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

Kennedy's
Disease
Association

QUARTERLY NEWSLETTER

SPRING 2026

Welcome to the Spring 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.

Uniting to Conquer Kennedy's Disease - Supporting Those Affected

We're pleased to share our renewed vision, created to clearly define why the Kennedy's Disease Association exists and who we serve.

Everything we do at the KDA is focused on improving the lives of those affected by Kennedy's Disease, today and in the future.

We're dedicated to advancing research to develop treatments and ultimately a cure for Kennedy's Disease while supporting our members through education, information, and meaningful community connection.

READ VISION & MISSION

Upcoming Events

10th Annual DimSum Give Some
April 19, 2026 | 12 PM to 3 PM
Milwaukee, Wisconsin
BOOK RESERVATIONS

14th Annual Golf Scramble
May 2, 2026 | Magnolia, Texas
REGISTER

Support Groups

Men's Support Group: Get Connected

Carrier Support Group: Get Connected

Care Partners Support Group: Get Connected

More Resources

Highlights From the KDA 2026 International Patient and Scientific Conference

The 2026 International Patient and Scientific Conference was a tremendous success, bringing together patients, caregivers, researchers, and advocates for a powerful few days of learning, connection, and inspiration.

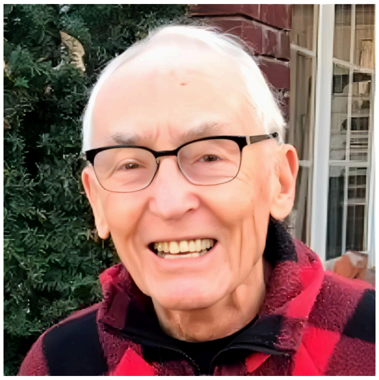
➡️ **CONFERENCE HIGHLIGHTS & PHOTOS**

Reflections and Gratitude From the KDA Community

The Kennedy's Disease Association (KDA) honors the life and legacy of Dr. William R. Kennedy, whose groundbreaking work forever changed the lives of individuals and families affected by spinal and bulbar muscular atrophy (SBMA), a rare neuromuscular disease now known around the world as Kennedy's disease.

➡️ **DOWNLOAD**: In Memory of Dr. William R. Kennedy
By Terry Thompson, President
Kennedy's Disease Association

Donate in Memory of Dr. Kennedy



Dr. William Robert Kennedy (1927-2026)

Learn More About Dr. Kennedy's Life and His Remarkable Journey

Remembering Dr. William R. Kennedy, A Legacy That Lives On for Kennedy's Disease

Dr. Kennedy's obituary, published by the Minnesota Star Tribune: William Robert Kennedy Obituary | 1927 - 2026

A Visit With Dr. William Kennedy, by Terry Thompson, President, KDA

LATEST NEWS

Advancing SBMA Research Through Global Collaboration

Dr. Rachel Harding (University of Toronto, SGC-Toronto), in collaboration with Agora Open Science Trust and the Structural Genomics Consortium (SGC), is leading a project focused on accelerating the development of targeted therapeutic strategies for Kennedy's Disease, also known as Spinal Bulbar Muscular Atrophy (SBMA). Dr. Harding received a research grant from the KDA in 2025 to fund this project. She will collaborate with SBMA researchers in Italy and the UK in project implementation.

READ THE NEWS RELEASES:
New Open Science Project Funded to Accelerate Therapeutic Discovery for Spinal Bulbar Muscular Atrophy
➡️ AGORA Open Science Trust
➡️ Structural Genomics Consortium

2026 SBMA Research Grants and SBMA Fellowship

Applications are still being accepted for KDA SBMA Research Grants and the Waite-Griffin SBMA Fellowship.

LEARN MORE

➡️ **DOWNLOAD:** 2026 SBMA Research Grants - Request for Proposals

➡️ **DOWNLOAD**: 2026 KDA Waite-Griffin SBMA Fellowship - Request for Proposals

WhyBehindWeakness.org

Late-Onset Neuromuscular Disease Consortium (LONDC)

Why Behind Your Weakness

The Late-Onset Neuromuscular Disease Consortium (LONDC), a project of the American Neuromuscular Foundation (ANF), recently launched its national campaign about the 20 identified late-onset neuromuscular diseases, including KD/SBMA, that are frequently misdiagnosed or not diagnosed because of the lack of familiarity by physicians. KDA has been a member of the LONDC since its inception, and KDA President, Terry Thompson has served on the Steering Committee working on the campaign and related topics for the past three years.

