Kennedy's Disease Association

OUR MISSION

inform, support, educate, fund research, and find a cure for Kennedy's Disease

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Happening This Week

MDA Muscular Dystrophy Association

MDA Webinar Friday

Updates in Research and Care for SBMA

Learn about recent recent advancements in understanding SBMA.

Friday, February 28th at 6pm EST

Click here for more information and to register

The featured presenter of this webinar is **Jeffrey Rosenfeld, PhD., MD**, FAAN of Loma Linda University. Participants will explore current clinical trials, innovative therapeutic approaches, and best practices in multidisciplinary care while discussing their potential impact on disease management. Attendees will have the opportunity to ask questions during a live Q&A session directly following the presentation.

In partnership with KDA, this webinar will also include a short presentation from **Jameson Parker, Vice President of Kennedy's Disease Association** (KDA). He will provide an overview of the KDA and current efforts toward the treatment of SBMA.

Rare Disease Day - Bay Area

Fred Briones and his extended community in the San Francisco Bay Area are doing their annual RARE DISEASE DAY 2025 this Saturday, March 1st. This has been one of the biggest fundraisers for the KDA for the past several years and we are thankful they are at it again!

Donations have already started, so don't wait and [click here](#)!

#RARE DISEASE DAY

MARCH 1, 2025

RARE DISEASE DAY BAY AREA 2025

FREE

WHEN: SATURDAY, MARCH 1, 2025
WHERE: 198 JACKSON ST. SAN JOSE, CA
TIME: 12-5

RARE DISEASE DAY®

Featured Performers
THE OSADA 3
MIKE ANUZI & AL PACE
TAMISH PULAPADI
5FTJYANTS
AND MORE

Patients & Advocates
ISABEL BUESO
RARE ACTION NETWORK
DIEGO RAMIREZ
JULIE METRAUX
CURE GM1 FOUNDATION
AND MORE

DJ Sets by
DJ FRANKIE B
DJ NETWERK
DJ CAZIUS CLAY
DJ ETHAN S

THE GET DOWN

TOP TILTIFY FUNDRAISER

198 JACKSON ST, SAN JOSE, CA 95112

Below, is a message from Fred.

"We are excited to host Rare Disease Day Bay Area for the 7th year on Saturday March 1st from 12-5pm. We will be back at the beautiful San Jose JapanTown. We'll be hosting the event at The Get Down Dance Studios and with weather permitting, have live performances, guest speakers right outside of the studio. DJ will be on rotation providing the vibe throughout the day. We are super excited to have 3 live bands joining this year. There will be patient advocates, rare disease patients, wellness demos, raffle and more. As usual, we will be live streaming the entire event for those that can't physically make it out in person. Use our LinkTree for links to our social media and LiveStreaming Links. https://linktr.ee/rarediseasebayarea

If you are a rare disease patient and would like to share your story or be a part of our event please send me a direct message. Thank you. #rarediseaseday #rarediseaseawareness

Thank you for all of your support and as usual...Stay Strong."

Other Major Fundraisers Happening Soon!

Dim Sum Give Some is scheduled for April 13th in Milwaukee, MI

Texas Golf Scramble is scheduled for May 3rd, 2025 in Magnolia, TX

More information coming soon...

Dan Jacobs of “Top Chef” Raises Awareness of Kennedy’s Disease and Inspires Viewers

Brain&Life

Despite a rare neuromuscular disorder, Dan Jacobs impressed the judges on Bravo's Top Chef and inspired viewers to overcome their own challenges.

Read the full article in Brain & Life By Robert Firpo-Cappiello

Also featured in a Brain & Life podcast, Dr. Daniel Correa is joined by Dan Jacobs who shares his Kennedy's disease diagnosis his love of cooking and how he is planning for his future.

Research Highlights

Active drug trials for the treatment of SBMA

View the National Institutes of Health (NIH) to learn more about drug trials and how to find them in the US.

AnnJi
安基生技新藥股份有限公司
AnnJi Pharmaceutical Co. Ltd

AJ201 exerts multiple cellular effects - activating nuclear factor erythroid 2-related factor 2 in response to oxidative damages, Nrf1 to enhance the ubiquitin proteasome system - mediated degradation, and heat shock factor 1 to promote protein folding.

Click here for Annji's published information about AJ201.

News about the results of the phase 2 trial are expected soon!

NIDO
BIOSCIENCES

NIDO-361, an androgen receptor allosteric modulator in development for the treatment of SBMA. The company has started a phase 2 study of the drug which is expected to finish November of this year.

Click here for Nido Biosciences press release on NIDO-361.

The KDA moved our yearly conference from Nov. 2025 to Feb. 2026 so that Nido can announce the results of their study

Shinichiro Yamada of Nagoya University is starting a clinical trial of Mexiletine Hydrochloride that starts in 2025. Here is their clinical submission.

Gianni Soraru of the Department of Neurosciences - University Hospital of Padua, Italy is starting a drug trial with Clenbuterol.

Both of these researchers were awarded grants by the KDA, 2021 and 2024 at the conference.

