# AMYLOIDOSIS CENTER REPORT

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www.bu.edu/amyloid


*2014 is a particularly notable year for us, as it is the 20th anniversary of the first use of high dose chemotherapy and peripheral blood stem cell transplantation for treatment of AL amyloidosis.*

*David C. Seldin, M.D, Ph.D*

*John Berk, M.D.*

*Lawreen Connors, Ph.D*

*Vaishali Sanchorawala, M.D.*

## From the Director

Dear Friends,

On behalf of our researchers, clinicians, and staff, I am pleased to introduce this year's Amyloidosis Center report. 2014 is a particularly notable year for us, as it is the 20th anniversary of the first use of high dose chemotherapy and peripheral blood stem cell transplantation for treatment of AL amyloidosis. This treatment, pioneered at our Center, was the first effective treatment for AL (light chain) amyloidosis, the most commonly diagnosed and rapidly progressive form of amyloidosis. In this report, Dr. Vaishali Sanchorawala, amyloid hematologist and Director of the Stem Cell Transplant Program at Boston Medical Center, has asked some of our transplant patients to share their stories. In the 20 years since that first patient (who is still in remission from his disease) was treated, we have worked to develop other effective therapies for patients with AL amyloidosis; now patients have a number of effective options for treatment. Even patients with advanced heart disease can be considered for treatment: some of them may be eligible for a heart transplant through our collaborative program with the Massachusetts General Hospital followed by a stem cell transplant at BMC. These options give new hope for patients with AL amyloidosis and for their families.

2014 is also a special year because of breakthroughs in treatment of the most common familial type of amyloidosis, due to mutation in the transthyretin (TTR) gene. At the very end of 2013, Dr. John Berk, our Clinical Director, and an international group of collaborators, reported in the Journal of the American Medical Association that an inexpensive anti-inflammatory drug, diflunisal, reduces the progression of nerve disease in patients with familial ATTR. This provides an oral, low cost, widely available treatment for patients with this type of amyloidosis. Tafamidis, marketed by Pfizer, also seems to help ATTR, and these drugs may also prove to benefit patients with ATTR heart disease, including those patients with age-related ATTR caused by the normal TTR protein (formerly termed "senile systemic amyloidosis"). A number of promising other agents are in clinical trials; Dr. Berk's column on TTR amyloidosis will update you in more detail.

2014 was also an International Symposium on Amyloidosis year. In April, we attended the XIVth Symposium in Indianapolis, an exciting opportunity for researchers from around the world to share their work. At the Symposium (which followed a very informative Patient's Day run by Dr. Martha Skinner, our emeritus director, and Dr. Merrill Benson, the Symposium host), we presented 18 papers on clinical and laboratory amyloidosis research. Dr. Julie Fu, our amyloid internist this past year, won a prize for her comprehensive study of amyloidosis involving lymph nodes, and our new internist, Dr. Katherine Bever, presented work on blood clots in patients with amyloidosis. Many other exciting laboratory and clinical findings were presented; details are in Dr. Connor's column on research in the Gerry Amyloid Laboratory. We are most grateful to donors who supported travel to the Symposium for many of our trainees.

In addition to Dr. Bever, we are pleased to welcome Dr. Edward Miller, a talented cardiologist with expertise in new imaging techniques, and Dr. Allison Rosenberg, an amyloid nurse practitioner, to our clinical staff. The clinical programs of the Amyloidosis Center continue to grow, providing more and more opportunities for patients with all forms of amyloidosis to receive help with diagnosis and treatment. With the growing number of clinical trials for TTR amyloidosis, we are very pleased to welcome Victoria Lattanzi, Caitlyn Rafferty, and Anthony Akinbami as new clinical trials coordinators.

