



2015 ANNUAL REPORT

The Kennedy's Disease Association
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A Message from the President

2015 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 twelve years, **90¢ of every dollar** spent by the KDA **went toward Kennedy's Disease research (81¢) and education (9¢)**. Note: The Scientific Review Board recommends which grants to fund and the amount funded to each grantee.
3. **\$670,000 in research grants have been awarded** since 2003.

There were several accomplishments to report for 2015:

- **We received over \$175,000 in donations.** Approximately \$39,000 of this amount, was from various foundations. Thank you for your continued support.
- The **KDA awarded \$100,000 in research grants in 2015.** \$50,000 was awarded to Dr. Miltiadis Paliouras and Dr Lenore Beitel, assistant professors at McGill University and \$50,000 to Dr Constanza Cortes, post doctoral researcher at the Al LaSpada lab at the University of California-San Diego.
- **Major Fundraising Drives** coordinated by volunteers included:
 - The fifth 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 \$40,000 in donations and netted almost \$27,000 after expenses.
 - The 3rd 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 \$14,000.
 - Jason Cooper raised \$9,000 by putting together a golf fundraiser in central NY.
 - Led by Heather Montie, the 1st Ed Montie Race to Cure Kennedy's Disease raised \$1,749.
 - Students of the University of Sioux Falls sponsored a fundraiser for the KDA by selling Chapstick during the semester and raised over \$1,100.
- The KDA **Conference and Education Symposium** was held in October in Chicago, IL. It was another record year for the conference and more than \$50,000 was raised!
- The KDA has now over 1,000 registered associates located in over 40 countries.
- We published a Spring and Winter newsletter in addition to monthly one page updates. The input is done by Board members and Association 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”**

Lou Tudor
2016 President

2015 Statement of Activities

Income	\$	(U.S.)
Donations & Other Contributions	\$	122,537
Golf Scramble		26,918
Queen Anne Race (See Note 1)		14,144
Jason Cooper Golf Fundraiser		9,000
Ed Montie 5k Race		1,749
Conference Registration		10,180
Sales and Other Income		1,480
Total Income	\$	186,008

Charitable Operations	\$	(U.S.)
Research Grants	\$	100,000
Education and Conferences		21,871
Total Charitable Expenses	\$	121,871

Other Expenses	\$	(U.S.)
Operating Expenses	\$	4,871
Other Misc. Expenses		0
Total Expenses	\$	4,871

Gain/(Loss)	\$	59,266

Notes:

- (1) \$1,000 has been set aside in a separate bank account to be used for set-up costs for the 2016 fundraiser.
- (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(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 2016:

- 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 San Diego, CA area in November 2016.

We are also planning the following activities:

- Publish two KDA newsletters and monthly one page updates.
- Continue to update the KDA website with information on research and clinical trials, create a greater level of security software for our associates, and emphasize the 'KDA Family' theme.

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 (81¢) and Education (9¢)
- 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

2016 KDA Officers and Board of Directors

Lou Tudor, President
Andrew Cassar, Vice President
Paul DeSchamp, Corporate Secretary
Maria Montie, Treasurer

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

Retired Board members who continue to assist:
Bruce Gaughran, Mike Goynes, John A. Coakley, Sr.