OUR MISSION

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

KD-UK, KDA Great Road Trip A Resounding Success

Researchers from the Universities of Milan, Padova, and Trento, welcome the little red 2CV

Go to www.thegreatroadtrip.net to see the many photos, articles and news coverage of this epic adventure.

On July 24, the little red Citroen 2CV completed its nearly 7,000 mile journey from Los Angeles to Rome with a grand finale at Castel Gandolfo south of Rome. The event was hosted by the Italian KD patient advocacy group (AIMAK) and was the sixth gathering bringing together patients, families, researchers, and clinicians to raise awareness of Kennedy's Disease. Other events took place in California, Maryland, the UK, and Italy. In addition, KD research teams in Irvine, Bethesda, Philadelphia, London, Oxford, Milan, Padova, and Trento turned out to support the Great Road Trip.

These gatherings and meetings point to two of the most important outcomes of the trip: the strengthened collaboration between KD patient advocacy groups and the importance of face-to-face meetings. The Great Road Trip also generated over $100,000 (after expenses) in donations for KD research.

We are all indebted to Kim Slowe, KD-UK Trustee, for conceiving, organizing, and managing this epic adventure across two continents and five countries. We would also like to thank our corporate sponsors and everyone who helped plan and organize the Great Road Trip as well as all those who participated. It was truly a once in a lifetime experience, and provided a huge boost in the public awareness of Kennedy's Disease.

KDA commissioned a watercolor by a Maryland artist, April Rimpo, to memorialize the Great Road Trip. A limited number of prints signed and numbered by the artist are available for a donation of $200 or more to the KDA. If you're interested, please email info@kennedysdisease.org with the subject line "Great Road Trip Print" for more information.

KDA Family Reunion!

After a two-year hiatus it’s coming up again!

Please join us in San Diego on November 9-11 for the 2022 KDA Conference, The Global KD Family: Together Again.

As always, it will be filled with talks on how to live with Kennedy’s Disease and the latest information on research toward a cure. But what’s been missing for the past two years is the personal connections and the ability to speak directly with other patients, families and the doctors/researchers studying KD. While people have greatly appreciated and benefited from our virtual conferences, they have also commented that they miss the personal interaction.

We often refer to ourselves as a family, and the truth of this was brought home to me especially clearly this past April. I was traveling to San Diego in connection with the kick-off of The Great Road Trip, and as I left the airport and stepped out into the sunshine and mild breeze, I was overcome with a feeling of anticipation and joy. We’ve held several previous conferences in San Diego and I suddenly realized that returning there elicited the conditioned response of happiness at being reunited with my KDA colleagues. Although we’re a diverse group, we ARE like a family. The difference is that what joins us is a common purpose — finding a cure for KD — and the unique ability to understand each others' situations.

While we will still offer a way to participate virtually, we are looking forward to seeing as many of you there as possible. For more information, click here.

"After a few years away due to COVID, I'm so very much looking forward to gathering together at this year's KDA meeting! I've found it to be an energizing meeting, with abundant opportunities to interact with patients and their families and to learn about new discoveries in KD research from investigators around the world."

Andy Lieberman, MD PhD
Chair, KDA Scientific Review Board

KD/SBMA Patient Registry

Pharmaceutical companies are starting to plan clinical trials of potential treatments for Kennedy's Disease. However, they need KD patients enrolled in a patient registry in order to move forward.

Please enroll today!

Online: CoRDS at Sanford Health

Phone: You can also call CoRDS at 1-877-658-9192.

To learn more about the Sanford CoRDS patient registry, click here.

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

Now You Can Donate Stocks

To donate financial securities, please send an email to <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.

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