I hope you enjoy reading this report and learning more about this past very special year. Our hopes for 2015 are high; progress is only possible with the assistance of so many generous supporters of our Center. ■

Sincerely,

David C. Seldin, M.D., Ph.D

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# 20th Anniversary of HDM/SCT

## Patient Stories

**Introduction by:**
**Dr. Sanchorawala**

In June we celebrated the 20th anniversary of the first patient treated at Boston Medical Center with high dose chemotherapy and autologous peripheral blood stem cell transplantation, the most aggressive, innovative and successful treatment for AL amyloidosis. We commemorated this event with a gathering of current and past members of the Amyloidosis Center at Boston University, including Dr. Martha Skinner, who directed the Amyloidosis Center; Dr. Daniel Wright, then Chief of Hematology-Oncology; Dr. Evan Vosburgh, our first transplant hematologist; Ms. Kathy Finn, the original nurse manager of the transplant program; and many other friends and supporters of our Center and our patients. Dr. David Seldin was presented with an anthology compiling notes and photographs from individuals who fought this disease with extraordinary courage and bravery, as a celebration of their lives, honoring survivorship and orchestrating hope. I view this book as a celebration of my own career as a physician in practice, education and research. I remember very vividly my first day as a trainee in hematology at what was then the Boston University Hospital, when I was assigned to care for the first patient undergoing this treatment. This encounter, and the disease, fascinated and challenged me to make improving treatment of amyloidosis my career goal.

This newsletter includes a few of the notes from the survivorship book. The people who live in the pages of that book are heroes, whether they claim that label or not. There is nothing more heroic, nothing more human, than confronting head-on the possibility of loss of health and independence, and striving for an able-bodied, pain free life. These and many other patients bravely fought the disease and the complications of treatment. These people have learned to live with uncertainty, gathering utter strength from their remarkable tenacity and spirit.

Since 1994, more than 650 patients have undergone treatment with high dose chemotherapy and autologous peripheral blood stem cell transplantation at BMC, and this has become a standard of care for amyloidosis patients worldwide. The outcomes and successes exceed all expectations that my colleagues and I could have imagined in July 1994, on my first day of learning about this disease. However, much more remains to be done: many patients still succumb to amyloidosis, sometimes because they are diagnosed too late, they are too sick, or melphalan chemotherapy and stem cell transplant does not work for them. Much has changed in 20 years, and many new treatments have been developed through patients participating in clinical trials at our and other centers.

I wish to update you on our current clinical trials for AL amyloidosis. Novel agents including Pomalidomide, an immunomodulatory agent; Carfilzomib; a second generation proteasome inhibitor; Ixazomib, an oral proteasome inhibitor; Bendamustine, an alkylating agent; and NEOD001, an anti-fibril antibody are being studied for the treatment of relapsed AL amyloidosis. Additional information on these trials can be found on our website. Data on these clinical trials will be presented at the American Society of Hematology meeting to be held in San Francisco in December 2014. Recently, we concluded a trial of two cycles of induction treatment with Velcade followed by stem cell transplantation and presented the promising results at the International Symposium on Amyloidosis in Indianapolis in April.

I would like to honor and applaud all of our patients who have participated in these clinical trials, and thank the remarkable multidisciplinary team of doctors and nurses who have made these studies possible.

### Wonderful Care

*Dr. and Mrs. Harold Forbes*

In early 2005, having gone almost a year before a diagnosis was made, I was so concerned about getting an appointment quickly I personally delivered my slides from another institution to BMC. Huffing and puffing I walked in just as the weekly patient review meeting was breaking up, and I met Dr. Skinner and Dr. Seldin who seemed impressed that I came with my own slides. Two weeks later I had the comprehensive three-day evaluation that provided support, quick feedback with recommendations. Drs. Skinner and Sanchorawala spent as much time as my wife and I needed. Although I was sick I qualified for high dose chemotherapy and a stem cell transplant (and that turned out to be a mixed blessing). My pre- and post-stem cell transplant course was rocky with four hospitalizations. But the care that was provided by Dr. Sanchorawala, Natasha Yancey, all the nurses, and the covering physicians and consultants was exceptional. I happily recovered with a complete response at one year, but my two-year evaluation showed elevated free light chains. I feel great now nine years from my stem cell transplant, but in order to keep the free light chains down I have had intermittent treatment including three clinical trials. Again I have had wonderful care from Dr. Sanchorawala and Anthony Shelton, RN.

