Kennedy's Disease Association



Annual Report
**2025**

UNITING FOR

# PATIENTS
# FAMILIES
# A FUTURE WITHOUT KENNEDY'S DISEASE

**Together, we are advancing research, strengthening connections, and bringing hope to families affected by Kennedy's disease.**

## The Kennedy's Disease Association is a non-profit corporation

KDA is a community united by a shared commitment to improving the lives of those affected by Kennedy's disease. Patients, families, caregivers, researchers, volunteers, and supporters work together to advance research, provide education and support, and bring us closer to effective treatments and a cure. We are men with KD, carriers of KD, caregivers, parents and children, family, friends and researchers. We give our time and talents to help fulfill the mission of the KDA - to inform, support, educate, fund research, and find a treatment and cure for Kennedy's Disease.

## The Mission of the Kennedy's Disease Association

- Raise funds for Kennedy's Disease research and education.
- Share information about Kennedy's Disease with those who seek it.
- Create a support system for those living with the disease.
- Increase public awareness of Kennedy's Disease and its effect upon families.
- Increase awareness of Kennedy's Disease in the medical community and in pharma and biotech industries."

# A MESSAGE FROM THE PRESIDENT



Thanks to the extraordinary generosity and commitment of our supporters, 2025 became one of the most significant years in KDA's 25-year history. Together, we achieved historic milestones in research funding, strengthened international partnerships, and witnessed encouraging progress toward potential treatments for Kennedy's disease.




None of this would have been possible without the unwavering generosity of our patients, families, donors, and volunteers. Thanks to the continued support of our community and record-setting fundraising efforts — including Bay Area Rare Disease Day, Dim Sum Give Some, the KD Golf Scramble, the Ed Montie 5K, Once Upon a Tee Time WGA Member Guest Tournament, and the 100-Step Challenge — KDA was able to contribute nearly $1 million to Kennedy's Disease research worldwide in 2025, our largest annual investment to date.



*Researchers Collaborating at the Banbury Workshop*

In addition to funding our annual research grants, fellowship awards, and the Banbury SBMA Workshop, KDA expanded its support for emerging investigators by providing travel grants that enabled junior researchers to attend the biennial Gordon Research Conference on CAG Repeat Expansion Diseases. We were also proud to contribute directly to the conference itself, helping to foster collaboration and accelerate scientific discovery.

Clinical research reached important milestones this year. AnnJi Pharmaceuticals completed its Phase 2 clinical trial and reported positive results at the World Muscle Society Conference in Vienna, Austria. Nido Biosciences completed its Phase 2 study, which unfortunately did not meet its objectives but provided critical input for future research. At the same time, new clinical trials were launched at Nagoya University in Japan and the University of Padua in Italy, further expanding the global effort to develop effective therapies for SBMA.

*Continued...*

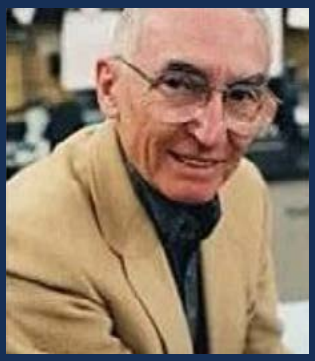


DECEMBER 18, 2025

International Kennedy's Disease Newsletter: Fall 2025



*Dr. Charlotte Sumner, clinician and faculty member at the Johns Hopkins School of Medicine.*



*Dr. William Kennedy (1927-2026)*

Our international partnerships continued to strengthen in 2025. Working closely with Kennedy's Disease patient advocacy organizations around the world, KDA, with help from KD-UK, launched the International Kennedy's Disease Newsletter, with editions published in both the spring and fall. KD patient groups from Australia, France, Italy, Japan, and the United Kingdom contributed articles and updates. KDA also sponsored the first regional gathering of Kennedy's Disease patients and families in Toronto, creating an opportunity for individuals to receive research updates, share experiences, and connect with others who understand the unique challenges of living with SBMA.

KDA's leadership also grew stronger this year with the addition of two new members to our Board of Directors. Lew Myers and Dr. Nicholas Holdgate bring valuable expertise from the pharmaceutical industry and clinical medicine, respectively, and we look forward to the contributions they will make in the years ahead. We were also delighted to celebrate the election of Dr. Charlotte Sumner of Johns Hopkins University — a member of KDA's Scientific Review Board — to the prestigious National Academy of Medicine. In addition, Chef Dan Jacobs continued to raise awareness of Kennedy's Disease through his public advocacy, including a feature interview in Brain & Life magazine.

On a personal note, one of the highlights of my year was the opportunity to meet Dr. William Kennedy and members of his family in St. Paul, Minnesota. Spending time with the first American to identify the unique symptoms of SBMA was a truly memorable experience. Dr. Kennedy shared that he was initially uncomfortable when colleagues began referring to SBMA as "Kennedy's Disease." Over time, however, he grew more accepting of the name. Remarkably, at 98 years old, he still followed developments in the research community with great interest, maintaining the same curiosity and humility that characterized his distinguished career. Sadly, Dr. Kennedy passed away in January, 2026, age 98.

