Kennedy's
Disease
Association

OUR MISSION

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

2024 - KDA Conference and 25th Anniversary

The KDA Conference is a unique opportunity to learn more about Kennedy's Disease, how to live with it, and what is being done to develop a treatment for it. The in-person registration is fully booked for our 2024 annual conference. However...

You can still attend ONLINE!

The conference is streamed live! Click this link for info or to register. The sound and video for the conference are professionally supported so that the livestream is excellent quality. You will also have ongoing access to conference recordings, in case you want to rewatch something or miss a session. As such, there is a $50 fee to cover this cost.

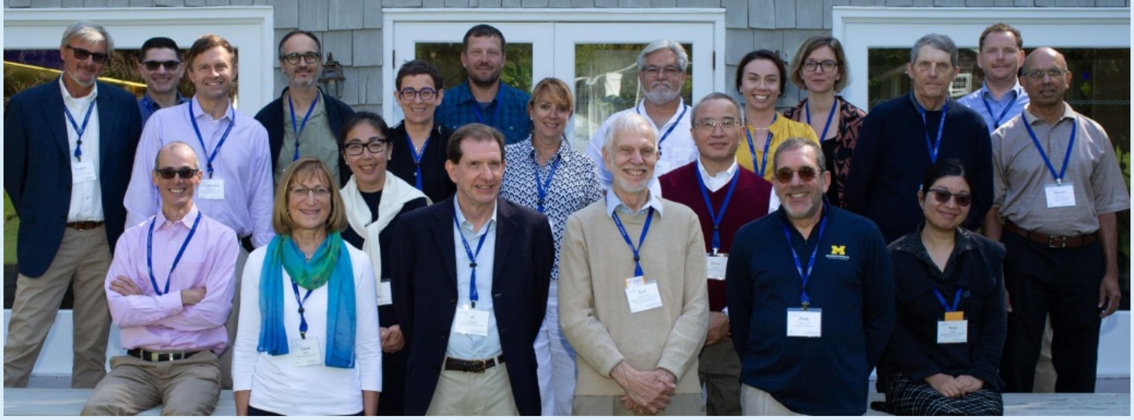
2024 Banbury SBMA Research Workshop

The Kennedy’s Disease Association sponsored the second SBMA research workshop at The Banbury Center on Long Island on September 8-10, 2024. These workshops are made possible thanks to the annual Texas KD Golf Scramble.

The topic for *Banbury 2024* was "Harnessing Protein Quality Control in Spinal and Bulbar Muscular Atrophy (Kennedy’s Disease)." The sessions included the following areas:

1. Clinical Overview and Living with Kennedy’s Disease
2. PolyQ-AR Proteostasis
3. Protein Quality Control Pathways

The participants were international experts on protein metabolism, with about half of the researchers previously not involved in KD research.



Banbury SBMA Research Workshop 2024 Participants

KDA's Banbury workshops are designed to be collaborative efforts with scientists from related fields joining SBMA researchers to share research ideas and discuss possible approaches to therapies and a cure. This should not only provide new perspectives to KD research but also bring new, experienced scientists into the KD research community. The topic for our first workshop held in September, 2023 was on the Neuro-Muscular Junction. Following that workshop, KDA awarded two $100,000 grants to collaborating research teams.

KDA Support Group Meetings Online

You Are Not Alone! Connect with those who know your struggles. Encourage someone who faces what your too have to live with.

- Men's KD Support Group - This Saturday, Oct 12th at noon (EST). Contact Doug Ciskowski for more information. The Patient Zoom meeting is just people with KD talking. We share problems, tips, and experiences among ourselves. It is informal, you can talk or just listen.
- Carrier Support Group - Nov 13 at 5:30 PM (EST). Carrier group on Facebook
- Care Partners Zoom Support Group - Name changed from Caregivers to Care Partners. Next meeting is Nov. 14th at 3 PM (EST). Reach out to Anita Hallman Kowalski for more information.

Check out the 10 groups listed on the KDA support site!
kennedysdisease.org/living-with-kd/support.html

Fundraising News

Thanks to the generosity of KD patients, families, friends, and researchers, the Kennedy’s Disease Association has awarded more than $665,000 since early last year, and over $2,500,000 since 2000 to support KD research. Your donations have allowed us to support research in six countries and facilitate collaboration with specialists in other neuromuscular diseases.

With publication of the 2023 study indicating a higher prevalence of the gene mutation that causes KD (SBMA), we believe there are more people with the disease than previously known.

New Fundraising Committee Forming

We are looking for a few energetic and motivated volunteers to help us establish a Fundraising Committee. We need to keep the momentum going forward!

Photo by Dylan Gillis on Unsplash

Committee responsibilities include building a toolkit for fundraising events, developing new ideas and channels for fundraising, and working with the KDA Board to expand and improve our fundraising activities.

If you are interested in getting involved email us at info@kennedysdisease.org.

Did you know...

Qualified charitable distributions allow eligible IRA owners up to $105,000 in tax-free gifts to charity

IR-2023-215, Nov. 16, 2023 — The Internal Revenue Service today reminded individual retirement account (IRA) owners age 70½ or over that they can transfer up to $105,000 to charity tax-free each year.

IRS Link About The QCD

IRS

Sneak Peak... The Great Road Trip II

They're at it again! Stay tuned for more information on another epic, international road trip to raise money and awareness for Kennedy's Disease.

One little tidbit for now... this CV2 is electric!

Research Highlights

Two Scientific Papers of Interest!

KDA members may be interested in two recent papers related to KD/SBMA research. The first summarizes the results of the survey conducted by NIH of over 200 KD patients, including many KDA members. The paper summarizes the symptoms and impacts reported by KD patients.

The second paper summarizes a 2023 SBMA research workshop held in the Netherlands. Scientists from 11 countries met to discuss current research in an effort to consolidate knowledge and discuss a unifying approach to fight Kennedy's disease.

Both papers are available on the KDA website.

Student Travel Grants Available

Graduate students and post-docs working in established labs on projects related to Kennedy's disease (SBMA) are eligible to apply. KDA travel grants are limited to one per student per year. For more information, email "info@kennedysdisease.org."

Thanks to generous contributions from one of our member families, the Kennedy’s Disease Association (KDA) is able to offer travel funds for post-doctoral scholars and graduate students who would like to present their current Kennedy’s disease (SBMA) research at a conference related to neuromuscular diseases, neurology, or related topics.

The purpose of these grants is to allow graduate students and post-doctoral researchers the opportunity to attend conferences to summarize their research with a presentation or poster. The goal of this program is to increase awareness of Kennedy's disease (SBMA) among researchers and clinicians who attend these conferences and to provide an opportunity for junior researchers to gain exposure to the broader research community and obtain feedback on their research.

From the KDA Website

There is a wealth of information on our website. Here are some topics posted under practical guidance on our "Living With KD" section.

- Surgery Concerns - Anesthetics
- Exercises
- Choking and Swallowing Issues
- Safe Mobility - AFO
- Medical ID Card
- Covid 19 Vaccinations and Treatment Guidelines
- Information for people with or affected by Kennedy's Disease - MNDA

- YouTube Videos

Do you have a story you'd like to share in the newsletter?
Send them to Jameson at jparker@kennedysdisease.org

The KDA is a 100% Volunteer Organization

As an all-volunteer organization, KDA is looking for volunteers who can spend a few hours working on KDA activities. Our current needs include

- **Fundraising committee (see article above)**
- **Public relations and social media**
- **Conference planning**

info@kennedysdisease.org

Connect with us