



Amyloidosis Research Foundation

2007 ANNUAL REPORT

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The mission of the Amyloidosis Foundation is to increase education and an awareness of amyloidosis within the community leading to earlier diagnosis and improved treatment

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Message from the President

2007 has been an exciting year for the foundation and without the support of all of you none of the activities detailed in this report would have been possible. From moving into new offices, expanding our services and staff, and improving the make up of our board of directors, all of the changes move us closer to our **vision of the Amyloidosis Foundation being a leading organization working to care for and cure patients with amyloidosis.** We can not thank all of you enough for your generosity and look forward to your continued support in the future.

Activities

In 2007 the AF was successful in recruiting three new members to the board of directors. They include; Robert Kyle, MD, Isabelle Lousada and Martha Skinner, MD.

Dr. Kyle is Professor of Medicine and Laboratory Medicine at the Mayo Medical School, Rochester, MN. He received his MD degree with distinction from Northwestern University Medical School. Dr. Kyle has published over 380 articles relating to hematology and oncology and another 600 abstracts and editorials. He has also served both as a guest lecturer and as a Visiting Professor throughout the world.

Originally from the UK, Isabelle Lousada, an architect, has worked on architectural design projects throughout Europe, Australia and the United States. With Alsop and Stormer Architects, she managed the team that designed the Peckham Library in London, which won the 2000 Stirling Prize for Best U.K. Building. Ms. Lousada is an amyloid patient in complete remission for over 12 years.

Dr. Skinner is Professor of Medicine at Boston University Medical School and also Director of Special Projects for the Amyloid Treatment and Research Program. As a member of this team Dr. Skinner collaborated on over 300 publications that have been written and published in numerous medical journals on various aspects of amyloidosis.

The addition of these individuals to the board brings the knowledge and understanding of amyloidosis to a higher level, and we welcome them.

AF was in attendance at several meetings and exhibits in 2007. 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 overall tone of the meeting was that the US government's support is not increasing due to the current budget, but that



there is limited grant money available for the non-profit sector to be advocates for their diseases.

AF exhibited at several medical meetings including the American Heart Associations Scientific Session and the American Society of Hematology Annual Meeting. At these meetings AF distributes information on the diagnosis and treatment of the different types of amyloidosis to the physicians in attendance. We also inform the doctors of the various services the AF has to support patients as they struggle with many issues upon being diagnosed with the disease. In the short time since AF started attending these meetings, the number of physicians that visit the booth has increased dramatically. More importantly, the number of physicians that have a familiarity with the disease, it's diagnosis and treatment is growing, especially among the ranks of the younger doctors.

The most important activity that occurred in 2007 was the merge of the Amyloidosis Support Network of Marietta, GA and the Amyloidosis Research Foundation. With the merge of these two organizations the foundations name was changed to the current Amyloidosis Foundation. In merging these two organizations, we blend the respective missions of supporting patients with accurate information, increasing the awareness of the disease in the medical community and supporting basic science and medical research for the disease.

As separate organizations, many accomplishments have been made. The ASN was instrumental in increasing the awareness of the disease amongst the medical community by attending medical conferences, in partnership with NORD, published *The Physician's Guide to Amyloidosis*, and distributed over 30,000 booklets. In addition, ASN published *Hereditary Amyloidosis – Questions and Answers* to fill a void of patient and family literature. ASN developed an excellent website with up to date information on amyloidosis in both English and Spanish. The ARF established a Junior Research Grant Program and awarded over \$100,000 in grants since 2004.

Merged, we become a stronger organization supporting the previous goals and objectives, and going forward we will develop new programs and services. The mission of the foundation is to increase education and awareness of amyloidosis within the community leading to earlier diagnosis and improved treatment. Our vision is to be a leading organization working to care for and cure patients with amyloidosis.

The AF moved the offices in 2007 to our current location in Clarkston, MI. Along with the office move, staff has increased to support our additional services. As part of the office move we were able to



obtain the toll free number 1-877-AMLOID. The staff now includes the President/CEO, an administrative assistant and plans to bring a development director on board in early 2008.

Research

Supporting innovative research for amyloidosis of all types is a key activity of the AF. In the past your support for research into amyloidosis has enabled young doctors to train to become amyloid doctors at Mayo Clinic and Boston University and has helped investigators at those centers to make important new contributions to knowledge about amyloidosis. Your support has enabled investigators at Memorial Sloan-Kettering Cancer Center in New York and at the Medical College of Wisconsin in Milwaukee to develop new ways of understanding the cells that cause amyloidosis and the effects of amyloid on the heart.

