



OUR MISSION

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

2021 Annual Conference

**GLOBAL MOMENTUM:
BRINGING THE KD
COMMUNITY TOGETHER**

2021 KDA CONFERENCE
Online | October 28-29 2021
For more information go to: kennedysdisease.org

Thursday and Friday, October 28-29 - 10:00 AM - 2:30 PM EST

You spoke and we listened! The agenda for the 2021 KDA online/virtual conference, **Global Momentum: Bringing the KD Community Together**, is centered around the ideas and suggestions many of you offered last year.

This year's agenda includes:

- Stories and tips from patients themselves
- How to managing your symptoms
- Q&A session between patients and clinical staff
- Presentation on the latest in mobility devices
- In-depth talk on speech issues
- Round table discussion with researchers on developments in research and clinical trials
- And of course breakout sessions for KD men, carriers, and partners/caregivers which you have the option to join

This will again be a virtual event and will run from 10:00 AM to 2:30 PM EST on Thursday October 28 and Friday October 29. This is your opportunity to get information not available from any other source on Kennedy's Disease and how to live with it.

[Click here for more information and to register](#)

The Great Road Trip Summer 2022

With our first ever transcontinental fundraiser, the KDA & KD-UK are organizing the "Great Road Trip". It starts in Los Angeles, USA and finishes in Rome, Italy!

Classic Car clubs from across the United States will join along in segments. There are also several schedule media events planned, dinners and volunteer drivers and passengers from the KD community and beyond... it is going to be a truly epic event that you do not want to miss!

Do you want to drive?
Do you want to tag along or follow in your own vehicle and be a part of the festivities?

[Click here to learn more about the GREAT ROAD TRIP!](#)



Road trip vehicle Citroën 2CV 29 HP - 35-years-old

It is affectionately known as the tin snail, is a cult car in Europe. It was first manufactured in 1948 and production ceased in 1990.

This 2CV has been comprehensively refurbished for the trip. The cost of the 2CV, and its restoration, has already been funded by a generous donor.

USA

Start in Los Angeles
on 19 April 2022



Europe

Start at Land's End in the South
West of the UK on 7 July 2022



A seven-day trans alpine cycling event will be run alongside the road trip from Chamonix to Nice in July.

NEW! NIH Natural History Study

**Seeking twenty-five men
for a two year study.
[NIH Clinical Trial Link](#)**

The NIH has launched a new study titled "Clinical, Molecular and Imaging Biomarkers in Spinal and Bulbar Muscular Atrophy (SBMA)". The study is underway and men with Kennedy's Disease can volunteer for this study. The object of the study is to identify measurements that change over time in SBMA.

Armed with this knowledge, researchers will have a much better way to measure the effectiveness of medicines and

NIH U.S. National Library of Medicine

ClinicalTrials.gov



Participants can expect the following:

treatments!

Eligibility:

- Men with genetically confirmed KD diagnosis
- Over the age of 18
- Able to walk
- Able to travel to the NIH Clinical Center in Bethesda MD for 5 visits over 2 years (NIH will cover travel expenses).

Men without KD can also participate, they will have 1 study visit.

[To learn more, click here to watch a video explaining the study goals and what participants can expect \(34 minutes\)](#)

Contact [Angela Kokkinis](#) for information or to volunteer.

[NIH Clinical Trial Link](#)

- A physical exam
- Complete questionnaires
- Blood and urine tests
- Neuromuscular ultrasound
- Muscle strength and function tests (which include pushing, pulling, rising from a chair and sitting back down, and/or walking).
- Wear an activity tracker on their wrist for 10 days at home every 3 months.
- Lower limb magnetic resonance imaging (MRI) and optional whole-body MRI
- Lung function tests
- Speech and swallow tests
- A lumbar puncture to obtain spinal fluid
- Optional body scans to measure bone density and lean body mass
- Optional muscle biopsies



Now You Can Donate Stocks

A new channel for donations!

KDA has always relied on the generosity of KD patients and their families for the donations that fund our annual research grants and education and awareness activities.

Now, thanks to **Merrill Lynch**, KDA can also accept donations in the form of financial securities.

For more information or for specifics on donating 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.

THANK YOU FOR YOUR SUPPORT!



MERRILL
A BANK OF AMERICA COMPANY

Securities can include

- publicly traded stocks
- mutual funds
- other financial instruments

Donate

KD/SBMA Patient Registry

Over 200 people have registered so far!

We learned at the 2020 KDA conference that multiple pharmaceutical companies are considering clinical trials of potential treatments for Kennedy's Disease. However, they need KD patients enrolled in a patient registry in order to move forward.

After several months of collaborative work with the NIH and Sanford Health, the KDA is thrilled to share the CoRDS patient registry. The development of this registry is crucial to future research and a key moment in our quest for a treatment or cure and we want you to participate. Please enroll today!

Online: [CoRDS at Sanford Health](#)

Phone: You can also call CoRDS at 1-877-658-9192 and they will enter data on your behalf.

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

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

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