



2012 ANNUAL REPORT

The Kennedy's Disease Association
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A Message from the President

2012 was another challenging year for the KDA, but thanks to the support of our Board of Directors, its volunteers, the Scientific Review Board and the Kennedy's Disease research community, it was another successful one. Before we review our accomplishments, I need to stress two points:

1. The KDA is an **all-volunteer organization**. We remain this way because our focus is on Kennedy's Disease research, education and providing support to all individuals whose lives are affected by Kennedy's Disease.
2. Over the last seven years, **89¢ of every dollar** spent by the KDA **went towards Kennedy's Disease research (69¢) and education (20¢)**. Note: The Scientific Review Board recommends what grants we should fund and the amount funded to each grantee.

In 2012 there were several accomplishments to report:

- **We received almost \$80,000 in donations.** Thank you for your continued support.
- The **KDA awarded a \$25,000 research grant to Jamie A. Johansen, Ph.D.**, Central Michigan University, Mount Pleasant, MI. Her proposal: "Mechanisms of anti-androgen treatment in SBMA mice muscles."
 - **\$370,000 in research grants have been awarded** since the KDA's inception.
- Last fall the second annual **KDA Golf Scramble** was held in Houston, Texas. Thanks to a team of volunteers they were able to raise over \$20,000 in donations.
- The **KDA Conference and Education Symposium** was held in October in New Orleans. 55 attended the conference, including 22 researchers.
- A major milestone was reached this last summer when the KDA website had its one millionth visitor. The website averages 50-60,000 visitors each month.
- The KDA now has **1,195 registered associates located in 43 countries** of which 950 are active. 82 of these associates are doctors and researchers.
- The KDA supported the development of a KDA Forum for those living with KD in Great Britain.
- The KDA established a **chat room schedule** that will encourage greater participation for those living in Europe and the Pac Rim.
- We **published a spring and fall Newsletter** thanks to board members and volunteers.
- Bruce Gaughran, Association President for the last seven years, resigned at the end of the year. Mr. Gaughran will continue to serve on the board as well as maintain and update the KDA website.
- 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 7,000 per month while the forum averaged a remarkable 27,500 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”**

Ed Meyertholen
2013 President

2012 Statement of Activities

Income	\$ (U.S.)
Donations	\$ 58,234
Golf Scramble <i>(See Note 1)</i>	21,228
Conference Registration	7,511
Sales and Other Income	298
Total Income	\$ 87,271

Charitable Operations	\$ (U.S.)
Research Grants	\$ 25,000
Education and Conferences	20,611
Total Charitable Expenses	\$ 45,611

Other Expenses	\$ (U.S.)
Operating Expenses	\$ 9,309
Golf Fundraising Expenses	1,370
KDA Store – Inventory purchase <i>(See Note 2)</i>	1,916
Total Expenses	\$ 12,595

Gain/(Loss)	\$ 29,065
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Net Assets	\$ (U.S.)
Beginning of Period	\$ 95,748
End of Period	\$ 124,813

Notes:

- (1) \$5,000 has been set aside in a separate bank account to be used for set-up costs for the 2013 fund raisers.
- (2) Restocking of the KDA Store with cups and shirts.
- (3) Revised 2011 EOY Net Assets (Original assets shown = \$76,561)
- (4) 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 2013:

- Raise a minimum of \$70,000 in donations.
- Provide funding for up to three Kennedy's Disease Association research grants.
- Sponsor a KDA conference and research symposium in San Diego, California in the fall of 2013
- Fund three research scholarships to the Gordon Conference for CAG repeat disorders.

We are also planning the following activities:

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

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

2013 KDA Officers and Board of Directors

Ed Meyertholen, President

John A. Coakley, Sr., Vice President

Mike Goynes, Vice President

Bruce Gaughran, Member

Jameson Parker, Member

Robert Behymer, Member

Terry Waite, Exec. Dir. & Treasurer

Paul DeSchamp, Corporate Secretary

Lou Tudor, Vice President

Sean Blasko, Member

Andrew Cassar, Member

Honorary Board Member – Susanne Waite, President Emerita