

Winter 2010

Issue 24

BOSTON  
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BOSTON  
MEDICAL

Amyloid Treatment and  
Research Program

## Program News

### Inside this issue:

#### FROM THE DIRECTOR 1



David Seldin, MD, Ph.D.

#### Fundraising Events 2- (Continued) 3

#### People, Photos 4



Rosemary O'Connell, M.D.  
Internal Medicine



Saulius Girnius, M.D.  
Internal Medicine



Maite Cibeira, M.D., Ph.D.  
Visiting Scientist

Dear Friends,

Welcome to the Winter 2010 Amyloid Treatment & Research Program Newsletter! This year, the major focus of our Newsletter will be on you! We will highlight some of the wonderful activities and events that our patients, families, and friends sponsor or participate in that raise awareness of amyloidosis and support patient-related activities and important amyloidosis research in our Program. Your hard work has been responsible for many significant advances in our understanding of amyloidosis and its treatment. When you turn the page, you will be amazed to learn about some of the interesting, exciting, and moving activities that go on around the country.

I will use this page to fill you in on some of the exciting news from Boston. First, let me introduce you to some of the new folks in the Program. In the lab, we are very pleased to have the help of Rupesh Patel and Anna Badiie. Rupesh is a pre-med BU graduate working on characterizing protein deposits using immunohistochemical techniques. Anna is a BU Bioinformatics student who is working on our patient database, which is so important for correlating disease and treatments. In the clinic, our new amyloid internists are Rosemary O'Connell, M.D., a board-certified internist and geriatrician, and Saulius Girnius, M.D., a recent graduate of the BMC internal medicine program who will become a Hematology-Oncology fellow next year, and thus will work with us for a number of years to come.

We also are very pleased to have a visiting hematologist from Spain. Maria Teresa Cibeira, M.D., Ph.D. is a member of the outstanding program in Barcelona, where she has carried out research and patient care in the Myeloma and Amyloidosis Program run by the internationally known hematologist Joan Bladé, M.D. We are very pleased to have this new collaboration with the group in Barcelona, and we enjoyed Dr. Bladé's visit here in November.

Our research programs continue to make progress on the causes and treatments for amyloid diseases. In coordination with the Clinical Trials Office and Stem Cell Transplant Programs, studies of combination therapies and transplant regimens are ongoing. Promising results of some of these will be presented by Drs. Sloan and Sanchorawala at the American Society of Hematology Annual Meeting in December.

Although funding from the National Institutes of Health continues to be restrictive in this challenging economic climate, we are encouraged by three awards for research. 1. Dr. Lawreen Connors received a grant from the National Institute of Aging to study age-related cardiac amyloidosis. 2. Dr. Flora Sam, received a grant from the National Heart, Lung, and Blood Institute to study mechanisms of heart damage and remodeling in amyloid patients. 3. Dr. Fredric Ruberg received a grant from the Amyloidosis Foundation to study cardiac amyloid. In addition, Terry and Ann Peel, our Washington advocates testified to Congress and asked NIH to fund amyloidosis research (see Congressional Record language on our website), and gained us a place on the Appropriations Committee bill (pending)

New initiatives and innovative studies need support at a time when federal dollars are so limited. For this we rely upon the generosity of our patients and our friends. Through fundraising efforts including golf tournaments, dinner dances, ski races, and motorcycle rides, you support our mission to find better treatments and a cure. Thank-you.

## Fundraising Events



We never had the pleasure of meeting Eileen Cochran, David Jamieson, Pop Radecher, Joe Solimando, or David Levine, but they have now become part of our family. And they all have something in common; they died too soon from amyloidosis. Their grieving family and friends decided to work towards a cure for the disease that took their beloved family member. Family and friends have been hosting fund raising events and their efforts are giving other families HOPE and TIME.



Eileen Cochran was just 50 when she died of amyloidosis in 2003. In her memory family and friends started a "Walk for an Angel" event and have just completed their 7th walk. Their diligent efforts have raised over \$75,000 for support of graduate students research on amyloidosis.

David Jamieson was the head concierge at a big city hotel. He was ill only a few weeks before he died of amyloidosis. His memory lives on with a photo and tribute in the hotel lobby. And his family and friends get together each year for the David Jamieson golf tournament that supports a fund in his memory for amyloid research.



The Nassau Wings Motorcycle Club hosts an annual "Pop's Run" in memory of biker colleague's father, Pop Radecker. Their visit to the laboratory to deliver the check in person on a Saturday in October has become a favorite annual event. Their support has helped build the Stem Cell Transplantation Suite in the new J. Joseph Moakley Building at Boston Medical Center as well as buy equipment and fund laboratory research projects. Their next event is scheduled for August 22, 2010.



