

## FROM THE DIRECTOR

December, 2015

### Dear Friends,

This year was sad for us with Dr. David Seldin's death due to cancer in June, but we go forward with the legacy he left us and our mission to develop better treatments and cures for amyloid diseases. Dr. Seldin was part of our group as a hematology/oncology doctor and basic science researcher since 1994, and was the director of the Amyloidosis Center since 2007. We miss his expertise in the direction of our basic research. We miss his guiding hand in the advancement of our stem cell transplant program and the evaluation of the clinical trials we offer. Most of all we miss his gentle nature, his happy laugh, and his warm friendship.

As we go forward, Dr. Vaishali Sanchorawala has been appointed the Associate Director of our Center by Dean Karen Antman of Boston University School of Medicine, and I will serve as Interim Director. Dr. Sanchorawala, a hematologist and oncologist, has been part of our Center since 1994. She was a key physician in developing the highdose chemotherapy and stem cell transplant treatment for AL amyloidosis and is currently the director of the Stem Cell Transplantation Program. She is an active participant in the development of multi-centered treatment clinical trials and internationally recognized as a leader for the treatment of AL amyloidosis.

In this issue, we will highlight the clinical trials that are taking place in our clinic. In the past few years, we have been able to offer patients with AL and ATTR amyloidosis a number of opportunities to participate in a clinical trial. Many trials are undertaken in partnership with pharmaceutical companies. And some of the trials are "investigator initiated", meaning the trial was developed by amyloid doctors to answer a question that was prompted by laboratory data or a clinical finding presented by patients. Please see pages 2-4 for information on our current trials. The research team in the Alan and Sandra Gerry Amyloidosis Laboratory, under the direction of Dr. Lawreen Connors, continues its outstanding work to find clues and answers to why and how misfolded proteins form amyloid fibrils. This year, we are proud to note that one of Dr. Connors' graduate students, Clarissa Koch, received her Ph.D. in amyloid studies and will go to Northwestern University in Chicago for post-doctoral work. For a report on our research activities see page 5.

In Dr. Seldin's memory, we have set up an endowment fund to help support young investigators who are doing research on amyloidosis. Students were close to Dr. Seldin's heart and he recognized the importance of training young scientists to work on amyloid diseases. The endowment is named the "David C. Seldin M.D., Ph.D. Amyloid Research Training Fund". Many of you have already contributed to the Fund and we are very grateful. See the report on pages 8-9.

Two new physicians have joined the amyloid clinical team this year. Dr. Cindy Varga has joined the section of hematology/oncology of Boston Medical Center and will be a consultant for our patients in clinic. Dr. Varga has a special interest in hematologic malignancies and plasma cell dyscrasia including AL amyloidosis and multiple myeloma. Dr. Hassan Yameen is a new amyloid internist joining the team to see patients as they come to the clinic and to guide them through their evaluation.

We thank you for your steadfast and generous support of our Center. We wish you good holidays with family and friends, and hope your next year will be healthy and happy.

Sincerely yours, Marthe Skinner



Dr. Vaishali Sanchorawala



Dr. Lawreen Connors



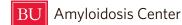
Dr. John Berk





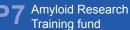


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# CLINICAL TRIALS AT THE

## CLINICAL TRIALS FOR AL AMYLOIDOSIS

By Vaishali Sanchorawala, M.D.

### What is a clinical trial?

A clinical trial uses a device, drug or combination of drugs to find out if it is safe, effective, or possibly better than medications that are currently available for a disease. Clinical trials are often called research studies. These studies follow each patient over the course of time, using study drugs and documenting their safety, effectiveness, as well as other information to better understand either the drug, disease, or both.

### Why should you participate in a clinical trial?

Clinical trials play an important role in the development of new drugs to treat specific diseases, and are vitally important for rare diseases, such as AL amyloidosis. Many of the drugs we see today, were first tested in research studies-including lenalidomide, bortezomib, and even high-dose melphalan and autologous stem cell transplantation! Without the participation of volunteers in these clinical trials, we may have never known the powerful properties of these drugs and their effectiveness. At Boston Medical Center and Boston University Amyloidosis Center, we are proud to have led the way in all of these foundational trials.

We are also excited to be able to offer patients with AL Amyloidosis promising new study drugs, including the proteasome inhibitor Ixazomib first-in-class fibril disrupting monoclonal antibody, only recently available and only in clinical trials.

