



# 2013 ANNUAL REPORT

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

2013 was a successful year for the KDA, thanks to the support of our Board of Directors, its volunteers, the Scientific Review Board and the Kennedy's Disease research community. I need to stress three 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 course of the last eleven years, **90¢ of every dollar** spent by the KDA **went toward Kennedy's Disease research (80¢) and education (10¢)**. Note: The Scientific Review Board recommends which grants to fund and the amount funded to each grantee.
3. **\$470,000 in research grants have been awarded** since 2003.

### **There were several accomplishments to report for 2013:**

- **We received a little over \$136,000 in donations.** Approximately 16% of this amount, \$22,500, was from four foundations and Google Matching Gifts. Thank you for your continued support.
- **The KDA awarded \$100,000 in research grants in 2013.** \$50,000 was awarded to Heather Montie, Ph.D., Philadelphia College of Osteo Medicine, Philadelphia, PA, and \$50,000 To ARMGO Pharma, Inc.
- Major fundraising drives coordinated by volunteers included:
  - The third annual **KDA Golf Scramble** was held last fall in Houston, Texas. Thanks to a team of volunteers, they were able to raise over \$37,000 in donations and netted over \$23,000 after expenses.
  - The first annual **Queen Anne's Race** was held last spring in Cooksville, MD. Thanks to a team of volunteers, the event netted over \$13,000.
- The **KDA Conference and Education Symposium** was held in November in San Diego. 55 attended the conference, including 22 researchers.
- The KDA now has **over 1,200 registered Associates located in 46 countries**, of which over 1,000 are active. 92 of these Associates are doctors and researchers.
- We **published a Spring and a Winter Newsletter** thanks to Board members and volunteers.

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”**



John Coakley, Sr.  
2014 President

## 2013 Statement of Activities

Income	\$ (U.S.)
<b>Donations</b>	\$ 87,305
<b>Golf Scramble</b>	23,279
<b>Queen Anne Race</b> <i>(See Note 1)</i>	13,604
<b>Conference Registration</b>	12,073
<b>Sales and Other Income</b>	292
<b>Total Income</b>	<b>\$ 136,553</b>

Charitable Operations	\$ (U.S.)
<b>Research Grants</b>	\$ 100,000
<b>Education and Conferences</b>	16,390
<b>Total Charitable Expenses</b>	<b>\$ 116,390</b>

Other Expenses	\$ (U.S.)
<b>Operating Expenses</b>	\$ 4,228
<b>Other Misc. Expenses</b>	0
<b>Total Expenses</b>	<b>\$ 4,228</b>

<b>Gain/(Loss)</b>	<b>\$ 15,935</b>
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Net Assets	\$ (U.S.)
<b>Beginning of Period</b> <i>(See Note 2)</i>	<b>\$ 132,548</b>
<b>End of Period</b>	<b>\$ 148,483</b>

**Notes:**

- (1) \$4,000 has been set aside in a separate bank account to be used for set-up costs for the 2014 fundraiser.
- (2) Revised 2012 EOY Net Assets (Original assets shown = \$124,813)
- (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(c)(3) 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 2014:

- 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 the Baltimore, MD area in the fall of 2014.

We are also planning the following activities:

- Publish two KDA newsletters
- Improve the KDA website by upgrading to the latest secure software, update information on research and clinical trials, create a greater level of security for our associates, and emphasize the 'KDA Family' theme.

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### ***The Mission 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 (80¢) and Education (10¢)
- 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 Goal***

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

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### ***2014 KDA Officers and Board of Directors***

John A. Coakley, Sr, President  
Lou Tudor, Senior Vice President  
Mike Goynes, Vice President  
Ed Meyertholen, Member  
Maria Montie, Member

Terry Waite, Exec. Dir. & Treasurer  
Paul DeSchamp, Corporate Secretary  
Andrew Cassar, Member  
Jameson Parker, Member

#### ***Honorary Board Members:***

Susanne Waite

Bruce Gaughran

**Legal Council:** Sean Blasko