To every donor, volunteer, patient, family member, researcher, and partner who supported KDA in 2025: thank you. Your generosity and commitment are helping transform scientific possibilities into meaningful progress. Together, we are building a future in which effective treatments — and ultimately a cure — for Kennedy's disease are within reach.

**Terry Thompson**, President

## MAJOR FUNDRAISERS

Throughout 2025, dedicated volunteers, families, and supporters organized fundraising events that brought communities together and generated critical support for Kennedy's disease research. From golf tournaments and community gatherings to individual fundraising challenges, each event demonstrates the extraordinary difference people can make when united for a common purpose.




**Bay Area - RARE DISEASE DAY**
March 1st
San Francisco, CA



**Dim Sum Give Some**
April 13th | Milwaukee, WI

Chef Dan Jacobs (left)
with KDA Board Member John Lauber

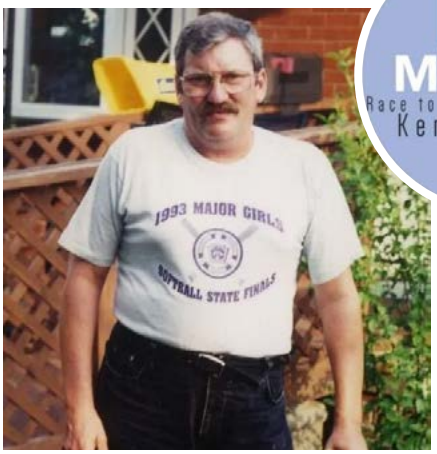
## MAJOR FUNDRAISERS




**Texas Golf Scramble**
May 3rd | Magnolia, TX



**The 100-Step Challenge**
Started by John Lauber,
the KDA Treasurer.
This is a year-long fundraiser.




**The Ed Montie 5K**
September 20 | Lincoln Park




**Once Upon a Tee Time WGA Member Guest Tournament**
October 17-18th
Ballantyne Country Club in Charlotte, North Carolina

## 1ST VIRTUAL MEETING WITH THE BOARD OF DIRECTORS - OPEN TO ALL -

### October 18

The voices and experiences of individuals and families affected by Kennedy's disease guide KDA's priorities. In October, more than 38 members joined the Board of Directors for an open discussion about treatment progress, community needs, and opportunities to strengthen KDA's support and advocacy efforts.

## 1ST AREA REGIONAL KDA MEETING HELD IN TORONTO -

### November 7

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. For many participants, the gathering provided their first opportunity to connect face-to-face with others who understand the challenges of living with Kennedy's disease. These connections help reduce isolation, strengthen the community, and remind individuals and families that they are not facing the disease alone.




*KDA Vice President, Jameson Parker address the conference attendees.*



## GOALS FOR 2026

- Establish a platform for patients and care partners to share their lived experience with pharmaceutical companies to assist in therapy development
- Hire a full-time Executive Director to help KDA get to the next level of fundraising and research support.
- Sponsor the fourth annual Banbury SBMA workshop using funds from the Texas KD golf scramble
- Select a venue and begin planning for the next KDA conference in November 2027
- Pursue the inclusion of Kennedy's Disease (SBMA) in the International Classification of Diseases (ICD-10) with support from NIH and other stakeholders in the medical community.
- Fund grants and fellowships to help find a cure or treatment for SBMA.
- Continue to publish seasonal newsletters.

# 1ST KD CLINICAL TRIAL TO MOVE TO PHASE 3!

## AnnJi Pharmaceutical Co., Ltd

- May 21, 2025 AnnJi Pharmaceutical Company Announces Positive Phase 1/2a Results for AJ201 in Spinal and Bulbar Muscular Atrophy Patients
- October 27, 2025 AnnJi Showcases Promising Results for AJ201 in Kennedy's Disease Clinical Trial
- AnnJi Pharmaceutical Co., Ltd. presented groundbreaking Phase 2a results for AJ201 at the 2025 World Muscle Society International Congress in Vienna. The study, presented by Dr. Tahseen Mozaffar, leader of a participating trial site, showed positive functional outcomes and strong therapeutic potential. AJ201 receives Orphan Drug Designation from both the U.S. FDA and the European Medicines Agency.
- AnnJi plans to move AJ201 into Phase 3 clinical trials and pursue global collaborations.




# GORDON RESEARCH CONFERENCE:

## CAG Triplet Repeat Disorders

- The KDA funded travel grants for seven early-career researchers to participate in the Gordon Research Conference. By investing in the next generation of scientists, KDA is helping cultivate the expertise, collaboration, and innovative thinking essential to advancing Kennedy's disease research.



# 3RD ANNUAL BANBURY WORKSHOP -

## Exploring Metabolic Dysregulation in SBMA

- These 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. By bringing together leading scientists from multiple disciplines, including international experts, the Banbury Workshops encourage innovative approaches to Kennedy's disease research. These collaborations introduce new expertise, strengthen scientific partnerships, and create opportunities to accelerate progress toward potential treatments.

# GRANTS AND FELLOWSHIPS AWARDED IN 2025

As of November 2025, the KDA has awarded $4,080,600.00 in research grants to help find a cure or treatment for Kennedy's Disease.