### **Clinical Trials Team for AL Amyloidosis**

Hematologists: Vaishali Sanchorawala, J. Mark Sloan, and Cindy Varga

Clinical research nurse: Anthony C. Shelton

Clinical research and stem cell transplant nurse practitioner: Dina Brauneis

Stem cell transplant coordinator: Taylor Teschner

Clinical research associates: Stephen Lo, Jill McRae

Clinical trials administrative director: Salli Fennessev



Clinical Trials Team for AL Amyloidosis Front row: Dr. Cindy Varga, Taylor Teschner Back row: Anthony Shelton, Dr. Vaishali Sanchorawala, Salli Fennessey, Dina Brauneis, Dr. Mark Sloan

### Clinical trials available for AL amyloidosis at Boston **Amyloidosis Center**

IRB #H-33808/Velcade Randomized: Phase III Trial of High-Dose Melphalan and Stem Cell Transplantation vs High-Dose Melphalan and Bortezomib and Stem Cell Transplantation in Patients with AL Amyloidosis/ ClinicalTrials.gov Identifier NCT02489500

IRB #H-31082/Pomalidomide: A Phase I/II Trial of Pomalidomide and Dexamethasone in Subjects with Previously-Treated AL Amyloidosis/ ClinicalTrials.gov Identifier: NCT01570387

IRB #H-32790/AMyC 11-MM-02: A Phase I Dose-Escalation Study of Carfilzomib in Patients with Previously-Treated Systemic Light-Chain (AL) Amyloidosis/ClinicalTrials.gov Identifier: NCT01789242

IRB #31928/CUMC: Phase II Study of the Combination of Bendamustine and Dexamethasone in Patients with Relapsed AL Amyloidosis/ClinicalTrials.gov Identifier NCT01222260

WIRB #2012-1122/Millennium C16011: A Phase III, Randomized, Controlled, Open-label, Multicenter, Safet and Efficacy Study of Dexamethasone Plus MLN9708 o Physician's Choice of Treatment Administered to Patien With Relapsed or Refractory Systemic Light Chain (AL) Amyloidosis/ClinicalTrials.gov Identifier NCT01659658

IRB #H-32377/Karmanos #2011-155: Phase I Study of Pomalidomide, Bortezomib, and Dexamethasone (PVD) as First-Line Treatment of AL Amyloidosis or Ligh Chain Deposition Disease/ClinicalTrials.gov Identifier NCT01728259

WIRB #2015-0681/Prothena Neotope CL002: A Phase 3 Randomized, Multicenter, Double-Blind, Placebo Controlled, 2-Arm Efficacy and Safety Study of NEOD00 Plus Standard of Care vs. Placebo Plus Standard of Care in Subjects with Light Chain (AL) Amyloidosis/ ClinicalTrials.gov Identifier NCT02312206

IRB #H-34138/Gilead IdALAMP: A Idelalisib for IgM-Associated AL Amyloidosis (Approval Pending) ClinicalTrials.gov Identifier: Pending

### **Results of Stem Cell Transplant Clinical Trials**

Some of you have participated in several sequential institutional review board-approved clinical trials of high dose chemotherapy and stem cell transplantation during the past 20-years. This experience was recently publish as a correspondence in the journal, Blood. (Long-term outcome of patients with AL amyloidosis treated with high-dose melphalan and stem cell transplantation: 20 year experience. Sanchorawala V, Sun F, Quillen K, Slo JM, Berk JL, Seldin DC.Blood. Nov. 12, 2015 pp 2345-2347. Please let us know if you would like a copy of this landmark paper.

### Words from our patients about Clinical Trials **Participation**

"In August 2015, I completed my second clinical trial through the Amyloidosis Clinic at BMC. Before entering into each trial, I gave the situation careful and thorough consideration. My clinical trials research nurse and doct explained things in depth. They diligently answered eac of my questions in face to face conversations as well as answering all my phone calls and emails. Their care throughout these trials was exemplary. I experienced minimal to no side effects in both trials. My total response by the conclusion of each trial was excellent. Each clinical trial was a positive experience resulting in improved health." Jean Boshco

