Kennedy's
Disease
Association

2020 ANNUAL REPORT

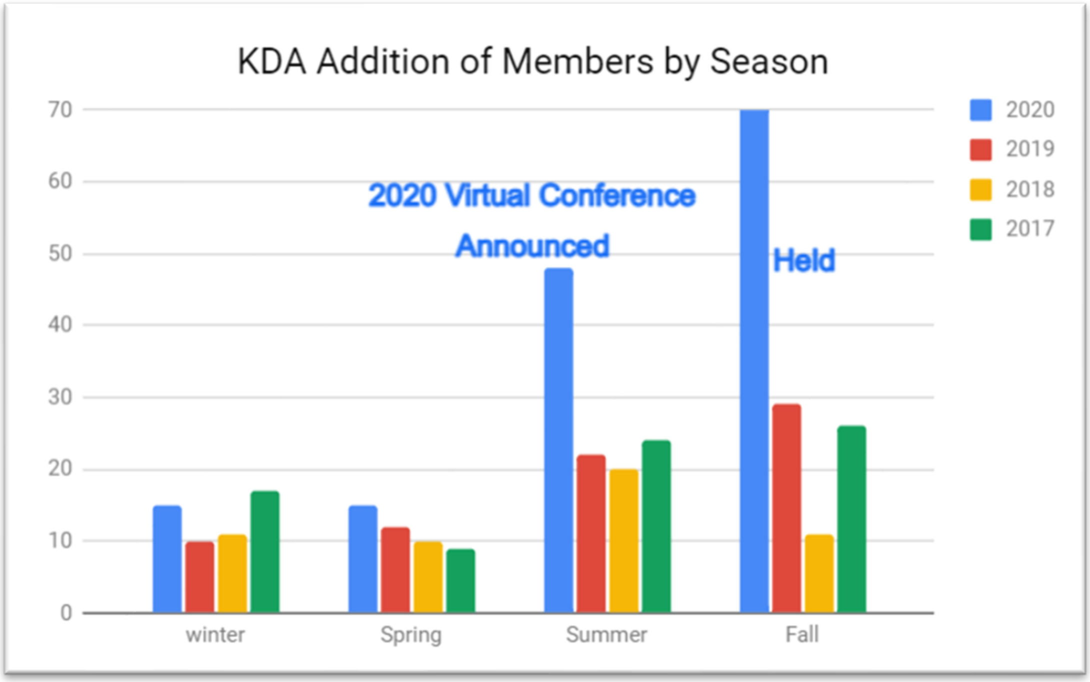
The Kennedy's Disease Association
P.O. Box 1105
Coarsegold, CA 93614
Telephone: 1-855-KD-ASSOC

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

A Message from the Board of Directors

We all experienced a most unusual year with the Covid-19 virus sending most of our lives into retreat. And though widespread quarantining stopped many in-person fundraising efforts and prevented the annual physical gathering of our community, we are thrilled to report that the KDA had the most growth it has ever experienced. And with this growth has come more awareness of Kennedy's Disease, more funding and more people than ever working toward a cure!

Going to a virtual and free conference resulted in unprecedented growth for the KDA. A typical, in person, conference usually has approximately 100 people register. For the 2020 conference, "Moving Forward Together" we had 252 registrations! Typically, we add around 25 new KDA members per season. With the announcement and holding of the 2020 virtual conference we experienced more than double the normal growth of new members. Going forward, a virtual offering will always be a part of all future conferences.



We are amazed at how the KD community has come together to provide more funding for research. Even though many of the major fundraising efforts of years past could not be held due to the Covid pandemic, the community gave extra resulting in donations totaling over $195,000. We passed all that money onto promising research projects to help understand the mechanisms of KD to find a treatment or cure.

Accomplishments for 2020

Despite a global pandemic of Covid-19, the KDA soldiered forward with your help and support. The following is a review of what happened with the KDA this year.

- Annual Conference: KDA joins forces with KD-UK in order to host its first ever virtual conference and breaks a record with over 250 attendees!
- Fund Research: KDA commits $150,000 to fund research on finding a treatment or cure for Kennedy's Disease.
- New Website: KDA reveals its new website with a sleek design aimed at making is easier to find information and provide support.
- Provided content and updated social media sites connected to Kennedy’s Disease.
- Started Developing a Patient Registry: The KDA has joined forces with members of the National Institutes of Health to define the requirements and ways to host a Kennedy's Disease Registry with the aim to aid world-wide researcher efforts for finding a treatment or cure.
- Support of Research: KDA helps NIH-supported research survey to examine impact of COVID-19 on rare diseases community.
- Published seasonal KDA email updates on what is happening in the world of Kennedy’s Disease and information on how KD patients are in the “high risk” category as it relates to Covid-19.
    - Regular KDA website updates with information on research and clinical trials.

