Kennedy's Disease
ASSOCIATION

2017 ANNUAL REPORT

The Kennedy's Disease Association
P.O. Box 1105
Coarsegold, CA 93614
Telephone: 1-855-KD-ASSOC

(855-532-7762) or (734) 288-5580
Email: info@kennedysdisease.org
Web Site: www.kennedysdisease.org

A Message from the President

2017 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** (85¢) **and education** (7¢). Note: The Scientific Review Board recommends which grants to fund and the amount funded to each grantee.
3. **$1,019,000 in research grants have been awarded** since 2003.

There were several accomplishments to report for 2017:

- **We received over $325,000 in donations**. Thank you everyone for your continued support!
- The **KDA awarded $199,000 in research grants in 2017, the most ever awarded in one year.**
  - $50,000 was awarded to Anna Pluciennik, Ph.D., Thomas Jefferson University, "Targeting AR toxicity in SBMA by modulation of USP7 activity";
  - $50,000 to Xia Feng, Ph.D., National Institute of Neurological Disorders and Stroke, National Institute of Health, "Identification of New Polyglutamine-Specific Mutant AR-Interacting Proteins in SBMA Motor Neurons";
  - $33,000 to Laura Bott, Ph.D., Postdoctoral Fellow, Molecular Biosciences, Northwestern University, "Transcellular regulation of the proteostasis network in Kennedy's disease";
  - $33,000 to Carlo Rinaldi, MD, Ph.D., University of Oxford, "One gene, many proteins: investigating the role of AR isoform 2 as a therapeutic target for SBMA";
  - $33,000 to Thomas M. Durcan, Ph.D., Assistant Professor, Montreal Neurological Institute, McGill University, "The use of induced stem cells and microfluidics for developing new assays to identify new therapies for Kennedy's disease."
- **Major Fundraising Drives** coordinated by volunteers included:
  - The 6th annual KDA Golf Scramble held last fall in Houston, Texas. Thanks to a team of volunteers, led by Ed Noack, they were able to net almost $39,000 after expenses.
  - Led by Heather Montie, the 3rd Ed Montie 5k Race raised approximately $10,000.
- The KDA **Conference and Education Symposium** was held in October in Alexandria, VA. It was another great year for attendance and more than $39,000 was raised!
- 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.

Andrew Cassar
2017 President

2017 Statement of Activities

Income	$	(U.S.)
Donations & Other Contributions	$	238,229
Texas Golf Scramble		38,847
DimSum		25,025
Ed Montie 5k Race		10,270
Other Fundraisers		11,780
Unspent Grant Funds Returned		1,561
Conference Registration		12,825
Sales and Other Income		2,670
Total Income	**$**	**341,207**

Charitable Operations	$	(U.S.)
Research Grants	$	199,000
Education and Conference		16,833
Total Charitable Expenses	**$**	**215,833**

Other Expenses	$	(U.S.)
Operating Expenses	$	7,482
Total Other Expenses	**$**	**7,482**

Gain/(Loss)	**$**	**117,892**

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 2018:

- 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 San Diego area in October/November 2018.

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 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 Goal

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

2017 KDA Officers and Board of Directors

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

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