

A CALL TO ACTION THE POLITICS
OF DISEASE ADVOCACY

HON. RUSH D. HOLT

OF NEW JERSEY

IN THE HOUSE OF REPRESENTATIVES

Thursday, December 7, 2006

Mr. HOLT. Mr. Speaker, I want to bring to my colleagues' attention an October 10, 2006 article in the Wall Street Journal by Amy Dockser Marcus, entitled "Advocacy Overload?" The article reviews the current state of disease-funding advocacy, and specifically cites the efforts of the Princeton-based Melanoma Research Foundation to coordinate the advocacy activities of a wide variety of melanoma organizations. In the past year, MRF has worked to organize a coalition of these groups in order to develop a coordinated message to Congress and the National Institutes of Health. The goal of this "One Voice" for melanoma research is to develop a common agenda, focused on securing the additional resources to fund the research into better treatments and cures for melanoma.

The Melanoma Research Foundation (MRF) was founded 10 years ago and has become the leading research foundation for melanoma. The Foundation has worked closely with the research and medical communities encourage dialogue and education about melanoma through their research congresses; participated in National Cancer Institute initiatives; organized the first steps of a melanoma coalition for advocacy; and hosts an interactive website for patients and caregivers. Their three part mission—supporting basic and translational research, education of patients and caregivers, and advocating for the melanoma community—is funded primarily through community fundraisers across the United States organized and managed by MRF volunteers. Other primary sources include memorial donations, individual gifts, and unrestricted grants from pharmaceuticals.

The need for a coordinated attack on melanoma is more critical now than ever before. Here are some of the facts about melanoma: It's the fastest growing cancer currently in the U.S.; It's the most common cancer in young adults aged 20 to 30; For women, age 25 to 30, melanoma is the primary cause of cancer death; For women, age 30 to 35, it's the second leading cause of cancer death, after breast cancer.

One of the primary causes of melanoma is UV exposure, most of which comes from too much time in the sun. Melanoma is survivable, if diagnosed early. When a superficial melanoma is found and diagnosed early, the 5 year survival rate is 100 percent. But at the opposite end, when the melanoma advanced to what's called Stage IV, when it's disseminated to major organs, the 5 year survival rate drops as low as 7 percent. Yet, despite these figures and the growing incidence of melanoma, no significant advances in medical therapies (or survival) for patients with advanced melanoma has occurred in the past 30 years.

Clearly, there's a great need for public awareness of the dangers of overexposure to the sun. There's also a need for increased research in identifying the causes and potential cures for melanoma. Once again, I commend

the good work of the Melanoma Research Foundation in bringing greater public awareness to this disease, and advocating for more public and private sector funding for melanoma research.

[From the Wall Street Journal, Oct. 10, 2006]

ADVOCACY OVERLOAD?

ACTIVISTS SEEK TO UNIFY EFFORTS OF GROUPS
TARGETING DISEASES; A BRAIN-TUMOR COL-
LABORATIVE

(By Amy Dockser Marcus)

At the national Brain Tumor Foundation, executive director Rob Tufel has a standard reply for well-meaning families and patients who want to set up a patient-advocacy group: "Please don't start another organization."

There are 141 patient-advocacy groups that cover brain tumors, according to Mr. Tufel, while 43,000 people in the U.S. are diagnosed every year with primary brain tumors, benign or malignant. That's roughly one group for every 305 new patients. "It just doesn't make sense from the point of view of funding, or from the point of view of patients and families," who must sort through the numerous organizations and Web sites for information, Mr. Tufel says. "Competition is good because it keeps us on our toes, but at some point . . . it becomes ineffective."

Competition is an issue that many patient-advocacy groups wrestle with as they struggle to raise funds for research, attract greater interest in their diseases, and speed up the search for a cure. Increasingly, advocates are asking: When it comes to a disease like cancer, is it possible to set a common agenda and speak with a unified voice?

Now some groups have begun to debate whether the large number of organizations may be hindering as much as helping in their efforts. Many diseases—including AIDS, autism and Parkinson's disease—have more than one group that lobbies Congress for more funding and reaches out to patients and families. With cancer, in particular, there has been an explosion in the number of foundations and advocacy groups in recent years, as the Internet allows patients to connect with one another more easily. It's particularly true in rarer cancers such as brain tumors or melanoma, where the ratio of the number of groups to the number of people who actually get the disease is especially high. There are an estimated 40 groups in the U.S. for melanoma—a disease that will see about 62,190 new cases and 7,910 deaths in 2006, according to the American Cancer Society.

Many of these groups wind up competing with each other for the same donors and the same researchers to sit on their boards. There is the chance that groups will duplicate one another's efforts, wasting resources by offering the same programming or services. And busy legislators find themselves uncertain about what the greatest need is for patients because each group emphasizes different issues or aspects of the disease.

There is also recognition that as cancer research increasingly focuses on using costly, cutting-edge technology to identify genes and cellular changes as an avenue to new treatments, progress is going to take huge sums of money that small patient-advocacy groups are unlikely to be able to raise on their own.

