met with 'Birth To 3' therapists who set a schedule for follow-up. At 2 months we attended our first multi-disciplinary Spina Bifida clinic. Actual therapy began around 6 months.

As you might expect, Nicholas generated a lot of interest as a fetal surgery patient. He was evaluated by a neurosurgeon, an orthopedic surgeon, a urologist, a cardiologist and a host of other health care professionals. Of primary concern was the function of his kidneys and bladder. The urodynamic testing revealed high bladder pressures, bladder spasms, incomplete emptying of the bladder and urine reflux into the kidneys. We were scheduled for a head and spine MRI that showed a tethered spinal cord (common in children with Spina Bifida) and was therefore inconclusive. The neurosurgeon wanted to perform surgery to 'de-tether', or release, the spinal cord. We wanted another opinion. After additional tests and consultations in Philadelphia and Boston, it was decided that surgery was not required but urologic intervention was necessary.

Today, Nicholas' bladder and bowels do not function properly. He requires two medications daily to allow his bladder to fill at low pressure, to prevent bladder spasms and to prevent urinary tract infections. We catheterize Nicholas five times each day to completely empty his bladder and we are working on a bowel-training program to hopefully achieve social continence. At three-and-a-half years old Nicholas has attended Spina Bifida clinics in Connecticut, Pennsylvania, Springfield Massachusetts, and Boston, where he is currently treated. He receives physical therapy, occupational therapy, speech therapy and developmental therapy—each once per week.

Despite all of this, believe it or not, Nicholas has what is considered a "mild" case of Spina Bifida. He walks on his own without the aid of braces or crutches. Due to the positive changes that occurred in his brain as a result of the fetal surgery, Nicholas has not required a shunt. At three-and-a-half years old Nicholas had his first surgery since birth this past July 5th. The little girl sharing his room also had Spina Bifida, was the same age, and was recovering from her 23rd surgery. Can you imagine the physical, emotional, and financial toll that must have on such children and their families?

With Spina Bifida, the physical ability you have today may be gone tomorrow. It is an ever-changing defect, which rarely, if ever, improves. The main problems that plague individuals with Spina Bifida fall into four main categories: neurological, orthopedic, urologic and developmental. Most children with Spina Bifida have a tethered spinal cord, meaning the cord is attached usually at the level of the spinal defect. This mainly occurs as a result of scarring from the original closure surgery. As the child grows their spinal cord is stretched. This often requires surgery to de-tether, or release, the spinal cord and occasionally surgery to decompress the brainstem where it enters the top of the spinal column. These are extremely critical procedures with a high degree of risk. Left uncorrected, they can result in loss of motor function, paralysis, and in the case of brainstem compression, even death. Chronic bladder problems and urinary tract infections can result in loss of kidney function. Furthermore, the problems associated with incomplete bowel and bladder control can have a huge effect on an individual's self-esteem and overall social interaction. Finally, shunt malfunctions and infections can result in increased developmental delays.

As parents of a child with Spina Bifida, we are very grateful to Congress for its assistance and leadership regarding helping to reduce and prevent Spina Bifida and improving the quality of life for individuals with Spina Bifida. The Early Childhood Intervention program (ECI), in particular, has made a big difference in the early lives of children with Spina Bifida. However, there is a lot more that needs to be done with respect to prevention and quality of life issues.

A Federal allocation of \$3 million in fiscal year 2003 for a National Spina Bifida Program would provide a crucial necessary next step to help reduce the occurrence of Spina Bifida and to help those already affected. Such a national program would help improve public awareness—which I believe should be considered a top priority. Most people I have spoken with during “awareness events” have never heard of Spina Bifida. Once the public knows what Spina Bifida is and understands how it affects the individual, prevention will evolve automatically.

More also needs to be done to improve the quality of life for those individuals and families—such as mine—living with Spina Bifida. The No. 1 concern from parents and individuals is that few improvements have been made in the area of bowel and bladder continence. This is a problem that has devastating emotional and social consequences for the individual. Families often have to change plans because a facility or area is not equipped to handle the needs of an individual with Spina Bifida. Children with Spina Bifida often are excluded from events and activities because a facility or even a friend’s home cannot accommodate them and their needs.

