



OUR MISSION

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

Covid 19 Vaccination



You may ask, "I have Kennedy's Disease and am wondering if it safe to get the Covid vaccine."

We wondered the same thing! So we asked the people who would know the answer and here is what we found out.

Dr. Christopher Grunseich, MD, a long time friend of the KDA and a staff clinician at the National Institutes of Health states that the NIH recommends people with Kennedy's Disease get the Covid vaccine. People with KD have no additional risks of complications due to the vaccine. However, people with KD are at a higher risk for severe complications if they contract the Covid-19 virus. To read his letter, click [here](#).

Also, the **Sunnybrook ALS/Neuromuscular** clinic at the University of Toronto states that patients with KD may experience respiratory impairment and, should they contract the Covid virus, are at increased risk of complication of respiratory infections. The Sunnybrook clinic recommends that KD patients be a priority group to receive vaccination for COVID-19. To read their letter, click [here](#).

KDA Annual Conference 2021

October 28th and 29th — SAVE THE DATE!

To the question of whether there will be a KDA conference this year, the answer is a resounding, "YES!" And we're going virtual one more time. Evaluations from the 2020 conference were overwhelmingly positive, with many who would not otherwise have been able to attend expressing their appreciation for the opportunity.

The virtual format allowed us to reach many more people in a much greater geographical area, and the quality of the talks was outstanding. We hope to do as well or better this year.

More details will be coming out soon, but for now, please put Thursday and Friday, the 28th and 29th of October, on your calendar for the 2021 KDA Conference!

From last years conference, we are pleased to share that two more

presenters gave us permission to post their conference talks from last year's virtual conference.

Physical Therapist Joe Shrader from the NIH made for us a special set of videos [Exercise Recommendations for People with KD](#).

[Priorities in Managing KD's Symptoms](#) - Luca Zampedri, University College London, presents results of a KD patient survey he conducted prior to the KDA/KD-UK joint conference in 2020.

Men with KD - Help the NIH Understand!

A Quality-of-Life survey is being conducted by the National Institutes of Health (NIH) along with the University of Rochester. They are studying the issues and symptoms that are most important to patients with spinal bulbar muscular atrophy (SBMA). **You have the opportunity to provide your insights about SBMA and help researchers ask the right questions.** This information will help the NIH and other researchers determine the most important outcome measures to monitor during future SBMA clinical trials.

You are eligible for this research study if you are a man who has Kennedy's Disease and are 18 years of age or older. The survey will take 20-30 minutes to complete and all responses are completely anonymous.

This is a great opportunity to help researchers determine the best ways to help us! Click the link here to find out more information and to take the Quality-of-Life survey.

<https://redcap.link/QOL.SBMA>

Study Contact Email: akokkinis@cc.nih.gov

Other News and Updates

KD RARE DISEASE DAY FUND RAISING EVENT RAISES OVER \$20,000

Thank you to Ralph Briones and the Briones family who raised over

\$20,000 for the KDA in this weekend event! A-MA-ZING! His original goal was \$5000 over the weekend which was surpassed on day one. It was a pleasure to watch the Rare Disease Day - Bay Area event unfold. The dance, the cooking, the food demos, all so great.

“**DIAGNOSIS CAN BE THE
LONGEST DETECTIVE
MISSION**”



**RARE DISEASE
BAY AREA**

Donate to the

RESEARCH UPDATE

Effect of leuporelin in bulbar function of spinal and bulbar muscular atrophy patients: observational study for 1 year. This study aimed to investigate the effect of androgen suppression therapy using leuporelin focused on the bulbar function of patients with spinal and bulbar muscular atrophy (SBMA). To learn more, click [here](#).



What happens to the money you donate to the KDA? Most of it (over 90 cents of every dollar) goes to funding research for a treatment or cure to Kennedy's Disease. Soon, we will announce the 2020 grant recipients totaling over \$150,000!

Coming Soon - a KD Patient Registry!

At the October 2020 KDA-KD/UK conference, several pharmaceutical companies are starting to think about clinical trials of potential treatments for Kennedy's Disease. Clinical trials are lengthy studies of the effects of a drug or therapy on human participants. They are designed to answer specific research questions.

The good news for SBMA patients is that there ARE MULTIPLE COMPANIES currently designing clinical trials for KD treatment. To prepare for these trials, we need your help fill in the **KD patient registry!**

The KDA has recently signed an agreement with Sanford CoRDS to build a patient registry for SBMA patients. We ask that you be prepared to enter your personal health history and your experience with Kennedy's Disease into the CoRDS system that we will use to recruit participants for future clinical trials. Information gathered will be key to patient participation in future clinical trials that, we all hope, will lead to a successful treatment of this debilitating disease.

Thank you from the KDA Board of Directors

Do you have a message to share with us?
Let me know it! JParker@kennedysdisease.org

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