This year we awarded a single research grant to a young cardiologist at the Medical College of Wisconsin in Milwaukee. He has presented his findings at both the American Heart Associations Scientific Session and the American College of Cardiologists Annual Meeting.

The AF will continue the grant program concentrating on supporting young researchers and we will work on growing the program to expand our support to larger multi year projects. The AF board of directors strives to find and support innovative projects that have good probability of helping to better understand the mechanisms of the disease leading toward our ultimate goal, a cure for amyloidosis.

Generous Support

The AF is thankful for all the private donations that have been given. These donations make our work possible. These private donations are our lifeblood and we appreciate your commitment to our mission. Many of the private donations are gifts in memory of someone who has recently passed away. Our condolences and heartfelt sympathy are shared with all who have lost loved ones to this menacing disease.

As in the past, the foundation benefited from a number of private fundraisers in 2007. A group of people in New York City have initiated an annual benefit for the foundation. It is held at New York University in Manhattan, and it is planned to be repeated every spring. In addition a Poker Run (motorcycle ride) was held in Nebraska. It was organized by a new widower and friends. These fundraisers are a very important source of income for the foundation, and we greatly appreciate the effort that goes into organizing something of this magnitude.



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We make every attempt to keep this list accurate and apologize if we missed anyone that donated at least \$100 or more.

**Finances**

The AF's fiscal year began January 1, 2007 and ended December 31, 2007

Carry Over from 2006 \$88,854

Income for 2007

Mail Campaign	\$ 5,527	
Memorial Donations	\$53,842	
Unsolicited	\$ 8,349	
Fundraisers	\$55,248	
Gifts in Kind	\$ 6,319	
Grants	\$45,000	
Interest/Dividends	\$ 5,944	\$180,299

Expenses for 2007

Postage	(\$ 896)	
Fundraising	(\$17,739)	
Legal/Accounting	(\$ 2,370)	
Office Supplies	(\$ 1,676)	
Printing	(\$ 2,572)	
Web site	(\$ 490)	
Travel/Mtg Exp	(\$ 3,806)	
Conferences	(\$ 3,223)	
Food/Lodging	(\$ 5,819)	
Memberships	(\$ 100)	
Wages	(\$ 5,982)	
Books/Subscriptions	(\$ 485)	
Occupancy	(\$ 8,441)	
Utilities	(\$ 1,123)	
Insurance	(\$ 643)	
Equipment	(\$ 585)	
Graphic Design	(\$ 1,500)	
Misc. Fees	(\$ 80)	
Unrealized Losses	(\$ 9,882)	
Other	(\$ 636)	(\$ 58,899)
Grant Program Expense		(\$ 30,000)
Awareness Program Expense		(\$ 8,149)

Funds Available December 31, 2007 \$171,035



The Future

In September 2007 a workshop was convened with all the current board members to develop our plans for the future. We concentrated on patient services, research programs, and physician education. These discussions led us to develop our tag line;

Education - Awareness - Support - Research

As a result we have developed as part of our business plan a number of initiatives that will be implemented over the course of the next few years, and we are very excited to begin launching them in 2008. The following is a list for each of the above mentioned areas that we will be working on.

Education - develop continuing education classes for physicians to learn more about amyloidosis, it's diagnosis and treatments to allow for earlier diagnosis of the disease.

Awareness - continue to attend medical meetings for various disciplines such as hematologist, nephrologists, cardiologist to increase awareness of the disease.

Support - develop publications for patients, establish a toll free hot line, free patient teleconferences, and maintain an accurate web site and send out regular e-newsletters and print newsletters with current information, We will also help in making clinical trial information more easily found for the patients.

Research - as we continue to support our current grant program, we will develop a scientific agenda so that we can expand the terms and conditions of the program.

We have set some major goals for the foundation, and for us to meet them successfully your continued support is extremely important. With your generosity we can look forward to the future development of better treatments that are specifically targeted to amyloidosis and lead to our goal of a cure.

On behalf of the board of directors, thank you for your generosity and continued support as we work towards finding a cure for amyloidosis.

Mary E. O'Donnell
President/CEO