*Harold Forbes*
*Arlington, MA*

### Reason to Hope

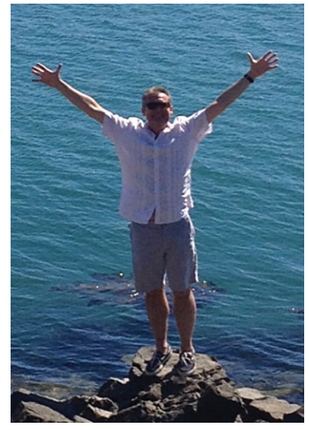
*Dr. Jeffery Howe and Ms. Reva Dolobowsky*

The Boston University Amyloidosis Center saved my life. In the fall of 2008 I was diagnosed with AL amyloidosis – the first time I had ever heard of this disease. As a fifty-seven year old college professor of art history, it was far outside my field of expertise. The symptoms that caught my attention were visual – swelling in my feet and foamy urine. Although neither my primary care physician nor my first nephrologist had encountered amyloidosis before and were not expecting it, they ordered very thorough lab tests and amyloid was detected in a kidney biopsy. They recommended the BMC program, and just over two months from showing symptoms I was at the Moakley Building for a full evaluation, which confirmed the diagnosis. A treatment plan including an autologous stem cell transplant was prescribed. Naturally, I was scared and confused – no one wants to hear the phrase "life threatening illness" from a physician – but Dr. Sanchorawala and the entire team of doctors and nurses inspired confidence that I would receive the best care possible. In January, I had a stem cell transplant which included a course of Velcade as part of a clinical trial. The transplant process was not easy, but the experienced and caring staff helped me through all complications. I live nearby and was able to go home each night, which was a relief. At the end of a month I was released from the program to continue my recovery. I could slowly return to a normal diet, and my immune system (and my hair) began to recover. At six months, I was given the good news that I seemed to have had a complete positive response to the treatment, a diagnosis that was confirmed at the end of a year. With energy and health improving all the time, I returned to full-time teaching at Boston College in the fall of 2009. Fortunately, I had my extraordinary wife Reva with me throughout this journey as a committed caregiver and best friend, and she provided me with motivation to continue to live life to the fullest. We take long bike rides together, travel frequently, and cherish every minute. I continue to be in complete remission, and my kidneys have recovered from the amyloid assault. Although I initially feared the worst and began to prepare myself for it, it has turned out well. In the last five years I have seen a change in the way the diagnosis is presented; there is much more optimism now. The research led by the BMC has been extremely valuable, and they give patients reason to hope. I will always be grateful to the team at the BMC, and look forward to continuing to be classed as a survivor.

*Jeffery Howe*
*Waltham, MA*

### Four Years

We came to the Amyloid center from Southern California four years ago, scared and sad. Minutes after meeting with Dr. Vaishali Sanchorawala (aka Dr. Lasix) we were given great hope for the future. I enrolled as a patient in a clinical trial of high dose Velcade chemotherapy and Stem Cell transplant. My wife Tracy and I felt we had found the best treatment in the country. All of the staff from Aura (mi amiga) who took my vitals every day and Nurse Janet who gave me my growth factor shots showed great passion and professionalism for their patients and their work. Thanks to Anthony Shelton



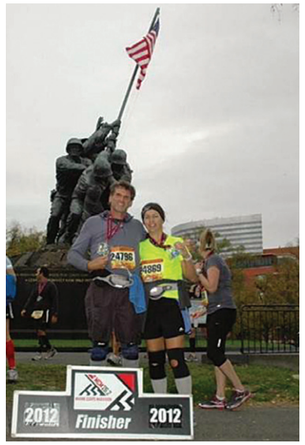
*Mr. Daniel Lape*

and Kathy Finn who kept us informed and let us know what to expect day by day! Aside from the science and medicine involved in my treatment, it is the wonderful people that we got to know that left the greatest impact on me. I still remember all of their faces and voices and how comforting they all were to us. Thanks to all and a special shout out to Dr. Sanchorawala aka My Hero!

