International Kennedy’s Disease Newsletter, Spring 2026

Introduction

Welcome to the Spring 2026 edition of the International Kennedy’s Disease Newsletter.In this edition, we’re excited to welcome the Chinese KD community into our global alliance of patient advocacy groups.Mr Hu Yu-you is the founder of the “China Kennedy Disease Association” that will support the growing number of Kennedy’s disease patients being diagnosed in China. Mr. Hu and his family attended the 2026 International Kennedy’s Disease Patient and Scientific Conference in Orlando, Florida earlier this year and provided the introductory article included below. Mr. Hu also connected us with the Chinese KD research community, significantly increasing the opportunities for international collaboration in research and therapy development for Kennedy’s disease.

Please also note all the activities reported by AIMAK (Italy) and SBMA Japan, including AIMAK’s national meeting in May and SBMA Japan’s assistance in the production of a manual on fall prevention. Australia had no updates for this edition but will provide an article for the Fall edition.

Italy, AIMAK (Associazione di Malattia di Kennedy)

Dott. Fabrizio Malta, President

aimak.it

AIMAK has a broad range of activities scheduled in the weeks and months ahead. Highlights include:

- Engaging with the Telethon Network This April, AIMAK will participate in the National Meeting for all associations within the Telethon Foundation network, strengthening our collaborative efforts in rare disease advocacy.
- AIMAK National Meeting | May 8-9, Padua (Italy) We are proud to announce the XI National Meeting on Kennedy Disease. This two-day event is a cornerstone of our community: May 8: Scientific Sessions; May 9: Patients and Families Forum. Updates will be provided on clinical trials including NIDO-361, Clenbuterol, AnnJi’s AJ-201, and the pre-clinical study of ARV-027 by Arvinas. In addition, attendees will learn about the Telethon Foundation Program Project: A multicenter study dedicated to preclinical research for neuromuscular diseases.

- Support Services for 2026 AIMAK continues its commitment to improving quality of life. Throughout 2026, we are offering our members 4 Online Physiotherapy Sessions, Group Psychotherapy for Patients, Group Psychotherapy for Caregivers.

In addition, AIMAK is currently planning Speech Therapy workshops for the next semester, focusing on chewing, swallowing support, and speech improvement.

ARMK
Association pour le soutien àlaRecherche et auxpersonnes concernées par la Maladie de Kennedy

France, ARMK (Association Française de la Maladie de Kennedy)

Catherine David-Mariscot, President

ARMK has recently welcomed a new member to its scientific advisory board : a patient who is also a pharmacist, bringing a valuable dual perspective to our work.

SBMAの会
Japan SBMA Association

Japan, SBMA Japan

Yukihiko Hamada, President

sbma.jp

SBMA Japan Association assisted with the research and publication necessary for the production of a manual on fall prevention.
Falls among SBMA patients can lead to sprains, fractures, and other injuries, and may significantly impact their daily lives. Therefore, it is extremely important for SBMA patients to prevent falls and fractures.
The National Hospital Organization Higashinagoya National Hospital, Japan published the "Manual for Preventing Falls and Fractures in SBMA Patients" in 2025.
This manual was co-authored by Dr. Ikuko Aiba, nurses, physical therapists, occupational therapists, pharmacists, and registered dietitians at Higashinagoya National Hospital, along with Dr. Shinichiro Yamada and Dr. Masahisa Katsuno of Department of Neurology, Nagoya University Graduate School of Medicine, Nagoya, Japan.

https://sbma.jp/sbma.html#tentou

In addition, Nagoya University published a paper on the bone fragility and fracture characteristics of SBMA patients in December 2025.

https://doi.org/10.1111/ene.70457

United Kingdom, KD-UK

Kim Slowe, Chair of Trustees

kd-uk.com

Kennedy Disease UK (KD-UK) has focused in recent months on improving local access to care for KD patients. The charity, with the support of University College London Hospitals, is working with the Motor Neurone Disease Association (MNDA) to educate the 23 MND centres around the UK on how to diagnose and manage KD patients. This initiative will be transformative for UK patients.

KD-UK provided travel grants for UK researchers to attend the highly successful International KD Conference in Orlando in recognition of the fact that these events play a vital role in ensuring that the international fight against the disease is coordinated.

