Our mission is to inform, support, educate, fund research, and find a cure for Kennedy's Disease.

Kennedy's Disease Association

QUARTERLY NEWSLETTER

SUMMER 2025

Welcome to the Summer issue of the KDA Quarterly Newsletter!

We're excited to share recent KDA news, stories from the community, updates on research, and opportunities to get involved. Thank you for being part of our mission.

Year in Review: 2024

Thanks to the continuing generosity of the KDA community, we were able to contribute more to research, award grants and fellowships to five researchers and sponsored an SBMA workshop with specialists from several related disciplines.

We look forward to a great 2025! Download the 2024 Annual Report.

Just $10 a Month Can Make a Tremendous Impact

Help us fund life-changing research, provide more resources for patients and families, and support the global KD community.

DONATE

LATEST NEWS

KDA is Pleased to Welcome Dr. Nicholas Holdgate to the Board of Directors!

Dr. Nicholas (Nick) Holdgate is a community-based Rheumatologist based in Charleston, South Carolina. Originally from Nantucket, Massachusetts, Nick earned a degree in physics with minors in mathematics and engineering at the College of Charleston. He began his career at NASA's Goddard Space Flight Center before returning to Charleston to attend medical school at the Medical University of South Carolina. He later completed a Rheumatology fellowship at Duke University.

In addition to his clinical work, Nick participates in disease registries and clinical trials and is deeply motivated to better understand Kennedy's Disease, both as a physician and as someone personally affected by it. His active involvement in the KDA community and commitment to advancing research make him a valuable addition to our board.

Please join us in welcoming Nick to the KDA Board!

Get to Know Nick

Registration for the 2026 International Kennedy's Disease Patient and Scientific Conference Opens in August!
Look for the email with all the information next month in your inbox.

Read the Press Release: AnnJi Pharmaceutical Company Announces Positive Phase 1/2a Results for AJ201 in Spinal and Bulbar Muscular Atrophy (SBMA) Patients

Promising News for KD Patients

Early Trial of New Drug Shows Positive Results

AnnJi Pharmaceutical shared encouraging results from an early clinical trial of a potential new treatment for KD - AJ201.

Summary of the Clinical Trial

In a recent 12-week study, patients with KD who took AJ201 showed improvements in physical and muscle function, including walking farther in a walking test, while those on a placebo saw slight declines. The drug was well tolerated with no major side effects. Based on these promising results, AnnJi plans to move forward with the next phase of clinical trials.

KDA Earns a Four-Star Rating From Charity Navigator

We're excited to share that the KDA has been evaluated by Charity Navigator, the nation's largest charity evaluator, and earned a Four-Star Rating. This is the

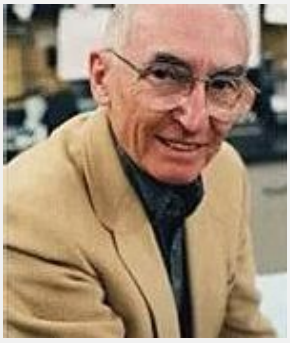
highest possible rating on Charity Navigator.

This achievement for the KDA couldn't have happened without you and your support.

Thank you for being part of our family as contributors, advocates, funders, and volunteers - you're all an important part of our mission.

COMMUNITY NEWS

A Visit with Dr. William Kennedy



Terry Thompson recently spent an afternoon with Dr. Kennedy in his home in St. Paul, Minnesota to talk about his medical career and the disease named after him.

Learn about the remarkable life and legacy of Dr. William Kennedy, the neurologist who first identified Kennedy's Disease. Get to know the man behind the name and the lasting impact of his groundbreaking work.

Read the Full Story

Driven by Love: A Journey Through Kennedy's Disease

Carla shares the story of her late husband Stanley, a Master Automotive Technician with a lifelong passion for cars. This heartfelt tribute is a reminder of why continued research and support are so important.

Read the Full Story

Upcoming Events

Virtual Meeting with the Board of Directors
October 18, 2025, 11 AM EST
You're invited to a special meeting with the Board—a time for open conversation, collaboration, and shared ideas. Learn More

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2026 International Patient and Scientific Conference
February 27-March 2, 2026
Registration Opens in August!

