

STATEMENT BY
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BEFORE
THE SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES,
EDUCATION AND RELATED AGENCIES
COMMITTEE ON APPROPRIATIONS
U.S. HOUSE OF REPRESENTATIVES

CONCERNING
THE NEED TO ADDRESS THE DISEASE AMYLOIDOSIS

March 29, 2006

Mr. Chairman, I appreciate the opportunity to appear before the Committee on the issue of amyloidosis. My wife, Ann, and I are here today to ask that you continue to include language in the Committee's report for fiscal year 2007 drawing attention to amyloidosis. We also request that you provide assistance for the Amyloid Treatment and Research Program at the Boston University School of Medicine and the Boston Medical Center.

Two years ago my wife and I appeared before the Committee for the first time and appealed to you to take steps to highlight the need for more attention to be paid to amyloidosis. Also with us at that time, and here today, is one of the heroes of amyloidosis research, Dr. Martha Skinner. She is the director the Boston Amyloid Treatment and Research Program.

Amyloidosis, which is often fatal, leads to heart, kidney, liver and other organ failure.

I had never heard of amyloidosis until my wife was diagnosed with primary amyloidosis. It is a disease that is often misdiagnosed or diagnosed too late. Less than one percent of the U. S. population has been identified to have this disease. Many feel that the disease is vastly under diagnosed, especially in the African-American community.

Thousands die never knowing they had amyloidosis. Thousands of others die because they found out too late to obtain effective treatment. The small number of those with amyloidosis who are lucky enough to obtain treatment face the risk of high dose chemotherapy and stem cell replacement.

Left untreated the disease has an average survival rate of about 15 months. It literally can kill people before they know what has hit them.

For the past three years Ann has moved through her own life and death struggle with amyloidosis. We want to join hands with all concerned to use this experience to help others.

WHAT IS AMYLOIDOSIS?

Amyloidosis occurs when cells malfunction and produce proteins that settle on organs, such as the heart, kidney and liver. These folded proteins clog the organs until they no longer are able to function—sometimes at a very rapid pace.

In addition to primary amyloidosis, there are also cases of inherited or familial amyloidosis and secondary or reactive amyloidosis. All three types of amyloidosis, left un-treated or not diagnosed, are fatal.

There is also no explanation for how or why amyloidosis develops.

Amyloidosis has no known cure.

HOW IS AMYLOIDOSIS TREATED?

Until twelve years ago there was little that could be done to effectively stop amyloidosis—only two percent of patients responded to low doses of oral chemotherapy treatment. The average survival rate at that time was about a year.

Boston University School of Medicine and other centers for amyloidosis treatment have found that large dose intravenous chemotherapy followed by stem cell replacement, or rescue, is an effective treatment in many patients. Bone marrow is eliminated through high dose chemotherapy and the patient's own extracted stem cells are replaced in order to improve the recovery process.

My wife is one of the few people to undergo this procedure twice. Her life has literally been saved by Dr. Skinner and her team.

The high dose chemotherapy and stem cell rescue has increased the remittance and long term survival rate dramatically: increasing from two percent to almost 50 percent the number of patients with total remission.

WHAT NEEDS TO BE DONE?

Only through more research is there hope of increasing that survival rate. Specifically research needs to be done in developing targeted treatments that will specifically attack the amyloid protein produced in the bone marrow. Additional funding for research and equipment is needed to accomplish this task.

Timely diagnosis is also of great concern to us. Fortunately, Ann was diagnosed at an early stage by an alert doctor here in Washington. However many people are diagnosed after the point that they are physically able to undertake treatment.

Early treatment is the key to success. More needs to be done in this area to alert health professionals to identify this disease.

WHAT STEPS HAVE BEEN TAKEN?

In part through the leadership of this Committee and the further involvement of the U. S. Government, a number of positive developments have occurred since our last appearance two years ago. There has been increased basic and clinical research at the Amyloid Treatment and Research Program: a model for the disease has been developed for the first time; markers that cause protein mis-folding are being identified; and new clinical trials are underway.

Increased Federal funding for equipment for research and treatment has been another important element. This has been of key importance to speed the pace of discovery for basic research.

There has also been new recognition of the problems of amyloidosis by the United States Government. The National Institutes of Health (NIH) will hold its first ever symposium on amyloidosis in June. NIH will also participate for the first time through the Rare Disease Group in an International Symposium on Amyloidosis to be held in Massachusetts in November.

Finally, in the last two years there has been recognition by Medicare that aggressive treatment for amyloidosis has proven to be effective. Medicare has concluded that patients undergoing the high dose chemotherapy treatment followed by stem cell transplant will be covered by Medicare benefits, opening this treatment to patients previously unable to afford it.

WHAT ARE THE NEXT STEPS?

Mr. Chairman, we ask that the Committee do four things to help address this deadly disease.

- First, continue language in your report identifying amyloidosis as an important concern and encouraging more research to find a cure.
- Second, encourage the Centers for Disease Control and the National Institutes of Health to educate the American public and medical profession on the need to diagnose this disease at an early stage.
- Third, provide fiscal year 2007 funds within the Department of Health and Human Resources for equipment and related assistance at the Boston University School of Medicine and the Boston Medical Center to assist in methods for treating and curing this tragic disease.
- Finally, assure that NIH is following through on the recommendations made by the Committee in its fiscal year 2005 and 2006 reports.

Treatment has proven effective for my wife. We want to turn what has been a devastating experience into hope for others.

One of my favorite role models is Helen Keller. She stated: "Alone we can do so little, together we can do so much."

Before the involvement of this Committee amyloidosis was on its own and alone.

Now we can do so much more by working together.

Thank you for your consideration.

TERRY R. PEEL
BIOGRAPHY AND DISCLOSURE STATEMENT

BIOGRAPHY

Terry R. Peel currently serves as Partner and Executive Vice President for Edington, Peel and Associates, Inc., a public affairs firm. Mr. Peel specializes in consultation on international development and health issues.

Prior to joining the firm, Mr. Peel served for almost 20 years on the staff of the U. S. House of Representatives Committee on Appropriations. While on the Committee he served as Staff Director of both the Foreign Operations and Military Construction Subcommittees. During this period he worked on international issues regarding development, economic, military, trade, human rights, child survival and health.

Before joining the Committee on Appropriations, Mr. Peel served as the Capital Improvement Coordinator in the office of Washington, D. C. Mayor Walter E. Washington. He was also in the United States Army during the Viet Nam era. He began his infatuation with Washington D. C. when he came here at age 14 to serve as a page to former Illinois Senator Everett Dirksen.

Mr. Peel has also directed and written the book for five original musicals and one play that have been produced in Washington D. C. He is a member of the Board of Trustees for Arena Stage and serves as Chair of the Community Engagement Committee and Chair of the Community Engagement Benefit. He has also recently been a member of the Board of Directors of the Friends of the National Zoo. In May he will begin serving as a voluntary member of the Board of Visitors for the Boston University School of Medicine.

Mr. Peel received his Bachelors degree from Millikin University and his Master of Public Administration and Urban Affairs degree from American University. He has also served as an advisor for Harvard University related to transitions in government in the Former Soviet Union.

He is married to Ann Peel, who after a 25 year teaching career received a Masters degree in the History of American decorative Arts. She is currently a consultant on 18th century glass and furniture and a tutor for children with learning disabilities. His daughters Amanda and Allison teach first grade—in New York and San Francisco.

DISCLOSURE STATEMENT

Pursuant to House Rule XI, Clause 2(g) I disclose that I have not received any Federal grants, sub grants or contracts during the current fiscal year or either of the two previous fiscal years.