



# **Amyloidosis Research Foundation**

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## **2006 ANNUAL REPORT**

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**Our Mission is to support scientific and medical research searching for the cause of, diagnostics and treatments for amyloidosis**

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## Activities

The ARF was successful in recruiting two additional advisors to the Scientific Advisory Board in 2006. Rodney Falk, MD, a cardiologist with a keen interest in cardiac amyloidosis is currently at Harvard Vanguard Associates in Massachusetts. Dr. Falk previously worked at the Boston University Amyloid Treatment and Research Center. He has played a key role in the treatment of cardiac amyloid patients and has written several articles on the subject and continues to be active and involved in research and treatment of amyloidosis.

Jeffery Kelly, PhD was also recruited as an advisor. Dr. Kelly is currently Vice President and Dean of Student Affairs at Scripps Research Institute in La Jolla, CA. Dr. Kelly is a bio-chemist whose group has made many critical discoveries regarding amyloid proteins and their research has found promising treatment potentials that are in clinical trials for a specific type of amyloidosis

The addition of these gentlemen brings much knowledge, experience and other specialties to the Advisory Board.

The foundation saw a change to the Board of Directors appointments. Anne Johns, RN and Rajul Parikh, MD stepped down from their positions in 2006, which led to a number of positions that needed to be filled. Stephen P. Miller and Jeana Rossi-Miller were elected to the board in the spring of 2006. Steve brings business acumen to the board and Jeana brings her educational background. In addition Richard Cwiek and Raymond Comenzo, MD accepted appointments to the board in the fall of 2006. Rick has been involved with the foundation since its inception and has been participatory in safely investing our assets. Dr. Comenzo from Memorial Sloan-Kettering Cancer Center is a practicing physician and active researcher for both amyloidosis and multiple myeloma.

ARF was in attendance at several meetings and symposiums in 2006. The foundation was invited to attend the National Organization for Rare Diseases (NORD) Annual Meeting in Bethesda, MD. The major subject of the meeting was government financial support for rare disease research. The over all tone of the meeting was that the US government's support is not increasing due to the current budget situation, but that there

This meeting attracts clinicians and researchers from around the world, presenting their current findings on the diagnosis and treatment of amyloidosis. The foundation also manned a booth at the American Society of Hematologists Annual Meeting(ASH) in Orlando, FL. Over 20,000 hematologists from around the world attend this 5 day meeting.

### **Research**

The ARF continued with the Junior Research Program in 2006. On the suggestion of the SAB the grant cycle was delayed to coincide with the XIth International Amyloid Symposium in November, 2006. Grant applications became available in October and were also distributed via CD's at the symposium and the American Society of Hematologists Annual Meeting. **Four proposals were submitted and have** been given to the SAB for review, rating and comments. Final approval of award will be discussed and finalized at the February 2007 board meeting.

A new project was initiated this year, Travel Awards for young researchers who were first authors of abstracts submitted and accepted at the XIth International Amyloid Symposium. This was an initiative that was suggested by the SAB which the board approved. The maximum value of these awards was \$1000 each. The criteria for award not only included innovative research proposals, but the targeted audience was for researchers within 5 years of receiving their doctorate degree or completing their clinical fellowship. A total of 3 travel awards were given out to attend the symposium.

ARF continued its support of the graduate student Fellowship at Boston University School of Medicine. This student's project "Cellular Internalization and Response to Amyloidogenic Light Chain" aims to better understand how cells interact with amyloid proteins. The findings were presented at the Keystone Symposium on Protein Folding Disorders in February 2006.

The foundation provided financial support in 2006 to a new project at Memorial Sloan-Kettering Cancer Center. This project's findings have shown that there is a specific protein found on the outside of the cells that cause systemic AL amyloidosis. This protein is then a target for monoclonal antibody therapy. "Monoclonal antibodies are like magic bullets that can destroy their target cells. They attack proteins that stick out like flags on

the surface of cancer cells, and cause the cells to die. Patients with breast cancer and others with lymphoma have benefited from modern monoclonal antibody therapy. In some patients, their cancers have been eliminated, and their lives have been improved and prolonged. Memorial Sloan-Kettering Cancer Center has shown that the protein CD32B has been found on the outside of the cells that cause systemic AL amyloidosis. CD32B then is a target for monoclonal antibody therapy for AL patients and, based on this a clinical trial of monoclonal antibody therapy against CD32B for AL patients is planned for the near future”.

The ARF Board of Directors strives to find and support innovative projects that have a good probability of helping to better understand the mechanisms of the disease and also discover potential treatments for patients.

### **Generous Support**

The ARF relies on private donations to make our work possible. While we do receive some industry grants, our lifeblood is you and your commitment to the mission. We cannot thank you enough for the support you give each year.

In addition to our mail campaign, the foundation is deeply appreciative when named as the memorial for those who have passed due to amyloidosis. There were 58 named memorials in 2006 generating over 750 individual donations. Our condolences and heartfelt sympathy are shared with all who have lost loved ones to this insidious disease.

In 2006 we were benefited by a number of private fundraisers that were held. They included a talent show at a New York University and a scavenger hunt in a community in Vermont. In addition there are a number of individuals who help to spread the word about amyloidosis and solicit funds from their friends and families. Our deepest appreciation goes out to these individuals that organize these benefits.

We value all of our supporters at every level. Each of you makes an important impact on the programs that will help people with amyloidosis.

## Generous Support

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**Finances**

The ARF's fiscal year began January 1, 2006 and ended December 31, 2006.

Carry over from 2005			\$44,999
Income for 2006			
Mail Campaign	\$11,675		
Memorial Donations	\$46,151		
Unsolicited	\$ 2,267		
Volunteer Fundraisers	\$ 4,535		
Gifts-in-kind	\$ 1,837		
Interest	\$ 3,390		
Other	\$ 100	\$69,955	
Expenses for 2006			
Postage	(\$ 1,279)		
Fundraising	(\$ 415)		
Legal	(\$ 100)		
Office Supplies	(\$ 1,747)		
Printing	(\$ 778)		
Web Site	(\$ 615)		
Travel, Mtg. Exp.	(\$ 1,866)		
Conferences	(\$ 1,511)		
Food/Lodging	(\$ 2,113)		
Memberships	(\$ 140)		
Promotions	(\$ 525)		
Transfer fees	(\$ 15)		
Miscellaneous	(\$ 39)	(\$11,124)	\$103,830
Grant Program Expense			(\$12,000)
Travel Award Program			(\$ 2,976)
Funds Available December 31, 2006			\$88,854

## **The Future**

The future of ARF is bright. Relationships with the specialty centers in the United States have been strengthened in 2006. The ARF was also successful in developing relationships with a number of pharmaceutical companies in 2006 and will continue to build these bonds with other companies.

There are plans in place to provide more services to patients and their families to better understand the disease and what their options are, and where the best treatment is available, and over the course of the next year or so ARF will work with the amyloidosis specialists to develop seminars for physicians to attend to learn more about the disease allowing for the chance of early diagnosis to improve.