Kennedy's
Disease
Association

KENNEDY'S
DISEASE
ASSOCIATION
KDA · 25 YEARS · MAKING A DIFFERENCE

Annual Report
2024

UNITING FOR

PATIENTS
FAMILIES
A FUTURE WITHOUT KD

The Kennedy's Disease Association is an all volunteer, non-profit corporation

The people who make the KDA possible are all people impacted by Kennedy's Disease. 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 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.

A MESSAGE FROM THE PRESIDENT

2024 was a year of excitement and growth for Kennedy's Disease Association (KDA), marked by our 25th Anniversary conference. KDA Founder and President Emerita Susanne Waite gave an inspiring keynote address about the start of the KDA 25 years ago. Then Dr. Al La Spada, who identified the genetic mutation responsible for Kennedy's Disease, presented a summary of KD research. More than 100 attendees joined in recognizing Dr. William Kennedy, who first described the symptoms of the disease later named for him, on his 97th birthday.

Chef Dan Jacobs competed in the TV series *Top Chef Wisconsin*, finishing as runner-up. He inspired us all, bringing attention to Kennedy's Disease (KD) through his personal narrative while showcasing his exceptional culinary skills. His determination highlighted the resilience of men with KD.

Thanks to donor contributions, our 2024 grants program grew by over 20% compared to 2023 and set a KDA record for the most money given to research in a single year. We awarded 13 individual grants, including seven student travel grants and grants to two biotechnology companies working on potential therapies for Kennedy's Disease. We also sponsored the second annual Banbury SBMA Workshop, facilitating an interdisciplinary exchange among international scientists and KD researchers.

The KDA Board of Directors expanded adding John Lauber as Treasurer and Joan Sorensen and Randy Soo Hoo as Independent Directors. We initiated the Care Partners support group for spouses and family members, adding to our existing support groups for KD Men and Carriers.

Looking ahead to 2025, we plan to enhance our fundraising capabilities and prepare for the International Kennedy's Disease Patient and Scientific Conference in early 2026. As always, we will maintain focus on our mission of supporting patients and their families and supporting research to find a cure.

Thank you for your ongoing support of our mission and your trust in the KDA.

Terry Thompson, President

2024 | YEAR IN REVIEW

2024 was a very busy, productive and eventful year as the KDA continues to focus on and strive to find a cure for Kennedy's Disease. Below is a snapshot of some of the year highlights.

KDA Conference in Orlando - Celebrating 25 YEARS

Conference attendees agreed that the 2024 Orlando KDA Conference was our best yet! And it was a meaningful way to celebrate KDA's 25 years of serving the Kennedy's Disease community of patients, families, clinicians, and researchers.

More than 250 people attended the conference in early November for a packed agenda of presentations about patient challenges, clinical trials, and updates on the latest research.

If you missed it, you can see several videos from the 2024 conference at kennedysdisease.org.

12th Annual Texas Golf Scramble Results

Saturday, April 20th, the 12th annual Kennedy's Disease Texas Golf Scramble went off without a hitch! We had a record breaking 28 golf teams! Watching everyone work so hard to help make this tournament a success was touching. Very few people in attendance had ever heard of Kennedy's Disease before our first tournament in 2011, and now we had more volunteers wanting to help than we knew what to do with. This annual event has successfully raised awareness for KD, and since 2011 we have donations to KDA approaching $400k.

KDA Supports the Most Detailed SBMA Patient Report to Date

The Voice of the Patient report is a study of 232 participants with SBMA. Participants provided input regarding 18 themes and 208 symptoms that affect patients with SBMA. Participants were asked about the relative importance of each symptom, and analysis was conducted to determine how age, education, disease duration, CAG repeat length, and ambulation status relate to symptom prevalence. *Click here for reports*.

Dan Jacobs - Inspirational "Top Chef" Finalist and KD Patient

KDA member Dan Jacobs made it to the finale of the Top Chef competition, season 21. Throughout the series, Dan demonstrated his amazing culinary skills and tremendous perseverance in a physically and psychologically demanding competition. He also brought national attention to our little-known disease and represented us extremely well, especially when he gave a well-spoken testimony on what Kennedy's Disease is and how it impacts us all differently. Thank you, Dan, for showing the world that people can achieve their highest aspirations despite difficulties such as Kennedy's Disease.

Recognition of Our Top Rating Status by Candid and Charity Navigator

Candid's GuideStar is an information service specializing in reporting on U.S. nonprofit companies. It provides information on several million organizations. The KDA earned a 2024 Platinum Seal of Transparency! Check out our updated #NonprofitProfile on Candid: guidestar.org. From Charity Navigator, the KDA earned a score of 98%, giving us the highest possible rating available: Four-Stars.

Platinum
Transparency
2024
Candid.

Charity Navigator
★★★★
FOUR-STAR

GOALS FOR 2025

- Improve our impact by expanding public relations.
- Consider adding paid positions to improve fundraising and public relations efforts.
- Collaborate with the KD research community to plan a 4-day KDA and international KD research conference for early 2026, engaging both internal and outside/professional support for implementation to improve fund raising efforts.
- Continue to fund research and fellowships.
- Continue to publish seasonal newsletters.
- Add a medically qualified person knowledgeable of KD on the Board to directly answer questions asked by the KD community.
- Increase revenue by 30%
- Finalize 3-year Kennedy's Disease fundraising plan
- Update KDA's ByLaws to ensure compliance with California not for profit law and be reflective of the growth of the KDA.
- Re-evaluate our accounting system to improve transparency and ease of use.
- Engage The KD "Army" with new fundraising opportunities.

