



OUR MISSION

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

2022 KDA Conference



Presentations at the Fall 2022 KDA meeting in San Diego, CA

Our first hybrid KDA conference was a success, both for those in San Diego and for virtual attendees. It was a wonderful opportunity for patients, families, researchers to meet again and collaborate in San Diego, with an agenda that offered unique and valuable information and some new features.

One of the new features was the inclusion of a Patient Focused Drug Development (PFDD) meeting on the first day. The PFDD will provide the Food and Drug Administration a picture of the impact Kennedy's Disease has on patients and families. This is information the FDA will use when making decisions related to drug development and approval.

It turns out that holding the PFDD was very timely since we also heard from three conference speakers about research efforts that are expected to come to fruition soon. One of these, the AnnJi Pharmaceuticals' work on AJ201, has already resulted in the implementation of a clinical trial starting this month.

Among the talks on managing KD there was also something new: a summary of a national protocol for Kennedy's Disease. While this protocol was developed in France, it will likely serve as a model for other countries and more broadly throughout the global medical community as a guide for treating KD. There was also a new approach to the research talks,

organizing them by topic as opposed to lab affiliation. These more concise talks were easier to understand and put into context.

The conference attracted hundreds of patients, families and researchers from around the world. With the return of an in-person component, our theme this year was spot-on: The Global KD Family: Together Again.

SAVE THE DATE!

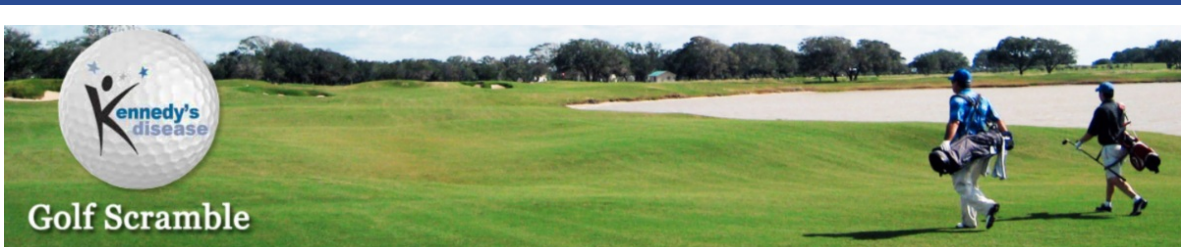


CONFERENCE INVITATION

The first ever global KD conference will be held in London in November 2023. Patient days will be 4-5 November (Saturday and Sunday) and research/medical presentations the following Monday and Tuesday (6-7 November). Patients will be able to attend in person and online.

Details to follow.

Fund Raising News



11th annual KD Golf Scramble
April 22, 2023
Meadow Ranch

Magnolia, Texas.

We're excited to announce the date for our 2023 11th Annual KD Golf Scramble. Mark your calendars to save the date for April 22, 2023!

The goal of our 11th annual tournament is to raise funds to help find a cure for Kennedy's Disease, raise awareness of the disease, and give HOPE to anyone affected by it.

Our past success propels us forward and we have set another lofty goal for this event. So please join us in our DRIVE TO \$350K! To make a donation, sign up to participate, or purchase a raffle ticket, click below.

KD Golf Scramble

Reflections on Last Year's Golf Scramble - by Louise Goforth

The weather was perfect, the laughter and smiles abundant, and when the tournament was over and we said good-bye to our friends, family, and supporters, we had raised \$40,000 for Kennedy's Disease Association. Generosity was on display like we couldn't believe! We are humbled by the kindness of so many; we are grateful that so many are willing to come together. This was our 10th year to do this golf tournament (we did not have tournaments in 2020/2021 due to Covid). When we decided to "try" this idea of having a golf tournament to raise money for KD research in 2011, we weren't at all sure if we'd be successful. To date, counting this year's golf tournament, we have given \$300,000 to KDA!!

What is the recipe for our success? You, and others like you. We have folks all over the United States supporting us - we also have supporters in Canada, Thailand and Australia! Without generous believers supporting us, we wouldn't have a golf tournament. We also go through the extra effort to make sure our event is a truly fun experience so folks will want to come back. And, I'd be remiss if I didn't give a shout out to our small volunteer committee that works so hard to make the tourney a success. This committee is composed of families directly affected by KD, but also those who have no connection to KD except knowing those of us who are affected.

There are so many folks to thank and we can't possibly thank everyone, but we do want to acknowledge the Goynes family - from Florida to Texas. This family has supported us every year monetarily, with auction donations, being on our committee, and/or by attending the tournament from far and wide. The Goynes' have even ingeniously used a GoFundMe family page to raise money for this event! Way to go to all the Goynes, and THANK YOU!!!

How can you help? Start your own fundraiser! No donation is too small!

Let Your Voice Be Heard!



The KDA Newsletter needs your help. Please consider writing ONE article for the newsletter this year on a topic of interest to you and others with KD. We are interested in a wide variety of topics. For example:

- How to select a scooter or power chair?
- Your favorite accessible travel destination.
- What to do when a Laryngospasm starts?
- Tasty, easy to chew meals.
- Best websites for accessible travel.
- Anything of interest to you is fair game.

We are looking for short (200-300 words) articles with one or two images. If you are interested, send an email to our 'new' newsletter editor, Bob Borden (rcborden@kennedysdisease.org) and we can get started.



WIKIPEDIA
The Free Encyclopedia

KDA is on Wikipedia

Check out the section about KDA under [Supporting Organizations](#) in the Wikipedia article on Spinal and Bulbar Muscular Atrophy (i.e. Kennedy's Disease). If you have any ideas on how to improve the SBMA article, please send your suggestions to [Bob Borden](#).

KD/SBMA Drug Trials



安基生技新藥股份有限公司
AnnJi Pharmaceutical Co. Ltd

Enrollment is now open for a clinical trial to evaluate how safe and tolerable is AnnJi Pharmaceutical's investigational drug AJ201 in adult male participants with SBMA.

For more info, click [HERE](#).

Pharmaceutical companies are starting to plan clinical trials of potential treatments for Kennedy's Disease. However, they need KD patients enrolled in a patient registry in order to move forward.

Please enroll today!

Online: [CoRDS at Sanford Health](#)

Phone: You can also call CoRDS at 1-877-658-9192.

To learn more about the Sanford CoRDS patient registry, [click here](#).

You can also contact the KDA with questions
(855) 532-7762 Outside U.S. (734) 288-5580

Now You Can Donate Stocks

To donate financial securities, please send an email to [<info@kennedysdisease.org>](mailto:info@kennedysdisease.org) and in the subject line put "**Stock Donation Question**". We can either answer your questions or put you in touch with the Merrill Lynch executive managing the KDA account.

Kennedy's Disease Association
P.O. Box 1105, Coarsegold, CA 93614-1105
(855) 532-7762 Outside U.S. (734) 288-5580
info@kennedysdisease.org

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