



2009 ANNUAL REPORT



2009 Annual Report

A Message from the President

In last year's report, I commented on the KDA's ability to provide information to individuals seeking answers concerning Kennedy's Disease. While we believe we are still the best resource for information related to Kennedy's Disease, there is still more that can be done to get the message out there. Several times a week, we are contacted by those seeking answers to their questions and concerns. Fortunately, when we do not have the answer, one of the members of our Scientific Review Board (SRB) comes through. Their support, along with the support of our board members and volunteers, makes my job a lot easier.

In 2009, there were several major accomplishments to report:

- It was another tough year for donations. In November and December, however, many of our associates as well as other supporters came through. **The KDA finished the year raising \$52,484 in donations.**
- In November, the **KDA awarded three research grants totally \$55,000.** This year's recipients are **Parsa Kazemi-Esfarjani**, B.Sc., Ph.D. at the University of California, San Diego, **Maria Pennuto**, Ph.D. at the Italian Institute of Technology, Genova, Italy, and **Lenore Beitel**, Ph.D. at the SMBD-Jewish General Hospital, Montreal, Quebec, Canada. The KDA grant will allow these three researchers to continue their studies focused on the mutant Androgen Receptor gene.
- **The KDA now has 908 associates located in 40 countries.** 537 of the associates are men with the defective gene (59%) and 103 are carriers (11%). We also have 76 doctors and researchers who are registered with the KDA.
- Last spring we **moved the KDA's electronic records to an offsite server** for more secure records retention. Daily offsite backups are now part of our new I.T. infrastructure.
- We **published three KDA Newsletters.** Based upon feedback from our associates, the newsletters were informative and the best we have published.
- **The KDA Discussion Forum continues to be a useful resource. The forum had 127,000 page views in 2009 (347 views per day).** Page views were up 87% from 2008.

I started a web log (blog) this last fall called "[Living with Kennedy's Disease](#)." I have published over one hundred articles, many concerning personal stories of living with the disease. There are also articles on Kennedy's Disease research, technology, and interviews with researchers.

As mentioned above, even with tough economic conditions, KDA supporters have continued to donate. Because of your continued support, we have awarded \$230,000 in research grants over the last five years and a total of \$280,000 in grants since the program's inception. Because of the continued efforts of many dedicated researchers around the world, **those of us living with Kennedy's Disease are much closer to seeing a treatment for the disease.** We are truly thankful for all of you who support the association, our cause, and Kennedy's Disease research. Your kindness and generosity is greatly appreciated.

**"Working together to find a cure ...
for our generation, and for our children and our grandchildren"**

Bruce A. Gaughran



2009 Annual Report

FY-09 Statement of Activities

Income	\$ (U.S.)
Donations	\$ 52,484
Conference Registration	0
Sales and Other Income	760
Total Income	\$ 53,244

Charitable Operations	\$ (U.S.)
Research Grants <i>(See Notes 1 & 2)</i>	\$ 68,827
Education and Conferences <i>(See Note 3)</i>	21,132
Total Charitable Expenses	\$ 89,959

Operating Expenses	\$ (U.S.)
Total Expenses	\$ 6,433
Gain/(Loss)	\$ (23,666)

Net Assets	\$ (U.S.)
Beginning of Period <i>(See Note 4)</i>	\$ 80,635
End of Period	\$ 37,487

Notes:

- (1) The U. of PA. returned \$11,058 - the unused portion of a 2007 research grant.
- (2) \$24,884 in 2008 grant funds were returned and reissued in 2009 (when a researcher moved from one institution to another)
- (3) \$19,482 of 2008 conference expenses were paid in 2009.
- (4) 2008 Net Assets were changed from \$55,850 to \$80,635 (see Note 2) after adjustments were made in early 2009 by the tax consultant.
- (5) 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.



2009 Annual Report

Looking Toward the Future

The KDA's Board of Directors has approved the following goals for 2010:

- Raise a minimum of \$60,000 in donations
- Fund one or more Kennedy's Disease research grants
- Sponsor a KDA conference and research symposium in San Diego, CA in November

We are also planning the following activities:

- Publish three KDA newsletters
- 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
- Improve KDA chat room participation by increasing the number of guests and having more focused topics

The Objectives of the Kennedy's Disease Association

- Raise funds with a target of earmarking at least 90% of every donated dollar for Kennedy's Disease research and education
- Share information about Kennedy's Disease with those who seek it
- Create a support system for those living with the disease
- Increase public awareness of Kennedy's Disease and its effect upon families
- Increase awareness of Kennedy's Disease in the medical community

Kennedy's Disease Association Board of Directors

Bruce A. Gaughran, President
John A. Coakley, Sr., Vice President
Terry Waite, Exec. Dir. & Treasurer
Mike Goynes, Vice President

J. Murray Williams, Senior V.P.
Paul DeSchamp, Corporate Secretary
Lou Tudor, Member at Large
Ed Meyertholen, Member at Large

Honorary Board Member – Susanne Waite, President Emerita



2009 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 an open 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, Carriers and Significant Others”** only.

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
-

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