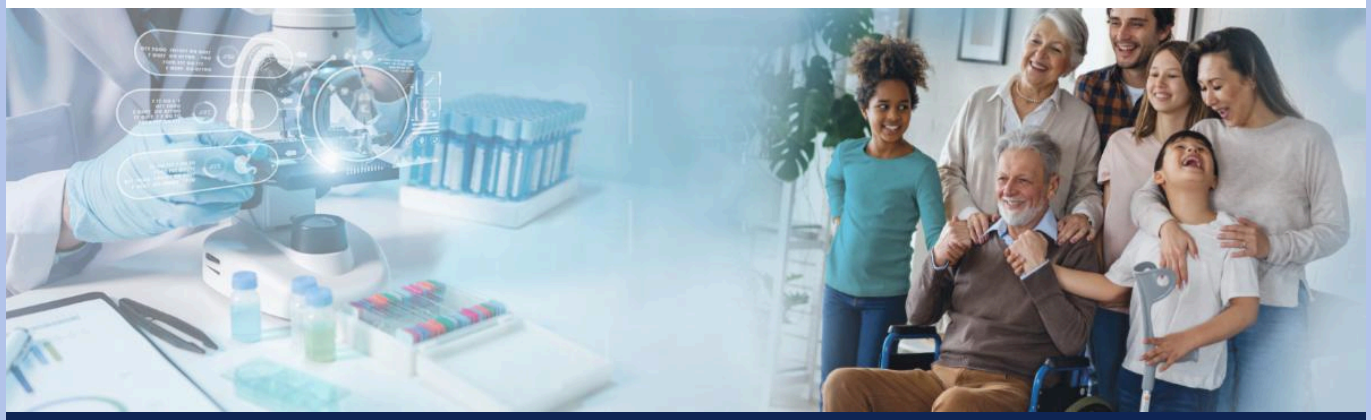
Our mission is to inform, support, educate, fund research, and find a cure for Kennedy's Disease.

Kennedy's Disease Association



QUARTERLY NEWSLETTER

SUMMER 2026

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.

Uniting to Conquer Kennedy's Disease - Supporting Those Affected

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

➡️ READ VISION & MISSION

Upcoming Events

October 4-6, 2026: KDA Banbury Workshop

Support Groups

Men's Support Group: Get Connected

Carrier Support Group: Get Connected

Care Partners Support Group: Get Connected

More Resources

COMMUNITY NEWS

KDA Welcomes Two New Members to Our Board of Directors

The KDA is pleased to welcome Pete Sariano and Eric Park, M.D. to our Board of Directors. Pete and Eric bring valuable expertise, personal connections to the KD community, and a shared commitment to advancing research, support, and hope for individuals and families affected by Kennedy's Disease.

Meet Pete Sariano

Pete became involved with the KDA while searching for clinical trial opportunities for a family member living with KD. That experience inspired him to to volunteer and join the Board to make a meaningful impact for the KD community.

Pete holds a Ph.D. in Biomedical Engineering and brings extensive experience at the intersection of science, healthcare innovation and business strategy. He has supported pharmaceutical companies with Research and Development strategy, corporate strategy, and transformation initiatives, and currently leads strategy and transformation efforts efforts at a medical technology company.

➡️ Get to Know Pete

Meet Eric Park, M.D.

Eric was diagnosed with Kennedy's disease in 2025 after many years of gradually developing symptoms. After attending his first KDA conference in Orlando earlier this year, Eric was inspired to become more involved the KDA community and help advance efforts towards treatments and therapies.

Eric brings more than 20 years of clinical development and medical affairs experience in the biotech industry, with expertise in in designing and executing Phase 1-3 clinical trials. A nuclear medicine physician by training, Eric previously practiced in the San Francisco Bay Area and is eager to apply his medical and research expertise to support KDA's mission.

➡️ Get to Know Eric

Please join us in welcoming Pete and Eric to the KDA! We are grateful for their commitment and look forward to the expertise, passion, and leadership they bring to our community.

KDA Launches Search for Our First Executive Director

KDA has launched a nationwide search for our first Executive Director. This new leadership position is an important step in strengthening our organization and expanding our ability to raise funds that support research, patient programs, and our mission to accelerate the development of effective therapies—and ultimately a cure—for Kennedy's Disease.

The position is fully remote and open to qualified candidates anywhere in the United States. (LinkedIn lists a Maryland location only because a location is required for the posting).

If you know someone with nonprofit leadership and fundraising experience who would be a great fit, please share the job posting with them.

➡️ **Read and Share the LinkedIn Job Posting**: Executive Director Opportunity at Kennedy's Disease Association

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Arvinas Advances ARV-027 Clinical Development for Kennedy's Disease

Arvinas, Inc., a biotechnology company specializing in targeted protein degradation therapies, recently announced that it is sharpening its research and development focus following the approval of the PROTAC degrader therapy.