Advocacy groups need to ask, "Couldn't we better leverage some of these resources that you're all spending?" says Paula Kim, whose Translating Research Across Communities consulting group in Green Cove Springs, Fla., and Fallbrook, Calif., works with pa-

tient advocates. Many times, groups end up "recreating the wheel" in doing very similar work, she says.

Different strategies are being tried in order to organize the patient-advocacy community. Some advocacy groups for major cancers, such as breast cancer and prostate cancer, have formed coalitions that have been effective in lobbying on common issues. Others end up merging; two separate lymphoma patient-advocacy groups decided to join forces and create one organization instead, the Lymphoma Research Foundation. "One Voice Against Cancer" is a coalition of many public health groups that lobbies Congress for more federal funding for cancer research. Eight brain-tumor foundations, including Mr. Tufel's group in San Francisco, formed the Brain Tumor Funders' Collaborative to pool money to fund large projects. Earlier this year, they announced their first joint funding initiative, giving grants of \$2 million to each of three scientific projects.

Not all smaller groups see the proliferation of foundations as a problem that needs fixing. Many advocates started their work because they lost someone to the disease, and want to focus on highly personal goals or local projects. Small groups also sometimes worry about having to divert too much of their meager funds to big projects. "I don't agree with the idea that there are too many melanoma groups," says Colette Coyne, who founded the Colette Coyne Melanoma Awareness Campaign in New York with her husband, Patrick, after their daughter died of melanoma. "Many work in their community. I think it is a healing thing for people to create a foundation when they have lost someone."

The Coynes concentrate their efforts in New York, where they live. They have helped promote shade coverings in playgrounds and helped push through tough legislation regarding the use of tanning salons by minors. But they rely mainly on volunteers and raise around \$50,000 through a yearly walk and dinner dance. "I'd be concerned about being committed to large amounts of money for a coalition when we're never very sure what our income will be," says Ms. Coyne. Nonetheless, Ms. Coyne says she believes a coalition is necessary, and she wants to find a way for her group to join.

It is within the melanoma community that one of the most interesting and important debates is going on regarding advocacy groups, amid growing attention to the disease. Steven A. Rosenberg recently announced that he and other National Cancer Institute scientists genetically engineered advanced melanoma patients' own white cells to recognize and attack their cancer cells. In a report published about 15 of the patients, two of the patients saw their disease regress. Translational Genomics Research Institute in Phoenix and the H. Lee Moffitt Cancer Center and Research Institute in Tampa, Fla., are working together to create a kind of map of the human melanoma genome for researchers. These are the kinds of projects that a coalition of melanoma advocacy groups could help by lobbying for more federal funding and generating greater public awareness about the projects and the need for support.

Nineteen different melanoma groups came together in Bethesda, Md., in late March for a meeting planned by the Melanoma Research Foundation in order to debate whether they should form a "One Voice Melanoma" coalition to increase the impact of the community on a federal level. At the melanoma coalition meeting, one of the key

speakers was Connie Mack, who was the U.S. senator from Florida from 1989–2001, and is a melanoma survivor. Sen. Mack, who now serves as chairman of the board of the Moffitt center, told the patient representatives that their organizations could do much more, especially on Capitol Hill, if they joined together. “Our challenge is to see that our voice is heard,” he told the advocates, “but the only way that this will occur is if we speak with one voice.”

In an interview later, Sen. Mack said that the individual organizations were all doing important work, but that members of Congress and officials at the NCI were constantly meeting with patient advocates, including melanoma groups with different ideas and requests. Congress has limited resources available to give these groups, says Sen. Mack, and without a common agenda, “funding levels haven’t achieved the level where they can accomplish anything of significance.”

Linda Pilkington, a melanoma survivor who is executive director of the Melanoma Research Foundation in Princeton, N.J., says that the coalition talks had already made a difference. In the wake of the meeting, the groups agreed on some common goals. While discussion about the coalition’s structure and mission continue, as a result of the group’s discussion, the Melanoma Research Foundation was able to work with a lobbyist and Ms. Kim to craft language that was included in the current Senate Labor, Health and Human Services, and Education appropriations report for fiscal 2007. It calls on the National Cancer Institute to convene a group of patients and researchers to develop a five-year strategic plan for melanoma research, including focusing on the issue of how to speed up the development of new therapies.

The effort hasn’t been easy. “Putting groups together is like having your children work together,” says Valerie Guild, president of the Charlie Guild Melanoma Foundation in Richmond, Calif., and part of the steering committee working on the melanoma coalition. It seems to make sense because they’re all siblings, “but try to get someone to decide what movie to go to on a Sunday night.” Despite the challenges, a coalition can work, says Ms. Guild, who started her group in 2004 after her daughter died of melanoma. “Everybody really wants to get to the same place at the end of it all—a treatment for the disease.”

Ms. Kim, the consultant, who is helping the melanoma groups create a coalition, says there are a number of models that can help small or financially strapped organizations contribute to a coalition. Among them: sliding-scale dues based on the size of a group’s budget, or a program for helping coalition members raise additional funds. Ms. Kim—who herself co-founded an advocacy group called the Pancreatic Cancer Action Network in 1999 after her father died of pancreatic cancer—argues that “for rare diseases, coalitions are vital. It’s a lot harder to make noise when there are not a lot of people to advocate for you. It’s harder to get people on the bandwagon.”

