KENNEDY'S DISEASE - UK

International Kennedy's Disease Newsletter, Autumn 2025

Introduction

Welcome to the second edition of the International Kennedy's Disease Newsletter. This edition features updates on activities in Australia, France, Italy, Japan, the UK and U.S. The bonds among and between Kennedy's disease patient advocacy groups continue to grow and strengthen.

We hope the information in this edition is informative and helpful for the KD community. We plan to publish this newsletter twice each year, and welcome suggestions on topics you would like to see in future editions.

Australia, KD-Downunder (Facebook Group)

Rod Kent and Matt Benson, administrators

facebook.com/groups/KDDownunder

Thanks to the generous support of the KD Downunder members, the Florey Institute in Melbourne are expecting the arrival of the new KD Mice in the coming months, representing the growing collaboration among the global KD research community. This will allow Prof. Brad Turner and his team to continue the great work they are undertaking to find a treatment for Kennedy's Disease.

KD Downunder will be launching a quarterly KD Support Group meeting via Zoom. Details will be posted on the Group page when available.

A survey will be created on the Group page for Australian members. We are asking members to identify the state and regions they live to help us identify key regions for future events.

An approach has been made to have Kennedy's Disease officially included in a national patient organisation. If successful, this will increase the recognition of KD and open more services to KD patients in Australia.

ARMK
Association pour le soutien
à la Recherche et aux personnes
concernées par la Maladie de Kennedy

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

Catherine David-Mariscot, President

In recent months, ARMK vice-president Henry de Bailleul has initiated direct exchanges with AnnJi Pharmaceutical, the Taiwanese company preparing the phase 3 clinical trial of AJ201. The discussions focused on the progress of the study and the possibility of extending patient recruitment to France. In parallel, Henry also met with Professor Jean-François Pradat at La Pitié-Salpêtrière Hospital in Paris, one of the country's leading specialists in SBMA. Professor Pradat expressed interest in exploring ways to involve French patients should the opportunity arise. These combined efforts reflect ARMK's commitment to keeping French patients closely connected to global research developments.

ARMK also warmly thank our fellow associations for sharing their news and for the spirit of collaboration that strengthens the entire KD community worldwide.

AIMAK
Associazione Italiana Malattia di Kennedy

Italy, AIMAK (Associazione di Malattia di Kennedy)

Dott. Fabrizio Malta, President

aimak.it

Recent Accomplishments

The 2025 Bike Tour took place - From Turin to Bari. The solo bike tour was a resounding success. From north to south Italy, AIMAK met doctors and researchers studying Kennedy's disease. A journey of hope, knowledge, and resilience.

Two New Neurology Centres Opened. AIMAK have inaugurated two new specialized centres for Kennedy's disease: in the cities of Naples and Bari

Group Psychotherapy for Patients and Caregiver. Two online group psychotherapy sessions were held for Kennedy patients and two groups for caregivers

Online Meeting on nutrition in Kennedy's Disease. An online meeting with a dietitian was held to explain the importance of maintaining a healthy diet in Kennedy's disease. The Mediterranean diet is a useful and sustainable model.

Online Meeting with Dr. Maria Pennuto. Dr. Pennutto presented the latest research studies from her department at the University of Padua.

Up Coming events

In December, AIMAK will participate in an important Italian Television program dedicated to rare Diseases

The National Conference on Kennedy's Disease will be held on May 8-9, 2026 in the City of Padua

Clinical Trials

AIMAK continue to monitor and support the Clenbuterol and Nido trials in Italy.

Japan, SBMA Japan

Yukihiko Hamada, President

sbma.jp

Recent Accomplishments

HAL® (Hybrid Assistive Limb®) is the world's first wearable cyborg developed based on the concept of Cybernics, which integrates humans, robots, and information systems. By detecting bio-electrical signals transmitted from the brain to the muscles, HAL assists the user's voluntary movements, thereby promoting the reorganization of motor functions and recovery through neuroplasticity.

HAL has been utilized for the treatment of patients with spinal cord injury, stroke, and neuromuscular diseases, and is currently used as a certified medical device in more than 23 countries, including Japan, Europe, and the United States. It received CE marking in Europe and is covered by public workers' compensation insurance in Germany. In Japan, HAL was approved in 2015 as a novel medical device and is covered by national health insurance for designated progressive neuromuscular diseases. Several peer-reviewed studies have demonstrated significant improvements in walking ability, muscle strength, and quality of life (QOL) achieved using HAL in medical treatment.

