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

Kennedy's
Disease
Association

QUARTERLY NEWSLETTER

FALL 2025

Welcome to the Fall 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.

Don't Miss Your Chance to Save and Secure Your Spot for the 2026 KDA Conference

EARLY BIRD RATE ENDS NOVEMBER 30

Kennedy's Disease Association

2026 INTERNATIONAL PATIENT AND SCIENTIFIC CONFERENCE

ADVANCING AWARENESS, COLLABORATION, AND RESEARCH TOWARD A CURE FOR KENNEDY'S DISEASE

Orlando, Florida | February 27 – March 2, 2026

Experience two patient-focused days followed by a two-day international SBMA research conference. Join us for the entire four days to make the most of opportunities to collaborate and get the latest information from leading experts across the globe.

See the Preliminary Agenda

Register Today

Upcoming Events

2026 International Patient and Scientific Conference
February 27-March 2, 2026
Early Bird Rate Extended to November 30, 2025
REGISTER

Turkey Trot 5K Run & Walk
DONATE

Giving Tuesday
December 2, 2025
SAVE THE DATE!

Support Groups

Men's Support Group: Get Connected

Carrier Support Group: Get Connected

Care Partners Support Group: Get Connected

More Resources

LATEST NEWS

Exciting News for the Kennedy's Disease Community!

AnnJi Pharmaceutical Co., Ltd. presented groundbreaking Phase 2a results for AJ201 at the 2025 World Muscle Society International Congress in Vienna, an oral treatment candidate for Kennedy's Disease, also known as spinal and bulbar muscular atrophy (SBMA).

The study, presented by Dr. Tahseen Mozaffar, leader of a participating trial site, showed positive functional outcomes and strong therapeutic potential. The presentation given by Dr. Mozaffar was chosen as one of only seven Late-Breaking Abstracts, a special recognition reserved for research with important new findings.

AJ201 has also received Orphan Drug Designation from both the U.S. FDA and the European Medicines Agency (EMA).

AnnJi plans to move AJ201 into Phase 3 clinical trials and pursue global collaborations.

Read KDA News:

AnnJi Showcases Promising Results for AJ201 in Kennedy's Disease Clinical Trial

FDA Grants Fast Track Designation for AJ201

A Breakthrough in Huntington's Disease Research Brings Hope for Kennedy's Disease

Last year, the KDA partnered with ReviR Therapeutics on the potential use of its innovative gene editing technology as a novel therapeutic strategy for Kennedy's Disease. Reducing or eliminating the toxic protein that causes the disease will be life-changing for people living with KD.

In a related and recent development, UniQure has announced positive results from its Phase I/II clinical trial of AMT-130, a one-time gene therapy for people living with Huntington's Disease.

Read the Article

COMMUNITY NEWS

Highlights from the 2025 Banbury Workshop

Member of the KDA Scientific Review Board Elected to the National Academy of Medicine

Dr. Charlotte Sumner, clinician and faculty member at the

Exploring Metabolic Dysregulation in SBMA

The 3rd annual SBMA Research Workshop was held at the The Banbury Center on Long Island on September 14-16.

This year, clinicians, researchers, and patient advocates gathered to explore Metabolic Dysregulation in Spinal and Bulbar Muscular Atrophy (Kennedy's Disease). The sessions included:

- Clinical Overview and Living with Kennedy's Disease
- Metabolic Homeostatic Pathways
- Metabolic Dysregulation in Disease Models
- Altered Metabolism in Patients

KDA's Banbury workshops are designed to be collaborative efforts with scientists from related fields joining SBMA researchers to share research ideas and discuss possible approaches to therapies and a cure. The workshops not only provide new perspectives to KD research, but also bring new, experienced scientists including international experts, into the KD research community.

Thanks to Banbury for hosting another great workshop! The annual workshop was sponsored by the KDA, and made possible with thanks to the annual Texas KD Golf Scramble.

Johns Hopkins School of Medicine, and a valued member of the KDA Scientific Review Board, has been elected to the National Academy of Medicine, an independent organization of leading professionals in health-related disciplines.

Congratulations, Dr. Sumner!

Read the Article

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!

KDA Announces Over $900,000 in Grants and Fellowships

KDA received an unprecedented number of research proposals this year and has awarded the highest number of grants and fellowships in our history. Congratulations to the following researchers on their awards.

Individual Grants

- Laura Bott, PhD, Northwestern University
- Rachel Harding, PhD, University of Toronto
- Janghoo Lim, PhD, Yale University
- Rika Maruyama, PhD, University of Alberta

Banbury Team Grants

Andy Lieberman, MD, PhD, University of Michigan
- Sokol Todi, PhD, Wayne State University
- Sami Barmada, PhD, University of Michigan

Al La Spada, MD, PhD, University of California Irvine
- Asuka Eguchi, PhD, University of California Irvine

Xavier Salvatella, PhD, Institute for Research in Biomedicine, Barcelona

- Diane Merry, PhD, Thomas Jefferson University
- Sokol Todi, PhD, Wayne State University

Waite-Griffin SBMA Fellowships

- Chris (Changwoo) Lee, PhD, Yale University
- Caroline Rodrigues, PhD, Case Western Reserve University
- Ellen Scott, PhD, Philadelphia College of Osteopathic Medicine

We are grateful to the scientists who submitted so many strong proposals for this year's program. Project summaries for all awards will be published in the near future on the KDA website. We are especially grateful for the generosity of our donors who made it possible to reach the highest level of funding in KDA's history. With your continuing support, we can sustain and hopefully surpass our funding to accelerate research toward a cure for Kennedy's Disease.