*Daniel Lape*
*Aliso Viejo, CA*

**Continued on page 4**

## Heroes



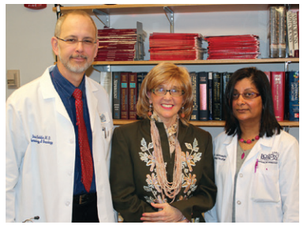

*Mr. and Mrs. Frank Nappi*
*"13 years post SCT - I ran the Marine Corps Marathon"*
*October 2012 - Washington, D.C.*

Congratulations to the Boston University Amyloidosis Center on the 20th anniversary of the first successful treatment of high dose melphalan and stem cell transplantation for AL amyloidosis. The amount of progress that has been achieved to treat this disease is awesome. HEROES! That is how I describe your staff. Heroes save lives and the Amyloidosis Center saved mine almost 15 years ago. I arrived in Boston in 1999 with little hope and what I thought was very little time. A few days later I left with great hope for survival. My journey through the stem cell transplant process was no fun, but the memories of the people I met will last forever. The staff was compassionate, caring and loving while still being competent, dynamic and state-of-art. I would like to specifically mention the outstanding care provided by Dr. Skinner and Dr. Sanchorawala. Of course, there was also Dr. Seldin. I trusted in him like I would in a brother. I still remember what I told Dr Skinner "Dr. Seldin is the best". The Amyloidosis Center staff became family to me. We can never thank you enough. You will always be my HEROES.

*Frank Nappi*
*Valrico, FL*

## Purple Eyes

My story began with purple eyes. My family are hockey players, so most people just assumed I took a puck in the eye until a biopsy showed I had amyloidosis. Chemotherapy with Velcade proved unsuccessful. For me a decision for a stem cell transplant occurred about 1½ years after my initial diagnosis. It was a much bigger undertaking than I anticipated. The worst part of the process for me was the ice therapy (to think, I used to like snow cones). It helped that I had the most wonderful team at Boston Medical Center. The stem cell transplant team and amyloid doctors are second to none. And the interesting thing is that they are really nice people.



*Ms. Sullivan (center) with Dr. Seldin and Dr. Sanchorawala*

*Diane Sullivan*
*N. Andover, MA* ■

# Research and Training News

**By Lawreen Connors, John Berk, David Seldin**

The Gerry Amyloid Laboratory, directed by Dr. Lawreen Connors, is the epicenter of research on amyloidosis at BU, and also coordinates training of the next generation of amyloid investigators. This month, Yanyan Lu became Dr. Lu, receiving her Ph.D. in biochemistry for mass spectrometric analysis of immunoglobulin light chains in urine and tissues, work mentored by Dr. Cathy Costello. Clarissa Koch and Jacqueline Sikora are also working towards their Ph.D.s; their work is discussed below.

The Gerry Laboratory staff enjoyed having two high school students working in the lab in the summer, Georgina Giampaolo and Hansika Iyer; Hansika is the fourth student from the Catalyst science program at Governors Academy. Richard Wilson, a cardiology fellow, was mentored by Dr. Flora Sam in a study of the effect of doxycycline on cardiomyocyte remodeling in light chain-induced cardiac amyloidosis that was presented at the American Heart Association annual meeting. Visiting from Italy to develop skills as clinical amyloid cardiology researchers, Dr. Francesco Salinaro analyzed strain abnormalities on echocardiography in work mentored by Dr. Rick Ruberg, and Dr. Christine Quarto analyzed echocardiographic changes in patients treated with diflunisal in the international phase III trial.