Thanks to the generosity of our donors and supporters, KDA awarded a record $931,000 in research grants and fellowships in 2025—the largest annual research investment in the organization's history. These awards support promising scientific investigations, foster collaboration among leading researchers, and help develop the next generation of scientists dedicated to finding effective treatments and a cure for Kennedy's disease.

## 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

**For more information, visit:**
https://kennedysdisease.org/research/grant-award-recipients/2025-grant-aaward-recipients.htm

# FINANCIALS

## STATEMENT OF FINANCIAL POSITION

In 2025, KDA made an unprecedented investment in Kennedy's disease research, reflecting the organization's commitment to advancing promising scientific opportunities. This historic level of funding was made possible in part by financial resources accumulated during the COVID-related pause in activities. The Board of Directors authorized the strategic distribution of these resources to support additional research grants and fellowships.

This deliberate investment contributed to a reduction in net assets during 2025 and reflects KDA's commitment to putting available resources to work in pursuit of its mission.

| | 12/31/2025 | 12/31/2024 | Change |
|---|---|---|---|
| **ASSETS** | | | |
| Cash | 128,615 | 354,435 | (225,820) |
| Contributions Receivable | 8,660 | - | 8,660 |
| Prepaid Expenses | 42,840 | - | 42,840 |
| Investments | 352,167 | 524,645 | (172,478) |
| **TOTAL ASSETS** | **532,282** | **879,080** | **(346,798)** |
| **LIABILITIES** | | | |
| Accounts Payable | 6,269 | 1,064 | 5,205 |
| Grants Payable | 300,000 | 327,887 | (27,887) |
| Deferred Revenue | 29,300 | - | 29,300 |
| **TOTAL LIABILITIES** | **335,569** | **328,951** | **6,618** |
| **NET ASSETS** | | | |
| Without donor restrictions | 160,553 | 527,129 | (366,576) |
| With donor restrictions | 36,160 | 23,000 | 13,160 |
| **TOTAL NET ASSETS** | **196,713** | **550,129** | **(353,416)** |
| **TOTAL LIABILITIES AND NET ASSETS** | **532,282** | **879,080** | **(346,798)** |

# FINANCIALS (CONT)

## STATEMENT OF ACTIVITY AND CHANGES IN NET ASSETS FOR THE YEAR ENDED DECEMBER 31 2025

| | WITHOUT DONOR RESTRICTIONS | WITH DONOR RESTRICTIONS | TOTAL |
|---|---|---|---|
| **SUPPORT AND REVENUE** | | | |
| Contributions | 711,846 | 28,660 | 740,506 |
| Investment Income | 23,311 | - | 23,311 |
| Subtotal | 735,157 | 28,660 | 763,817 |
| Net assets released from restriction | 15,500 | (15,500) | - |
| **TOTAL SUPPORT AND REVENUE** | **750,657** | **13,160** | **763,817** |
| **FUNCTIONAL EXPENSES** | | | |
| Program services | 1,003,105 | - | 1,003,105 |
| Management and general | 23,994 | - | 23,994 |
| Fundraising | 90,134 | - | 90,134 |
| **TOTAL FUNCTIONAL EXPENSES** | **1,117,233** | **-** | **1,117,233** |
| INCREASE (DECREASE) IN NET ASSETS | (366,576) | 13,160 | (353,416) |
| NET ASSETS AT BEGINNING OF YEAR | 527,129 | 23,000 | 550,129 |
| **NET ASSETS AT END OF YEAR** | **160,553** | **36,160** | **196,713** |

**NOTE:** An Audit has been performed on the 2025 KDA Financial Statements. The Audit Report is available upon request.

## 2025 KDA OFFICERS AND BOARD OF DIRECTORS

KDA's Board of Directors provides volunteer leadership, strategic oversight, and a shared commitment to advancing research and supporting individuals and families affected by Kennedy's disease. Their dedication helps ensure that the organization remains focused on its mission and responsible stewardship of donor contributions.

**Terry Thompson**, President

**Jameson Parker**, Vice President

**John Lauber**, Treasurer

**Kathy Thompson**, Secretary

**Ron Moffett**, Director

**Steven Rittmaster**, Director

**Dale Traxler**, Director

**Joan Sorensen**, Director

### Welcoming two new directors to the KDA board



**Mr. Lew Myers.**
**Lew has been instrumental in onboarding people to help with fundraising efforts and public relations.**



**Dr. Nicholas Holdgate.**
**As a medical practitioner, Nicholas brings much needed expertise to the board.**



Every advancement in Kennedy's disease research begins with a commitment to finding answers. With your continued support, KDA can fund promising research, strengthen the scientific community, and provide hope to individuals and families affected by Kennedy's disease. Together, we can move closer to a future without KD.

**Donate at kennedysdisease.org/get-involved/donate.html**


**Kennedy's Disease Association**

1445 Woodmont Lane NW, #1805
Atlanta, GA 30318
Telephone: 1-855-KD-ASSOC
(855) 532-7762 or (734) 288-5580
info@kennedysdisease.org
**www.kennedysdisease.org**