Not bad for a group of volunteers who, just like you, have been impacted by Kennedy's Disease. We have committed to inform, support educate, fund research, and find a cure for KD and we need your continued support! ***As we welcome in 2021, consider giving the KDA your time and money. Together, we can continue to fight the good fight!***

Thank you everyone for your continued support! 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”

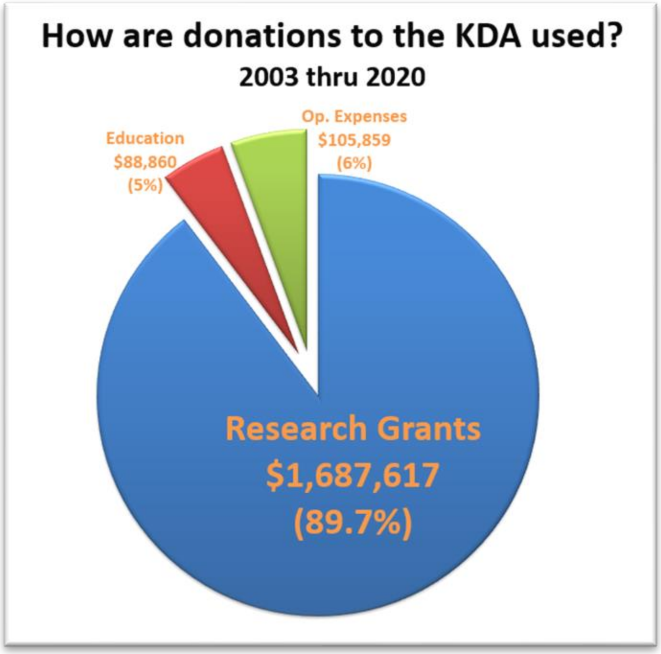
2020* KDA Awards Grants

A summary of all research projects is provided on our website: https://kennedysdisease.org/research/research-grants

Grants totaling $196,200 to the following SBMA researchers.

- Dr. Gerry Pfeffer (University of Calgary)
    - Characterizing the high prevalence and founder effects for Kennedy's disease in Indigenous peoples of western Canada
- Antonella Falconieri, PhD (University of Padova)
    - Targeting the interaction of poly-Q expanded AR receptor with pVHL to ameliorate SBMA
- Manuela Basso, PhD (University of Trento)
    - A drug repurposing strategy to inhibit AR transcriptional coactivators as a therapeutic approach in SBMA
- Mariarita Galbiatti, PhD (University of Milan)
    - Unveiling regenerative and metabolic features of SBMA muscle cells to identify new therapeutic targets

From 2003 to November 2020 the KDA has awarded a total $1,687,617 in research grants to help find a cure or treatment for Kennedy's Disease. Over the course of the last 17 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, caregivers, 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 to the KDA board which grants to fund and the amount funded to each grantee.

**** Due to delays caused by the Covid-19 pandemic the 2020 awards were officially awarded and announced in 2021.***

There will be additional research awards announced in 2021 by Oct/Nov totaling up to an additional $200,000

2020 Statement of Activities

Income	$ (U.S.)
Direct Donations to the KDA	114,151
Dim Sum Give Sum (held in 2019, given in 2020)	35,100
Facebook	19,304
In Memory/Honor	7,143
Misc Fundraisers	7,327
Conference Registration/Donations	10,285
Sales and Other Income	1,000
Total Income	$195,754

Charitable Operations	$ (U.S.)
Research Grants	196,200
Conference Costs	0
Total Charitable Expenses	$196,200

Other Expenses	$ (U.S.)
Operating Expenses	6,094
Total Other Expenses	$6,094

Gain/(Loss)	**$ (10,340)**

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 2021.

We will continue to:

- Raise money to give to research and support our cause (a goal of $200,000).
- Provide grant funding of $200,000 with at least one multi-year grant to support sustained research.
- Sponsor a virtual KDA conference and educational symposium in the fall of 2021.
- Support the efforts of the NIH groups that are dedicated to understanding KD and finding a cure or treatment for KD.
- 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.

In addition, we also look to:

- Establish an online patient registry for men and women who are diagnosed with KD to enter diagnosis information and long-term health status.
- Seek new sources of funding, including but not limited to foundations aimed at helping people with rare diseases.
- Expand the talent pool of the KDA volunteers (board members and/or leaders) to include people who
  - broaden the social media reach of the KDA
  - lead Zoom sessions for different groups with the KDA
  - specialize in supporting fundraising efforts
- Continue and expand our working relationships with counterpart advocacy groups in the UK, Australia, Italy, and other countries.

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

2020 KDA Officers and Board of Directors

Maria Montie, President and Treasurer
Jameson Parker, Vice President
David Yelton, Secretary
Kathy Thompson, Member
Todd Allen, Member
Ron Moffett, Member
Steven Rittmaster, Member

Retired Board members who continue to assist:
Ed Meyertholen, Patient Advocate to the Scientific Review Board