International Kennedy's Disease Newsletter, Fall 2026

KENNEDY'S DISEASE - UK

Introduction

Welcome to the Fall 2026 International Kennedy's Disease Newsletter.

As the SBMA community eagerly anticipates the launch of the Phase 3 ROMA-KD trial evaluating AJ201 (Rosolutamide), a second promising therapy has entered clinical development. Arvinas Therapeutics is conducting a Phase 1/1B trial in the Netherlands of ARV-027, an investigational oral, peripherally restricted PROTAC designed to selectively degrade the toxic polyglutamine-expanded androgen receptor in skeletal muscle. Both trials have global implications for Kennedy's Disease patients and their families. We will continue to monitor the progress of these developments and share updates in this newsletter.

In this edition, we are happy to welcome ASEK-E, the Spanish Kennedy's Disease Association, and the Kennedy Hope Education Foundation in Canada. Both of these new organisations are helping to build awareness of Kennedy's Disease and support patients and research.

Other highlights in this edition include:

- KDA awards almost $400,000 in research grants to investigators in Japan, the UK, and U.S. And, with the help of KD-UK, a Waite-Griffin SBMA fellowship to a junior investigator at Oxford University
- An inspiring story from an Australian KD patient who is a Para World Sailing Champion in his class and an active participant in Australian organizations dedicated to fighting neuromuscular disease.
- AIMAK (Italy) initiatives to provide speech therapy and psychological support for KD patients.
- KD-UK is organising a further awareness raising Great Road Trip, this time to the Arctic Circle!
- Updates on the latest activities from France and Japan, including SBMA Japan's participation in the Patient and Public Involvement In Research (PPI) initiative sponsored by the Japanese Agency for Medical Research and Development.

AIMAK
Associazione Italiana Malattia di Kennedy

Italy, AIMAK (Associazione di Malattia di Kennedy)

Dott. Fabrizio Malta, President

aimak.it

1. Scientific Research

Arvinas Phase 1 Trial: We are closely following the upcoming Phase 1 trial by Arvinas for Kennedy's Disease (SBMA), which is set to launch soon at the CHDR in Leiden, Netherlands.

- ANJII Pharmaceutical: We are in active contact with ANJII Pharmaceutical to discuss and support the process of bringing their Phase 3 Trial to Italy and Europe.
- Telethon Collaboration: We are maintaining an ongoing, continuous dialogue with Telethon, who is doing incredible work for Kennedy's Disease.

2. Support Services

- Speech Therapy 2027: We are currently organizing a series of 5 online Speech Therapy sessions for Kennedy patients, scheduled for 2027 (focusing on chewing, swallowing, and phonation to help patients speak better).
- Psychological Support: Before the end of this year, we will host a new online group meeting with a psychotherapist focusing on a specific topic.

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

Thanks to the ARMK website, new patients and families regularly discover our association, contact us and become members. I continue to provide them with personalized advice and our neuro-nutrition program designed for people living with Kennedy's disease.

By reviewing the blood test results shared with me by patients, as well as the medications they have been prescribed, I have been struck by the extent of the metabolic and liver-related disorders in some of them, particularly high LDL cholesterol. Although such disorders are known to be associated with Kennedy's disease, they appear to be especially pronounced in several of the patients who have contacted ARMK.

We are also currently in contact with a woman who reports experiencing symptoms similar to those observed in men affected by Kennedy's disease. Her situation deserves particular attention, as women carrying the genetic mutation are generally described as only mildly symptomatic.

Finally, we are delighted to welcome Pablo Bolivar and the new Spanish Kennedy's disease patient association to our international alliance. We look forward to learning more about their work and developing closer links with them.

SBMAの会
Japan SBMA Association

Japan, SBMA Japan

Yukihiko Hamada, President

sbma.jp

SBMA Japan continues their engagement in activities with patients and researchers. In the past, they have participated in a study to identify patient-reported outcome measures for SBMA, and in an international study on genetic literacy. In 2025, they attended the 66th Annual Meeting of the Japanese Neurological Association focused on “Early Treatment Methods for SBMA, and are currently participating in a clinical trial of mexiletine as a potential KD therapy.

The organization is also working closely with the Japanese Agency for Medical Research and Development on the Patient and Public Involvement in Research (PPI) initiative:
“Through PPI activities, we believe that shifting patients' awareness from a passive "supportive position" to an active "contribution" is a key to improving QOL (quality of life). Going forward, we want to actively participate in PPI as a patient group, collaborating among patients, healthcare professionals, and researchers to establish treatments and improve the lives of patients and carriers.”

Click Here for the SBMA Japan website

KD UK
KENNEDY’S DISEASE - UK

United Kingdom, KD-UK

Kim Slowe, Chair of Trustees

kd-uk.com

KD-UK continues to make progress with its programme to improve regional access to care for people living with Kennedy’s Disease (KD) across the UK. Much of this care will be delivered through the 22 MND Centres around the country, and it complements the gold standard specialist support provided by the dedicated Kennedy’s Disease Clinic in London.

