



## QUARTERLY NEWSLETTER

FALL 2026

### 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.

### 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

**November 7-9, 2027:** KDA Patient & Scientific Conference

### 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 New Executive Director

#### [Get to Know Delery Rice](#)

We are delighted to welcome Delery Rice as KDA's first Executive Director who joined the KDA team on October 5, 2026. With more than 20 years of nonprofit leadership experience, Delery brings a wealth of expertise in fundraising, strategic development, disability advocacy, and building partnerships that make a difference in people's lives. Most recently, she served as CEO of *My Life Talks*. Her experience and passion for supporting individuals with disabilities and their families will help strengthen KDA's work and advance its mission to find effective treatments and, ultimately, a cure for Kennedy's Disease.



While Delery's career has taken her to many different places, New Orleans has always been home. Outside of work, Delery's family is at the center of her life. She is the proud mom of four boys, Edward, Stephen, Patrick, and David.

When she's not working, Delery enjoys spending time with her sons, family and friends, cooking, relaxing at the beach, and travelling. She also enjoys reading, going to the gym, following LSU football, and playing Mahjong.

[➔ Get to Know Delery](#)

[➔ Read the KDA News Announcement: Kennedy's Disease Association Hires Its First Executive Director](#)

We're excited to get to know Delery better and look forward to the experience, energy, and leadership she brings to the KDA. Please join us in giving her a warm welcome to the KDA community!

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## Partnering for a Cure for Kennedy's Disease

### The KDA Launches KD Voices

#### We Want to Hear From You!

KD Voices is a new KDA initiative designed to bring the real-world experiences, perspectives, and priorities of the KD community directly to pharmaceutical and biotechnology companies developing potential therapies and conducting clinical trials.



#### Be a Strong Voice Representing the KD Community

If you are living with KD, are a family member or care partner, or have another connection to the KD community, we encourage your participation.

[➔ Learn More](#)

[➔ Complete the KD Voices Volunteer Interest Questionnaire](#)

***Your experience matters. Your perspective matters. Your voice can help shape the future of KD research and therapy development.***

Thank you for helping us make sure the KD community has a meaningful voice in the development of future therapies.

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## KDA Connects with Kennedy's Disease Researchers at VIMM in Italy

Building connections between the Kennedy's Disease community and researchers around the world is an important part of KDA's mission.

Recently, Kathy and Terry Thompson visited the Veneto Institute of Molecular Medicine (VIMM) in Padua, Italy. Professor Andy Lieberman and his wife were also in Padua at the time and joined the visit. Together, they met with Professor Maria Pennuto and members of her research team. The visitors were honored to meet Mrs. Giustina Destro, President of the Foundation for



Advanced Biomedical Research, the host organization for VIMM.

Left to Right: Caterina Marchioretto, Emanuela Zucarro, Janice Lieberman, Andy Lieberman, Kathy Thompson, Terry Thompson, Giustina Destro, Maria Pennuto

The KDA is grateful to Professor Pennuto and the VIMM team for welcoming Kathy and Terry. Connections like this helps strengthen our community and brings us one step closer to better treatments and, ultimately, a cure.

## Connecting with the Neuromuscular Community at AANEM

The KDA participated in the 2026 Annual Meeting of the American Association of Neuromuscular & Electrodiagnostic Medicine (AANEM), which took place September 29-October 2 in Orlando, Florida.

The meeting brought together physicians, researchers and other healthcare professionals from around the world who specialize in neuromuscular and electrodiagnostic medicine to share knowledge, learn about emerging developments, and improve the diagnosis and care of people with neuromuscular diseases.

The KDA attended to help raise awareness of Kennedy's Disease among healthcare professionals who may encounter it in their practice. Our tabletop display helped us gain visibility within the broader neuromuscular community and build connections that can ultimately benefit people affected by KD.



Left to Right: Dr. Christopher Grunseich, Lewis Myers (KDA Board Member), Dr. Abdullah Al Qahtani

## Advancing Earlier Recognition of Neuromuscular Diseases

The day before AANEM, Terry Thompson attended the annual summit of the Late-Onset Neuromuscular Disease Consortium (LONDC) Steering Committee.

The summit focused on expanding use of the [LOND Diagnostic Decision Tool](#) which was first made available in March 2026. The downloadable clinical decision tool helps physicians identify a possible late-onset neuromuscular disease, including Kennedy's Disease.



KDA has been a member of the LONDC since its inception. KDA President, Terry Thompson has served on the Steering Committee for the past three years.

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



Photo Credit: Cold Spring Harbor Laboratory/Constance Brukin

This fall, leading researchers from around the world came 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 research.

The topic of the three-day workshop: *Transcriptional and Epigenetic Dysregulation in Spinal Bulbar Muscular Atrophy (SBMA)* focused 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

The KDA Banbury Workshop is made possible with thanks to the annual Texas KD Golf Scramble.

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.

## International Kennedy's Disease Newsletter



Stay tuned for for news, stories, and updates from the global KD community!

The Fall 2026 edition of the *International Kennedy's Disease Newsletter* is coming soon.

## CLINICAL TRIAL UPDATES

### AnnJi Pharmaceutical Moves Promising Kennedy's Disease Treatment into the Final Stage of Testing



AnnJi Pharmaceutical announced that its experimental drug AJ201 (also called rosolutamide) is moving into a Phase 3 clinical trial for Kennedy's Disease. The trial, called ROMA-KD, follows encouraging results from a 2025 Phase 2 study.

A potential treatment is a meaningful step forward for the Kennedy's Disease community and everyone impacted by the disease. The KDA will keep our community updated as the trial progresses.

