



# 2011 ANNUAL REPORT

**The Kennedy's Disease Association**  
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## *A Message from the President*

2011 was another great year for the KDA thanks to the support of our Board of Directors, committee volunteers, the Scientific Review Board and the Kennedy's Disease research community. Before we review our accomplishments, I need to stress two points:

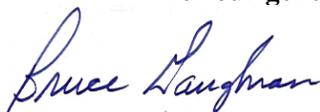
1. **You are not alone.** We are here to help and look forward to hearing from you.
2. The KDA is an **all-volunteer organization.** We remain this way because our focus is on Kennedy's Disease research, education and providing support. Over the last five years, **90¢ of every dollar** spent by the KDA went towards **Kennedy's Disease research (80¢) and education (10¢).**

In 2011 there were several accomplishments to report:

- We **launched the [new KDA website](#)** in February and it drew a record number of readers this past year.
- We **received \$64,908 in donations.** Thank you for your continued support.
- The **KDA awarded \$65,000 in research grants:**
  - Masahisa Katsuno, M.D. – Ph.D., Nagoya University Graduate School of Medicine, was awarded \$25,000. Proposal: Elucidation of neuronal death signaling pathways and development of disease-modifying therapies for Kennedy's disease
  - Elise Kikis, Ph. D., Northwestern University, was awarded \$20,000. Proposal: Modeling SBMA: from understanding proteotoxicity to identifying therapeutics
  - Sara Parodi, Ph.D., Department of Neuroscience and Brain Technologies, Genoa, Italy, was awarded \$20,000. Proposal: Identification of PKA signaling as a new therapeutic approach for SBMA
  - **\$345,000 in research grants have been awarded** to date.
- We **funded two research trainee scholarships** to attend the Gordon Conference.
- In October the first annual **KDA Golf Scramble** was held in Houston, Texas. Thanks to a team of volunteers, the KDA raised \$14,600.
- The **KDA Conference and Education Symposium** was held last November in Bowie, Maryland. 55 attended the conference, including 19 researchers.
- The second edition of the **KDA Cookbook was published** thanks to the efforts of our Fund Raising Committee. KDA muscle shirts and polo shirts were also added to the [KDA Store](#).
- The KDA now has **1,031 associates located in 43 countries** of which 860 are active. We also have 77 doctors and researchers who are registered with the KDA.
- We **published a spring and fall Newsletter.**
- **Susanne Waite was a finalist** in the Energizer "Keep Going - Hall of Fame" contest raising Kennedy's Disease awareness. With this recognition came a donation of \$1,000.
- The "[Living with Kennedy's Disease](#)" blog and [KDA Forum](#) continue to be strong performers in regards to activity and comments. Page-views for the blog averaged 7-10,000 per month while the forum averaged a remarkable 23-30,000 page-views per month.

We are truly thankful for all of you who support the association, our cause, and Kennedy's Disease research. Your kindness and generosity are greatly appreciated.

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



Bruce A. Gaughran

## 2011 Statement of Activities

Income	\$ (U.S.)
<b>Donations</b>	\$ 44,679
<b>Golf Scramble</b>	14,600
<b>Conference Registration</b>	9,193
<b>Sales and Other Income</b> <i>(See Note 1)</i>	11,843
<b>Total Income</b>	<b>\$ 80,315</b>

Charitable Operations	\$ (U.S.)
<b>Research Grants</b>	\$ 65,187
<b>Education and Conferences</b>	14,218
<b>Total Charitable Expenses</b>	<b>\$ 79,405</b>

Operating Expenses	\$ (U.S.)
<b>Operating Expenses</b>	\$ 3,523
<b>Website Development Costs</b>	3,787
<b>Total Expenses</b>	<b>\$ 7,310</b>

<b>Gain/(Loss)</b>	<b>\$ (6,400)</b>

Net Assets	\$ (U.S.)
<b>Beginning of Period</b>	<b>\$ 101,817</b>
<b>End of Period</b> <i>(See Note 1 &amp; 2)</i>	<b>\$ 76,183</b>

**Notes:**

- (1) Includes \$6,214 credit from the return of an unused portion of a 2009 grant.
- (2) \$4,000 has been set aside in a separate bank account to be used for set-up costs for the 2012 golf scramble.
- (3) Complete financial statements are available upon request from the KDA.

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*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 2012:

- Raise a minimum of \$65,000 in donations
- Fund two or more Kennedy's Disease research grants
- Sponsor a KDA conference and research symposium in the New Orleans area in November
- Support the proposed NIH clinical trials

We are also planning the following activities:

- Publish two KDA newsletters
- Represent the KDA at the annual NORD (National Organization for Rare Disorders) Conference in Washington, DC
- Continue to remain involved in and support of NORD and the FDA Alliance
- Improve KDA chat room participation in the Pac Rim and Europe by adding two un-hosted chats on the third Saturday of each month

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### *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

### *Our Mission*

**To help find a treatment or cure for Kennedy's Disease**

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### *2012 Board of Directors*

Bruce A. Gaughran, President  
John A. Coakley, Sr., Vice President  
Mike Goynes, Vice President  
Ed Meyertholen, Member at Large

Terry Waite, Exec. Dir. & Treasurer  
Paul DeSchamp, Corporate Secretary  
Lou Tudor, Member at Large  
Sean Blasko, Member at Large

Honorary Board Member – Susanne Waite, President Emerita