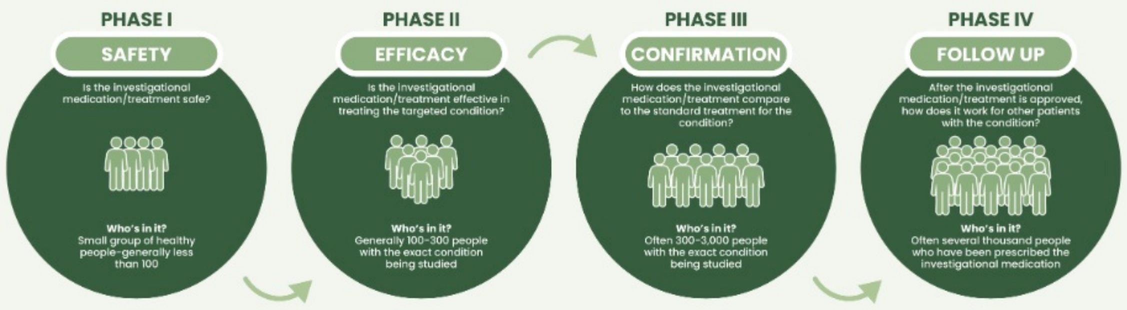
respectively. Click here to read about their grants and to see a complete history of KDA grants.

The Japanese are also reporting on improved walking ability in SBMA patients. See Combined Therapy with Leuprorelin and Robot Suit HAL in 2022 . HAL researchers believe that if therapies other than Leuprorelin are available, we can expect even better results. Many thanks to Yukihiko HAMADA, President of SBMA Association for this information.

Did you know...

The Food and Drug Administration (FDA) is responsible for protecting the public health by assuring the safety, efficacy, and security of human and veterinary drugs, biological products, medical devices, our nation's food supply, cosmetics, and products that emit radiation. In order to become legal to distribute or sell in the US, all drugs must go through a rigorous, multi-year, scientific process detailed below.

The HealthTree Foundation for Multiple Myeloma has an excellent explainer and video of the phases required for drug trials in the United States.



KDA Support Groups Online

You Are Not Alone! Connect with those who know your struggle...
Here are 10 groups listed on the KDA support site.

KDA Celebrates 25 Years at Orlando Conference

More than 250 people attended, either in person or via livestream, the KDA 2024 conference in Orlando in early November.

KDA founder and President Emerita Susanne Waite launched the conference with a keynote address highlighting the early days of the KDA. Ed Meyertholen followed this with a fascinating description of "The Ten Things I've Learned in my 25 Years with KD." Both talks set the stage for a packed agenda of presentations about patient challenges, clinical trials, and updates on the latest research.

Those in attendance agreed

Dr. Al La Spada, *discoverer of the gene mutation causing Kennedy's disease*, gave an informative overview of the state of research and potential therapeutic pathways. His talk was followed by updates by researchers from Australia, Canada, France, Italy, Japan, the United Kingdom, and United States.

Recipients of 2024 KDA grants and NIH grants to SBMA researchers were announced, and previous KDA grant recipients presented results of their projects.

that KDA 2024 was the **best conference ever** and a meaningful way to celebrate KDA's 25 years of serving the Kennedy's disease community of patients, families, clinicians, and researchers.

If you missed it, you can see several videos from the 2024 conference ON OUR WEBSITE.

New KDA Board Member

Lew Myers

The KDA is happy to announce a new board member! Lew brings a broad array of skills to the Kennedy's Disease Association Board of Directors. An accountant by trade, he began his career with PriceWaterhouseCoopers. He worked his way through various Finance and Operations positions with several fortune 500 organizations, including Baxter International, Inc. Subsequently, Lew designed and implemented patient support services, specializing in medication compliance, training and reimbursement support for patients with long term chronic diseases. Lew will be responsible for Marketing and Outreach for the KDA, initially focusing on fundraising. Please join us in welcoming Lew to the KDA Board!

Click here to see more about "our team" at the KDA.

If you are interested in getting involved email us at info@kennedysdisease.org.

KDA Grants Program Update

All of the 2024 KDA research grants and the Waite-Griffin fellowship have now been paid out. The announcement requesting proposals for the 2025 grants program was sent via Constant Contact to the research community on February 1. And, based on the discussion we had with the Scientific Review Board (SRB) in Orlando about consolidating our grants process onto a common timeline, the requirements for the Banbury grant for last year's workshop was emailed to participants on the same day. All proposals are due on June 2, with awards announced in September after SRB review.

All grant awards new and old can be found on the on the KDA Website under Research Grants.

KDA Funds the Next Generation of Researchers

Gordon Research Conference: CAG Triplet Repeat Disorders
The KDA will fund the the request for $5,000 to support seven student travel grants to this year's GRC. We can testify to the value of funding young researchers. We want to support the minds that will dedicate themselves to finding a cure.

From the KDA Website

There is a wealth of information on our website. Here are some topics posted under practical guidance on our "Living With KD" section.

- Surgery Concerns - Anesthetics
- Exercises
- Choking and Swallowing Issues
- Safe Mobility - AFO
- Medical ID Card
- Covid 19 Vaccinations and Treatment Guidelines
- Information for people with or affected by Kennedy's Disease - MNDA
- YouTube Videos

Do you have a story you'd like to share in the newsletter?
Send them to Jameson at jparker@kennedysdisease.org

The KDA is a 100% Volunteer Organization

As an all-volunteer organization, KDA is looking for volunteers who can spend a few hours working on KDA activities. Our current needs include

- **Fundraising committee**
- **Public relations and social media**
- **Conference planning**

info@kennedysdisease.org

Connect with us

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