→ Read the Article: [Promising Kennedy's Disease Treatment Moves into the Final Stage of Testing](#)

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

Arvinas, Inc. 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.

→ Read the Article: [Arvinas Advances ARV-027 Clinical Development for Kennedy's Disease](#)



## 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.

## Traveling With KD: Tips from My Disney World Trip

By Dale Traxler, Kennedy's Disease Patient

Traveling with Kennedy's Disease can take some extra planning, so you don't have to sit on the sidelines while your family enjoys the experience.

I recently visited Walt Disney World in Orlando with my family, including my grandchildren, and learned a few things that made the trip much easier, safer and more enjoyable. The tips below may be helpful, whether you're planning a trip to Disney World or another destination.

### ✓ Always have a game plan with some flexibility

Plan your park visits ahead of time and prioritize the attractions and experiences that matter most to you and your family. Disney World is huge, and trying to do everything can be exhausting.

### ✓ Listen to your body

If you overdo it one day, you may spend the next two days recovering. What worked for me was to start with a half-day in the park, followed by a full day, once I knew how my body was responding.

### ✓ Learn about current accessibility options before your trip

Policies and eligibility may change, so it's important to get current information before you arrive. Disney changed their Disability Assistance Services (DAS) program, so don't assume the process will be the same as it was on a previous visit. Disney's DAS program allows you to avoid standing in long lines and meet up with your group closer to the front of the line.

### ✓ Plan your trip and visits ahead of time

Explore your transportation options before your trip, as it means less walking and will make it much easier to conserve energy. If mobility is an issue for you, a scooter can be a game changer, whether you rent one or bring your own. Disney is designed to accommodate mobility devices. We stayed at The Swan and Dolphin and the location made a huge difference. There was easy access to several parks through boats, Sky lift and walking paths to Epcot and Hollywood Studios. Buses to Animal Kingdom and Magic Kingdom were also helpful. The staff were incredibly accommodating and made us feel like family.

### ✓ Pace yourself - always set a moderate pace and use indoor attractions for recovery

Think of your day as alternating activity with recovery. Don't think of taking a break as missing out. We used shows and indoor attractions as opportunities to sit down, cool off and recharge while still enjoying the park. For example, at Animal Kingdom, the Festival of the Lion King gave me a chance to rest while enjoying a great show. At various attractions, staff were able to direct us to accessible entrances and seating.



### ✓ One of the most important lessons from my trip was: ask!

Ask about the accessibility arrangements at each attraction before getting in line. What works for one ride may not work for another. Don't assume you can't go on the rides. I wanted to experience the rides with my family, and in many cases, Disney staff were able to find a way to make it work. For several attractions, I could take my scooter close to the ride and then make a short transfer. For example, at The Twilight Zone Tower of Terror, I could transfer to a wheelchair and be assisted through the line. I needed to take a few steps to transfer onto the ride, but



the staff helped make the process manageable. I also rode Avatar Flight of Passage, Remy's Ratatouille Adventure, Soarin' and TRON Lightcycle / Run.

### ✓ Ask about attractions where you can remain in your wheelchair

Some attractions may have options that minimize or eliminate transfers. These little accommodations can make a huge difference. I love *It's a Small World*, and I was able to ride without transferring from my wheelchair. At the Haunted Mansion, I was able to take my scooter close to the ride vehicle, where staff stopped the ride so I could safely transfer.

### ✓ Plan your evening too

The fireworks were another highlight. Disney has designated accessible viewing areas, and our entire group of seven was accommodated together. For me, knowing that I had a place where I could comfortably watch the show meant I could enjoy the evening instead of worrying about where I would stand or how I would manage the crowd.

### ✓ Don't overlook accessible restrooms

Know where accessible restrooms are located before you need one to reduce any stress. I found the restroom situation surprisingly manageable. Whenever possible, we used the companion/family accessible facilities. Having enough room for my wife, Kathy, to assist me made getting in and out much easier.

### ✓ Let your family help

One of the biggest reasons the trip was successful was my family. Traveling with KD doesn't mean you have to do everything independently. Accepting help with transportation, transfers, navigating crowds or simply keeping an eye on your energy level can make the experience much more enjoyable. Accessibility accommodations can help you stay connected with your family.

### ✓ Enjoy the experience, not just the itinerary

My biggest piece of advice? Don't try to keep up with everyone else. Set your own pace. Take a break. Use the scooter. Ask for assistance. Sit down when you need to. And don't be afraid to change your plans.

For me, the most memorable part of the trip wasn't the rides. It was seeing the faces of my grandchildren and being able to share those experiences with them.



I am so thankful for my family for helping make the trip memorable and safe. The smiles on my grandkids' faces were priceless, and worth every bit of planning.

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## 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](mailto: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.

## FUNDRAISERS

## Mark Your Calendar for Tuesday, December 1!

Giving Tuesday is an opportunity to come together for the causes that matter to us. For the KDA community, it is a chance to help move Kennedy's disease research forward and bring hope to individuals and families affected by KD.

Our community has always been at the heart of KDA's work. By making a gift or sharing KDA's mission with friends and family, you can help build support for research toward effective treatments.

Watch for more details in the coming weeks. Thank you for being part of this community and for all you do to keep progress moving forward.

[GIVE TODAY](#)

## 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.

#### KDA Circle of Friends

*No one should face this challenge alone.*



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.

#### KDA Virtual 5K

*Recognizing a Special member of the KD community.*



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.



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.



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](mailto:events@kennedysdisease.org) to get started or find out more.

**DONATE TO KDA**



### 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**



### 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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