



## OUR MISSION

inform, support, educate,  
fund research, and find a  
cure for Kennedy's Disease

## KDA Loses Two Key Contributors

2023 ended on a sad note for KDA with the loss of two of our most active and valued members. Both these men dedicated their lives to supporting KDA and KD patients, and made lasting contributions to our association. As we mourn their loss, we will honor David's and Bob's memories by dedicating our association to work even harder to find a cure for Kennedy's Disease.

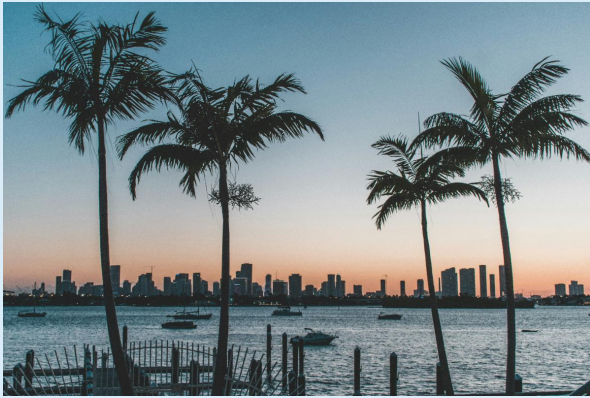


**David Yelton**, KDA Treasurer and Board member, died on December 18, age 70, from complications resulting from a bad fall. David was very active in the KDA since his initial diagnosis. (A “professional volunteer,” David was also a founding board member of Interfaith Hospitality Network of Warren County, now known as Family Promise of Warren County.) He served on the KDA Board for many years as Secretary and, most recently, as Treasurer where he applied the accounting, auditing, and management skills honed during his career at NCR Corporation and Duke Energy to maintaining KDA’s financial records. His insights helped KDA achieve its highest-ever funding levels, providing the funds for more than \$430,000 in grants and fellowships in 2023.



**Bob Borden**, long-time KD patient and KDA volunteer, died suddenly on November 2, age 67. Diagnosed with KD at 29, Bob focused on a non-physical career in environmental engineering. After earning a PhD at Rice University, he became a professor at N.C. State University where he invented processes that are now the most widely used technologies in the world for remediating groundwater contamination. Bob was also a committed KDA volunteer. In 2023 alone, he edited the KDA newsletter, developed “one-pagers” or short reference guides for KD patients and doctors, established a link between KDA and the Muscular Dystrophy Association, and revised the Wikipedia pages on Kennedy’s Disease and the KDA.

2024 - KDA Conference and 25th Anniversary



The KDA returns to the warm and accessible city of Orlando, Florida.

Join us for the KDA's FIRST WEEKEND conference!

We will get together, share information, and hear from the experts on Kennedy's Disease.

The [Rosen Plaza](#) is again our venue. Our first trip there in 2019 was the most attended KDA conference ever!

Save the date and let's get together to celebrate the beginning of KDA's 25th year.

## International Kennedy's Disease Conference - 2023

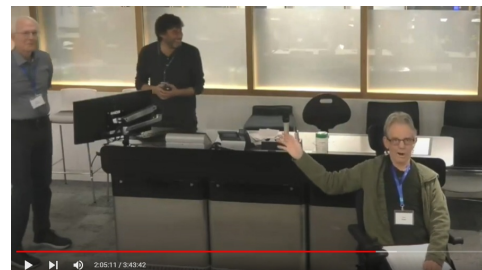
KD-UK and the University College of London (UCL) hosted a four-day international conference on Kennedy's Disease in early November 2023.

The first two days were patient-focused and can be viewed online (links to the right).

Day One included clinical descriptions of KD, ongoing research in UK KD labs, presentations by patient advocacy groups, and a breakout session for KD men.

Day Two included presentations on respiratory and bulbar management, physical activity, mobility and home adaptations for KD patients, and the genetics of Kennedy's Disease. The second day also included updates on clinical trials, a researcher roundtable chaired by Dr. Fischbeck, and a keynote address on Huntington's Disease.

The third and fourth days were devoted to scientific presentations by and for KD researchers. KDA provided sponsorship support for both conferences. The patient days and scientific conference were well-attended and included several KDA



[Watch Conference Recordings](#)

KDA would like to thank UCL and KD-UK for an informative and productive conference.

[KD-UK Website](#)



members from the U.S.

## Connections

### Support for the Ladies - SBMA Carrier Group Meeting

Special guest speaker is Abdullah Alqahtani (MD), Neurologist with Johns Hopkins University. He is recipient of the 2022 and 2023 American Association of Neuromuscular Medicine President's Research Initiative Award. His research focuses on the identification of biomarkers of disease progression in patients with spinal and bulbar muscular atrophy. In addition, he is recipient of the 2022 KDA Waite-Griffen SBMA Fellowship.

