



2007 ANNUAL REPORT



2007 Annual Report

A Message from the President

In 2007, the KDA focused on funding Kennedy's Disease research and providing education and support for those who seek it. There are several major accomplishments to report including:

- Thanks to the generous support of so many, the KDA raised \$55,687 in donations. Several thousand dollars were raised by local and regional sponsored events. Because the KDA is a **totally volunteer organization, 91% of the donations went towards funding Kennedy's Disease research and education.**
- 102 new associates joined the KDA in 2007. We now have 840 active associates located in 35 countries. Of the 840 associates, 539 men and 88 women have the defective chromosomes.
- At the end of the year, the KDA awarded two research grants.
 - **A \$25,000 grant was awarded to Maria Pennuto, Ph.D.** from the National Institute of Health. Dr. Pennuto has spent the past few years investigating the molecular switches on the AR that are involved in the movement of the AR into the nucleus upon addition of hormone. She has discovered that certain chemical changes to the AR seem to reduce the ability of the AR to bind to hormone and thus not enter the nucleus (and cause KD). She has discovered that the exposure of cells to a substance known as IGF-1 can induce these chemical changes to occur to the mutant AR and thus prevent the movement of the AR to the nucleus. Thus, the addition of IGF-1 to a cell with mutant AR appears to prevent the formation of the toxic fragment and thus the cell stays alive. Dr. Pennuto will continue this work by determining if any other chemical changes to the AR may alter its movement to the nucleus and she will also determine if IGF-1 prevents the formation of KD symptoms in a KD mice model. This work could lead to new therapies for KD.
 - **Another \$25,000 grant was awarded to Udai Bhan Pandey, Ph.D.** from the University of Pennsylvania. The proposal by Dr. Pandey and Dr. Paul Taylor continues the work that they did (in part thanks to a previous KDA grant). They previously reported that KD symptoms in a fly model of KD could be reduced by activating another mechanism for destroying the KD in the nucleus, by passing the need for the proteasome. This alternate pathway, known as autophagy, apparently is capable of destroying the toxic fragment. They did this by making the fly over-produce another protein known as HDAC6. By doing this, they were able to demonstrate that the overproduction of HDAC6 did not show cell death despite the presence of the mutant KD. They will now try to continue this work as they attempt to find other proteins that may affect this activity of HDAC6 to stimulate autophagy and thus help prevent the cell death associated with KD.
 - Note: Because of the holidays, the grant checks were not issued until the first week of January.
- In November, the KDA held a three day conference and symposium in Las Vegas. The theme for the conference was "An Eye on the Future." 48 associates and 10 doctors and researchers attended the event. We are hoping that "what was learned in Las Vegas will not stay in Las Vegas."



2007 Annual Report

- The KDA helped sponsor a doctoral researcher to attend the Gordon conference. This bi-annual conference brings together researchers from all over the world that are focused on “Triple Repeat Disorders” including Kennedy's Disease. A member of the KDA board of directors also attended the conference.
- The KDA became a member of the “Alliance for a Stronger FDA.”

This past year I mentioned in a newsletter that **“research just doesn't happen ... it has to be funded by someone.”** The federal government has reduced the funding available for medical research. As a result, research projects for Kennedy's Disease, along with other lower public profile illnesses, are being seriously under-funded. Research is crucial to finding a treatment and possibly a cure for this disease that has affected all of our lives. Over the last three years, the KDA awarded \$125,000 in research grants. This wouldn't have happened without your generous support. Moreover, without the continued efforts of the doctors and researchers, we would not be so close to finding a treatment for Kennedy's Disease. **“Without you, there is no KDA.”**

Once again I want to leave you with my hope and my prayer. With your continued support, I believe we will soon be celebrating the discovery of a treatment and possibly even a cure for Kennedy's Disease.

**“Working together to find a cure ...
for our generation and for our children and our grandchildren”**

A handwritten signature in blue ink that reads "Bruce A. Gaughran".

