2018 ANNUAL REPORT

The Kennedy’s Disease Association
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A Message from the Board of Directors

2018 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. Highlights include:

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 14 years, **93¢ of every dollar** received is spent by the KDA on **Kennedy's Disease research and education** . Note: The Scientific Review Board recommends which grants to fund and the amount funded to each grantee.
3. **$1,219,000 in research grants have been awarded** since 2003.

There were several accomplishments to report for 2018:

- **We received over $170,000 in donations**. Thank you everyone for your continued support!
- The **KDA awarded $200,000 in research grants in 2018, $50,000 each was awarded to:**
    - **Helen Cristina Miranda**, Assistant Professor Case Western Reserve University Department of Genetics and Genome Sciences "Using SBMA patient derived stem cells to investigate differential AR gene expression regulation in affected cell types.";
    - **Riccardo Cristofani**, PhD Dipartimento di Scienze Farmacologiche e Biomolecolari (DiSFeB) Università degli Studi di Milano "Selective translation of androgen receptor isoform A to prevent polyQ mediated toxicity in Kennedy's Disease.";
    - **Laura Tosatto**, PhD Institute of Biophysics, National Council of Research, Unit of Trento Italy "Role of Ser96 phosphorylation in AR pathogenesis."
    - **Marco Pirazzini**, Ph.D Neurotoxins, Neurodegeneration and Regeneration Lab University of Padova Dept. of Biomedical Sciences "Investigating the role of the Excitation-Contraction-Coupling machinery in SBMA muscle pathology."
- **Major Fundraising Drives** coordinated by volunteers included:
    - The seventh annual KDA Golf Scramble held Houston, Texas. Thanks to a team of volunteers, led by Ed Noack, this year's event provided approximately $31,000 after expenses.
    - Led by Heather Montie, the 4th Ed Montie Race to Cure Kennedy's Disease raised $14,500.
    - Dim Sum Give Some event held for the second year and again contributed $25,000 for KD research.
    - The KDA **Conference and Education Symposium** was again held in San Diego CA. and raised almost $17,000!

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"**

2018 Statement of Activities

Income	**$**	**(U.S.)**
Donations & Other Contributions	$	92,393
Texas Golf Scramble		31,632
Dim Sum Give Some		25,000
Ed Montie 5k Race		14,500
Other Fundraisers		5,923
Conference Registration		12,055
Sales and Other Income		1,704
Total Income	**$**	183,207

Charitable Operations	**$**	**(U.S.)**
Research Grants	$	200,000
Education and Conference		12,324
Total Charitable Expenses	**$**	**212,324**

Other Expenses	**$**	**(U.S.)**
Operating Expenses	$	4,396
Total Other Expenses	**$**	**4,396**

Gain/(Loss)	**$**	**(33,513)**

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 2019:

- Raise a minimum of $200,000 in donations.
- Provide grant funding of $200,000 or more.
- Sponsor a KDA conference and educational symposium in October/November 2019.

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

2018 KDA Officers and Board of Directors

Andrew Cassar, President
David Yelton, Secretary
Maria Montie, Treasurer
Ron Moffett, Member
Steven Rittmaster, Member

Jameson Parker, Vice President
Louise Goforth, Member
Todd Allen, Member
Kathy Thompson, Member

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