One of the unanswered questions in the amyloid field is how normal or wild-type transthyretin (TTRwt) can cause cardiac amyloidosis in older patients, in a disease known previously as senile systemic amyloidosis or SSA. Over the past 5 years, with funding from the National Institute on Aging at the NIH, Dr. Lawreen Connors has enrolled more than 100 patients with ATTRwt onto a study to analyze temporal changes clinical, laboratory, and cardiologic data. Data from this study gives us a better understanding of how ATTRwt progresses and will help us to determine what biomarkers present in blood may correlate with disease. Dr. Connors presented her findings at the XIVth International Symposium on Amyloidosis held in Indianapolis this past spring and is preparing a manuscript on this work. Her student Jacqueline Sikora is studying how elements in the TTR gene itself modulate disease in these patients. She has found a genetic variant that appears to protect from the disease, as well as four other variants associated with age of onset and survival. Jackie's work, which will help us to understand why some people are at risk of developing this disease, will soon be published in the journal Human Genetics. In related studies on TTR amyloidosis, post-doctoral fellow Dr. Michael J. Greene is studying how a "chaperone" in the blood called clusterin can work with the drug diflunisal to modulate TTR amyloid fibril formation. In addition, with funding from the E. Rhodes and Leona B. Carpenter Foundation, Dr. Greene will examine the concentrations of more than 360 blood proteins in samples from patients with ATTRwt and other types of amyloid cardiomyopathy, in the hopes of identifying biomarkers that may aid in diagnosis and treatment. Graduate student Clarissa Koch is investigating the response of cardiac cells to amyloidogenic forms of transthyretin. She is testing the toxicity-blocking potential of drugs, such as doxycycline, diflunisal, and kiacta. Clarissa is conducting parallel studies using cardiac cells generated from induced pluripotential stem (iPS) cells derived from blood from our patients, created in collaboration with Dr. George Murphy in the Center for Regenerative Medicine here at BU. In addition, Ms. Koch is characterizing the levels of retinol binding protein, a natural partner of TTR, in patients with ATTR amyloidosis. Some of her work will be published in the proceedings of the XIVth International Symposium on Amyloidosis.

*Dr. Berk (seated front left) and the international investigators for the difluinisal trial celebrating the results*

The end of 2013 heralded the beginning of a new era in TTR amyloid management, with the publication of results from the Diflunisal Trial. This study, headed by Dr. John Berk and conducted by more than 20 investigators at 8 sites around the world, was a phase III double-blind trial to determine if diflunisal, a well-known generic non-steroidal anti-inflammatory medication, would be effective in treating ATTR. The trial was supported by the National Institutes of Health, the Food and Drug Administration, the Boston University Clinical and Translational Sciences Institute, the Young Family Amyloid Research Fund at Boston University, and other Amyloid Center donors. Merck Sharp and Dohme provided the diflunisal pills. This study was based upon the ground-breaking work of our collaborator Dr. Jeffery Kelly at the Scripps Institute in California, who showed that diflunisal stabilizes TTR in the test tube, and postulated it might do the same thing in patients, preventing aggregation of TTR into amyloid. Results of the Diflunisal Trial, published in the Journal of the American Medical Association proved Dr. Kelly's hypothesis to be correct. Diflunisal is remarkably effective in inhibiting the progression of polyneuropathy in patients with familial ATTR amyloidosis. Tafamidis, a proprietary drug marketed in Europe and Japan by Pfizer, has similar properties. We are optimistic that diflunisal, tafamidis, or other TTR stabilizers will also be effective in treating ATTR cardiomyopathy. Ongoing clinical trials will answer this question. We are grateful to patients who have participated or will participate in these important trials.