To gain a better understanding of the challenges patients face in accessing appropriate care and support, the Clinic, with the backing of KD-UK, recently circulated a detailed questionnaire to all UK registered patients. The responses are now being evaluated and will help inform future improvements in patient care.

Supporting specialist research and clinical care
KD-UK continues to fund the specialist clinical research nurse and clinical research physiotherapist based in London, helping to maintain vital expertise and support for patients.

The charity was also delighted to support the funding of the Waite-Griffith SBMA Fellowship, which was awarded to the talented young Oxford researcher Ambra Speciale. In addition, KD-UK is funding important drug repurposing research being undertaken by Dr Helen Devine at Newcastle University. This work explores the potential of existing drugs as possible treatments for Kennedy’s Disease.

KD-UK Champion Award 2026
The 2026 KD-UK Champion Award was presented to Terry Thompson in recognition of his outstanding contribution to the international Kennedy’s Disease community.The award citation read:
‘Terry has demonstrated outstanding leadership as President of the Kennedy’s Disease Association. Under his leadership, he has helped extend the reach and impact of the organisation far beyond the borders of the United States. Terry has played a pivotal role in bringing together the international Kennedy’s Disease community, fostering collaboration and strengthening the global effort to find a cure. KD-UK is proud to recognise Terry’s exceptional commitment, leadership and dedication to the Kennedy’s Disease community worldwide.’

The Great Arctic Road Trip – August 2027
KD-UK is busy organising an exciting new fundraising and awareness adventure: the Great Arctic Road Trip!
In August 2027, our trusty red Citroën 2CV will set off from Oxford on an epic journey to the Arctic Circle and beyond, travelling through the Netherlands, Germany, Denmark, Sweden, Finland and Norway before reaching North Cape. The aim of this ambitious adventure is to raise awareness of Kennedy's Disease and generate vital funds to support research into the condition. The trip follows the tremendous success of the Great Road Trip, which travelled from Los Angeles to Rome in 2022.

Looking ahead to 2027 and 2028
There is plenty more to look forward to. KD-UK is organising a patient day in Oxford in July 2027, bringing together UK patients. It will be an opportunity to share experiences, exchange information, and meet others affected by the condition.

Looking further ahead, the charity is also supporting the planning of another European International Kennedy's Disease Conference in 2028. This will provide a valuable opportunity for patients, clinicians and researchers from across Europe and beyond to share knowledge, strengthen international collaboration and continue working towards better treatments and, ultimately, a cure.

Through its commitment to patient support, clinical care, research and international collaboration, KD-UK remains determined to make a meaningful difference to everyone affected by Kennedy's Disease.

Click Here for the KD-UK website

Kennedy's Disease Association

United States, Kennedy's Disease Association (KDA)

Terry Thompson, President

kennedysdisease.org

KDA is pleased to announce the awarding of $398,000 in 2026 research grants and fellowships to investigators in Japan, the United Kingdom, and the United States. The following research teams and individuals received funding:

- Albert La Spada and Eric Wang, University of California Irvine
- Marni Falk and Melis Close, Medical College of Wisconsin, together with Christopher Grunseich, National Institutes of Health
- James Sleigh and Annalucia Darbey, University College London
- Annalucia Darbey, Alex Cammack, and Petro Fratta, University College London
- Tomoki Hirunagi, Nagoya University, Japan

In addition, a Waite-Griffin SBMA Fellowship was awarded to Ambra Speciale of the University of Oxford. This fellowship was jointly funded by KDA and KD-UK. KDA congratulates all of the award recipients and looks forward to the important discoveries and advances that will result from their research projects.

KDA sponsored the fourth annual Banbury SBMA Workshop, held October 4-6, 2026, in New York.

Organized by Professors Albert La Spada, Andrew Lieberman, and Diane Merry, the workshop brought together 19 scientists from the United States, the United Kingdom, and Italy to explore the theme, “Transcriptional and Epigenetic Dysregulation in Spinal and Bulbar Muscular Atrophy (Kennedy’s Disease).”

KDA was represented by Vice President Jameson Parker and Dr. Ed Meyertholen. The workshop once again highlighted the power of collaboration, bringing together SBMA investigators and experts from related scientific disciplines to share ideas, advance research, and identify new opportunities for discovery. Several participants described the meeting as one of the most productive and impactful scientific conferences they had attended.

KDA has announced its next conference, to be held November 7-9, 2027, at the renowned Caesars Palace in Las Vegas, Nevada. This three-day event will bring together the Kennedy's Disease (SBMA) community for a unique program that combines patient-focused sessions with a scientific conference for researchers and clinicians. The conference will feature presentations and educational sessions for patients, carriers, and family members, as well as important updates on clinical trials and emerging therapeutic developments. Attendees will also have the opportunity to learn about the latest advances in laboratory research and ongoing efforts to develop effective treatments for SBMA.