Support Groups

Men's Support Group: Get Connected

Carrier Support Group: Get Connected

Care Partners Support Group: Get Connected

More Resources

FUNDRAISING EVENTS

Dim Sum Give Some Serves Up Support and Awareness

Milwaukee's culinary stars came together once again for the annual Dim Sum Give Some fundraiser, led by Top Chef finalist Dan Jacobs. The April 13th event featured over 25 celebrated chefs—including two James Beard Award winners and seven of Dan's fellow Top Chef contestants. This year's event treated guests to an unforgettable tasting experience

while raising critical funds for the Kennedy's Disease Association. Since it began, the event has raised over $150,000 to support research and awareness for Kennedy's Disease.

A Record-Breaking Day at the 13th Annual KD Golf Scramble

The skies cleared just in time for the 13th Annual KD Golf Scramble, and what a day it turned out to be! With 120 golfers, a packed venue, heartfelt moments, and incredible generosity, this year's event raised a record-breaking $42,000 for the Kennedy's Disease Association, bringing the Texas Golf Scramble's total to $425,000. From the golf auction to raffle tickets, every act of support mattered.

Read the Article

Bay Area Community Shines on Rare Disease Day

Fred Briones and his dedicated community in the San Francisco Bay Area once again made a big impact with their Rare Disease Day 2025 fundraiser which took place on March 1st. They far exceeded their original goal of $5,000 by raising an amazing $9,625 in support of the Kennedy's Disease Association. This events is one of the KDA's largest annual fundraisers, and we are thankful for their continued commitment and generosity.

GET INVOLVED

Calling All Canadians

KDA is exploring the idea of hosting an informal community gathering in the Toronto area for Canadian individuals and families impacted by Kennedy's Disease, as well as researchers, the medical community and advocates. This gathering is an opportunity to connect, share experiences, explore options for local support, and begin the conversation about forming a Toronto-area KDA Chapter.

To make this event a reality, we need input from the Canadian KD community. Please Complete our Survey.

Ways to Make a Difference

Step Up for Kennedy's Disease

There's No Deadline to Make a Difference!

Join the 100-Step Challenge **anytime**, and in whatever way works best for you. Every step helps raise awareness and funds for Kennedy's Disease research. Participation is easy - and it's FREE! Learn more.

Not ready to participate but still want to support? Donate today!

Volunteer

Are You Passionate About Raising Awareness and Connecting the KD Community Around the World?

We're looking for volunteer support in these areas:

Social Media: Help us manage our social media pages. Some experience with social media platforms (Facebook, Instagram, LinkedIn and YouTube) and Canva is required, but we'll provide training and support in areas like content and video creation, developing a social media strategy and content calendar. Interested? Contact us today!

Event Volunteers: We're looking for dedicated volunteers to support the 2026 International KD Patient and Scientific Conference! Opportunities are available for photographers, videographers, and general volunteers, both on-site and behind the scenes. Your time and talent can help make this important event a success. Please reach out to us today to Get Involved!

See all Volunteer Opportunities.

Volunteer Testimony

I really enjoyed listening in and learning more about the work KDA is doing, from the creative and varied approaches to fundraising to all the exciting events planned for next month.

What stood out to me most was how focused and well-organized the meeting was, with each person contributing thoughtful updates.

It was inspiring to see how everyone plays a role in moving the organization forward.

Dan T., KDA Volunteer & Fundraising Committee Member

Next Volunteer Meeting

August 12 @ 3 PM EST | RSVP

Join the KD Global Patient Registry

This registry is one of the most important ways patients and carriers can contribute to advancing science and care.

Why it matters:

- Helps researchers design better studies
- Aids in recruitment for clinical trials
- Builds a clearer picture of how the disease affects people over time
- May lead to improved treatments and ultimately, a cure

Learn More About The KD Registry.

Enroll Now

Help Others Discover the KDA by Leaving a Google Review

Your story can inspire and support those newly diagnosed and searching for trusted information and a supportive community.

Write a Google Review

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