ety or nts )	"I was officially diagnosed with AL Amyloidosis in January 2005 and was treated with high dose chemotherapy and a stem cell transplant. I had a complete response (hematologic and clinical) at one year. At my second annual evaluation in 2007, I had a biochemical recurrence (elevated free light chains and positive urine immunofixation) without further clinical involvement of any organ system. Since then I have had six different treatments each providing me with partial or complete response followed by rise in free light chains except for the
	last treatment. Now, I have been off treatment with normal free light chains for almost 15 months.
se 001	Of the last six treatments, five have been clinical trials. Each clinical trial raised questions regarding risks and benefits. Study drugs may have more complications as the correct dose and safety parameters are being determined. There are also more frequent lab tests and imaging studies with clinical studies compared with standard treatments.
ıh ng hed	I chose to volunteer for clinical trials for two very important reasons. One is that there are only a small number of approved drugs for treating AL Amyloidosis, and I am able to expand my choices for treatment if I qualify for a study. Second because amyloid is a rare disease, accumulating enough patients for statistical significance of study results is difficult (or even impossible in some cases). I feel, as a patient, I want to contribute to the body of knowledge regarding treatment effectiveness so that in the future other patients with this disease will benefit from the additional choices of drugs." <i>Dr. Harold</i> <i>Forbes</i>
oan is 1	"Thanks to the fact that I chose to participate in the clinical trial, to the dedication of Dr. Sanchorawala and her outstanding team, and to the dedication and thoroughness of my husband as caregiver, I am proud to say that my amyloidosis is in complete response. I feel good and can enjoy my life and my work as a college professor today. I have been back at work full time since fall 2012. I am 61 and do not expect to retire any earlier than age 66. I am very aware that had I not had the excellent treatment I had at Boston Medical Center, I might be either very ill today, or possibly no longer alive." <i>Prof. Katherine Rowan</i>
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### CLINICAL TRIALS AT THE CENTER CONT.

## CLINICAL TRIALS FOR FAMILIAL AMYLOIDOSIS

By John Berk, M.D.

### **ATTR Clinical Trials**

The transthyretin amyloid (ATTR) clinical trials group has grown to include 3 clinical coordinators, a cardiologist (Dr. Ruberg), a neurologist (Dr. Wiesman), and the principal investigator of the Diflunisal Trial (Dr. Berk). Our clinical coordinators. Caitlin Brueckner, Victoria Lattanzi, and Victoria Lazzari, collectively provide years of clinical trials experience from Brown University Medical Center, Boston Medical Center, and industry research activities. Pharmaceutical sponsors repeatedly cite their care of subjects, data collection, and records management as the standard by which other research centers should be measured.

The studies in which the ATTR clinical trials group is actively involved include:

- Doxycycline Study (Boston Medical Center) --Safety and Effect of Doxycycline in Patients With Amyloidosis (NCT01677286) Enrollment closed, data collection complete. Analysis underway.
- Kiacta AA amyloid Study (CT Development of America, Inc) -- Efficacy and Safety Study of KIACTA in Preventing Renal Function Decline in AA Amyloidosis (NCT01215747): enrollment closed, data collection nearing completion. Analysis will not begin until mid-2016 at the earliest.
- Isis phase III ATTR polyneuropathy study (Isis Pharmaceuticals, Inc.) -- Efficacy and Safety of ISIS-TTR Rx in Familial Amyloid Polyneuropathy (NCT01737398): Nearing enrollment completion, data collection ongoing for another ~18 months.
- Alnylam phase III ATTR polyneuropathy study (Alnylam Pharmaceuticals, Inc.) -- APOLLO: The Study of an Investigational Drug, Patisiran (ALN-TTR02), for the Treatment of Transthyretin (TTR)-Mediated Amyloidosis (NCT01960348). Nearing enrollment completion, data collection ongoing for another ~18 months.
- Alnylam phase III ATTR cardiomyopathy study (Alnylam Pharmaceuticals, Inc.) -- ENDEAVOUR: Phase 3 Multicenter Study of Revusiran (ALN-TTRSC) in Patients With Transthyretin (TTR) Mediated Familial Amyloidotic Cardiomyopathy (FAC) (NCT02319005): Recruiting subjects.

Drug development for ATTR disease is in a period of unprecedented growth. In the space of 10 years we have gone from liver transplantation as the only treatment option for familial TTR amyloidosis to the discovery of TTR protein stabilizers (diflunisal/tafamidis) and, now, TTR gene silencing agents.

With your partnership, we can establish multiple medical treatments for people challenged by ATTR amyloid – now and for future generations.

We would be delighted to field questions about these trials and to discuss the candidacy of interested patients for the studies with continuing enrollment. Please contact us if you have any questions.



Familial Amyloidosis Clinical Trials Team Front row: Victoria Lattanzi. Caitlin Brueckner Back row: Dr. Janice Wiesman, Victoria Lazzari, Dr. John Berk, Dr. Frederick Ruberg



Dr. John Berk and Dr. Frederick Ruberg

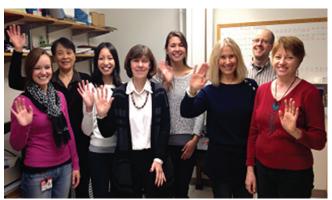


This has been an eventful year with ups and downs for all of us in the Gerry Amyloid Laboratory as members of the Amyloidosis Center team. Personal triumphs have included research presentations, manuscript publications, and graduations. Conversely, we have experienced great sadness in the untimely and tragic death of our director, Dr. David C. Seldin. In his memory, we remain strong and firmly committed to our research studies aimed at advancing the current understanding of amyloidosis. As a group of dedicated research scientists, graduate and postdoctoral students, and laboratory technical assistants, we continue the mission espoused by Dr. Seldin to find better treatments, improve diagnosis, and ultimately develop cures for these devastating amyloid diseases.

Our investigations focus on deciphering the molecular basis of amyloidosis. With the use a variety of model systems and highly technical instrumentation, and vital collaborations with affiliated laboratories at Boston University School of Medicine, we study the way genes and proteins lead to amyloid deposits, how protein aggregation occurs, and how amyloid deposition leads to cell and tissue damage in immunoglobulin light chain (AL) and transthyretin (ATTR) forms of amyloidosis. The model systems we use range from patient-specific stem cells to heart cell lines to animal models. Data from our studies will help us to better define amyloid onset and progression pathways, and direct us to therapeutic strategies that will slow, halt, and eradicate amyloidosis.

Highlights of the past year included graduations in May of Clarissa M. Koch and Gloria Chan. Clarissa, an international student from Amsterdam, received a PhD in Pathology after successfully defending her thesis research entitled, "Characterizing the Effect of Transthyretin Amyloid on the Heart." She showed that cardiac cells, including reprogrammed patient-specific induced pluripotent stem (iPS) cells from patient blood have a toxic response to aggregated forms of TTR and this toxicity can be inhibited with the antibiotic, doxycycline. Gloria, a biochemical research assistant who has worked with Dr. Connors since 2011, received an MS in Bioinformatics. Dr. Michael J. Greene, a former doctoral and post-doctoral trainee in the Gerry Lab, had his work demonstrating that clusterin can modulate TTR amyloid fibril formation published in Biochemistry (http://www.ncbi.nlm.nih. gov/pubmed/25478940). In addition, Jacquelyn Sikora Hansen, a Pathology doctoral graduate student in the lab, had some of her recent genetic studies of ATTRwt published in the journal, Human Genetics (http://www.ncbi. nlm.nih.gov/pubmed/25367359). Dr. Tatiana Prokaeva was invited to give a presentation at the 7th International Symposium: Clinical Applications of Free Light Chain

and Heavy/Light Chain Analysis which was held in Edinburgh, Scotland (April 2015). Lastly, Dr. Connors presented a talk entitled "The Translational Science of Transthyretin-associated Cardiomyopathies - Current Clinical and Basic Science Research" at the American Society for Investigational Pathology/Experimental Biology Meeting held this past March in Boston (https://asip.org/ meetings/2015/).



Gerry Laboratory Team, June 2015 Jacquelyn Sikora Hanson, Dr. Haili Cui, Gloria Chan. Dr. Lawreen Connors, Clarissa Koch, Dr. Tatiana Prokaeva, Brian Spencer, and Dr. Elena Klimtchuk



Drs. Clarissa Koch and Lawreen Connors, May 2015



Drs. Connors, Seldin, and Sanchorawala, June 2014



### Reva Dolobowsky - The "Informed Messenger"

Reva Dolobowsky has been coming each week to the Amyloidosis Clinic, for the past 2 years. She has become a credentialed volunteer at Boston Medical Center. When asked why she volunteers she replied "I come to make it more comfortable and a less stressful place for the patients." She enters the waiting room not knowing what to expect, as the patients change each week. This, she adds, is the exciting part as she has to figure out how to make people comfortable.