The company highlighted four priority programs, including ARV-027, an investigational treatment for Kennedy's Disease, also known as Spinal and Bulbar Muscular Atrophy (SBMA).

➡️ **Read the Article**: Arvinas Advances ARV-027 Clinical Development for Kennedy's Disease

2026 KDA Banbury Workshop: Advancing Research to Better Understand Kennedy’s Disease

This fall, 20 leading researchers from around the world will come together at the prestigious Banbury Center at Cold Spring Harbor Laboratory in Lloyd Harbor, New York, from October 4-6, 2026, for a focused scientific workshop dedicated to advancing Kennedy's Disease (SBMA) research.

The topic of the three-day workshop: *Transcriptional and Epigenetic Dysregulation in Spinal Bulbar Muscular Atrophy (SBMA)* will focus on how Kennedy's Disease disrupts the normal genetic instructions that tell cells how to function. The goal is to find ways to restore those instructions and keep muscle and nerve cells healthy to improve outcomes for people living with Kennedy’s Disease.

The annual workshop represents an important step toward uncovering new insights and potential treatment approaches for the Kennedy's Disease community. The workshop is made possible with thanks to the annual Texas KD Golf Scramble.

KDA Joins Rare Disease Organizations in Opposing Proposed Changes to Federally Funded Research Grants

The KDA has joined 34 rare disease patient advocacy organizations, along with the Muscular Dystrophy Association (MDA) to voice our concern about the proposed changes to regulations for federally funded scientific research grants.

The proposed changes call for increased political oversight at the expense of rigorous scientific review of grant proposals. It would also allow for termination of a federal grant at any time, limit the ability to use federal grants for publications or conference attendance, and reduce international collaboration among researchers on federal grants.

These proposed changes would have significant impact on federal grants for research into Kennedy's Disease and other neuromuscular diseases, potentially slowing the discovery of new treatments and therapies.

KDA is actively monitoring this issue to advocate for policies that support high-quality scientific research. We will keep our members informed on further developments.

➡️ Read the Joint Advocacy Letter

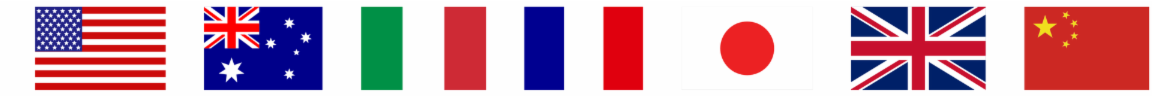
KD Voices Launching Soon!

KD Voices is a platform for patients and care partners to share their lived experience with pharmaceutical and biotechnology companies. This is the next step in the evolution of KDA's efforts to ensure patient and care partner experiences are considered in the drug development process. Like the 2023 Voice of the KD/SBMA Patient Report, KD Voices will provide important patient and care partner perspectives and insights for use in therapy development and the evaluation of clinical trial results.

KD Voices is modeled on similar "community advisory boards" in other rare diseases including "HD-COPE" (Huntington's Disease Coalition for Patient Engagement). A small number of volunteers will be selected to participate for 2-3 years and will be asked to be available for consultation with pharmaceutical and biotechnology companies when opportunities arise. Participants will meet at least annually to discuss research trends and learn about any upcoming clinical trials.

KD Voices will be managed by the KDA Board of Directors. More details and the opportunity to volunteer will be provided via email in the near future.

International Kennedy's Disease Newsletter



The Spring 2026 edition of the **International Kennedy's Disease Newsletter**, a collaborative effort of Kennedy's Disease patient advocacy groups in seven countries, was issued in May. The newsletter featured updates from each participating country, including Australia, China, Italy, France, Japan, the United Kingdom and the USA.

Our goal is to share information with the global community of people with lived experience of Kennedy's disease, including KD men, carriers, and family members as well as researchers working to find a cure.

This newsletter will be published twice each year.

➡️ **Download:** Chinese | French | Italian | Japanese

DOING IT MY WAY

Every person living with Kennedy's Disease has a unique story of adapting and moving forward.

Each quarter, we'll share real stories from members of the KD community who have found new ways to adapt, stay independent, and keep doing the things that matter most. We hope that through their experiences, you'll find new ideas, practical adaptations, and inspiration from others on a similar journey.

Still Doing What I Enjoy

Finding a Better Way to Grocery Shop

One member recently wrote….

When I was diagnosed with Kennedy's disease 20 years ago, I quickly learned there was more to living with KD than understanding the medical side of it. Every few years, KD seemed to change the rules. I had to find new ways to keep doing the things I enjoy. The activity may look different, but I'm still doing it.