A National Spina Bifida Program also will help with the establishment of multi-disciplinary care facilities. Spina Bifida is a complex defect that cannot be handled by ordinary healthcare professionals. With clinics established, the healthcare providers within that facility will become more experienced with the problems affecting Spina Bifida patients and how they interrelate. Through the National Center for Birth Defects and Developmental Disabilities at the Centers for Disease Control and Prevention, health care providers can become better educated about the full range of issues and challenges that face individuals and families affected by Spina Bifida. This in turn will help improve the quality of care they receive and subsequently improve quality of life.

In addition, we must have educated professionals within the school systems. Educators need to understand the types of learning disabilities associated with Spina Bifida and develop appropriate alternative methods of learning. They also need to teach independent living to those individuals who may not have a support network at home. Our collective goal should be for the majority of individuals with Spina Bifida to live long, healthy, independent, and productive lives.

Lastly, research into the cause of—and a cure for—all neural tube defects must be increased. Our job will not be complete until there is no longer a need for a National Spina Bifida Program.

Again, on behalf of my son, my wife, and myself, thank you Mr. Chairman for giving me the opportunity to tell our story to you today. It has meant a great deal to us and we stand ready to be of any assistance to you and your colleagues as you consider issues relating to this all too common birth defect.

Thank you.

Senator DODD. Let me turn to my colleague, Jack Reed, who has some other obligations, so I am going to have him go first with his questions, and I will follow up with some. I thank all three of you.

Senator REED. Thank you, Mr. Chairman.

I concur that it was extraordinary testimony by Mr. Pote, Dr. Green, and Mr. Liguori. Thank you so much. And let me once again thank the chairman for holding this hearing, but not just this hearing—I cannot think of any of my colleagues who has been more committed to helping the welfare and the health of children throughout their career than Chris Dodd, so thank you, Mr. Chairman, for that and for all that you do.

Let me raise just two questions. First, we talk about the cost of birth defects to the child and to the society, but it strikes me that any child with an illness of this severity has huge costs to other children in the family, to the family itself, costs that are very difficult to objectify, to put into numbers. But Mr. Pote and Mr. Liguori, if you could just comment on the impacts and the costs in regard to other siblings that we have to capture, because this too is a burden that we have to address.

Mr. POTE. I will just offer a couple of personal observations and then generalize it a bit. There are two significant impacts that we see in our families, and we are very lucky in our family—my older nephew, Tim, who is a very strong young man and has been a very

important part of helping his family deal with the challenges of spina bifida. But that is not always the case. Many siblings grow up feeling like they are not getting the attention from especially their mother, because the other important impact here is that the nature of spina bifida—and you heard Fred list the number of care providers that their family has to deal with—one of our chapter folks in Nashville told me one day that there are 15 doctors that she regularly visits with her son. It is a full-time job for one member of the family—it is almost always the mother, as it turns out—and that has tremendous demoralizing impacts. Women have given up their careers. They often feel guilty that they are not spending time with their other kids, and the siblings often feel like they are not getting their fair share. Those are all very important psychological issues.

Senator REED. Indeed. Thank you so much for your testimony.

Mr. Liguori, again, thank you for your testimony, and thank you also for flying those A-10s. That helps a great deal.

Mr. LIGUORI. Thank you, Senator.

Senator REEDS. Could we have your comments, because you see it as a parent—and by the way, I have the same tractor at home for myself; it is a perfect size for me.

[Laughter.]

Go ahead.

Mr. LIGUORI. That is his favorite.

As far as how it affects other children, it is a little early for us to tell. We do have another child who is 8 months old—he is not here today, thank God.

[Laughter.]

He is not quite as mellow as Nicholas. But we do see already that Nicholas does require a lot of attention just from the therapies that he receives, and of course, now that he has transitioned from birth to 3 into our local school system in Granby, which is doing a phenomenal job, he does receive therapy just about every day. So that means loading everybody into the car, taking him to the school, and it does take a lot of time away from the second child.

As far as the health care costs, right now at American Airlines, we have a \$1 million lifetime cap on our health insurance. That is something that I am very concerned about with Nicholas, and we do everything we can to keep his health care costs as low as possible, because that can be a factor.