Ian Scarrott, a KD patient and KD-UK Trustee, successfully ran the London Marathon to raise funds for the charity and two supporters ran the Bath Half Marathon.Later this year a KD-UK supporter is lined up to swim the English Channel, and the charity has 3 swimmers participating in the Swim Serpentine event in Hyde Park, London. The KD-UK fundraiser of the year for 2025 was Dominic Palmer Tomkinson who ran the Hastings half marathon for KD-UK in a pink tutu. As the only runner in fancy dress, he raised an impressive £30,000 to be shared between KD-UK and Parkinsons Disease.

KD-UK continues to fully fund the Clinical Research Physiotherapist at the Kennedy's Disease Clinic in London and part fund the Clinical Research Nurse. The charity has given a grant to Dr Helen Devine to carry out research into Unbiased Drug Screening for New Treatments in Kennedy's Disease. This project aims to test treatments to target and support mitochondrial function and metabolism, to protect motor neuron health, and potentially slow the course of the disease.

KD-UK has a supply of wristbands that it is happy to send out to European patients free of charge. The wristbands contain a QR code that leads to a page providing advice to Emergency Rooms on how to manage KD patients. The information is currently in English, French and Italian. We plan to add German, Japanese, and Chinese versions shortly. Please e-mail hello@kd-uk.com with your name and address to request a wristband. The KDA has a supply in the USA.

United States, Kennedy's Disease Association (KDA)

Terry Thompson, President

kennedysdisease.org

KDA completed the largest and most successful conference in our history from 27 February-2 March in Orlando Florida. Almost 300 patients, family members, and researchers registered for the conference with close to 200 people from 16 countries and 26 U.S. states attending in person. The agenda included two days of patient-focused presentations and two days focused on research. The research agenda included three poster sessions, many of which were presented by junior investigators.

This was a highly productive gathering of international researchers and clinicians, demonstrating the breadth and depth of ongoing KD research.

The Patient Group – 2026 International KD Conference Orlando.

Lunchtime presentations by AnnJi and Arvinas were highlights of the two patient days, and conference attendees enjoyed networking events including a wine-and-cheese poster session and gala banquet. KDA acknowledged International Rare Disease Day on 28 February, and collected video remembrances for Dr. William Kennedy, who passed away in January. Fundraising activities included silent and live auctions, an online raffle, and a 50-50 challenge at the gala.

Major KDA fundraising events were held in April and May. Chef Dan Jacobs, a KD patient who has appeared on celebrity chef competitions Top Chef and Tournament of Champions, hosted a highly successful "Dim Sum Give Some" event in Milwaukee, Wisconsin on 19 April. More than 20 chefs joined Chef Dan for an afternoon of delicious food, networking, and fundraising.

The annual KD Golf Scramble was held near Houston, Texas, on 2 May.Despite a very wet golf course saturated with over five inches of rain the day before the tournament, the Golf Scramble team was able to complete the 14th annual playing of the tournament and raise a record amount of donations for Kennedy's disease research. An important new study has been started about female carriers of the KD gene mutation.KDA Carrier Support Group co-chairs Joan Sorensen and Dr. Heather Montie are supporting a study launched by Drs. Gerald Pfeffer, University of Calgary, and Kerri Schellenberg at the University of Saskatchewan to review the lived experience of KD carriers. Dr. Abdullah Al Qahtani of Johns Hopkins University, an advisor to KDA's Carrier Support Group, is also participating.

China, Kennedy Disease Association (In Preparation)

Founded by Kennedy Disease patient Mr. Hu Yu you, the China Kennedy Disease Association is committed to building a professional support platform for patients across China. Our core goals include raising public and medical awareness of Kennedy Disease, reducing misdiagnosis rates, promoting standardised diagnosis and treatment, and fostering patient communication and scientific research cooperation.

Given China's large population base, the unmet needs of KD patients remain significant. We will focus on science popularisation, domestic and international academic exchanges, patient rights protection, and establishing a care and assistance mechanism for affected families.

We look forward to working closely with the international Kennedy Disease community to share experiences, advance research, and create a better future for all patients worldwide.

Please feel free to send association leaders any suggestions for future editions of this newsletter.

Click on the logos to visit the national websites: