



Spring 2026 International Kennedy's Disease Newsletter

2026 年春季版《国际肯尼迪病通讯》

INTRODUCTION

引言

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.

欢迎阅读 2026 年春季版《国际肯尼迪病通讯》。本期中，我们欣喜地宣布中国肯尼迪病患者群体正式加入我们的全球患者倡导组织联盟。Hu Yu-you 先生是中国肯尼迪病协会创始人，该协会将为中国日益增多的确诊患者提供支持。Hu Yu-you 先生及其家人于今年早些时候出席了在美国佛罗里达州奥兰多举办的 2026 年国际肯尼迪病患者与科学大会，并为本期通讯撰写了下文所载的引言文章。Hu Yu-you 先生还帮助我们与中国肯尼迪病研究界建立联系，显著拓展了肯尼迪病研究与治疗开发领域的国际合作机会。

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.

敬请关注意大利 AIMAK、日本 SBMA 协会报道的各项活动，包括 AIMAK 将于 5 月举办的全国会议，以及日本 SBMA 协会协助编制的防跌倒手册。澳大利亚本期暂无更新，将在秋季刊提供文章。



AIMAK 意大利

aimak.it

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

AIMAK 在未来数周及数月内安排了丰富的活动，重点包括

·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.

与 Telethon 网络合作：今年 4 月，AIMAK 将参加 Telethon 基金会网络内所有协会的全国会议，加强在罕见病倡导领域的协作。

·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.

AIMAK 全国会议 | 5 月 8-9 日，意大利帕多瓦：我们荣幸地宣布第十一届肯尼迪病全国会议召开。为期两天的会议是我们社区的核心活动：5 月 8 日：科学会议；5 月 9 日：患者与家属论坛。会议将更新多项临床试验进展，包括 NIDO-361、克仑特罗 (Clenbuterol)、AnnJi 公司的 Aj-201，以及 Arvinas 公司 ARV-027 的临床前研究。此外，与会者还将了解 Telethon 基金会计划项目：一项专注于神经肌肉疾病临床前研究的多中心研究。

·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
2026 年度支持服务：AIMAK 持续致力于改善患者生活质量，2026 年全年为会员提供 4 次线上物理治疗课程、患者集体心理治疗、照护者集体心理治疗。

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

此外，AIMAK 目前正计划下学期开展言语治疗工作坊，重点关注咀嚼、吞咽支持与言语功能改善



ARMK

法国

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.

ARMK 近期迎来一名科学顾问委员会新成员：一名兼具药剂师身份的患者，为我们的工作带来宝贵的双重视角。



SBMA

日本

sbma.jp

SBMA Japan Association assisted with the research and publication necessary for the production of a manual on fall prevention.

日本脊髄延髄肌萎縮症協会 (SBMA Japan) 协助完成了防跌倒手册编制所需的研究与出版工作。

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.

脊髄延髄肌萎縮症患者跌倒可能导致扭伤、骨折等损伤，可对日常生活造成显著影响。因此，对脊髄延髄肌萎縮症患者而言，预防跌倒与骨折极为重要。

The National Hospital Organization Higashinagoya National Hospital, Japan published the "Manual for Preventing Falls and Fractures in SBMA Patients" in 2025.

日本国立医院机构东名古屋国立医院于 2025 年出版《脊髄延髄肌萎縮症患者跌倒与骨折预防手册》。

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.

手册由东名古屋国立医院相叶郁子医生、护士、物理治疗师、职业治疗师、药剂师、注册营养师，以及日本名古屋大学医学研究生院神经内科山田真一郎医生、胜野正尚医生共同编写。

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

<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.

此外，名古屋大学于 2025 年 12 月发表了一篇关于脊髄延髄肌萎縮症患者骨质疏松性与骨折特征的论文。

は、転倒予防マニュアルの作成に必要な調査および出版活動において支援を行いました。

SBMA患者における転倒は、捻挫や骨折などの外傷につながる可能性があり、日常生活に重大な影響を及ぼすおそれがあります。そのため、SBMA患者にとって転倒および骨折の予防は極めて重要です。

2025年、国立病院機構 東名古屋病院は「SBMA患者の転倒・骨折予防マニュアル」を発行しました。

本マニュアルは、東名古屋病院の饗場郁子医師、看護師、理学療法士、作業療法士、薬剤師、管理栄養士に加え、名古屋大学大学院医学系研究科 神経内科学の山田晋一郎医師および勝野雅央医師との共同執筆によるものです。

さらに、名古屋大学は2025年12月、SBMA患者における骨脆弱性および骨折特性に関する論文を発表しました。

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

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



KD-UK

英国

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 (MND) 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.

英国肯尼迪病协会 (KD-UK) 近几个月专注于帮助肯尼迪病患者方便本地就医。该慈善机构在伦敦大学学院医院的支持下，正与运动神经元病协会 (MND) 合作，为英国全境 23 家运动神经元病中心提供肯尼迪病诊断与管理培训。此举措将为英国患者带来变革性影响。

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.