One big thing with spina bifida is that it is an ever-changing birth defect, and just because he is doing so well today does not mean that that is the case tomorrow, next week, or next year. That can change.

So those are our biggest concerns. We will see how it is when he gets a little older, how it affects our family. Like I say, right now, he does require a lot of extra care, and certainly the cost is a factor for us.

Senator REED. Thank you so much.

The other point that I think both you, Mr. Liguori, and Mr. Pote made is that the progress and the response from families that are well-educated and affluent and have access to health care is challenging, but just think of families who do not have a health care plan, and maybe do not have English as their first language. It is

a huge challenge, and that is our responsibility; that is where we have to step up to the plate, particularly helping those families.

Dr. Green, it is encouraging to hear about Nicholas' surgery, and I wonder if you might talk about the impact of in utero surgery in terms of limiting the number of surgeries going forward and potentially alleviating many of the symptoms of spina bifida. Could you comment on that?

Dr. GREEN. Sure. Fetal surgery is not all that new, and in fact it has been very well-established for quite successful treatment of other disorders that I mentioned—congenital diaphragmatic hernia, urinary tract obstructions. So that while there are issues which I think you heard around risks of pre-term birth, and so on, I think it is a well-established option for a number of different birth defects.

The spina bifida story is still early, as I mentioned. There are procedures being done in three centers, and as Mr. Pote correctly mentioned, the data seem most encouraging about one of the major difficulties with spina bifida being the need for a shunt for draining spinal fluid from the head, and it actually goes into the abdomen. I can tell you from taking care of lots of kids with those shunts that they are often a problem and result in innumerable surgeries and problems as well as potential association with learning problems and mental retardation if shunts are not adequately taken care of.

So the early data is that the fetal surgery may help avoid the need for a shunt and some of the complications associated with it. But again, it is early, and these programs are being evaluated, so at this point, it is at the clinical study stage.

Actually, there was a report in this week's New England Journal about three kids who had had fetal surgery for spina bifida, and they developed another condition associated with the surgery that they may or may not have had had they not had this fetal surgery, which in two of the three cases was treatable with another surgery, in one of the cases not.

So I think there is a lot to be learned and that we need to be cautious and study this very carefully, both in terms of short-term as well as long-term outcomes. The long-term outcomes, it is too early to say, so we do not know.

Senator REED. The other point and my last question—because the chairman has been very kind to let me go first—is there are three centers doing this type of surgery, which underscores the reality that to get access to the sophisticated health care and the counseling, you have got to be fortunate enough to live in one of these cities. Probably if you are in a rural area, you would be unlikely to logistically be able to access these services. You have got to be fortunate to live in a school system that is really—and Granby, I think, is—sensitive and is working with the families.

So we have a huge challenge to whatever we develop in terms of medical responses and educational responses to make sure that they are diffused fairly across the country. Otherwise, rural Americans and poor Americans—even if you are doing everything you can, you do not have the resources available.

Does that make sense? I see affirmation.

Mr. Chairman, thank you.

Senator DODD. Thank you, Jack, very much for your presence here today and your commitment to this issue as well. It has been tremendously helpful to have you with us here this morning.

I probably should have noted at the outset that one of the reasons that I have been involved in this issue is because I have been pleased every year for I do not know how many years now—I am trying to recall the number—I have been the honorary co-chairman with Bob Dole, my wonderful friend and colleague, former Senator, of the spina bifida dinner we have each year to raise dollars. I have enjoyed those roasts that we have here in Washington, where I have mostly been a “roaster”—and by the way, that is not an invitation for me to become the “roastee,” having seen what they do to people.

Mr. POTE. It has been duly noted.

[Laughter.]

Senator DODD. I am glad to be the honorary co-chair with Bob Dole and those involved. Judy Woodruff and Al Hunt are great friends, and they have done a wonderful job bringing us all together for that particular event.

Let me run down some questions for you—and this is an informal enough setting here so I want you to jump in and comment on these matters if you feel so inclined.

Let me begin with you, Mr. Pote. You mentioned in your statement that prevention, intervention and treatment therapies must be identified, and as you said in your statement, in order to identify these, it would require, in your view, either new medical breakthroughs, more research, or just funding.