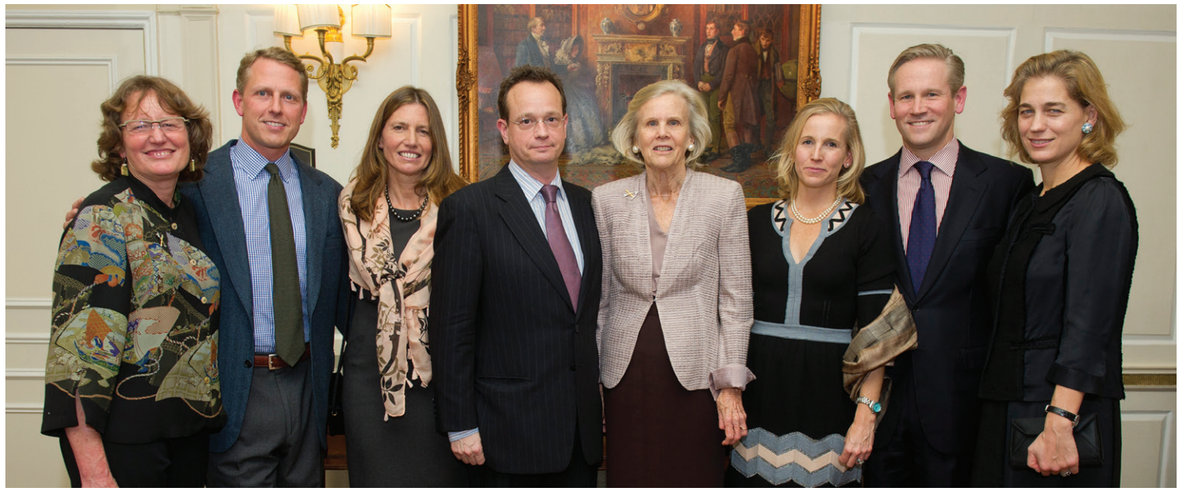
In addition to stabilizing existing TTR protein to prevent amyloid formation, what if you could also prevent synthesis of TTR protein? In theory, this would also slow or prevent development of TTR amyloidosis. In 2014, we now have tools to do that, with TTR gene silencers including anti-sense RNA oligonucleotides developed by ISIS Pharmaceuticals and small intefering RNAs developed by Alnylam Pharmaceuticals. In normal volunteers, both approaches knock down TTR protein levels. Clinical trials are now enrolling patients to learn if this reduces TTR amyloid formation and progression of polyneuropathy. If you are interested in learning more or participating in one of these studies, please contact us.

While light chain (AL) amyloidosis can be

**continued on page 6**

treated with stem cell transplantation and other drugs (see Dr. Sanchorawala's write-up elsewhere in this newsletter), we also hope to develop targeted therapies to block AL fibril formation. Dr. Jennifer Ward has been comparing the effectiveness of different tetracycline-derived antibiotics to disrupt AL amyloid fibrils. Working with Ms. Varuna Shibad, a talented research associate, Dr. Ward has established a method to measure the amount of amyloid present in tissues, to aid in evaluating drug efficacy. In collaboration with Dr. George Murphy in the Center for Regenerative Medicine, Dr. Ward is developing human LC-secreting iPS stem cells that will also be used for drug testing. Using a combination of biophysical and bioinformatic techniques, Dr. Elena Klimtchuk has identified "hot spots" in the light chain variable domains that promote misfolding and fibril formation. Complementing her previous biophysical studies of a role for the constant domain of the light chain in fibril formation, Dr. Tatiana Prokaeva has analyzed mutations in this domain in amyloidogenic light chains. These studies, supported by the Gruss and Wildflower Foundations, were reported at the XIVth International Symposium on Amyloidosis in Indianapolis. Dr. Prokaeva, Brian Spencer, and Haili Cui are also working on project supported by the Institute of Medicine to screen sera obtained from members of the Air Force who served in Vietnam and were exposed to the herbicide "Agent Orange" for abnormal light chains. Agent Orange has been implicated as a cause of multiple myeloma and of AL amyloidosis; the incidence of these diseases in veterans in not known. ■

# THE STEWART CHALLENGE



*The Stewart Family: Diane Stewart, William Patty, Sandi Stewart, Michael Abrams, Eliot Stewart, Eliot Patty, Ian Highet, Lea Highet*

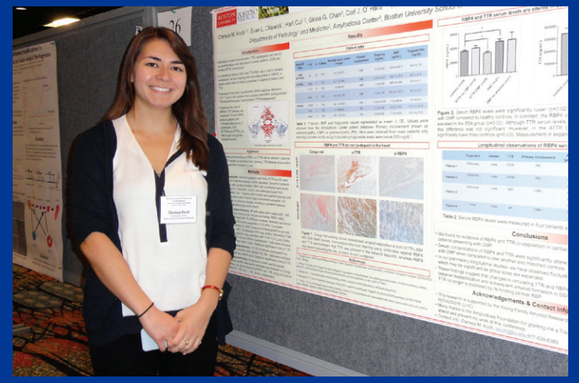
In the Spring Sandi Stewart organized her family and friends to offer a $50,000 Challenge Grant. The Grant was in memory of Sandi's Dad, John Stewart, a longtime patient and advisor to the Center until his death in 2011. The Stewart family and John Stewart's former McKinsey business colleagues generously offered to match gifts to the Center's Endowment Fund up to $50,000. Our endowment fund is maintained by Boston University and provides the Center with the interest on the endowed monies for research on amyloidosis each year. This regular support is critically important to insure sustainability of the Center's activities.

