2016 ANNUAL REPORT

The Kennedy's Disease Association
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A Message from the President

2016 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 would like to emphasize 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 13 years, **92¢ of every dollar** spent by the KDA **went toward Kennedy's Disease research** (84¢) **and education** (8¢). Note: The Scientific Review Board recommends which grants to fund and the amount funded to each grantee.
3. **$820,000 in research grants have been awarded** since 2003.

There were several accomplishments to report for 2016:

- **We received over $240,000 in donations**. Approximately $107,500 of this amount, was from various foundations. Thank you for your continued support.
- The **KDA awarded $150,000 in research grants in 2016, the most ever awarded in one year.**
  - $50,000 was awarded to Dr. Bilal Malik through professor Linda Greensmith's lab, UCL Institute of Neurology, UK, "Targeting pathways of disease in Spinal Bulbar and Muscular Atrophy (SBMA)";
  - $50,000 to Dr. Janghoo Lim, Yale University School of Medicine, "The role of VCP in the pathogenesis of Kennedy's Disease";
  - $50,000 to Manuela Basso, Ph.D. Assistant Professor, Laboratory of Transcriptional Neurobiology, Centre for Integrative Biology, University of Trento, Italy, "Insights into the molecular pathology of SBMA targeting PRMT6 to attenuate the disease."
- **Major Fundraising Drives** coordinated by volunteers included:
  - The fifth annual KDA Golf Scramble held last fall in Houston, Texas. Thanks to a team of volunteers, led by Ed Noack, they were able to raise over $37,000 in donations and netted almost $25,000 after expenses.
  - Led by Heather Montie, the 2nd Ed Montie Race to Cure Kennedy's Disease raised over $4,500.
- The KDA **Conference and Education Symposium** was held in November in San Diego, CA. It was another record year for the conference and more than $123,000 was raised!
- The KDA has now over 1,000 registered associates located in over 40 countries. 133 of these associates are doctors and researchers.
- 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

2016 Statement of Activities

Income	$	(U.S.)
Donations & Other Contributions	$	209,570
Texas Golf Scramble		24,895
Ed Montie 5k Race		4,569
Other Fundraisers		1,087
Unspent Grant Funds Returned (from 2015)		1,221
Conference Registration		15,670
Sales and Other Income		1,958
Total Income	**$**	**258,970**

Charitable Operations	$	(U.S.)
Research Grants	$	150,000
Education and Conference		9,817
Total Charitable Expenses	**$**	**159,817**

Other Expenses	$	(U.S.)
Operating Expenses	$	4,653
Other Misc. Expenses		0
Total Expenses	**$**	**4,653**

Gain/(Loss)	**$**	**94,500**

Notes:
(1) 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 Internal Revenue Service in the United States.

Looking Toward the Future

The KDA's Board of Directors has approved the following goals for 2017:

- Raise a minimum of $100,000 in donations.
- Provide funding for at least three research grants of $50,000 each.
- Sponsor a KDA conference and educational symposium in the Washington D.C. area in November 2017.

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

2017 KDA Officers and Board of Directors

Andrew Cassar, President
David Yelton, Corporate Secretary
Maria Montie, Treasurer
Lou Tudor, Member
Jameson Parker, Member
Louise Goforth, Member
Ron Moffett, Member
Todd Allen, Member

Retired Board members who continue to assist:
Bruce Gaughran, Mike Goynes, Ed Meyertholen