



2008 ANNUAL REPORT



2008 Annual Report

A Message from the President

A couple of times a week we are contacted by someone seeking to find answers to their questions about the disease or asking for some other type of help or support. Whether it be professionals, individuals with Kennedy's Disease, or their family and friends; they need answers and do not know where to go for help. We are often told that the Kennedy's Disease Association (KDA) is the greatest resource they have found for information on the disease. While this makes us proud, it also makes us want to do more and to be an even greater resource for those seeking information and support.

In 2008 there were several major accomplishments to report:

- Even in these difficult economic times, **the KDA raised \$43,350 in donations** thanks to the generosity of our supporters. Because the KDA is a totally volunteer organization, **over 94% of the association's income went towards funding Kennedy's Disease research (86%) and education/conferences (8%).**
- **The KDA now has 905 active associates located in 41 countries.** 65 new associates joined the KDA in 2008. Of the 905 associates, 570 men (63%) and 96 women (11%) have the defective gene.
- In November, 2008, **the KDA awarded a research grant for \$50,000 to Heather L. Montie, Ph.D.,** of Thomas Jefferson University. The KDA grant will allow Dr. Montie to continue her studies on the role of acetylation of the Androgen Receptor and to determine if blocking this process does reduce the death of cells with the mutant gene.
- Also in November, **the KDA held a three-day conference and research symposium in Washington, DC.** 45 associates and 17 doctors and researchers attended the event.
- We changed Internet service providers. We can now reach Asian countries that our previous host server could not. **The web site averaged nearly 3,000 page views a month last year.**
- **The KDA Discussion Forum averaged over 200 page views per day.** The views were up significantly from previous years.

As mentioned above, the KDA is experiencing the repercussions of the economic downturn like most everyone else in the world. Donations are down, people are less willing to commit their support (time and money), and operating costs continue to rise. Fortunately, because of the generous support of our associates, their families, neighbors, and friends, as well as our suppliers, the KDA has been able to award \$175,000 in research grants over the last four years and a total of \$225,000 since its inception. Without the continued efforts of many dedicated researchers around the world, we would not be so close to finding a treatment for Kennedy's Disease. We truly thank all of you for supporting the association and our cause. Your kindness and generosity is greatly appreciated.

**“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



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FY-08 Statement of Activities

Income	\$ (U.S.)
Donations	\$ 43,350
Conference Registration	10,930
Sales and Other Income	3,763
Total Income	\$ 58,043

Charitable Operations	\$ (U.S.)
Research Grants <i>(See Note 1)</i>	\$ 100,000
Education and Conferences	4,542
Total Charitable Expenses	\$ 104,542

Operating Expenses	\$ (U.S.)
Total Expenses	\$ 4,193
Gain/(Loss)	\$ (50,692)

Net Assets	\$ (U.S.)
Beginning of Period	\$ 106,532
End of Period <i>(See Note 1)</i>	\$ 55,840

Notes:

- (1) The 2007 research grants totaling \$50,000 were actually funded the first week of January, 2008. Another \$50,000 was awarded in November, 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.



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Looking Toward the Future

The KDA's Board of Directors has approved the following goals for 2009:

- Raise a minimum of \$50,000 in donations
- Fund one and possibly two Kennedy's Disease research grants
- Upgrade the KDA I.T. infrastructure by adding an off-site file server and remote back-up service
- Potentially sponsor a KDA conference and research symposium in the Chicago area in the fourth quarter

We are also planning the following activities:

- Help sponsor a doctoral researcher's attendance at 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
- Have a member of the KDA board of directors attend the Gordon Conference
- Increase the Association's focus on fund raising and other volunteer activities
- Represent the KDA at the annual NORD (National Organization for Rare Disorders) Conference in Washington, DC
- Increase KDA involvement in and support of NORD and the FDA Alliance
- Increase the frequency of professional guests in our KDA chat rooms
- Encourage the use of regional conferences

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., Vice President
Terry Waite, Exec. Dir. & Treasurer
Mike Goynes, Member at Large

J. Murray Williams, Senior V.P.
Ron Wiker, Vice President
Paul DeSchamp, Corporate Secretary
Ed Meyertholen, Member at Large

Honorary Board Member – Susanne Waite, President Emerita



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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 often invited to participate in the chats as featured guests to discuss the latest research, health issues, and quality of life topics. On **the second Saturday of each month** at 11:00 AM Eastern Time (8:00 Pacific) there is a chat for "Wives and Significant Others." A list of upcoming topics and guests are posted on our web site and on the KDA Community Calendar 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 living 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 and other related affiliations
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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

Note: All donations are considered tax deductible by the United States Internal Revenue Service