



OUR MISSION

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

Coordination of Rare Diseases at Sanford (CoRDS)

Enroll Now

 Represented Diseases  Participant Portal  Researcher Portal

CoRDS

Men with Kennedy's Disease Women who are carriers Enroll in the KD/SBMA patient registry!

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](#) or more info below.

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

Special Note: When entering your "Rare Disease Diagnosis" enter **sbma**,
the field will auto-fill in **Kennedy disease (sbma)**.
Fill in other rare diagnosis if applicable.

Diagnosis

Please select the participant's diagnosis from the "Rare Disease Diagnosis" section. You can

- If you have not officially been diagnosed with a Rare Disease, please enter "Undiagnosed"
- If you can not find your disease search for "Other" and add your diagnosis in the Other

Rare Disease Diagnosis 1

Rare Disease Diagnosis 2

Rare Disease Diagnosis 3

Rare Disease Diagnosis 4

Rare Disease Diagnosis 5

sbma

Kennedy disease (SBMA)

Here are important things for you to know about the KD/SBMA registry:

- There is no cost for entering your data into the registry.
- Sanford - CoRDS and the KDA will not share your personal identity or contact information with anyone.
- To protect your privacy, each participant is assigned a Global Unique Identifier that enables de-identification (anonymization) of the data when shared with researchers. Researchers must be approved by Sanford Health's Scientific Advisory Board. Your name and other identifying information will not be shared.
- The entire process should take about 30-40 minutes (less for carriers) and does not have to be done all at one sitting.
- Entering data into the registry requires completing the CoRDS profile and two questionnaires, the CoRDS standard questionnaire and the KD/SBMA questionnaire.
- Data can be entered into the registry online, on paper, or by phone with Sanford CoRDS. Learn more at <https://research.sanfordhealth.org/rare-disease-registry>.
- Providing your consent to give KDA access to your data will allow us to contact you for studies and clinical trials and help improve our understanding about where to drive our research.
- KDA's goal is to make CoRDS the global repository for KD/SBMA patients. The registry is compliant with U.S. Federal law and the European Union's General Data Protection Regulation.

Also, the Quality-of-Life Survey is still open!

Help researchers determine the best ways to help men with KD. Click here to learn more and to take the Quality-of-Life survey.

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

Study Contact Email: akokkinis@cc.nih.gov

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.

Kennedy's Disease Association
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