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

Kennedy's
Disease
Association

QUARTERLY NEWSLETTER

WINTER 2026

Welcome to the Winter 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.

Join Us in Orlando

Only 4 Weeks Left to Register for the 2026 KDA International Patient and Scientific Conference

Online registration is available through **February 23rd**. Onsite registration will be available at a higher rate.

See the Conference Agenda.

Register Today

Upcoming Events

2026 International Patient and Scientific Conference
February 27-March 2, 2026
REGISTER

Rare Disease Day
February 28, 2026
DONATE

Support Groups

Men's Support Group: Get Connected

Carrier Support Group: Get Connected

Care Partners Support Group: Get Connected

More Resources

Discover the Voices Shaping the 2026 KDA Conference

Momentum is building for the 2026 KDA International Patient and Scientific Conference, and we're excited to spotlight what's ahead.

If you missed it the first time, we're resharing a powerful video message from our keynote speaker, Dan Jacobs, who shares a preview of what he'll be bringing to the stage.

You can also learn more about Dan's story and see our lineup of KDA Conference Speakers, each bringing their unique expertise and lived experience to this year's program.

We can't wait to welcome you and bring our community together for a conference filled with connection, learning, and hope!

Limited Rooms Remain - Book Your Accommodations for the KDA Conference Today!

Rosen Plaza

9700 International Drive, Orlando, FL 32819

Book your stay at our official host hotel by this **Thursday, February 5th** to receive the exclusive KDA conference rate.

Book Your Room Here

Homewood Suites

5893 American Way, Orlando, FL 32819

Book your stay at our overflow hotel by **Wednesday, February 18th** to receive the exclusive KDA conference rate.

Book Your Room Here

Official 2026 KDA Conference Hoodies

Wrap yourself in comfort, community, and purpose with an official KDA Conference Hoodie, designed to keep you warm while showing your support for the KDA community.

This year's hoodies were thoughtfully selected and feature premium, sustainably sourced materials, offering a classic, comfortable fit that's perfect for conference days, travel, or everyday wear.

Order Options

➡️ Place your order by **February 6** for **delivery and pickup at the KDA Conference**.

➡️ Place your order for **delivery right to your home**.

For order assistance please, contact KDA.

With soft organic fabrics, durable construction, and a clean, modern look, these hoodies are made to last - *just like the strength of our community*.

Call for Silent Auction Donations – 2026 KDA Conference

The Silent Auction is a conference highlight that helps raise funds to support KDA initiatives while giving attendees the chance to win fantastic prizes.

We're seeking donations and welcome a wide variety of items, such as gift baskets, artwork, products, gift cards, or unique experiences. This is also a great opportunity to showcase your business to the KDA community!

If you'd like to contribute, please contact us. Thank you for helping make this year's auction our best yet!

LATEST NEWS

A Legacy That Changed Lives

It is with deep sadness that the Kennedy's Disease Association shares the passing of Dr. William Robert Kennedy, whose work fundamentally transformed the lives of individuals and families affected by Kennedy's Disease.

Dr. Kennedy passed away peacefully at the age of 98, leaving behind a legacy that continues to guide research, care, and community.

The Kennedy's Disease Association is deeply grateful for Dr. Kennedy's life, his work, and the hope he gave the KDA community.

Dr. Kennedy's work gave our community more than a diagnosis - it gave us visibility, validation, and a shared starting point for progress.

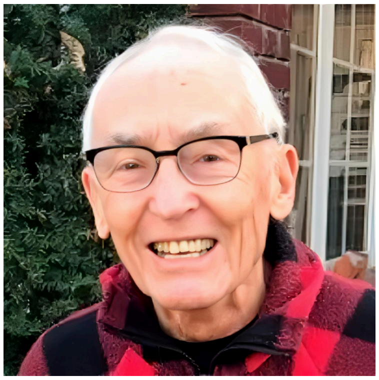
His legacy lives on through every person diagnosed, every family supported, and every step forward in research to find a cure for Kennedy's Disease. As we continue to support families and advance research, we do so standing on the foundation he built.

