International Kennedy's Disease Newsletter, Spring 2025

Introduction

As leaders of our respective national Kennedy's Disease patient advocacy groups, we are pleased to bring you the first International Kennedy's Disease Newsletter. We have collaborated on this project to share information with the global Kennedy's Disease community of people with lived experience including patients, carriers, and family members and with the global community of researchers working to find a cure. 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

KD Downunder is a Facebook Support Group which is currently managed by Rod Kent and Matt Benson. Our patient numbers are relatively small, but numbers are increasing as the population and awareness grows.

KD Downunder has a strong relationship with the Florey Institute which has been running Kennedy's Disease projects in conjunction with their Rare Disease and MND research. Florey recently hosted a "KD Info Day" for patients and family members.

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 France, there is still much work to be done to improve awareness and ensure better access to quality and appropriate care for SBMA patients. We have two priorities: the present, to preserve patients' quality of life and act on epigenetic factors, and the future, to contribute financially to research.

We are pleased to announce the launch of our website, which will serve as a platform for information and exchange. We are also launching a donation campaign to support research in France and would be interested in learning from the experiences of other associations in fundraising. For confidentiality reasons regarding insurance companies, we have chosen to create a private internal forum rather than using social media.

We are also continuing our individual support for patients, particularly in neuro-nutrition. We assist patients in adapting their diet and lifestyle based on the specific challenges of SBMA. We continue to deepen our knowledge in neuro-nutrition and stay informed in this field through the SIIN Institute.

AIMAK
Associazione Italiana Malattia di Kennedy

Italy, AIMAK (Associazione di Malattia di Kennedy)

Dott. Fabrizio Malta, President

We are busy following the Clenbuterol Trial and the Nido Bio Trial of Nido-361. The Nido Bio trial is underway at several centers in Italy as well as the UK and several EU countries. (See **Nido Biosciences** for more information.)

Our activities already planned for 2025 are:

- Wristband Medical information. Thanks to the support of Kim at KD-UK, we have also created a wristband and a card to give to all Kennedy patients in Italy
- We offer all AIMAK members (Kennedy's patients) 4 Individual Online Physiotherapy sessions with a Physiotherapist. This is Free for Patients
- We offer all AIMAK members (Kennedy patients and Caregivers), 3 Online group meetings with a Psychologist. This is Free for them.
- In July, a solo bicycle tour will start. A friend of AIMAK will do a Great Road Trip in Italy, to raise awareness of Kennedy's Disease from North to South and to raise funds. As soon as we have the definitive page, we will send you the link.
- In March we will participate in the National Telethon conference. Telethon is the most important foundation in Italy for the study and support of rare diseases and we have an excellent relationship with them.

Japan, SBMA Japan

Yukihiko Hamada,
President

The Japan SBMA Association is working with researchers at Nagoya University on clinical trials of Leuprorelin and Mexiletine. The Mexiletine trial begins this year and will be completed in 2027.

In Japan, anti-androgen therapy with leuprorelin acetate and cybernic treatment with a wearable cyborg hybrid assistive limb (HAL) are covered by insurance to prevent the progression of SBMA. Some patients have received this combination therapy, and there are case reports showing its effectiveness. The papers can be found at these links:

https://doi.org/10.3389/fneur.2022.905613

https://doi.org/10.3389/fneur.2023.1143820

https://doi.org/10.1016/j.jocn.2024.110778

United Kingdom, KD-UK

Kim Slowe,
Chair of Trustees

KD-UK is very active in raising awareness of SBMA among doctors and clinics in the United Kingdom. Our current focus is to set up a regional treatment path for all the KD patients who find it very difficult to make it up to London for routine appointments. There are 23 hospital-based Neuro Centres in the UK outside London, most of which are also specialist Motor Neurone Disease Centres. The goal is to develop a referral route into a select number of these centres, and to educate the centres on how they should manage KD patients.

KD-UK recently developed a wristband for KD men that provides essential information about the disease for use in case of medical emergency. KD-UK has provided these bands to the KDA and will send them out to people living with the disease in Europe. The advice is currently in English, French and Italian. Other languages will be added shortly.

KD-UK members are participating in the current clinical trial of the Nido Biosciences compound, Nido-361.

Kennedy's
Disease
Association

United States, Kennedy's Disease Association (KDA)

Terry Thompson, President

Thanks to the continuing generosity of the Kennedy's Disease community, KDA distributed almost $600,000 in research grants and student travel grants. In September, we will sponsor the third interdisciplinary workshop at the Banbury Center in New York. Banbury events include SBMA researchers with specialists from other, related diseases to share ideas about potential therapies.

Improving our fundraising is a major goal for 2025. We are updating our website and taking related actions to raise more money for research into potential therapies and a cure. We are also planning the "Kennedy's Disease Patient Support and International Scientific Conference" to be held in Orlando, Florida in February-March 2026. We expect this conference to be attended by patients and researchers from the global SBMA community.

KDA men have participated in the AnnJi clinical trial of AJ-201 and are actively engaged in research at the National Institutes of Health and various academic institutions across the United States. We look forward to the results of the Nido Bio trial ongoing in other countries.

Click on the logos to visit the national websites:

KD Downunder

ARMK
Association pour le soutien
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concernées par la Maladie de Kennedy

AIMAK
Associazione Italiana Malattia di Kennedy

SBMAの会
Japan SBMA Association

KD UK
KENNEDY'S DISEASE - UK

Kennedy's
Disease
Association

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