Where should the emphasis be from our standpoint?

Mr. POTE. I will just mention two, and I will reinforce something that Dr. Cordero mentioned. We will be cofunding and participating with CDC, NIH, and AHRQ in the coming year in a consensus conference which is, as you know—and you probably know this better than I—designed to bring together health care professionals, scientists and researchers, public health professionals, and members of our community to figure out what is it that we know about best practices, and what do we not know, and then to establish the agenda which hopefully will help us, with Dr. Cordero, figure out what the priorities are, but then will also lead to the promulgation of best practices with the participation of the academies and the Agency for Health Care Research and Quality.

So from the point of view of our families, I would say that our number one priority now is that the quality of care delivered to our families around the country is very uneven, and we need to establish those standards.

The second issue—and this is also why it is very complicated—is that there is no such thing as a spina bifida secondary condition. It is a urological or a neurological or a dermatological, and that makes it difficult for us to specifically pinpoint what we need to pursue next. That is why, as Dr. Green said, with the help of people like the March of Dimes and these other professional academics, we can focus on the two or three most important secondary conditions in each of those areas of treatment and make sure we have identified the research priorities to bring the level of care up in each of those specific areas.

Senator DODD. That is great.

Tell me—and this seems sort of self-evident, but I would like you to explain why you think this is important for an audience that may not be familiar with this and wants to know more—I find the idea of locating the National Spina Bifida Program in the National Center to be a wise one. But tell me what you think that is going to mean for spina bifida families. What does it really do for those living with spina bifida? What sort of difference does that make?

Mr. POTE. I think that it helps raise awareness, first of all. The fact that we are sitting here in 2002 talking about this issue says something about the level of awareness, and we in the spina bifida community accept our share of that responsibility, because we need to make sure this is a higher priority item.

I think the most important outcome of that center will be that we will be able to once and for all establish a clear national agenda and will be able to focus the efforts of the legislative world, the medical community, and the research community and make sure we are dealing with the most important issues in a very coordinated and focused way.

Senator DODD. That is a good enough reason.

Dr. Green, do you have any comments on that?

Dr. GREEN. I will give you three statistics. Up to 70 percent of neural tube defects can be prevented with folic acid. As Dr. Cordero mentioned, there is a 31 percent decrease. So there is a gap between what could be prevented and what has been prevented. And the third statistic is that only one-third of women of childbearing age take folic acid during the preconception period.

So we want to get to 100 percent prevention, so we need more research on what the other causes are that cannot be prevented by folic acid; we need to reach out to the public through health care providers directly to the public to get as much prevention as possible.

And I think Dr. Cordero's center at CDC is well-poised to do that and also to do the surveillance.

Senator DODD. Mr. Pote, in your written testimony, you mention that "With appropriate, affordable, high-quality medical, physical, and emotional care, most people born with spina bifida can lead relatively normal lives."

And your testimony, Mr. Liguori, about the difference between what the medical people told you and what you encountered with the family in Connecticut that you met was certainly instructive. It is also clear from your statement that ensuring access to this care is obviously necessary if we are to improve the quality of life for people.

But my question is this. How do you know how affordable it must be to be truly accessible? This is a complicated question, but I am trying to get some sense of this—and are there other obstacles such as lack of trained specialists—you have mentioned that to some degree already—which make this care inaccessible to those with spina bifida.

I would like all three of you to comment on that if you can.

Mr. POTE. I guess the point that I would emphasize is that once quality of care is accessible because the health community has been trained to the same level of awareness and skill, I think the next

issue, then, is making it clear to folks who have a child with spina bifida that there are places where they can go to get that kind of specialized attention.

The third issue is how do they pay for it. And as you mentioned earlier, Fred is fortunate enough to have a good, solid private insurance policy. The good news on those policies is that for the most part, they do fund what they should be funding, and as you know, that is not always the case. That is not to say that the families do not have to fight to get there, but most of those policies do pay where they should. The issue is the number of people who are not covered by those kinds of policies and are therefore totally reliant on the public safety net, and as you know here also, that does not always result in the highest-quality care.

