



OUR MISSION

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

KDA News

KDA Conference 2020

This year's conference is a joint effort with UK-KD and will be entirely online.



"Moving Forward Together"

While in recent months the world's attention has been focused on the Covid-19 pandemic, Kennedy's Disease research continues with significant developments and useful information to report.

- **Dates:** October 14 and 15 (Wednesday-Thursday)
- **Times:** Mornings in the U.S. and afternoons in the U.K.
- **Format:** Online using the Zoom platform.

Wednesday the 14th is patient-focused talks and possible breakout sessions. Thursday the 15th is devoted to research, with a theme of KD research leading to clinical trials: **Transition States: Moving from the Lab to the Clinic**. All the talks will be directed toward a general audience.

More specific information on the agenda and sign-up will be coming out shortly, meanwhile, mark your calendars!

NIH-supported research survey to examine impact of COVID-19 on rare diseases community

"For the millions of people living with a rare disease, the novel coronavirus disease COVID-19 presents challenges, from potential reduced access to needed medical care to possible heightened anxiety and stress. A new online survey launched by the National Institutes of Health-supported [Rare Diseases Clinical Research Network \(RDCRN\)](#) aims to find out how the COVID-19 pandemic is impacting individuals with rare diseases, their families and their caregivers. Results will help the rare disease research community shed light on the needs of people with rare diseases during the COVID-19 pandemic and other potential health crises, in addition to informing future research efforts."

- [To continue reading this article, click here.](#)
- [To take the survey, click here.](#)

Research survey for rare disease patients and their families about impacts of COVID-19

Complete a 20-minute online survey

Why are we doing this research?

The novel coronavirus pandemic is impacting people with rare diseases and their families. Your responses may help researchers understand the impacts of COVID-19 on the rare disease community.

Who can participate?

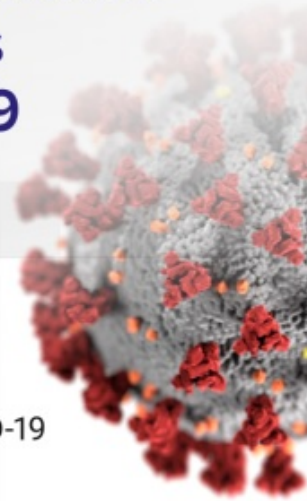
You qualify for this study if you or someone you care for has been diagnosed with a rare disease, is 0 to 89 years old, and currently lives in the United States.

Will you or your child be paid?

Participants will not receive payment for completing this survey.

What will happen in this study?

You will be asked to share your experience by completing our survey from home.



To complete the survey or learn more:



RareDiseasesNetwork.org/COVIDsurvey

Questions?

Email the study team at rd.covid19@cchmc.org



A National Institutes of Health-funded network of rare diseases research groups

RareDiseasesNetwork.org

[Visit the KDA website!](#)

Research Updates

Updates and summaries provided by Todd Allen - KDA Board Member.

Title of Paper: [Wide range of reduced penetrance alleles in spinal and bulbar muscular atrophy: a model based approach](#)

Original research published in the journal Neurogenetics, reveals that the occurrence of KD may be much higher than the previously estimated 1 in 40,000. Kennedy's disease, is an X-linked motor neuron disorder caused by an expanded CAG repeat in the gene coding for the androgen receptor (AR). Typically, a CAG repeat of 35 or greater in men

marks a possible risk to developing the symptoms of KD.

A study of the DNA from 112,000 people in the general population reveals that a CAG repeat of 35 or more occurs much more frequently than the previously estimate. It closer to **1 in 1,000**. This could mean that Kennedy's Disease is **NOT A RARE DISEASE** which could translate to additional research investments by pharmaceutical companies.

Sonic Hedgehog-Gli1 Signaling and Cellular Retinoic Acid Binding Protein 1 Gene Regulation in Motor Neuron Differentiation and Diseases

We employed the same strategy to engineer healthy vs. degenerated MN1 cells to model SBMA neurons [22]. MN1 cells containing AR-24Q (control) remain healthy, whereas MN1 cells containing the diseased version, AR-65Q, become degenerated in cultures. As shown in Figure 2b, the diseased SBMA/MN1 neurons, AR-65Q, also have a dramatically reduced CRABP1 level, as compared to the healthy control, AR-24Q.

These results, in two motor neuron disease models, consistently show that Crabp1 gene activity is positively correlated with a healthy state in motor neurons, whereas down regulation of the Crabp1 gene is correlated with degeneration in motor neurons, such as those in ALS and SBMA.

Other News

30th Anniversary of the A.D.A.

On July 26, 1990, President George H.W. Bush signed the Americans With Disabilities Act into law, banning discrimination against millions of people and requiring reasonable accommodations in schools, on transportation and in other areas of public life.

Read on at...

<https://www.nytimes.com/interactive/2020/us/disability-ADA-30-anniversary.html>

Do you have a message to share with us? Let me know it! jameson411@gmail.com

KDA Memorial Page

If you have a loved one with Kennedy's Disease who has passed away and would like to have them added to the KDA memorial page, let us know at Contact the KDA with the information and a picture.

Click here to see the [KDA Memorial Page](#)

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