The Amyloidosis Clinic has 15-20 patients each week, either for a new or a follow-up evaluation. Reva introduces herself and makes her way around the waiting room, answering questions and chatting with each patient and their family. She explains that she is not a health professional, but her husband is a patient and they went through this process. She answers questions varying from where to eat lunch, dinner, to how to navigate to the different appointments they might have.



Reva Dolobowsky

Reva recalls that the first time she came to the clinic with her husband was "very scary." She remembers being touched by speaking with someone in the waiting room who told her that she would pray for her. Reva said that she made it a point to remind all of her husband's health care providers that he is a regular person and not the medical record number or a disease. It is this sense of humanity that she tries to impart each week to the patients when she chats with them. Each patient has an amazing story about how they found out about their disease and the Amyloidosis Center, but each story is different from the next. Occasionally people will cry, being overcome with a multitude of emotions, and

she tries to be as reassuring as she can. Surprisingly, there have been only a few instances where someone declined to speak with her. "It's like an improv act," Reva says, "each week is different". Her husband has come back to the Amyloidosis Center a number of times. "And some follow-up evaluations", Reva said, "are tougher than others because the feeling in the waiting room is different". She looks around and sees some people chatting while others are looking fearful and clutch the handles of their seats. She thought to herself, "Wouldn't it be nice if there was an icebreaker?" While waiting to see their various physicians having someone to chat with to take their minds off their situation, albeit temporarily, would be a good distraction. This idea was the beginning of her volunteer work in our clinic.

She wanted to give back to the Amyloidosis Center because she is so grateful for the help that we are providing to her husband. While pondering what she could do, she remembered a particular visit to the clinic. She remembers an occasion where someone had a child about 5 or 6 years old with them in the waiting room. This child helped everyone in the waiting room by doing just what children do, he worked the room and was disarming! He casually walked around talking with different people and Reva felt the mood lighten. What a young source of inspiration!

She did not know how the idea would be received. She approached Dr. Vaishali Sanchorawala who supported her idea enthusiastically. And now she is in her second year as a volunteer in the Amyloidosis Clinic. I asked Reva what, if anything, in her background prepared her for this type of service. I found out that she managed a market research consulting company for a number of years. This type of research, focus groups, required her to quickly make a connection with total strangers to get them to open up quickly about various topics. It provided her with the expertise that the basis for her service is built on. She sees her role as a facilitator, helping to share information that she and other patients have discovered while here for their respective evaluations.

She heard the term "informed messenger" a few years back and thinks of herself as our "informed messenger" someone who has experience with the process firsthand and has come to help, inform and comfort others.

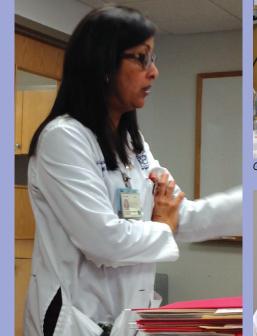


### David C. Seldin, M.D., Ph.D.

Dr. Seldin took special pleasure in working with students and young investigators. He had an extraordinary ability to critique their work respectfully and encourage them to strive for the best. He developed and was the first director of the graduate program in Molecular Medicine in the Division of Graduate Medical Sciences at Boston University, and established courses for graduate students in Cancer Biology and in Diseases of Protein Misfolding. He enjoyed training and mentoring a generation of physicians and post-doctoral and pre-doctoral fellows in the conduct of clinical, laboratory and translational research.

In his memory we have established a fund to support young investigators studying amyloid disease. We are very grateful to so many of you that have contributed. Our immediate goal is to reach \$100,000. We are almost there. As of now, we have reached more than \$70,000 from 160+ donors. Our heartfelt thanks to all of you!







Dr. Vaishali Sanchorawala in clinical meeting

Dr. Cindy Varga

# Amyloid research



## <u>AMYLOIDOSIS</u> CENTER



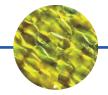
Gloria Chan. Amvloid Laboratorv



Drs. Carl O'Hara and John Berk, Amyloid Laboratory



Dr. Allison Rosenberg



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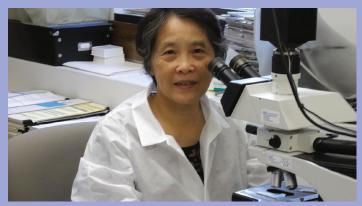
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