Senator DODD. You mentioned earlier, Mr. Liguori, that the Granby school system has been pretty good. We have been trying up here for the last number of years—I started about 10 years ago—to have the Federal Government live up to its commitment on special education costs. We have not gotten there yet, and when I go back home, and I meet with my first selectmen and mayors in the 169 cities and towns in Connecticut, one issue that is right at the top of the list all the time for them is special education dollars. And we are getting better at this—we are at about 12, 13 percent. We tried last year in the Elementary and Secondary Education Act to get those dollars up, and the Senate was overwhelmingly in support of it, but the House was not, and we did not have a lot of support out of the administration on this. I am hopeful that this year, that may change.

There are a lot of problems obviously with the fiscal issues associated with that. But I have also been concerned about how in communities, because of the costs associated with special education, in smaller towns, the pressures that can be exerted because people start to complain about the cost of taking care of a handful of children.

Tell me about the response in the community of Granby. Obviously, it has been a good one, but I would like people to hear about how that happened. How do you educate people about the importance of Nicholas getting the kind of education that the Granby school system is giving him?

Mr. LIGUORI. I have to go back to what Mr. Pote said. I think it comes back to public awareness. Public awareness is the most important thing in my mind, because I think that once the public is aware of what spina bifida is and how it affects children, you will see a change in prevention, you will see a change in fundraising—all that stuff will follow on, and it will also help to educate people on what the defect is, the developmental disabilities of these children, and the needs that they have in the school system.

We were with the birth to 3 program initially in Connecticut when we got back, and we were quite happy with the care that Nicholas was getting at that time—we did not know anything better, though—but he was continuing to fall behind developmentally. Once he turned 3, and he stepped into the Granby school system, they came up with a program for him that was significantly more than what birth to 3 was giving him, and he has just started that—

he is only 3½ years old—but we are very happy with the system that he has, and we hope to see him improve quite a bit.

But to answer your question, I think it just comes back to raising public awareness on the defect and how it affects children.

Senator DODD. I probably should have said this ahead of time, for those people who are not from Connecticut or from the area—Granby is a small town. It is not a large metropolis in the State of Connecticut, like Hartford or Bridgeport. Granby is a small community. So education is important, and local support is based on people being aware of the kind of assistance and support that Nicholas would need. And that made a difference in terms of the system being willing to step up to the plate and see that he gets that kind of help.

Mr. LIGUORI. Yes. And Senator, if I could make one more comment as well, as far as the health care professionals, like I said, a lot of the information that we got from them conflicted with the information that we got from the parents. And again, I think that goes to education, because a lot of the information that we did get from the professionals we were dealing with was—I do not want to say it was incorrect—it was old information. And with early intervention and multidisciplinary care, the children today do much better than they did 20 years ago.

Senator DODD. Dr. Green, why don't you pick up on that point? I would love to see us do something in this reauthorization that did a lot more in terms of providing that kind of support for health care professionals to have a far better understanding of these issues. What can we do that will achieve that? It seems to me that that is a major question here, and we need to put more emphasis on it.

Dr. GREEN. I think Dr. Cordero mentioned the program with the American Academy of Pediatrics and his Center, and that is a major mechanism for outreach to professionals, for pediatricians. It would also seem that it is important to reach out to the obstetrics side as well, perhaps to the American College of Ob/Gyn, since many of these decisions are made prior to the delivery of the child.

In fact, the March of Dimes has been working with ACOG, the College of Ob/Gyn, on educational efforts in this and other aspects of health care for infants and children. That is not it—obviously, outreach needs to be made to the nursing staff, and as you have heard, there is a whole spectrum of health care needs and health care providers involved in care for children with serious birth defects like spina bifida. So educational outreach really needs to be directed at this spectrum so that you get coordinated care.

Senator DODD. Let me ask three other quick questions if I can. One, can you go into a little more detail about what is being done on the research side—we have talked about it—but what areas of research are showing some real promise in the prevention or treatment in the area of birth defects?

Dr. GREEN. The question came up earlier about genomics, and certainly identifying genes so there can be screening and prediction of course—maybe some children are affected with specific birth defects because of some genes in their mothers or themselves. The genetic diversity may help to explain some of the spectrum of dis-

order, so that is important to know in terms of making decisions, planning treatments and interventions.

