



OUR MISSION

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

The Great Road Trip Begins SOON... April 18th!

A joint adventure by the KDUK and KDA, The Great Road Trip is a multi-continental journey of 6600 miles, from **Los Angeles, California to Rome, Italy** (with a boat ride across the Atlantic).

The special vehicle for this adventure will be a 1987 vintage Citroen 2CV, featuring its standard 29-horsepower engine. Affectionately known as the "tin snail," the 2CV is now a cult car in Europe and revered by Citroen Car Clubs across America.

The purpose of the Great Road Trip is to raise awareness of Kennedy's disease and support several ongoing research studies that show promise for a treatment or cure.

**We want YOU to join in this exciting event!
Drive, ride along or join the caravan!**

Volunteer drivers and passengers from the KD community are welcome to participate, along with Citroen car clubs from across the United States. It is going to be a truly epic event that you do not want to miss!

Click the link below to see the website dedicated to this event. You'll see pictures, UPDATES as the trip happens and ways to get involved!



THE NORTH AMERICAN LEGS

18 April	Los Angeles: Start of the Great Road Trip
19 April	Media event in Irvine; Irvine =====> San Diego
20 April	Rest / Media day in San Diego
21-22 April	San Diego =====> Flagstaff (AZ)
23 April	Rest / Media day in Flagstaff
24 April	Flagstaff =====> Gallup (NM)
25 April	Gallup =====> Santa Fe (NM)
26 April	Rest / Media day in Santa Fe
27 April	Santa Fe =====> Amarillo (TX)
28 April	Amarillo =====> Wichita Falls (TX)
29 April	Wichita Falls =====> Dallas (TX)
30 April	Rest / Media day in Dallas/Ft. Worth
1 May	Dallas =====> Little Rock (AR)
2 May	Little Rock =====> Memphis (TN)
3 May	Rest / Media day in Memphis
4 May	Memphis =====> Nashville (TN)
5 May	Rest / Media day in Nashville
6 May	Nashville =====> Indianapolis (IN)
7 May	Rest / Media day in Indianapolis
8 May	Indianapolis =====> Detroit (MI)
9 May	Detroit =====> Toronto (Canada)
10 May	Rest / Media day in Toronto
11 May	Toronto =====> Niagara Falls (NY)
12 May	Niagara Falls =====> Carlisle (PA)
13-14 May	Carlisle Auto Show
15 May	Carlisle =====> Washington (DC)
16 May	Rest / Media day in Washington
17 May	Washington =====> Philadelphia (PA)
18 May	Rest / Media day in Philadelphia
19 May	Philadelphia =====> New York (NY)
20 May	Media Events in New York

[The Great Road Trip -North America](#)

Want to drive, ride along, join the caravan or just have a question?

[Let us know!](#)



April 2nd - The Texas Golf Scramble is BACK!



**10th annual KD Golf Scramble
April 2nd, 2022
High Meadows Ranch
Magnolia, Texas.**

In 2011, we started this tournament with more heart than knowledge on how to conduct charity event. But the Kennedy's Disease Association had little attention, and less donations, so we decided to test the waters to see what we could do to help. And when our first tournament ended and donated \$5,000 to the KDA, we were proud as peacocks!

As the years rolled by, the word got out and so many people stepped up to help us and not just local folks. Many of those that helped us are reading this newsletter right now! As of this writing, we've conducted 9 tournaments and have donated over \$250,000 to the KDA.

Realizing how fortunate we are to have so many people help us in the endeavor makes our eyes moist. It takes a lot of people, and a lot of good hearts, to have this kind of success and we are so grateful.

This year, we've set a really lofty goal for ourselves hoping to make our total donations to the KDA \$300,000! There are many ways to help us;

- make a donation
- invest in a sponsorship
- play golf with us
- simply buy a raffle ticket

Right now we're having an Early Bird Special on raffle tickets so don't miss out! The top 3 raffle prizes are cash prizes and you need not be present to win. If you'd like to help drive us to this goal, please visit our website.

www.kdgolfscramble.com

Keep us in your thoughts and prayers for a good, successful tournament on April 2nd!

Support for Carriers

My name is Joanie Sorensen and I am helping the KDA establish Zoom support groups for women carriers of SBMA in the US and internationally.

For the past two years a small group of carriers from the KDA have been getting together on Zoom. We have found that the face to face meetings have enabled us to navigate being a carrier and all that that entails. We have formed friendships and enjoy our time together receiving support and advice. We love having a safe and confidential space to share our stories and now feel less alone on this journey.

Carriers experience a unique collection of emotional and physical issues ranging from unsubstantiated guilt, feeling disregarded by the medical community, sadness, grief, wondering how to start family planning and concern for our sons, fathers and brothers who struggle with SBMA, the list goes on... Whatever situation you find yourself in as a carrier, it truly makes a difference to get together with women who GET IT.

Please email me at Jsoren3@yahoo.com to let me know if you are interested in joining a group where you live.

NIH Natural History Study

The NIH study is underway and men with KD can volunteer. The object of the study is to identify measurements that change over time in SBMA.

Eligibility:

- Men with genetically confirmed KD diagnosis
- Over the age of 18
- Able to walk
- Able to travel to the NIH Clinical Center in Bethesda MD for 5 visits over 2 years (NIH will cover travel expenses).

Contact [Angela Kokkinis](#) for information or to volunteer.

[NIH Clinical Trial Link](#)

[Video link explaining the study goals and what participants can expect](#)

KD/SBMA Patient Registry

Pharmaceutical companies are starting 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>](mailto: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.

Kennedy's Disease Association
P.O. Box 1105, Coarsegold, CA 93614-1105
(855) 532-7762 Outside U.S. (734) 288-5580
info@kennedysdisease.org

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