Take grocery shopping.

For years after my diagnosis, I shopped the way I always had. I'd run in, grab a few items, check out and head home.

As walking became more difficult, I made my first adaptation. I started taking a shopping cart, not because I needed it to carry groceries, but because it gave me something to lean on—much like a rollator.

Eventually, that wasn't enough. Halfway through the store, I'd need to stop and rest. One grocery store kept pallets of rock salt in the back corner. Those bags became my favorite resting place whenever my legs needed a break.

Later, I switched to the store's motorized carts. They worked well until getting on and off the cart to reach items on the top shelves or deep in the freezer cases became difficult.

I adapted again. Today, I order my groceries online and pick them up curbside. I still choose exactly what I want, but I don't have to walk the store. If a day comes when driving is no longer an option, there's always home delivery.

Over the years I've learned that adapting isn't admitting defeat. It's simply finding another way to keep doing the things that matter to me. I simply think of it as *doing it my way*.

Could Your Story Help Someone Else?

Every person living with Kennedy's Disease has discovered their own ways to adapt and continue doing the things that matter most and things they enjoy. By sharing our experiences, we can learn from one another—and remind each other that we're not alone on this journey.

Have you found a simple tip, a creative solution, or a new way to stay active and independent? We'd love to hear your story.

Send your story to info@kennedysdisease.org to be featured in a future edition of **Doing It My Way**. Your experience may be just the encouragement another family needs.

FUNDRAISING NEWS

Dim Sum Give Some 2026 - A Celebration of Food, Community, and Hope

The 7th annual Dim Sum Give Some event took place on Sunday, April 19, 2026, at the Italian Community Center in Milwaukee, WI. The event brought together an extraordinary community of chefs, supporters, sponsors, and volunteers for another unforgettable evening in support of the KDA. This year's event raised $37,000, bringing the event total to nearly $200,000 since its inception.

Hosted by award-winning chefs Dan Jacobs and Dan Van Rite, the event brought together 35 acclaimed chefs from across North America to showcase their culinary talents while raising awareness and support for individuals and families affected by Kennedy's Disease. The cast of participating chefs and food personalities included:

- Dan Jacobs and Dan Van Rite (DanDan and EsterEv, Milwaukee) - Event hosts and co-founders
- Tory Miller (L'Etoile, Madison) - Serving specialties like Kimchi Jeon
- Kaleena Bliss - Returning Guest Chef and Top Chef alum

Guests enjoyed an incredible lineup of dishes created by some of the industry's most celebrated chefs, including fellow Top Chef and Tournament of Champions competitors, along with award-winning culinary talent from New York, Boston, Miami, Denver, Austin, Salt Lake City, Raleigh, Oahu, and beyond.

This years event was especially meaningful as it marked 10 years since Chef Dan Jacobs was diagnosed with Kennedy's Disease. Over the past decade, Dan has transformed his personal journey into a powerful platform for advocacy, inspiring the culinary community and supporters around the world to join the fight against this rare neuromuscular disease.

We extend our heartfelt thanks to Chefs Dan Jacobs and Dan Van Rite, the participating chefs, sponsors, volunteers, and every guest who helped make this year's event such an outstanding success.

Dim Sum Give Some continues to demonstrate the incredible impact that happens when a community comes together with a shared purpose.

We can't wait to see what next year's Dim Sum Give Some has in store!

