



OUR MISSION

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

International Kennedy's Disease Conference



Registration is now open for in-person and remote attendance at the London International Kennedy's Disease conference. The conference will be hosted by KD-UK and the University College of London (UCL) in UCL facilities from November 4-7, 2023. Days 1 and 2 will

focus on patient issues, including information for caregivers and carriers of Kennedy's disease, and will also feature a summary of research and clinical trials. Days 3 and 4 will be devoted to scientific sessions primarily intended for researchers and clinicians. To register, please click the link below.

[London Conference Information and Registration](#)

Clinical Trial Opens

AnnJi Tests AJ201

Avenue Therapeutics and AnnJi are excited to announce the first patient to be dosed in the clinical trial of AJ201.

Please see the [press release from Avenue Therapeutics](#) for more information. And see below for the expected schedule for the remaining clinical test sites.



Mike S. is the first KD patient to participate in the clinical trial at the University of California, Irvine.

Clinical Trial Site	Status
University of California, Irvine (UCI)	open and currently enrolling patients
Stanford University	open and currently enrolling patients
National Institutes of Health (NIH)	will begin screening and enrolling patients by end of July 2023
Washington University in St. Louis	will begin screening and enrolling patients by end of July 2023
Mayo Clinic Rochester (MN)	will begin screening and enrolling patients in August 2023
Mayo Clinic Jacksonville (FL)	will begin screening and enrolling patients in August 2023

French National Protocol for Kennedy's Disease

The Kennedy's Disease Association Board of Directors & Scientific Review Board encourages individuals with KD to share "[*The French national protocol for Kennedy's disease \(SBMA\): consensus diagnostic and management recommendations*](#)" and a one page summary with their physicians and other clinicians.

This document was developed by a team of specialists and therapists with experience in the diagnosis and management of Kennedy's Disease to provide a reference care pathway for patients with KD both for general practitioners and general neurologist who may be less familiar with the condition. The protocol is based on the currently available research and provides guidance on the care of KD patients.

Laryngospasm

Laryngospasm is an uncontrolled contraction (spasm or muscle cramp) of the vocal folds, that causes a sense of choking where air cannot enter or exit your windpipe (trachea). These spasms are often accompanied by a high-pitched breathing sound (stridor) as air is forced through a narrow gap in the laryngeal sphincters. In most cases, the laryngospasm will subside within a minute or so. Doctors will tell you not to worry; if you pass out, the muscle will relax and you will start breathing again. However when first experiencing a laryngospasm, it is terribly frightening to you and others around you.

Laryngospasms are common in KD patients and may be triggered when water, saliva, food or other substance passes through the vocal folds into the trachea. Brothers with KD have offered the following advice.

1. Don't panic -it's a laryngospasm; it will gradually subside. You are NOT going to suffocate.
2. Try to relax. Hold your breath without inhaling or exhaling for a few seconds. Then try to slowly take a small breath. As the spasm slowly subsides, you should be able to breathe a little more.
3. Some with KD find that humming, shallow breathing through the nose, or a tiny sip of water can help.
4. Some people have learned to recognize a laryngospasm beginning, and take action to prevent it. They slow down whatever they're doing, relax, take a sip of water, fully clear their throat of food or liquids; and take slow steady breaths.

To learn more about laryngospasms, check out articles on [Wikipedia](#) and [Laryngopedia](#), or view this [video](#).



Kennedy's Disease/SBMA
Voice of the Patient Report

The KD/SBMA Voice of the Patient (VOP) report has been finalized and is available for [download](#) from the KDA website. The VOP summarizes a series of in-person and recorded interviews with individuals living with KD, caregivers, and family members conducted as part of the Patient Focused Drug Development (EL-PFDD) meeting. This report contains important patient and caregiver insights and perspectives which we hope the FDA and the research community will use to ensure that patients have a voice in therapies developed for their disease and in the evaluation of clinical trial results.

Individuals with KD may want to share this report with their physicians to help them gain a better understanding of key issues of concern to individuals with KD.

KD Golf Scramble A message from the organizers



Pictured left to right:
Ed Noack, Terry Thompson, Kathy Thompson, Louise Noack Goforth, Dana Noack Mowe.

As we looked out over the sea of faces – about 155 folks – we were humbled. This was the 11th annual Kennedy's Disease golf scramble in Texas. We knew why we were there...our family has this rare genetic disease; we have a sense of urgency to find a cure or treatment (our eldest brother died this last December from Kennedy's Disease complications). But it's impossible to put into words what it means to have so many others, some who have never even heard of this disease prior to this golf tournament, supporting us so grandly.

The day of the tournament was filled with merriment, excitement, and nerves hoping everything went smoothly. Great fellowship was enjoyed with so many folks uniting for the purpose of raising awareness and funds to help find a treatment or cure for Kennedy's Disease.

We had people join us from Canada, Maryland, Florida, Connecticut, South Carolina, Virginia, and various places from all over Texas. Two notable attendees were Terry and Kathy Thompson from Maryland. Terry is the KDA President and Kathy is an invaluable Board of Director for KDA. Their presence meant a great deal to the small golf committee, with Terry graciously thanking all the attendees for helping us in this endeavor.

This day brought so many nice surprises. The most important one is that as a result of the 2023 Texas Golf Scramble, we donated \$43,000 to the Kennedy's Disease Association. This brings the total donation from the

Texas Golf Scramble to the KDA to just over \$340,000.

The generosity of folks this day knew no bounds. We had first, second, and third place money prizes for the golf teams. Three brothers from Texas won first place and set the tone when they donated their first-place winnings back. Right behind them, the second and third place team winners did the same. We also had five top raffle prizes with the #1 prize being \$1,000, #2 prize \$500, and #3 prize \$250 – all three top money prizes were donated back. My eyes literally welled with tears at so much generosity. We put our hearts into hosting this golf tournament together each year, and to see people care so much for our cause was emotionally overwhelming.

But that's not where it ends....we had tons of folks donate prizes for our auction (a 5 day, 4 night resort stay in Myrtle Beach, SC for example) and smaller raffle prize giveaways. We also had many of you – many of you – donate online either to buy a raffle ticket, donate in someone's memory or honor, sponsor a hole, or even donate to our Tree of Hope. *All of you are what makes this possible and our tournaments successful!!*
Thank you from the bottom of our hearts.

Genetic Literacy Survey

In the very near future, KD men and female carriers will receive a survey on the topic of "genetic literacy." Researchers at Nagoya University have conducted this survey in Japan and would like KDA members to complete it to allow for a cross-cultural comparison of genetic knowledge about SBMA and its transmission among families. Upon completion, this research will be published as a further contribution to the understanding of SBMA transmission among families. Please note that because KDA members live in many countries, there is a question about the country you live in. This is an important data point for analysis in a cross-cultural survey. Thanks in advance for your cooperation in completing this survey.

Medicare now cover wheelchair seat elevating systems

The Centers for Medicare & Medicaid Services (CMS) have issued a decision extending coverage of power seat elevation equipment on power wheelchairs (PWCs) and related equipment. For more information, go to

[Medicare Officially Covers Seat Elevation Systems](#)

Cycling Across the Alps for Kennedy's Disease

Please support KD-UK and a team of cyclists who are riding from Chamonix to Nice to raise money to support research into Kennedy's disease. Over six long days, these international heroes will peddle up (and up) the most challenging cols that the French Alps have to offer. More than 600 kms and nearly 16,000 metres of vertical just so you can sponsor their sweaty efforts and be a critical part to finding a cure for this thoroughly debilitating disease.

DONATE NOW

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