Building a Stronger Presence in Canada

On November 7, 2025, the KDA hosted its First Canadian Regional Meeting in the Toronto area. The event brought together individuals and families affected by Kennedy's Disease, along with researchers, clinicians, and supporters from across the country. Jameson Parker, Vice President, represented the KDA Board of Directors.

The meeting created a meaningful opportunity for participants to connect, learn, and share personal experiences, as well as hope for a cure for Kennedy's Disease. For many attendees, it was their first time meeting others in person who truly understand the challenges of living with KD.

We would like thank our guest speakers, Dr. Gerald Pfeffer from the University of Calgary and Dr. Kerry Schellenberg from the University of Saskatchewan, neurologists and research experts who shared Best Practice Recommendations for the Clinical Care for Kennedy's Disease in Canada. Dr. Homira Osman, PhD, from Muscular Dystrophy Canada also spoke about MDC's ongoing support for the Kennedy's Disease Community in Canada.

The meeting sparked valuable discussion and encouraged collaboration within the Canadian KD community.

Special thanks to KDA volunteers Cameron Bell, Andrew Cassar, Cecilio Gregorio, Patrick Mozola, Jurgen Richter, and Jinyuan Wu who helped organize the event and ensured a warm and welcoming experience for all attendees.

The KDA is excited to continue building a stronger presence in Canada and looks forward to expanding future regional meetings, educational opportunities, and support initiatives.

The Ed Montie 5K Raises $15,000 to Support Kennedy's Disease Research

Each year, the Kennedy's Disease community comes together to honor the life and legacy of Ed Montie, a devoted family man, beloved friend, and passionate supporter of the KDA.

This year's Ed Montie 5K, held on September 20, brought together families, friends, and supporters from

In Memory of Ed Montie

across the country, raising nearly $15,000 for research and education in support of the KDA.

Ed faced every challenge with courage and optimism, and his spirit continues to inspire participants from across the country who walk and run in his memory.

The KDA extends heartfelt thanks to everyone who participated, donated, and helped spread the word - and especially to the Montie family for keeping Ed's inspiring legacy alive through this meaningful tradition.

You can still make a contribution in support of the Ed Montie 5K through to the end of November.

DONATE

The Ed Montie 5K is more than just a race - it's a celebration of courage, connection, and commitment to finding a cure for Kennedy's Disease.

Women's Golf Association (WGA) Member Golf Tournament Raises $13,360

The 2025 ***Once Upon a Tee Time*** WGA Member Guest Tournament, held October 17-18th at the Ballantyne Country Club in Charlotte, North Carolina, was truly a magical event!

This year's ladies' golf tournament raised an impressive $13,360 in support of the KDA. Special thanks to everyone who participated, donated and helped make the event such a memorable success.

The KDA would like to thank and acknowledge Lisa Ballard and Pam Frailey for their outstanding leadership and dedication to bringing this event, in memory of Larry Ballard, to life. Their efforts not only helped raise funds to support research but also increased awareness of Kennedy's Disease and the KDA's mission.

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.ca, and let's work together to make it happen!

Together, We Can Turn Inspiration into Impact

FUNDRAISING

SAVE THE DATE - DECEMBER 2ND
Help Us Bring Hope This Giving Tuesday

What Is Giving Tuesday?

Giving Tuesday is a global day of generosity celebrated each year on the Tuesday after U.S. Thanksgiving. Since it started in 2012, Giving Tuesday has grown into a worldwide movement that inspires people everywhere to give, share, and make a difference - a day when communities come together to support the causes they care about most.

Join Us in Bringing Hope to the KD Community

This Giving Tuesday, we invite you to stand with the Kennedy's Disease Association and help bring hope to individuals and families affected by KD.

Your gift directly supports:

- Educational programs that inform and empower the KD community
- Research grants and fellowships that enable researchers and scientists around the world to pursue promising discoveries and move us closer to a cure for this devastating disease.

As an all-volunteer organization, the KDA is proud to devote 90% of every dollar raised directly to research and programs. We've earned top ratings for transparency and responsible fundraising, and it's all thanks to generous supporters like you.

Together, We Can Make a Difference

Mark your calendar for December 2nd - help us continue the momentum toward meaningful breakthroughs this Giving Tuesday.

Thank you for your generosity and ongoing support!

Give Hope This Giving Tuesday

The Saddle Creek Forest Run/Walk Club held its annual 5K Turkey Trot, a run and walk event to raise funds to help find a cure for Kennedy's Disease. Donations will be accepted through November 30th.

Donate

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

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 photographers, videographers, and general volunteers, both on-site and behind the scenes.

You can help make this important event a success. Please reach out to us today.

GET INVOLVED

See all Volunteer Opportunities.

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

Next Volunteer Meeting

November 18 @ 9:30 AM ET | RSVP

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.

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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.