14th Annual KD Golf Scramble Sets a New Fundraising Record

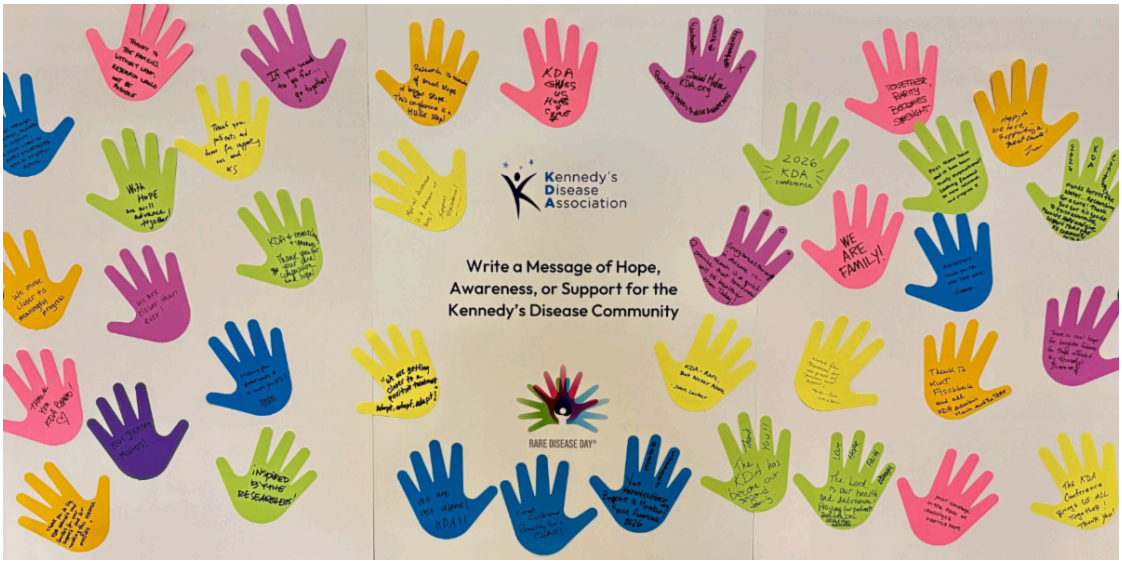
The 14th annual KD Golf Scramble was held on Saturday, May 2, 2026, at the High Meadow Ranch Golf Club in Magnolia, Texas. Although 5.5 inches of rain fell the day before and five teams were unable to participate due to the weather, the event was still filled with great energy, strong community spirit, and an outstanding turnout.

Your Generosity Continues to Drive Progress

Thanks to the incredible support of golfers, sponsors, volunteers, and the entire KD Golf Scramble community, this year's event turned out to be the most successful in its 14-year history.

The Texas KD Golf Scramble team will donate $54,000 to the KDA, bringing the event's lifetime contribution to $479,000. This year's gift is the largest single donation the tournament has made to date.

Thank you to everyone who participated, volunteered, sponsored, or donated. Your generosity is helping advance research, provide support for families, and bring us closer to better treatments for Kennedy's Disease.



Bay Area Rare Disease Fundraiser Celebrated its 8-year Anniversary

Standing Together for the Global KD Community

Fred Briones and his dedicated community in the San Francisco Bay Area once again made a big impact with their Rare Disease Day 2026 fundraiser which took place on February 28, 2026. As they did last year, they far exceeded their original goal and raised $7,500 in support of the Kennedy's Disease Association.

This event is one of the KDA's annual fundraisers, and we are thankful for their continued commitment and generosity.

DONATE TO KDA

FUNDRAISERS

Want to Help KDA Find a Cure for KD, but Not Comfortable Fundraising?

By John Lauber, Board Member, Treasurer, and KD Patient

We have heard, *"I'd like to help KDA, but I'm not comfortable fundraising"* many times over the years. If you've ever felt that way, you're not alone. The good news is that helping KDA isn't about becoming a fundraiser. It's about sharing your story with the people who care about you.

Your Story Matters

Your family and friends want to know how you're doing because they care about you and your journey. They want to celebrate progress with you and understand why finding treatments—and ultimately a cure—matters so much to you and your family.

To make it easy, KDA has created four simple campaigns. Each one offers a different way to share your story. Choose the one that feels most natural to you.

➡️ **Circle of Friends**

Invite family and friends to stay connected through occasional updates from KDA. There's no request for a donation—just an invitation to learn more about Kennedy's Disease and follow the progress being made toward better treatments. At the same time, you'll be helping more people learn about Kennedy's Disease and the hope that research is bringing to families like ours.

➡️ **Why I Still Hope**

Share why, despite the challenges of Kennedy's Disease, you continue to have hope. Tell your personal story and invite others to support the research and programs that make that hope possible.

➡️ **Virtual 5K**

Honor someone living with Kennedy's Disease—or remember someone you've lost—by creating a personalized Virtual 5K campaign. Invite family and friends to participate in whatever way is meaningful to them while honoring someone special and helping create hope for future generations.

➡️ **100 Step Challenge**

Help others experience, in a small way, what living with Kennedy's Disease is like. By asking people to imagine losing the ability to walk just 100 steps, this campaign creates understanding, empathy, and support for our mission.

Which Campaign is Right for You?

There isn't a right answer.

Not everyone is comfortable fundraising. Everyone is comfortable caring. These campaigns simply give you a way to share what you care about with the people who care about you.

Choose the campaign that feels most like you. We'll provide everything you need—templates, sample emails, graphics, and support. You can personalize as much—or as little—as you'd like.

Because this isn't about becoming a fundraiser. It's about inviting the people who care about you to become part of your journey. Together, one story at a time, we can create hope and accelerate the search for a cure.

The Most Powerful Voice for Kennedy's Disease isn't KDA's. It's Yours.

Ready to share your story? We'd love to help.

Send us an email at events@kennedysdisease.org to get started or find out more.

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

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!

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

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

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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.