So that, for instance, the 30 percent or so of women who are resistant to folic acid, so are at risk of having affected pregnancies, despite folic acid may need ten times the dose of folic acid or more, or other kinds of medical interventions for prevention.

So I think that gene identification is critical for prevention as well as for prediction of clinical course and therefore allows families to plan. So that is one aspect.

And certainly fetal surgery, as we have heard, has been important in a careful approach to assessing impact on these birth defects.

And then, the other issue is we should remember that research involves surveillance and keeping track, so for instance, that is how we know that Hispanics are at greater risk of having children affected by neural tube defects, and that has then led to outreach to providers and outreach to communities. So I think that surveillance is a very important aspect of this that the CDC helps to provide.

Senator DODD. The March of Dimes and the public educational messages that they have developed over the years for newly pregnant parents—have they been targeted to them, or is it sort of a general message?

Dr. GREEN. It is an interesting question, because if you think about folic acid needing to be taken by women of childbearing age, once you know that you are pregnant, if you start taking folic acid, it may be too late. Then, you have to really reach women from the ages of 16 to 45. That is very challenging.

If you think about other disorders like fetal alcohol syndrome, which was brought up today, similarly, you have to reach women early, although a lot of the public outreach on fetal alcohol and also smoking that is associated with pre-term delivery and low birth-weight of children, you can target more toward pregnant women.

It is obviously easier to reach more well-defined populations, and pregnant women are known to be more receptive to educational messages. They want healthy babies as well. So it depends on the disorder and the cause.

Some disorders associated with, say, medications—the thalidomide story is old, but one of the more active stories is with accutane, an acne medication. Again, you have to deal with the young adult female population. So one size does not fit all for this.

Mr. POTE. Senator, I would just add in terms of some of the outreach that the March of Dimes is doing, that next time you are in an airport, look for Daisy Fuentes talking about folic acid. And I am sure that, like me, you are an avid watcher of MTV, and you are very familiar with Daisy Fuentes, but she is exactly the kind of spokesperson that we need—a young, attractive Hispanic woman who is “cool,” and it is “cool” to take folic acid.

One of the things that we have said about food fortification is that if we could ever find a way to fortify soft drinks with folic acid, or if we could find a way to convince young women that—

Senator DODD. I was curious about that, whether we could incorporate it in food sources, working with the Department of Agri-

culture and others, so that this could become as much of a conscious choice as just normal eating habits and patterns.

Mr. POTE. You find it today in breads and cereals, and if you look on the back of most cereal boxes, I believe that what you will see is 170 micrograms in many cases—

Senator DODD. Not the 400.

Mr. POTE [continuing]. Not the 400—and then, of course, the question is when you look at the population that we are targeting, are they really eating the recommended daily dosage of breads and other grains than cereals.

Senator DODD. One thing you might think about doing—I just spoke over the weekend at the national convention of La Raza in Miami, and 2 weeks before that, I spoke at the national convention of LULAC. I was in the Peace Corps, so I have a strong interest in the culture and history. And I would think that through Telemundo and these other groups, and the “novellas” which are tremendously popular, obviously, in any language—these are the soap operas and so forth—among younger women, these are tremendously popular—I would bet that if you talk to these folks, with Dr. Cordero, about how you might incorporate it as part of the commercial programming, as part of the stories, it would have a tremendous impact.

With all due respect—and I am very grateful to CSPAN for covering a hearing like this—but the audience that we are going to reach probably is not going to be the one that we would like to be reaching. Maybe we should do this with simultaneous translation for people who speak other languages. But nonetheless, there is a greater likelihood, I think, through the commercial popular programming that we are able to get a better education through, and I bet if we had some contacts with them, they would be more than willing, particularly with the information you have shared with us here today about the particularly high incidence in the Hispanic-Latino community. I would bet you would have a tremendous response to this, and I will be happy to join you in getting in touch with them, if you would like to do that.

Mr. POTE. Thank you.

Senator DODD. I apologize—this could go on and on. I have been so impressed with all of you. I am tremendously impressed with you, Mr. Pote, for the work that you have done, a tremendous effort.

