



2010 ANNUAL REPORT



The Kennedy's Disease Association
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A Message from the President

It has been another busy year for the KDA. More people are using our website as well as the KDA forum to seek out answers to their questions concerning Kennedy's Disease. The KDA also celebrated its ten-year anniversary.

In this report I feel there is one important message that all of our supporters need to hear: **the KDA remains an all-volunteer organization.** We remain this way because our focus is on Kennedy's Disease research, education and support. Over the last four years, **90¢ of every dollar spent by the KDA went towards Kennedy's Disease research (80¢) and education (10¢).**

In 2010 there were several accomplishments to report:

- Donations were better than 2009 and we thank you for your support. The **KDA finished the year raising \$60,905 in donations.**
- The **results of the dustasteride and leuprorelin clinical trials were published** and we continue to field questions from those interested in the results.
- The KDA Conference and Education Symposium was held last November in San Diego. 69 attended the conference, including 17 researchers.
- **The KDA now has 977 associates located in 42 countries.** 575 of the associates are men with the defective gene (59%) and 108 are carriers (11%). We also have 76 doctors and researchers who are registered with the KDA.
- In early October work began on the new KDA website. Zebra Graphic Designs led the development work with the support from several associates.
- We **published three KDA Newsletters.**
- The **KDA Discussion Forum continues to be a useful resource for those seeking answers to their questions about Kennedy's Disease. The forum had 154,000 page views** this last year (an average of 422 views per day). Page views were up 21% from 2009.
- Twenty-three (23) regular chat room sessions were held including four with researchers as guests.

The Scientific Review Board did not feel that the research projects submitted for funding were strong enough this year. For this reason, no research grants were awarded in 2010.

My web log (blog) "[Living with Kennedy's Disease](#)" also continues to grow. Pages views for the blog have grown to over 7,600 a month. I published 164 articles in 2010; many concerning Kennedy's Disease research, technology, and support systems.

Researchers around the world continue to focus on finding a treatment for Kennedy's Disease. The KDA helps support this research through grants and our conferences. A total of \$280,000 in grants has been awarded to date. 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

2010 Statement of Activities

Income	\$ (U.S.)
Donations	\$ 60,905
Conference Registration	10,600
Sales and Other Income	6,622
Total Income	\$ 78,127

Charitable Operations	\$ (U.S.)
Research Grants	\$ 0
Education and Conferences	8,884
Total Charitable Expenses	\$ 8,884

Operating Expenses	\$ (U.S.)
Total Expenses	\$ 5,135
Gain/(Loss) (See Note 1)	\$ 64,308

Net Assets	\$ (U.S.)
Beginning of Period (See Note 1)	\$ 37,487
End of Period (See Note 1)	\$ 101,795

Notes:

- (1) Includes \$200 credit on previous expenses.
- (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.

Looking Toward the Future

The KDA's Board of Directors has approved the following goals for 2011:

- Raise a minimum of \$60,000 in donations
- Fund two or more Kennedy's Disease research grants
- Provide 2-4 scholarships for Kennedy's Disease researchers to the Gordon Conference on CAG repeat diseases
- Launch the [new KDA website](#) (*completed February 2011*)
- Sponsor a KDA conference and research symposium in the Baltimore-Washington, DC area in November
- Support the NIH clinical trial on exercise

We are also planning the following activities:

- Publish three KDA newsletters
- Change internet service provider (*completed February 2011*)
- 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 dollar spent 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

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