February 24th - 11AM EST

Email Joan Sorensen at [jsorensen@kennedysdisease.org](mailto:jsorensen@kennedysdisease.org) for the Zoom link or if you have any questions.



## Fundraising News

### Fall Fundraising Drive a Big Success

The "Seize the Momentum" campaign from October through December was very successful. KDA awarded \$437,000 in 2023, including four research grants and one Waite-Griffin SBMA fellowship. The Fall fundraising drive helped to replenish our coffers so we can prepare for another robust grants award program in 2024.

Thank you to all who contributed to this effort which allowed us to increase the amount of funds we use for research grants.

### Dim Sum Give Some is BACK!

March 2nd - Milwaukee, WI

Enjoy a variety of amazing tastes from over 25 renowned chefs while benefiting the Kennedy's Disease Association.

Chefs Dan Jacobs and Dan Van Rite are thrilled to rally up some of their most best known chef colleagues for their annual chef's tasting event! This annual event is a showcase of some of the country's top





national talent while raising money to fight Kennedy's Disease.

[Click here to find out more!](#)



Chefs  
Dan Jacobs  
and  
Dan Van Rite,  
owners of DanDan  
restaurant in  
Milwaukee, WI  
AND  
long time  
supporters of the  
KDA.

KDA member Dan Jacobs is competing in season 21 of the nationally televised Top Chef. We'll be rooting for you Dan! To see the story, click [here](#).

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## 12th Annual Texas Golf Scramble



April 20th at High Meadow Ranch Club, Magnolia, TX  
[Click here for more information](#)

On January, 2011, six people gathered at a Houston restaurant to discuss a way to raise funds and awareness for Kennedy's Disease. Watching their loved ones become increasingly compromised by this disease, they had a sense of urgency to do something. Thus, the Texas KD Golf Scramble was born!

Our first golf tournament raised \$5,000.00 and we were so proud! Fast forward to 2024, and we now have 11 golf tournaments under our belt, resulting in a total of \$343,000.00 being donated to the KDA. The 2023 golf tournament funding was used for a first-ever Banbury Center research workshop that brought researchers from other neuromuscular diseases together to brainstorm new approaches to research and treatment.

We love doing this tournament and we sure could use some help! How can you help us make a difference? Join us for golf! Get your friends and family to come out and golf with us! Help us sell raffle tickets! Make a donation to our tournament; make a donation to our Tree of Hope in memory (or honor) of a loved one (to be proudly displayed at the tournament); sponsor breakfast; ask your employer to sponsor breakfast or a hole on the golf course; donate something to our auction. The needs are endless and the rewards are great!

If you have any questions, please don't hesitate to reach out to Ed Noack 713.416.1511 or Louise (Noack) Goforth 281.330.0828.

Here's hoping we see you April 20th in Magnolia, Texas!



## KDA Highlights

GuideStar



# KENNEDY'S DISEASE ASSOCIATION

aka KDA | Coarsegold, CA | [www.kennedysdisease.org](http://www.kennedysdisease.org)

Candid's [GuideStar](#) is an information service specializing in reporting on U.S. *nonprofit* companies. It provides information on several million organizations. The KDA earned a 2024 Platinum Seal of Transparency! Check out our updated #NonprofitProfile on Candid: [www.guidestar.org/profile/77-0552005](http://www.guidestar.org/profile/77-0552005)

## The KDA Needs Your Help!

### A 100% Volunteer Organization

Throughout its history, KDA has relied on it's members to perform its many functions, from fundraising to communications to planning the annual conference, and many others. We are at an important stage in the growth of our association. To sustain the momentum we've built over the past several years, we need more help from our members, family members and friends. Basically, anyone who has skills we need and is willing to help is most welcome to

join our team.

The skills we need right now are **communications** and **event planning**.

To build and improve our communications efforts, we have an immediate need for one or more people with strong writing skills and graphics design. These folks would support social media, this quarterly newsletter, and other KDA communications.

We also need volunteers to help plan this year's KDA conference in Orlando in early November. A couple of people (we know who you are!) have offered to help during the conference, but the KDA annual conferences require a lot of work ahead of time and during the event, so there are more opportunities to help out.

If you or someone you know has any of the skills listed above, email [info@kennedysdisease.org](mailto:info@kennedysdisease.org) with the subject "**Interested in Volunteering.**" A member of the KDA Board will respond to your email.

Thank you for your interest and support of KDA!



Connect with us