And Dr. Green, we are excited to have you with the March of Dimes, with your background as a pediatrician.

It has been great to have Nicholas and Greg here with us. I cannot tell you how much I appreciate having these young people with us today. It makes a big difference.

And Mr. Liguori, you and Jill are terrific parents.

Mr. LIGUORI. Thank you, Senator.

Senator DODD. Okay. We will leave the record open for some additional questions.

I thank all of you for coming, and the committee stands adjourned.

[Additional material follows.]

ADDITIONAL MATERIAL



Embargoed for Release
12:01 AM, February 20, 2002

Contact:
Amy Goffe, 202-589-0940
Jenn Myers, 202-777-3504

States Get Poor Grades on Birth Defects Prevention

Group Calls for Better Systems to Track and Prevent #1 Cause of Infant Deaths

Washington, DC – Most states are doing a poor job of tracking and preventing birth defects, which are the #1 cause of infant mortality in the United States, a new report says. Birth defects account for almost 20% of all infant deaths each year.

The report -- *Birth Defects Tracking and Prevention: Too Many States Are Not Making the Grade* -- was authored by The Trust for America's Health (TFAH), a Washington, DC -based advocacy group. The report gives each of the 50 states, plus the District of Columbia and Puerto Rico, a letter grade based on their efforts to monitor and research birth defects. Only eight states receive an A, although even they need improvement, the report says. More than half the states received a C, a D or an F.

According to the report, state monitoring programs can play a crucial role in birth defects prevention by collecting information about which birth defects are occurring and where. But most states are doing an inadequate job of providing this data.

Exposure to environmental hazards may play a role in some birth defects. However, here again, researchers lack essential data to explore these and other links. Two-thirds of states with registries do not explore any possible links between birth defects and environmental exposures.

"Our report shows we lack the most basic tool for preventing birth defects -- information," said TFAH Executive Director Dr. Shelley Hearne. "Without knowing the causes of birth defects, we are helpless to prevent them. Health officials want to build health-tracking capacity, but they lack the necessary resources."

... continued

Birth Defects Take a Significant Toll

According to the March of Dimes, in the United States, approximately 150,000 babies are born each year with birth defects – one out of every 28 infants. Many factors, including genetic and environmental factors, can cause birth defects. However, the causes of as many as 80 percent of birth defects are currently unknown.

Beyond the often serious health problems experienced by the child, birth defects also place tremendous emotional and social burdens on parents, and financial costs that can range from \$140,000 to \$700,000 over a child's lifetime. It is estimated that for children born nationwide in 1988, the lifetime expenses associated with just 12 birth defects are more than \$8 billion in today's dollars.

Recommendations

According to the report, the most important steps needed at the state and federal levels are:

- States should improve their birth defects registries, create them where they don't exist, and ensure adequate funding;
- The CDC should establish minimum national standards and help fund birth defects registries in every state;
- Congress should establish a nationwide health tracking network for chronic diseases like birth defects, cancer and asthma. The Network would build on the birth defects registries and other current efforts to track chronic and infectious diseases and conditions.

About TFAH and This Report

The Trust for America's Health is a national non-profit organization whose mission is to protect the health and safety of all communities, especially those most at risk of environmental and other public health threats.

The full text of the report and state-specific fact sheets are available on the TFAH Web site at www.healthyamericans.org.



**BIRTH DEFECTS TRACKING—
DOES CONNECTICUT MAKE THE GRADE?**

Grade: C

PROGRAM INFORMATION

- **Name:** *Connecticut Birth Defect Prevention and Surveillance Program*
- **Parent Organization:** *Department of Health, Division of Environmental Epidemiology and Occupational Health*
- **Start Year:** *1995*
- **Status:** *Fully Operational*
- **Connecticut's Estimated Total Lifetime Cost of Selected Birth Defects*:** *\$95 million*
- **Website:**
http://www.dph.state.ct.us/OPPE/sha99/drinking_water.htm#BIRTH%20DEFECTS%20-%20PREVENTION%20SURVEILLANCE

*Note: 2001 estimate calculated by TFAH is based on lifetime expenses associated with 12 selected birth defects.
[Source: Harris J. and Levy J. (1997). State-by-State Cost of Birth Defects — 1992. *Teratology* 56(1-2): 11-16.]