We extend our deepest condolences to the Kennedy family and honor Dr. Kennedy with continued commitment to the community he helped bring together.

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

Honoring Dr. Kennedy's Legacy

In accordance with the family's wishes, donations may be made to the Kennedy's Disease Association in Dr. Kennedy's memory. If you choose to give, please be sure to select "In Memory of Dr. William R. 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

Donate in Memory of Dr. Kennedy

NIDO-361 Phase 2 Trial

A Moment of Reflection, Resilience, and Hope

Dear KDA Community,

With every clinical trial, there is hope - not only for a potential treatment but for the very possibility of change in a disease that affects so many lives. That's why this update comes with so many mixed emotions.

The recently completed Phase 2 trial of NIDO-361, an experimental treatment evaluated for Kennedy's Disease (SBMA), did not demonstrate the expected benefits in its primary outcomes, and the company developing it has decided to wind down operations.

For many in the KDA community, NIDO-361 represented hope, and we recognize this news may bring much sadness, frustration, and grief. These reactions reflect the love and commitment we have for one another and the possibility of a future without Kennedy's Disease.

At the same time, this trial taught us some valuable lessons. The execution of a complex, international clinical study shows that our community can come together across borders, contribute to science, and create a path for future research, even when the outcome isn't what we had hoped for. Every study builds knowledge, and helps researchers refine their tools, improve study design, and better understand what doesn't work, which is just as important as knowing what does. Our community's participation matters significantly, and your contributions advance science and honor the efforts of every volunteer.

We remain steadfast in our belief that innovation continues, researchers are learning, and new possibilities are emerging. Our commitment to treatments, support, and hope for patients and families living with KD remains unwavering.

Thank you for your strength, your hope, and your continued engagement as we walk together, not just through setbacks, but through every step forward.

With compassion and community,

The Kennedy's Disease Association

International Kennedy's Disease Newsletter

The second edition of the International Kennedy's Disease Newsletter was issued in Fall 2025, featuring updates on activities in Australia, France, Italy, Japan, the UK and U.S. The newsletter will be distributed twice each year.

DOWNLOAD NOW!

2026 SBMA Research Grants

Request for Proposals

This year, KDA plans to fund one or more research grants to further the understanding of the pathological mechanisms or possible treatments for Kennedy's Disease.

Applications from junior investigators and senior post-doctoral fellows are encouraged.

Learn more about the SBMA Research Grants and application guidelines:

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

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KDA Waite-Griffin SBMA Fellowship

A Career-Development Opportunity for Research into Kennedy's Disease

Request for Proposals

KDA believes it is important to support young researchers who are enthusiastic about their work. We believe that by doing so, we will encourage them to include research in SBMA in their future career research plans.

Learn more about the Fellowship, eligibility and application guidelines:

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

Schedule and Review Process for SBMA Research Grants and Fellowship

Completed Applications Due: June 1, 2026

Scientific Review Board Review: August 2026

Notification of Award: September 2026

COMMUNITY NEWS

With Gratitude – Honoring Joan's Service on the KDA Board

The KDA would like to share an important update with our community, along with our deepest thanks and appreciation to Joan Sorensen who has made a difficult decision to step down from the KDA Board of Directors, effective January 31, 2026.

Joan has been a dedicated, compassionate, and valued member of the Board, and we are incredibly grateful for the time, energy, and heart she has given to the KDA.

Grateful Beyond Words

While we will miss Joan's presence on the Board, we are grateful beyond words that her advocacy, leadership, and care for the KD community will continue in so many meaningful ways. Joan will remain an important part of KDA through her continued involvement in:

- Leading and co-leading the Carrier and Care Partner support groups
- Providing ongoing follow-up and outreach to individuals who need extra support
- Coordinating messages of care and gratitude on behalf of KDA
- Supporting the KDA's Welcome Committee
- Continuing her work on the Carrier Survey
- Hosting a Carrier breakout session for virtual attendees at the upcoming KDA conference

Please join us in thanking Joan for her outstanding service and in wishing her strength, good health, and continued success in the year ahead. KDA is better because of her, and that impact will be felt for many years to come.