We are pleased to report that nearly as soon as the Challenge went out it was enthusiastically met by you, the family and friends of the Center. Your generous gifts were doubled by the generosity of the Stewarts and our endowment has grown by $100,000.  We are very grateful to the Stewart family and friends and to all of you.



# AMYLOIDOSIS CENTER PHOTOS

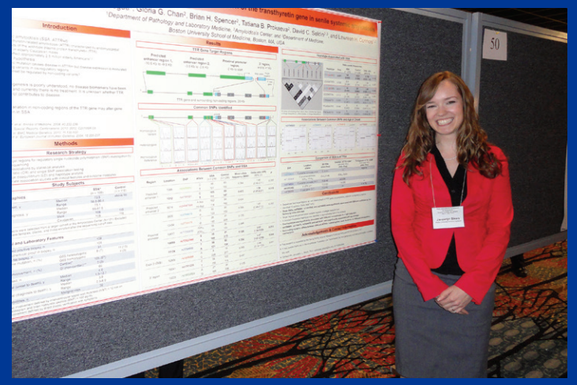
*Cardiology collaborators: Drs. Berk and Ruberg (Boston) with Drs. Salinaro and Perlini (Italy)*



*Graduate student: Ms.Clarrisa Koch at the XIVth International Symposium*

*Drs. Skinner and Merlini at the XIVth International Symposium*

*Boston group at the XIVth International Symposium*



*Graduate student: Ms. Jacqueline Sikora at the XIVth International Symposium*

*Dr. Marc Semigran, MGH collaborator, presenting heart transplant data*

# Amyloidosis Center Donor List 2012-2013

**The Amyloidosis Center at Boston University School of Medicine** is pleased to recognize the generosity of its many donors whose support has assisted us in enhancing and continuing our progress in discovering a cure for amyloidosis. We thank our donors for their ongoing participation and commitment. This donor list recognizes individuals who have made gifts totaling $250 or more to the Amyloidosis Center over 2 years since January 2012. We have made every effort to provide a complete and accurate list. We apologize in advance for any errors that may have been made. While space constraints prevent us from listing the names of donors of gifts under $250, we very sincerely appreciate the support of those many donors.

## Individual Donors

**$100,000 and above**
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Mr. and Mrs. Richard Nathanson
Mrs. Eliot Stewart, Mr. and Mrs. Ian Highet, and Mr. and Mrs. William Patty
Mr. and Mrs. Joseph M. Wikler

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James Hansell Memorial Marathon Run
Friends of Mary Miliano
Mike's Team
Nassau Wings Motor Cycle Club, Inc.
John Tempest Memorial Golf Tournament
University of New Hampshire NH A Capella
Walk For An Angel Fund

# Amyloidosis Center Report

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## Amyloidosis Center

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**Website** www.bu.edu/amyloid


The Amyloidosis Center gratefully accepts financial support for our research and clinical programs from patients, family, and friends.

For more information on bequests and other planned giving options contact us at the address listed above or by phone.

Donations can be made through our website or by mail.

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*2014 is a particularly notable year for us, as it is the 20th anniversary of the first use of high dose chemotherapy and peripheral blood stem cell transplantation for treatment of AL amyloidosis.*

*Hematologist: Dr. Mark Sloan*

*Dr. David Seldin and Ms. Janis Johnson*

*Cardiologist: Dr. Flora Sam*

*Internists: Drs. Katie Bever and Allison Rosenberg*

*Nephrologists: Drs. Andrea Havasi and Lauren Stern*

*Dr. David Seldin addressing guests at the 20th Anniversary Celebration*