CONNECTICUT BIRTH DEFECTS TRACKING

The mission of the Connecticut birth defects program is to (1) establish baseline prevalence of birth defects for residents of the state of Connecticut utilizing case definitions that are consistent with national reporting; (2) identify patterns of incomplete reporting of cases for cases expected to be recorded in either the birth or death registries and develop methods to improve reporting; (3) monitor trends of birth defects to detect increases in the incidence of specific malformations or increases in specific geographic areas; (4) develop a protocol for cluster investigation and investigate clusters detected by the system or reported by the community; (5) identify sentinel events of birth defects and develop a protocol to investigate or increase intervention activities to those identified at risk; and (6) work with the maternal and child health programs addressing the issue of folic acid in the prevention of neural tube defects.

Connecticut's program has passive ascertainment of all major structural birth defects and one other category of adverse birth outcome in babies from birth to age one year. The population-based program collects cases from the entire state. The program analyzes data, which is reported to the general public, directors of local health departments and the state medical society; however, the latest year of available data is 1997. Connecticut's program offers birth defects prevention programs and also conducts epidemiologic (prevention) research.

This grade is based on a new report, *Birth Defects Tracking and Prevention: Too Many States Are Not Making the Grade*, by Trust for America's Health. For more information or to obtain a copy of the full report, visit www.healthyamericans.org.

**COMPARE CONNECTICUT'S SCORE TO THE REST OF THE NATION—
SEE REVERSE SIDE**

State	Grade	State	Grade	State	Grade
Alabama	B	Kentucky	B	North Dakota*	F
Alaska	B	Louisiana	D	Ohio	F
Arizona	B	Maine	D	Oklahoma	A
Arkansas	A	Maryland	C	Oregon	F
California	A	Massachusetts	A	Pennsylvania	D
Colorado	B	Michigan	C	Puerto Rico	C
Connecticut	C	Minnesota	D	Rhode Island	D
Delaware	C	Mississippi	D	South Carolina	B
District of Columbia	F	Missouri	B	South Dakota	F
Florida	B	Montana	D	Tennessee	C
Georgia	A	Nebraska	B	Texas	A
Hawaii	A	Nevada	C	Utah	C
Idaho	F	New Hampshire	D	Vermont	F
Illinois	B	New Jersey	B	Virginia	B
Indiana	D	New Mexico	B	Washington	D
Iowa	A	New York	B	West Virginia	C
Kansas*	F	North Carolina	C	Wisconsin	D
				Wyoming	F

Note: States marked with an asterisk (*) have vital records reporting only.

BIRTH DEFECTS TAKE THEIR TOLL

Birth defects are the leading cause of death among infants in the United States. Every year, about 150,000 babies are born in this country with some kind of birth defect. Beyond the direct emotional and health impacts on these children and their families, there is a tremendous financial burden.

NEEDED: NATIONWIDE HEALTH TRACKING NETWORK

Birth defects monitoring programs meeting minimum standards would provide communities and public health researchers with information to help prevent future birth defects. Trust for America's Health (TFAH) calls for existing state registries to be improved, and established in states where they don't exist. TFAH also urges the creation of a Nationwide Health Tracking Network that would build on these registries and other current efforts to track chronic and infectious diseases and conditions. A health tracking network would provide health officials and communities information on where and when chronic diseases like cancer and asthma occur as well as their potential links to environmental factors. This information would help protect communities from the chronic illnesses that account for 70 percent of all deaths in this country.

You can do something about it! Write your state and national leaders and urge them to implement a stronger health-tracking network for birth defects and other chronic diseases.

*Governor John G. Rowland
210 Capitol Avenue
Hartford, CT 06106*

*Connecticut Department of Public Health
Joxel Garcia, Commissioner
410 Capitol Avenue
Hartford, CT 06134-0380*

*Senator Christopher J. Dodd
448 Russell Senate Office Building
Washington, DC 20510*

*Senator Joseph Lieberman
706 Hart Senate Office Building
Washington, DC 20510*

[Whereupon, at 11:34 a.m., the subcommittee was adjourned.]

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