Click Here for the Kennedy Disease Association website.

Australia, KD Downunder

Rod Kent, President

KD Downunder would like to recognize Chris Symonds, a Kennedy’s Disease patient who has excelled in international sailing competition and serves as an effective spokesperson with Australia’s Motor Neuron Disease association. Chris actively promotes the awareness of Kennedy’s Disease and MND through his Board and committee memberships. Through his lived experience he shares his acute understanding of the impact the disease has on individuals and families.

“The Quiet Achiever”

Chris Symonds is one of those men who quietly get things done but rarely hear about what they have achieved. Chris lives with his wife Fayellen in Wynyard, Tasmania, Australia and has four adult children.
Chris was diagnosed with Kennedy’s Disease in 2002. He admits he experienced a period of grief, but rather than waste his time complaining against the universe, he channeled his energy into more productive things.

A Boilermaker-welder by trade, Chris left employment in 2010 as a Senior Manager at Caterpillar Underground Mining, a large design and manufacturing facility based in Burnie Tasmania. Now retired, Chris worked at home preparing his house for the future. He built a deck and new kitchen, making it wheelchair accessible. He didn’t need it at the time, but as a person who likes to be prepared, it was all done for when he did. Chris says it was great to get back to working with his hands, which was something he hadn’t done for many years. It didn’t help with the physical progress of the disease, but it certainly helped his mental state. A sailor from the age of ten, Chris feared he might not be able to keep enjoying his favourite pastime as KD progressed. He refitted boats to make it possible to continue. He is now a national and international Para World Sailing Champion in his class.

Since 2016 the three-time World Champion has competed successfully at World, European, Asia Pacific, National and State levels. He is also a qualified Australian Sailing Coach and mentor to other sailors, has won Australian Sailings "Para Sailor of the Year" a record six times and is a qualified Instructor for powerboat licences and the Wynyard Marine Rescue Unit Commander.

Among his KD-related activities, Chris is:

- President of the Motor Neuron Disease Association Tasmania.
- Director of the Motor Neuron Disease Association of Australia.
- MND Australia Governance Committee member.
- Panel member of the Australian MND Care Guideline creation team.

Chris now focuses on his health, family, community, sailing and self-managing his National Disability Insurance Scheme. He focuses on physical and mental health by attending pool and home-based personal trainings for one hour, five times a week. Chris says a positive attitude, preparation and planning for his future, are key to his achievements and wellbeing.

Click Here for the KD Downunder Facebook page



Canada, Kennedy Hope Education Foundation

Jinyuan Wu, President

A new effort has been initiated in Canada to bring attention to SBMA. The Kennedy Hope Education Foundation (KHEF) is a new organization based in the Toronto metropolitan area focused on spreading awareness of Kennedy's Disease through educational programs starting at the high school level. This initiative is especially relevant as the disease occurs at a significantly higher rate among indigenous populations in Western Canada.

Their first event was a two-day awareness campaign at Iroquois Ridge High School (IRHS) in early October. Students and staff joined in a Strength Challenge that highlighted the impact of muscle weakness experienced by those living with SBMA, and a 100-Step Challenge that engaged more than 400 students. Educational displays were featured throughout the school, and the activity encouraged participants to reflect on how everyday tasks such as walking, climbing stairs, or standing from a chair can become increasingly difficult for individuals affected by the disease. Students and staff also wore blue "Cure Kennedy Disease" wristbands to show their support and raise awareness within the school community.

IRHS was honored to welcome Max Zhou, PhD, MS, who spoke with Grade 11 and 12 biology students about the impact of Kennedy's Disease on patients and families, and ongoing efforts to advance research and treatment development. His presentation included educational resources, classroom discussion, and a question-and-answer session that helped students gain a deeper understanding of the challenges faced by those living with rare neuromuscular disorders.

The event, supported by Muscular Dystrophy Canada and the KHEF, successfully increased awareness, encouraged empathy, and highlighted the importance of advocacy and research for individuals and families affected by Kennedy's Disease.



Spain

Pablo Bolivar, President

Our community is growing slowly, we are 21 KD brothers so far. We have created a WhatsApp group to support each other.

We are an association legally established in Spain, dedicated to providing support, information, and emotional guidance to people affected by Kennedy's Disease (bulbospinal muscular atrophy or Bulbospinal Muscular Atrophy – SBMA).

Our organization is officially registered and affiliated with the relevant authorities, forming part of nationally recognized associations representing patients with neuromuscular diseases.
Thanks to our membership in ASEM (Spanish Federation of Neuromuscular Diseases), we work alongside other organizations to improve visibility, research, healthcare resources, and the protection of the rights of people with Kennedy's Disease and their families.

Some of our members are attending "rare disease" meetings around Spain.

Click Here for SBMA Spain Website.

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