The website for the campaign, "**Why Behind Your Weakness**," is now live. It includes general information about these conditions, many of which are rare, and a downloadable "clinical decision tool" to help physicians identify a possible late-onset neuromuscular disease.

LEARN MORE

FDA Seeks Feedback from Rare Disease Community

The U.S. Food and Drug Administration (FDA) is inviting members of the rare disease community to share feedback on current educational resources that support the development of safe and effective therapies for rare diseases.

GET INVOLVED

Alleviating Barriers for Caregivers

Urge Congress to Support Family Caregivers

Family caregivers serve a vital role for many children and adults affected by neuromuscular diseases. Currently, there are two bipartisan bills that will help alleviate some of the challenges faced by caregivers:

1. The **Alleviating Barriers for Caregivers Act** (S. 1227 / H.R. 2491) requires CMS and SSA – with input from family caregivers, including caregivers with disabilities, and individuals entitled to or filing for benefits – to review and simplify processes for tasks such as establishing eligibility, enrolling in/maintaining eligibility, and utilizing the full benefits available in Medicaid, Medicare, CHIP, SSI, and SSDI.
2. The **Credit for Caring Act** (S.925/H.R. 2036) creates a non-refundable tax credit of up to $5,000 to offset some costs of caregiving.

Please urge your members of Congress to cosponsor these bills today!

Facing Change with Courage

John Lauber's Journey

Many older adults quietly face challenges like loneliness and isolation, loss of identity, and uncertainty about what the future holds. It's not always talked about, and that's why stories like John Lauber’s matter.

John, KDA’s Treasurer, was recently featured on *For The Love of Boomers*, a YouTube channel created by John Frantz, author of the *For The Love of the Baby Boomer* book collection of short stories, essays and poems.

In his interview, John shares his story of adapting to Kennedy’s Disease. It's a powerful reminder that even in the face of change, there is strength, resilience, and hope.

➡️ **WATCH NOW**: *For The Love of Boomers - John Lauber and John Frantz*

Stay Alert and Stay Safe Online

We’ve recently been made aware of suspicious activity and spam messages appearing on KDA Facebook posts. This is incredibly upsetting, and we want to make sure our community stays protected.

What to watch for:
✅Comments or messages from unfamiliar accounts
✅Links asking you to click and provide personal information
✅Profiles impersonating members of our community or the KDA

What to do:
🚫Do NOT click on any suspicious links
🚫Do NOT share personal or financial information

Important!
✅ Report the comment or profile to Facebook immediately
✅ Alert the KDA of suspicious activities
✅ Delete, block or ignore any suspicious interactions

We are actively monitoring and removing spam, but we will also rely on our community to help flag suspicious activity. Please contact the KDA if you have any concerns.

Let’s keep our social media pages safe, respectful, and supportive for everyone!

FUNDRAISING

Start Your Fundraiser Any Time, Anywhere in the World!

Every Step Brings Us Closer to a Cure for Kennedy's Disease

Many men affected by Kennedy’s Disease can’t walk 100 steps without assistance. There is no cure – yet, but there is hope. The 100-Step Challenge symbolizes their daily struggles, strength and perseverance. With greater awareness and the right support, we can help create a world where no one has to face this journey alone.

How It Works:

1. Sign up as an individual to start your own peer-to-peer fundraiser.
2. Raise funds your way by setting a goal that's meaningful to you.
3. Share your story and invite friends, family, and your network to support your efforts using our simple online tools. Create your fundraiser to access our easy-to-use email and social media templates.

Your participation helps shine a light on a condition that often goes unnoticed, while honoring the strength of every person living with Kennedy’s Disease and the people who support them.

Your steps, your story, your strength – they all matter. Let’s take them together!

Create Your Fundraiser

How the 100-Step Challenge Was Born

John Lauber, KDA’s Treasurer, was diagnosed with Kennedy’s Disease in 2005. In 2024, he turned determination into action by launching the 100-Step Challenge, and raised an incredible $35,000 for KDA. To date, the fundraiser has raised more than $115,000 for Kennedy's Disease. Discover the inspiring story behind how the 100-Step Challenge began.