Year-End Giving Campaigns

We want to take a moment to recognize one of the many ways our community came together to support the KDA in 2025.

Community Spotlight: Turkey Trot 5K - A Strong Finish to 2025 in Texas

Signage provided with compliments of Sign Gypsies, Inc. Thank you for helping bring the event to life!

On a bright and beautiful day November 15th, approximately 50 people gathered to raise funds and awareness for Kennedy's Disease by participating in Saddle Creek Forest subdivision's first ever KDA Turkey Trot in Waller, Texas. People walked, ran, waddled, golf carted, and even rode bikes to complete this 5K!!! Prizes were given for 1st, 2nd, and 3rd places, but everyone received a Turkey medal for completing the 5K.

A great time was had by all with donations from Chick-Fil-A, Cookie Meister (2nd place custom cookie basket), Sign Gypsies (custom Turkey Trot sign), Sabrina Metcalf (3rd place beautiful floral arrangement), and various local folks providing food, hot chocolate, Irish coffee, and multiple children's games.

The total amount raised was $1,238.40!!!!! Our thanks to Kathy Tovar who coordinated this event, and to all that supported us in such a magnificent way!!

By Louise Goforth

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!

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!

Thinking About Hosting a Fundraiser In Your Community?

Local events like the Turkey Trot 5K are a powerful way to raise awareness, build connection, and support the KDA community.

Sign made by Teresa Noack

We'd love to help you get started. Contact us.

FUNDRAISING

Rare Disease Day - February 28, 2026

Standing Together for the Global KD Community

On Rare Disease Day, the KDA will join millions of people from around the world to raise awareness for the 300 million people living with a rare disease, including those affected by Kennedy's Disease.

For the KDA community, Rare Disease Day is a reminder of the urgent need for research, education, and support for individuals and families navigating life with KD.

About Rare Disease Day

Rare Disease Day is the official international awareness-raising campaign for rare diseases, observed annually on the last day of February.

How You Can Help

RARE DISEASE DAY®

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.

Help Find a Cure

Your support fuels the work of the KDA to advance research, strengthen patient resources, and build hope for a future with effective treatments, and one day, a cure. Every gift, no matter the size, helps move us forward.

On this Rare Disease Day, we invite you to stand with the KD community to amplify our voices, honor those living with KD, and help drive progress toward better care and a brighter future. It's an opportunity to come together and make a meaningful impact.

Thank you for being part of this journey.

DONATE

GET INVOLVED

Ways to Make a Difference

"The KDA is extremely fortunate to have such a dedicated team of volunteers that work very hard to raise awareness and funds for Kennedy's Disease.

I am deeply grateful for all the work by KDA volunteers - they have worked countless hours and given unwavering effort to this group and the KDA.

The volunteer group has many ideas but too few volunteers to do the work to carry them out quickly enough.

I would like to appeal to others who are interested in finding a cure sooner than later to get involved in volunteering with us. This experience would prove to be highly rewarding."

Connie S.
KDA Volunteer & Fundraising Committee Member

Give Through Your Donor-Advised Fund (DAF)

A Donor-Advised Fund (DAF) is an easy and tax-efficient way to support the KDA and make a lasting impact on our search for a cure.

Volunteer

KDA is in need of dedicated volunteers for the 2026 International KD Patient and Scientific Conference

We need general volunteers, both on-site and behind the scenes. Please help make this important event a success.

GET INVOLVED

See all Volunteer Opportunities.

Next Volunteer Meeting

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

February 10 @ 3:00 PM ET | JOIN US

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

Charity Navigator
FOUR-STAR

Platinum
Transparency
2025
Candid.

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

MAKE SURE YOU DON'T MISS IMPORTANT KDA UPDATES

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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.