HONORING REVEREND ROBERT
MOORE

HON. RUSH D. HOLT

OF NEW JERSEY

IN THE HOUSE OF REPRESENTATIVES

Thursday, December 7, 2006

Mr. HOLT. Mr. Speaker, I rise today to recognize The Reverend Robert Moore for twenty-five years as Executive Director of the Coalition for Peace Action.

The Coalition for Peace Action began in 1980 when a group of religious congregations in the Princeton area joined together to sponsor a Teaching Conference and Interfaith Service on the theme “Can We Reverse the Nuclear Arms Race?” At a follow-up meeting several weeks later, a decision was made to form an ongoing organization dedicated to nuclear disarmament—the Coalition to Reverse the Nuclear Arms Race. Rev. Moore served as Steering Committee Chair of the NJ Nuclear Weapons Freeze Referendum in 1982 and was instrumental in its successful passage by two-thirds of New Jersey voters.

As the Cold War drew to an end in the late 1980’s, the Coalition’s goals expanded to include the related goals of reaping a major peace dividend—a peace economy—and halting weapons trafficking, both internationally and domestically. In 1993, to reflect this broader agenda, the members voted to change the name of the organization to the Coalition for Peace Action. As other peace-seeking organizations have come into existence and faded away over the years, the Coalition for Peace Action has remained vibrant because Rev. Moore has created an organization that is relevant, well informed, committed and practical.

Rev. Moore has been instrumental in the Coalition’s efforts to motivate and mobilize peace and non-violence activists. As an example, in the late 1980’s, the Coalition’s “Target Congress” project recruited and trained over 500 citizen letter-writers to regularly write to US Representatives. Those contacted showed significant movement toward pro-peace voting records.

Rev. Moore co-chaired the NJ Coalition Against War in the Middle East in 1990–1991, opposing the first Persian Gulf War, and later the N.J. Coalition Against War in Iraq from 2002 to the present. Under his direction, the Coalition successfully lobbied Congress, as part of a national effort, to stop funding for U.S. nuclear weapons testing. Despite an initiative engineered by the National Rifle Association to rescind the New Jersey ban on assault weapons, the law was preserved by an intensive lobbying effort led by the Coalition. In 1995 the first Peace Voter campaign in the country distributed tens of thousands of voter guides comparing candidates on peace and gun violence issues. In 2000, the Coalition provided the first-in-the-nation “NonPartisan Candidate Briefings” to five of six major party candidates in New Jersey’s U.S. Senate primary, and to 3 of 4 major party candidates in two House races.

Rev. Moore is hailed nationally for his ability to educate and mobilize citizens in the name of peace and disarmament. He is an outstanding example of a committed citizen tak-

ing action for what he believes. Rev. Moore is a teacher, advisor, and motivator.

Mr. Speaker, I ask you and my colleagues to join me in congratulating The Reverend Robert Moore on his twenty-fifth anniversary with the Coalition for Peace Action.

TRIBUTE TO CONGRESSMAN LANE
EVANS: A GREAT MAN

HON. KENDRICK B. MEEK

OF FLORIDA

IN THE HOUSE OF REPRESENTATIVES

Thursday, December 7, 2006

Mr. MEEK of Florida. Mr. Speaker, I am happy to join with Congressman COSTELLO and all of my colleagues in honoring a truly great man—Congressman LANE EVANS of Illinois, who will be leaving Congress after a quarter-century of service to our country.

When I was a freshman Member of Congress, and a new member of the House Armed Services Committee, LANE EVANS, a veteran himself, a senior member of Congress and the ranking Member of the House Veterans Affairs Committee, learned of my interest in veteran’s issues and took the time to show me ways to improve my service to veterans in my District and in our state. They were lessons from a master, and they have left an indelible impression on me.

His expertise is legendary. He knows the needs of veterans; their programs, history, problems and concerns. He forged alliances across the aisle and put together coalitions to pass legislation to keep this Nation’s promise to our veterans. As a Vietnam Veteran himself, he never forgot what it meant to serve this country in the military. His ability is so great that he can even make those who have never served also understand the military and its culture.

I will also never forget the fun we had when Mr. EVANS managed our Congressional basketball team. We played games to help raise funds for charity, and even though he was stricken with Parkinson’s disease, which prevented him from participating, it was obvious how much he loved the team and the good-natured competition. He is a joy to be around, and an inspiration.

Mr. Speaker, we need only look at the walls of the Speaker’s Lobby or our committee rooms to appreciate that the House of Representatives will continue on long after we are gone, and there is a certain comfort in the realization that this great institution, in which it is our honor to serve, will endure.

However, I want Mr. EVANS to know how much he has touched me and the other Members of this Congress; to thank him for his friendship, his leadership and for his service to our Nation; and to let him know of our commitment to build on the foundation that he laid down over his 24 years in Congress.