Upcoming Events

Ongoing research is exploring new therapeutic strategies that combine HAL with pharmacological treatments. Studies in the field of neuromuscular diseases have suggested synergistic effects between HAL-assisted training and hormone therapies, contributing to the maintenance and improvement of motor function. These efforts, originating from clinical studies in Japan, are now expanding internationally, paving the way for further evidence-based medical applications and wider clinical adoption of HAL technology.

United Kingdom, KD-UK

Kim Slowe, Chair of Trustees

kd-uk.com

Activity

Kennedy's Disease UK's focus in recent months HAS been to continue to work towards making treatment for KD patients accessible within proximity to where they live. The charity is trying to ensure that all the 23 Neurocentres in the UK have a working understanding of Kennedy's Disease and of the complex support that Kennedy's Disease patients need as the disease progresses. The Motor Neurone Disease Association in the UK (the ALS charity) has a network of clinal research nurses in all the Regional Neurocentres and these nurses are now being trained in Kennedy's Disease. The hope is that the national Kennedy's Disease Clinic will work with this network to ensure that patients who struggle with travelling to London for their care are supported locally.

KD-UK is running a series of interviews with researchers, clinicians, and key players in the fight against the disease. These can be viewed on the KD-UK website.

Funding Support

Kennedy's Disease UK is part funding the London based specialist Kennedy Disease research nurse and is continuing to fund a clinical research physiotherapist at the National Hospital for Neurology and Neurosurgery in London. The physiotherapist runs sessions both in person and over Zoom. He is accessible all UK patients regardless of whether they can travel to London. It is proving to be a very popular resource with the patients.

Trials

Fingers remain firmly crossed in the UK that either the NIDO or AnnJi drug trials will lead to a meaningful treatment. KD-UK looks forward to supporting the Phase 3 AnnJi trial should it come to the UK.

United States, Kennedy's Disease Association (KDA)

Terry Thompson, President

kennedysdisease.org

KDA Awards over $900,000 in Grants and Fellowships

This year's awards included four individual grants to researchers in the U.S. and Canada, Banbury grants to three international teams, and three Waite-Griffin SBMA fellowships to junior investigators. This is the largest number of grants and fellowships and highest amount of funding ever awarded by KDA, and we are very grateful to the donor community who continue to support the global research effort to find a cure for Kennedy's disease.

Banbury SBMA Workshop

The Kennedy's Disease Association (KDA) sponsored the third annual SBMA research workshop at the Banbury Center on Long Island, New York in September. These workshops are funded by generous donations to the KD Golf Scramble held in Texas each Spring.

The Banbury Center on Long Island is part of the renowned Cold Spring Harbor Laboratories (CSHL). James Watson, who in partnership with Francis Crick discovered the structure of DNA, led CSHL from 1994 until his retirement in 2007. The Banbury Center is well-known for hosting some of "the world's best discussion workshops on topics such as molecular biology, molecular genetics, human genetics, neuroscience, and science policy."

SBMA workshops at Banbury are not your typical scientific gatherings. Instead, they are centered around a carefully selected research topic and involves a select group of researchers from within and outside the KD research community. The primary objective is to facilitate collaborative discussions and exchange expertise on the chosen topic. By doing so, researchers aim to elicit valuable feedback and generate new perspectives that can advance the study of KD.

This year's workshop focused on Metabolic Dysregulation. It attracted 17 researchers, 14 from the US and 3 from abroad, including Italian researchers Maria Pennuto and Gianni Soraru. Among the attendees were 9 international experts in the field of metabolism and disease, while the rest were international experts in KD. The workshop covered topics such as Metabolic Homeostatic Pathways, Metabolic Dysregulation in Disease Models, and Altered Metabolism in Patients. The KDA anticipates that this workshop will foster new collaborative research topics and hopes to fund grant proposals that arise from this collaboration.

Canadian Guidelines

The KDA joins the global KD patient community in welcoming the "Best practice recommendations for the clinical care of spinal and bulbar muscular atrophy," published in September by Canadian researchers and clinicians Dr. Kerri Schellenberg and Dr. Gerald Pfeffer. These comprehensive guidelines will be helpful to clinicians and patients in understanding best practices for managing the many stages of their KD journey.

International Kennedy's Disease Patient and Scientific Conference 2026

The KD International Patient and Scientific Conference will be held in Orlando, Florida from 27 February through 2 March 2026. Modeled on the 2023 London conference, *KDA 2026* will include two days of patient-focused topics and two days of scientific presentations. Registration is now open, and Early Bird registration ends on 30 November. Visit the registration site to sign up soon!

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

Click on the logos to visit the national websites: