



# 2014 ANNUAL REPORT

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

2014 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 want 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 twelve 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. **\$570,000 in research grants have been awarded** since 2003.

### **There were several accomplishments to report for 2014:**

- **We received a little over \$161,000 in donations.** Approximately \$20,000 of this amount was from various foundations. Thank you for your continued support.
- **The KDA awarded \$100,000 in research grants in 2014.** \$50,000 was awarded to Anna Pluciennik, Ph.D, Thomas Jefferson University, Philadelphia, PA, and \$50,000 to Helen Cristina Miranda, postdoctoral researcher, La Spada Lab.
- **Major Fundraising Drives** coordinated by volunteers included:
  - The fourth annual KDA Golf Scramble was held last fall in Houston, Texas. Thanks to a team of volunteers, led by Ed Noack, they were able to raise over \$41,000 in donations and netted almost \$30,000 after expenses.
  - The 2nd annual Queen Anne's Race was held last spring in Cooksville, MD. Thanks to a team of volunteers, led by Sarah Kawa, the event netted over \$9,000.
  - Bob Tudor completed a hand cycle marathon in West Palm Beach, FL, and raised over \$10,000.
  - Jason Cooper raised \$8,000 by putting together a golf fundraiser in central NY.
- The **KDA Conference and Education Symposium** was held in November in Alexandria, VA. A record number attended the conference and raised more than \$35,000.
- 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 also sent single sheet **Monthly Reminders**.

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”**

Lou Tudor for  
John Coakley, Sr.  
2014 President

## 2014 Statement of Activities

Income	\$ (U.S.)
Donations	\$ 89,003
Golf Scramble	29,750
Queen Anne Race (See Note 1)	9,082
Bob Tudor's Hand Cycle Marathon	10,090
Jason Cooper Golf Fundraiser	8,000
Conference Registration	15,355
Sales and Other Income	212
<b>Total Income</b>	<b>\$ 161,492</b>

Charitable Operations	\$ (U.S.)
Research Grants	\$ 100,000
Education and Conferences	13,364
<b>Total Charitable Expenses</b>	<b>\$ 113,364</b>

Other Expenses	\$ (U.S.)
Operating Expenses	\$ 7,154
Other Misc. Expenses	0
<b>Total Expenses</b>	<b>\$ 7,154</b>

<b>Gain/(Loss)</b>	<b>\$ 40,974</b>

**Notes:**

- (1) \$4,000 has been set aside in a separate bank account to be used for set-up costs for the 2015 fundraiser.
- (2) 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 2015:

- 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 Chicago, IL, area in the fall of 2015.

We are also planning the following activities:

- Publish two KDA newsletters.
- Improve the KDA website by continuing to upgrade 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

### ***2015 KDA Officers and Board of Directors***

Lou Tudor, President  
Mike Goynes, Vice President  
Andrew Cassar, Vice President.  
Terry Waite, Exec. Dir. & Treasurer  
Paul DeSchamp, Corporate Secretary

Ed Meyertholen, Member  
Maria Montie, Member  
Jameson Parker, Member  
Ron Moffett, Member  
Louise Goforth, Member

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

Susanne Waite, Bruce Gaughran, John A. Coakley, Sr. **Legal Council:** Sean Blasko