英国肯尼迪病协会为英国研究者参会提供差旅资助，以支持他们参加在美国奥兰多成功举办的国际肯尼迪病大会，该类会议对保障全球协同抗击肯尼迪病至关重要。

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.

肯尼迪病患者、英国肯尼迪病协会受托人 Ian Scarrott 成功跑完伦敦马拉松，为该慈善机构筹集善款；另有两名支持者参加了巴斯半程马拉松。今年早些时候，一名协会支持者将计划横渡英吉利海峡，还有 3 名游泳选手将参加在伦敦海德公园举办的“蛇形湖游泳”赛事。2025 年度英国肯尼迪病协会筹款人是 Dominic Palmer Tomkinson，他身着粉色芭蕾舞裙为协会跑完黑斯廷斯半程马拉松。作为唯一一名身着奇装异服的参赛者，他筹集了令人瞩目的 3 万英镑善款，善款接收方为英国肯尼迪病协会与帕金森病协会

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.

英国肯尼迪病协会持续全额资助伦敦肯尼迪病诊所的临床研究物理治疗师，也部分资助临床研究护士。该慈善机构已向 Helen Devine 博士提供研究经费，用于开展肯尼迪病新疗法无偏药物筛选研究。本项目旨在筛选以线粒体功能与代谢为靶点的治疗方案，保护运动神经元健康，有望延缓疾病进展。

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.

英国肯尼迪病协会备有手环，可免费寄送给欧洲患者。手环内置二维码，链接至为急诊室提供肯尼迪病患者管理建议的页面。相关信息目前提供英语、法语、意大利语版本，计划近期新增德语、日语与中文版本。如需申领手环，请发送电子邮件至 hello@kd-uk.com，注明您的姓名和地址 美国肯尼迪病协会亦备有此手环。



Kennedy's Disease Association (KDA)

美国

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.

肯尼迪病协会 (KDA) 于 2 月 27 日至 3 月 2 日在美国佛罗里达州奥兰多成功举办了史上规模最大、成果最丰硕的国际会议。近 300 名患者、家属及研究者报名参会，来自 16 个国家/地区与美国 26 个州的近 200 人现场参会。会议日程包括两天患者专场报告与两天研究专场。研究专场设有三场壁报展示，多数由青年研究者汇报。本次国际研究者与临床医生的交流会成果丰硕，展现了肯尼迪病在研项目的广度与深度。



The Patient Group – 2026 International KD Conference Orlando

患者群体——2026 年奥兰多国际肯尼迪病会议

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.

AnnJi 与 Arvinas 公司的午餐会报告是两天患者专场的亮点，与会者还参与了多项交流活动，包括红酒芝士壁报交流会与盛大晚宴。肯尼迪病协会在 2 月 28 日国际罕见病日举办纪念活动，并为 1 月逝世的 William Kennedy 医生收集纪念视频。筹款活动包括静默拍卖、现场拍卖、线上抽奖，以及晚宴环节的 50/50 挑战筹款。

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.

肯尼迪病协会于4月与5月举办了大型筹款活动。曾参加《顶级大厨》和《冠军争霸赛》名人厨师大赛的肯尼迪病患者 Dan Jacobs 厨师，于4月19日在美国威斯康星州密尔沃基市成功举办“点心献爱心”活动。20余名厨师与 Dan Jacobs 厨师当天下午共同奉献美味佳肴、开展交流并筹集善款。年度高尔夫慈善赛于5月2日在美国得克萨斯州休斯敦附近举办。尽管赛前一天降雨量超过5英寸，球场极度湿滑，高尔夫团队仍成功完成第14届赛事，为肯尼迪病研究筹集了创纪录的捐款。

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.

一项关于肯尼迪病基因突变女性携带者的重要新研究已启动。肯尼迪病协会携带者支持小组联合主席 Joan Sorensen 与 Heather Montie 博士，正支持由卡尔加里大学 Gerald Pfeffer 博士与萨斯喀彻温大学 Kerri Schellenberg 博士发起的研究，旨在调研肯尼迪病携带者的真实生活体验。约翰斯·霍普金斯大学、肯尼迪病协会携带者支持小组顾问 Abdullah Al Qahtani 博士亦参与此项研究。

China, Kennedy Disease Association (In Preparation)

中国肯尼迪病联合会（筹备）

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 standardized diagnosis and treatment, and fostering patient communication and scientific research cooperation.

中国肯尼迪病联合会由肯尼迪病患者胡余友先生发起创立，致力于为中国患者搭建专业支持平台。我们的核心目标包括提升公众与医学界对肯尼迪病的认知、降低误诊率、推动规范化诊疗，并促进患者交流与科研合作。

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

鉴于中国庞大的人口基数，肯尼迪病患者未被满足的需求依然十分突出。我们将聚焦疾病科普推广、国内外学术交流、患者权益维护，并逐步建立面向患病家庭的关爱与救助机制。

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.

我们期待与国际肯尼迪病社群紧密合作，分享经验、推动研究进展，为全球患者创造更美好的未来。

このニュースレターの今後の号に関するご提案がございましたら、協会のリーダーまでお気軽にお寄せください。

ロゴをクリックすると各国のウェブサイトへアクセスできます。

