Kennedy's
Disease
Association

2019 ANNUAL REPORT

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

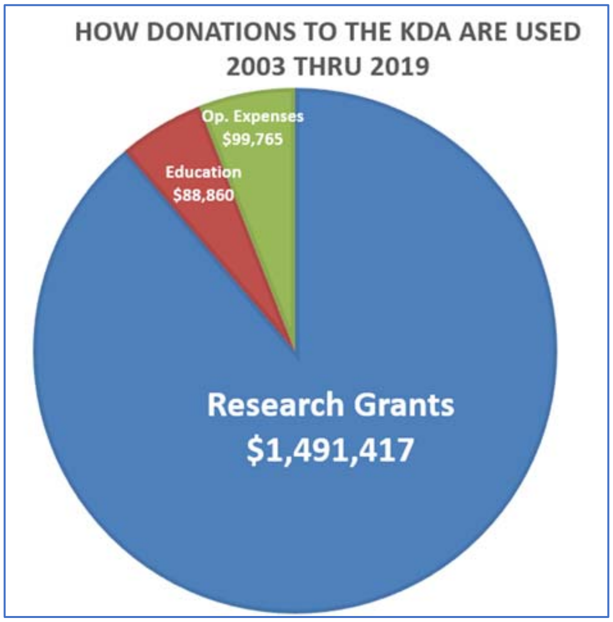
(855-532-7762) or (734) 288-5580
Email: info@kennedysdisease.org
Web Site: www.kennedysdisease.org

A Message from the Board of Directors

We are happy to report that 2019 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.

From 2003 to November 2019 the KDA has awarded a total $1,491,417 in research grants to help find a cure or treatment for Kennedy's Disease. Over the course of the last 16 years, **over 94¢ of every dollar received by the KDA is spent on Kennedy's Disease research and education**. This is only possible because the KDA is an all-volunteer organization, including the board of directors and everyone who engages in fundraising and our day-to-day operations.

This small group of volunteers who operate the KDA are all people impacted by Kennedy's Disease and include men with KD and carriers of KD, caretakers, parents and children, family and friends. We all give our time and talents to help fulfill the mission of the KDA - to inform, support, educate, fund research, and find a treatment and cure for Kennedy's Disease.



We need your help! If you would like to contribute to the mission of the KDA, we encourage you to contact us.

Note: The Scientific Review Board recommends which grants to fund and the amount funded to each grantee.

Accomplishments for 2019:

We received $172,700 in donations through the generous donation and fundraisers conducted by our members and supporters. Thank you everyone for your continued support!

This year, five research grants were awarded totaling $276,250. This is the most money the KDA has ever awarded to research in a single year. Award recipients were:

- **Kentaro Sahashi - Award $51,250** - Understanding of early-stage defects in SBMA by allele-targeted therapeutics.
- **Eric Anderson and Emanuela Zuccaro - Award $50,000** - Exploring the contribution of the function of mutant androgen receptor in the pathogenesis of SBMA
- **Bilal Malik - Award $50,000** - Investigating disease pathways and novel therapeutic targets in Spinal and Bulbar Muscular Atrophy.
- **Heather Montie - Award $75,000** - Generation of a high throughput in vivo assayto test potentials therapeutics for SBMA.
- **Wooi Fang and Catheryn Lim - Award $50,000** - Epigenetic signatures as novel non-invasive blood-based biomarkers for Spinal bulbar muscular atrophy or Kennedy's disease

The KDA also supported the work of the National Institutes of Health by helping with the collection of DNA samples for a KD study to identify genetic markers related to the onset and severity of symptoms in KD.

Major Fundraising Drives coordinated by volunteers included:

- The eighth annual KDA Golf Scramble held in Houston, Texas. Thanks to a team of volunteers, led by Ed Noack and Louis Goforth, this year's event provided approximately $29,400.
- The 5th annual Ed Montie Race to Cure Kennedy's Disease, led by PhD researcher, Heather Montie, raised $29,940, a record for their event more than doubling last year's total!
- Almost $94,000 came to the KDA through various donations, including personal Facebook and Go Fund Me event donations.
- The 19th annual KDA Conference and Education Symposium, "Fun in the Sun and Living Well with KD", was held in Orlando, FL and raised over $14,400 for research had the highest total attendance of any conference ever organized by the KDA. It is the first time we held our conference at a different location than the Neurological Society's annual conference.

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"**

2019 Statement of Activities

Income	**$ (U.S.)**
Donations & Other Contributions	$ 109,697
Texas Golf Scramble	29,402
Ed Montie 5k Race	29,940
Other Fundraisers	1,440
Conference Registration	20,075
Sales and Other Income	2,209
Total Income	**$ 192,763**

Research and Education	
Research Grants (net of prior unused grant funds)	$ 277,417
Education and Conference	23,264
Total Research and Education	**$ 300,681**

Other Expenses	
Operating Expenses	$ 8,636
Total Other Expenses	**$ 8,636**

Gain/Loss	**$ (116,554)**

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 2020:

- Raise a minimum of $200,000 in donations.
- Provide grant funding of $150,000 or more.
- Sponsor a KDA conference and educational symposium in the fall of 2020.

We are also planning the following activities:

- Publish seasonal KDA email updates on what is happening in the world of Kennedy's Disease. This includes information about fundraisers, research, the annual conference, and other information that supports the KD community.
- 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

2019 KDA Officers and Board of Directors

Maria Montie, President and Treasurer
David Yelton, Secretary
Todd Allen, Member
Steven Rittmaster, Member

Jameson Parker, Vice President
Kathy Thompson, Member
Ron Moffett, Member

Retired Board members who continue to assist:
Ed Meyertholen (Scientific Review Board – Patient Liaison)

In Memory

Bruce Alan Gaughran, age 72, passed away at home on October 24, 2019. He was the KDA president for eight years and made the KDA what it is today. He also authored several books and the Living with Kennedy's Disease Blog which continues to be a wealth of information. He was a veteran and leaves behind an amazing legacy.