Although we never met him, we know that Joe Solimando was very beloved. His family and friends have just held the 7th annual golf tournament since his death in 2002, to remember him and to raise money for amyloidosis research.

Family and friends of David S. Levine have honored his memory with an annual golf tournament for the last several years after his untimely death. The Solimando and Levine Funds generously support graduate students research on amyloidosis. These families are helping with the important work of finding a cure.

## Fundraising Events

Jo-Anne McCaleb, Kathleen Hanna, Keith Carpenter, Bill Cunningham, and Janet Duncan were part of our amyloid family, but their disease was overwhelming and we lost them too soon. Through the efforts of their families and friends special events take place across the country to raise money for amyloid research.



Jo-Anne McCaleb died of amyloidosis just after her 50th birthday. Her daughter, who is now an actor and musician, has performed with colleagues in several fundraising events over the years to support amyloid research. The proceeds go to the Jo-Anne McCaleb Awards, which are used to fund promising pilot amyloid research projects.

Kathleen Hanna, a mother of 10 children, needed a new heart but died before she could get one in 2004 at the age of 64. The Kathy Hanna Memorial Event became a reality in 2005 through the hard work and vision of family who wanted to pay tribute to a wife, mother, grandmother, great-grandmother, sister and friend. This year they held a dinner/dance with a slide show featuring Kathy with family and friends raising money to support patients and clinical research. A computer for patient use is in the Stem Cell Transplant Waiting Room in memory of Kathleen Hanna.



Keith Carpenter's family lost him when he was only 43 years old. His mother, Brendine Pennington, along with family and friends are doing their part to change the future outlook of the disease that took his life. They host an annual neighborhood "Tag Sale" to fund amyloid research.

Bill Cunningham was the technical director of the ski school at Cannon Mt., and had a mountain of friends when he died of amyloidosis. The Third Annual "Bill Cunningham Ski Race to Beat Amyloidosis" will be held at Cannon in his memory on March 6, 2010.



"Search for a Cure" is the name Dylan Duncan and his friends have given to the scavenger hunt they put on each year in memory of Dylan's mom, Janet Duncan, who died when Dylan was 17 years old. They have targeted their funds for familial amyloidosis research.

We are so grateful for the diligent and continued efforts of so many people. While one fund raising event may not seem like a lot, the cumulative effect of many is enormous. And *every penny* goes for research towards better treatments and a cure. Thank-you so much!

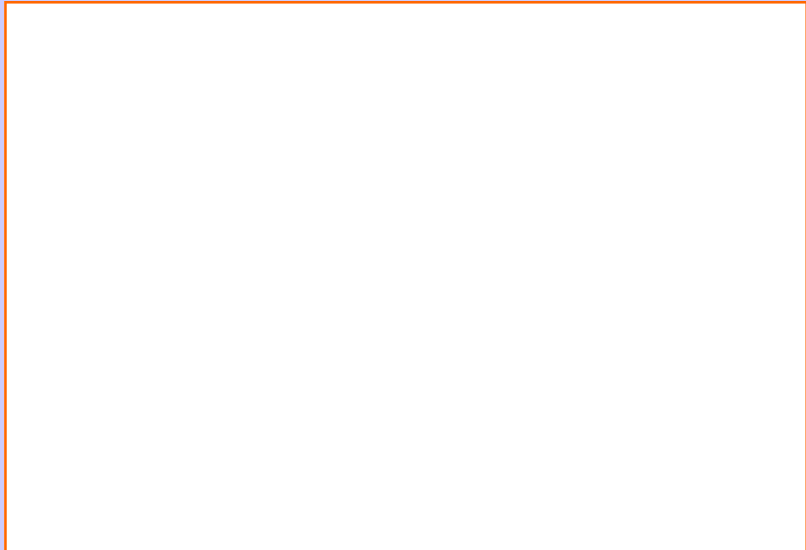
The Amyloid Treatment and Research Program gratefully accepts financial support for our research and clinical programs from patients, family and friends.

Donations can be made through our website:  
[www.bu.edu/amyloid](http://www.bu.edu/amyloid)

or by mail:

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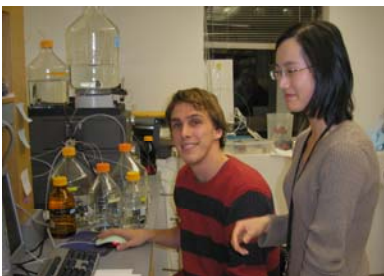
Mr. Wellington & the Amyloid group



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