READ NOW

John invites others to join him by following his simple steps to create a successful fundraiser.

➡️ **DOWNLOAD**: John's 100-Step Challenge Roadmap

Join the 100-Step Challenge

One of KDA's most anticipated events is back... and 2026 marks a truly meaningful milestone.

Book Reservations

Dim Sum Give Some 2026 - A Culinary Event with Heart

Sunday, April 19, 2026 | 12:00 PM to 3:00 PM
Italian Community Center, 631 E. Chicago St., Milwaukee, Wisconsin

Chefs Dan Jacobs and Dan Van Rite are proud to once again bring this incredible culinary fundraiser to life in support of the KDA.

This year also marks 10 years since Dan Jacobs was diagnosed with Kennedy's Disease, adding deeper purpose to an already powerful event.

This year's event is anticipated to be the largest yet, featuring a lineup of 35 chefs, including fellow *Top Chef* and *Tournament of Champions* contestants, alongside award-winning chefs from across the country.

Building on the momentum of previous years, and more than $150,000 raised to date, this event continues to raise awareness and funds for Kennedy's Disease through the power of food, community, and generosity.

14th Annual KD Golf Scramble

Saturday, May 2, 2026 | High Meadow Ranch Golf Club, Magnolia Texas

Where Hope Exists, So Does Purpose. Join the KD Golf Scramble!

What started in 2011 as a small but determined effort has grown into a meaningful fundraising tradition for the Kennedy's Disease community.

Six pioneers of the Kennedy's Disease (KD) Golf Scramble were united by purpose: to confront the lack of research, resources, and awareness surrounding this rare condition. They turned frustration into action, choosing the golf course as their platform to make a difference.

That first swing raised $5,000. Thanks to the generosity of supporters like you, the KD Golf Scramble has raised over $425,000, including a record-breaking $42,000 in 2025 alone. These funds directly support research, education grants, and initiatives like the important Banbury Conferences.

Here's how you can be part of the 14th Annual KD Golf Tournament:

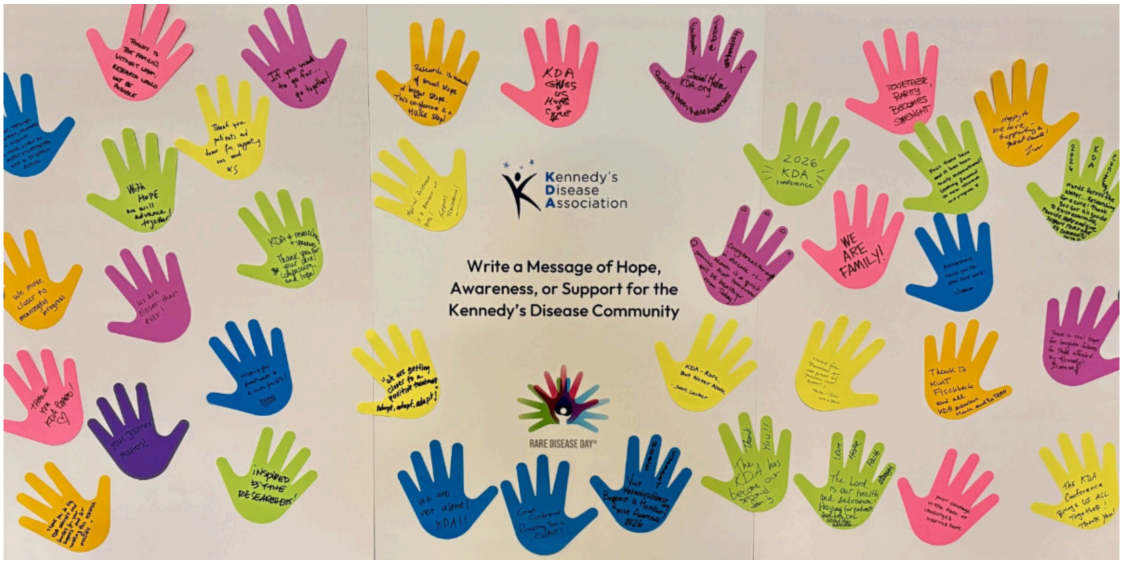
- Register to play, participate or support the event as a sponsor
- Donate to support KD research

- Purchase raffle tickets for exciting prizes

Let’s come together once again to drive change.

➡️ LEARN MORE
➡️ **DOWNLOAD**: 2026 KD Golf Scramble Brochure

REGISTER | DONATE | GET TICKETS



Bay Area Rare Disease Fundraiser

Standing Together for the Global KD Community

This summer, the Bay Area Rare Disease Fundraiser will return to celebrate its 8-year anniversary! Over the years, this incredible event has raised more than $100,000 to support Kennedy's Disease research and education initiatives.

The fundraiser will feature local artists, guest speakers from the rare disease community, films, a silent auction, and so much more. This year, the initial fundraising goal is $7,000.

Stay tuned – details on the date and location will be shared soon!

If you'd like to support this important effort, please make a donation through Tiltify.

DONATE

Have a Fundraising Idea?

Every great event starts with an idea, and we’d love to hear yours! Whether it’s a local walk, bake sale, trivia night, online auction, or something entirely new, your creativity helps fuel awareness, research, and support for those living with Kennedy’s Disease.

No Idea is Too Small - Every Effort Makes a Difference!

Just $10 a Month Can Make a Tremendous Impact

Help us fund life-changing research, provide more resources for patients and

The KDA can provide guidance, promotional materials, and online fundraising tools to help bring your idea to life.

Share your fundraising idea by emailing us at info@kennedysdisease.org, and let's work together to make it happen!

families, and support the global KD community.

Help Find a Cure

Shop. Support. Make a Difference.

Looking for a meaningful way to support the KDA community?

Every item purchased helps drive awareness and advances the search for a cure for Kennedy's Disease. It's a simple way to turn everyday items into a powerful show of support.

Thank you for supporting the mission that matters most: a world without Kennedy's Disease.

KDA Gift Shop

GET INVOLVED

Ways to Make a Difference

"Volunteering with the KDA is a way to honor my late husband's memory as well as those that passed before and since from Kennedy's Disease and their related causes.

Volunteering allows me to be part of something meaningful, that will help support the other members of my family that still live with Kennedy's Disease.

As a volunteer, I not only give of my time working behind the scenes, helping with projects to help raise money to support this organization, I also volunteer my story; my story as a partner of a KD patient, a wife, a mother of a carrier, a sister-in-law, a grandmother and now as a widow.

Please consider joining our group of volunteers! We have new projects in the works and would love to have your input, hear your thoughts, ideas and suggestions to help us make the KDA the best it can be!

Carla H.
KDA Volunteer & Fundraising Committee Member

Volunteer

GET INVOLVED

See all Volunteer Opportunities.

Next Volunteer Meeting

May 12 @ 3:00 PM ET | JOIN US

Kennedy's
Disease
Association

Give Through a Donor-Advised Fund

A Donor-Advised Fund (DAF) lets you support the causes you care about most — like the Kennedy's Disease Association, while maximizing tax benefits and giving on your schedule.

Make an impact today. Support families, research, and hope for a cure.

WHAT IS A DONOR-ADVISED FUND?

A Donor-Advised Fund (DAF) is a charitable account you fund now, then recommend grants from over time to the charities you love. It's a flexible, simple, and tax-efficient way to support the Kennedy's Disease Association.

TAX BENEFITS

Claim a charitable deduction when you fund the account.

FLEXIBLE GIVING OPTIONS

Recommend grants to the Kennedy's Disease Association now or over time.

SIMPLE GIVING

Manage all of your charitable donations from one account.

kennedysdisease.org

Contact us today at info@kennedysdisease.org

By recommending a grant to the KDA through your DAF, you can help fund research, education, and support programs for individuals and families affected by Kennedy's Disease.

LEARN MORE

Join the KD Global Patient Registry

Help Advance Research and Care for Kennedy's Disease

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

Your participation:

- 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

About Us | Contact Us | FAQs | Privacy Policy | DONATE

MAKE SURE YOU DON'T MISS IMPORTANT KDA UPDATES

Did you find this email in your junk or spam folder?
If you’re using **Gmail**, please drag this email to your Primary tab.
If you’re using **Outlook**, add us to your contacts to ensure you receive all future updates.