Bruce A. Gaughran
President

February 22, 2008



2007 Annual Report

FY-07 Statement of Activities

Income	\$ (U.S.)
Donations	\$ 55,687
Conference Registration	12,536
Sales and Other Income	10,556
Total Income	\$ 78,779

Charitable Operations	\$ (U.S.)
Research Grants (See Note 1)	\$ 200
Education and Conferences	16,828
Total Charitable Expenses	\$ 17,028

Operating Expenses	\$ (U.S.)
Total Expenses	\$ 4,883
Gain/(Loss)	\$ 56,868

Net Assets	\$ (U.S.)
Beginning of Period	\$ 49,959
End of Period (See Note 1)	\$ 106,826

- Notes:
- (1) The 2007 grants (\$50,000) were actually funded the first week of January, 2008
 - (2) Complete financial statements are available upon request from the KDA

The Kennedy's Disease Association is a non-profit corporation, incorporated in California on August 21, 2000. We are recognized under United States Internal Revenue Code 501 C3 as a publicly supported organization as described in sections 509 (a) (1) and 170 (b) (1) (A) (vi). Donations are considered tax deductible by the I.R.S. in the United States.



2007 Annual Report

Looking Toward the Future

The KDA's Board of Directors has approved the following goals for 2008:

- Raise \$100,000 in donations
- Fund at least two and possibly three Kennedy's Disease research grants
- Sponsor a KDA conference and symposium in the Baltimore-Washington, DC area in mid-November

We are also planning the following activities:

- Updating our IT plan including the possible adding of a file server
- Represent the KDA at the annual NORD (National Organization for Rare Disorders) Conference in Washington, DC
- Increasing our involvement in and support of NORD and the FDA Alliance
- Increasing the number of professional guests in our KDA chat rooms

The Objectives of the Kennedy's Disease Association

- Sharing information about Kennedy's Disease with those who seek it
- Creating a support system for those living with the disease
- Increasing public awareness of Kennedy's Disease and its effect upon families
- Increasing awareness of Kennedy's Disease in the medical community
- Raising funds for Kennedy's Disease research and education ... with a target of earmarking at least 70% of every donated dollar for Kennedy's Disease research

Kennedy's Disease Association Board of Directors

Bruce A. Gaughran, President

John A. Coakley, Sr., 1st Vice President

Terry Waite, Exec. Dir. & Treasurer

Mike Goynes, Member at Large

J. Murray Williams, Senior V.P. & Secretary

Ron Wiker, 2nd Vice President

Paul DeSchamp, 3rd Vice President

Ed Meyertholen, Member at Large

Honorary Board Member – Susanne Waite, President Emerita



2007 Annual Report

KDA Web Site

The KDA has a comprehensive web site to help share information in a cost-efficient and effective way. The web site is located at www.kennedysdisease.org. We constantly update related information as it becomes available. Please visit the site regularly to see 'What's New'.

KDA Chat Room

The KDA hosts a chat room on **the first and third Saturdays of each month** at 10:30 AM Eastern Time (7:30 Pacific). Doctors, researchers, and other specialists are invited to participate in the chats as featured guests to discuss the latest research, health issues, and quality of life topics. There is a chat for wives, carriers, caretakers, and significant others on **the second Saturday of each month** at 11:00 AM Eastern Time (8:00 Pacific). This chat is not intended to be available for men and no transcripts will be available. A list of upcoming topics and guests is posted on our web site along with transcripts from previous chats.

KDA Discussion Forum

The KDA Discussion Forum is a place to ask questions, express opinions, and post information of interest for others with Kennedy's Disease. The web page for the forum is located at http://www.kennedysdisease.org/disc_forums.html.

Other KDA Services

- Fund Research Grants
- Neurologist Mailers
- Share Research Updates
- Sponsor Educational Conferences
- Scientific Review Board
- Tissue Donation Program
- NORD Membership
- Networking
- Medical History Form
- Wallet Medical Condition Card
- Associates Database
- Clinical Research Trial Support
- Liaison with Research Organizations

Please direct all correspondence, questions, and donations to:

The Kennedy's Disease Association
P.O. Box 1105
Coarsegold, CA 93614

Telephone: 1-559-658-5950

Email: info@kennedysdisease.org

Web Site: www.kennedysdisease.org