GRANTS AND FELLOWSHIPS AWARDED IN 2024

The KDA awarded a record $530,500 in research grants and fellowships, thanks to the KD community's support!

Complete descriptions and history of awards can be found at kennedysdisease.org/research/research-grants/2024-grants-fellowship.

Mary McMahon, Phd.

Director of Biology at Therapeutics (ReviR)

AWARD: $99,500

GRANT TITLE:
Small-molecule RNA splicing to reduce toxic AR

Nathan Beckouche, Phd.

Atmos R-Institute of Psychiatry and Neurosciences of Paris

AWARD: $100,000

GRANT TITLE:
HSP-90 inhibitor ATS-033

Gianni Soraru, Md. Phd.

University Hospital of Padua, Italy

AWARD: $54,000

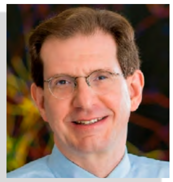
GRANT TITLE:
Investigate autonomic dysfunction in SBMA

Annalucia Darbey, Phd

University College London

AWARD: $77,000

FELLOWSHIP TITLE:
Define and develop a "therapeutic window" for AR silencing therapies and prove validity of muscle-specific treatment for KD



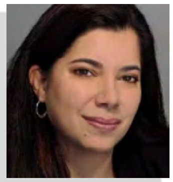
Al La Spada

Mina Gouti

Al La Spada, PhD,
University of California, Irvine, **and**
Mina Gouti, PhD,
Max Delbruck Center for Molecular Medicine in Berlin.

AWARD: $100,000*

BANBURY GRANT TITLE:
How skeletal muscle expression of mutant AR result in motor neuron degeneration in SBMA



Helen Miranda

Helen Miranda, PhD, and
Ashleigh Schaffer, PhD,
Case Western Reserve University in Cleveland

AWARD: $100,000*

BANBURY GRANT TITLE:
Gene expression, regulation by AR with different CAG repeat sizes in hiPSC-derived neuromuscular junctions.

**Grants awarded to joint participants in the 2023 SBMA Research Workshop held at the Banbury Center in New York. The workshop, funded by donations to the 2023 KD Golf Scramble in Magnolia, Texas, brought together participants from 15 labs in the U.S. and three other countries to discuss collaborative approaches between SBMA researchers and experts in other diseases.*

FINANCIALS

STATEMENT OF FINANCIAL POSITION

	12/31/2024	12/31/2023	Change
ASSETS			
Cash	354,435	334,824	19,611
Investments	524,645	452,031	72,614
TOTAL ASSETS	**879,080**	**786,855**	**92,225**
LIABILITIES			
Accounts Payable	1,064	40	1,024
Grants Payable	327,887	245,900	81,987
TOTAL LIABILITIES	**328,951**	**245,940**	**83,011**
NET ASSETS			
Without donor restrictions	527,129	530,915	(3,786)
With donor restrictions	23,000	10,000	13,000
TOTAL NET ASSETS	**550,129**	**540,915**	**9,214**
TOTAL LIABILITIES AND NET ASSETS	**879,080**	**786,855**	**92,225**

STATEMENT OF ACTIVITY AND CHANGES IN NET ASSETS FOR THE YEAR ENDED DECEMBER 31 2024

	WITHOUT DONOR RESTRICTIONS	WITH DONOR RESTRICTIONS	TOTAL
SUPPORT AND REVENUE			
Contributions	647,996	20,000	667,996
Conference Income	18,612		18,612
Investment Income	22,615		22,615
Other			
Subtotal	689,223	20,000	709,223
Net assets released from restriction	7,000	(7,000)	-
TOTAL SUPPORT AND REVENUE	**696,223**	**13,000**	**709,223**
FUNCTIONAL EXPENSES			
Program services	646,129	-	646,129
Management and general	23,600	-	23,600
Fundraising	30,280	-	30,280
TOTAL FUNCTIONAL EXPENSES	**700,009**	**-**	**700,009**
INCREASE (DECREASE) IN NET ASSETS	(3,786)	13,000	9,214
NET ASSETS AT BEGINNING OF YEAR	530,915	10,000	540,915
NET ASSETS AT END OF YEAR	**527,129**	**23,000**	**550,129**

NOTE: An Audit has been performed on the 2024 KDA Financial Statements. The Audit Report is available upon request.

2024 KDA OFFICERS AND BOARD OF DIRECTORS

Terry Thompson, President

Jameson Parker, Vice President

John Lauber, Treasurer

Kathy Thompson, Secretary

Ron Moffett, Director

Steven Rittmaster, Director

Simon Hill, Director

Dale Traxler, Director

Randy Soo Hoo, Director

Joan Sorensen, Director

Retired Board members who continue to assist:

Ed Meyertholen, Patient Advocate to the Scientific Review Board

Kennedy's Disease Association

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