

SEPTEMBER 2023



Activity in the past quarter has included a highly successful fund-raising bike ride from Chamonix to Nice and the KD-UK team, in partnership with the Kennedy Disease Association, have also made significant progress in creating a series of one page information leaflets on how to manage KD symptoms. These will start to be published on the KD-UK website shortly.

It's been a busy quarter at KD-UK.

Plans for the London International KD Conference have progressed well. It's an outstanding programme and record numbers of you have registered to attend the event. If you haven't already registered its not too late to do so at the website [here](#). We are also anticipating that we will given, at the conference, some early feedback on the ongoing drug trials. Do try and make it person; it really does promise to be a fantastic event.

The conference banquet, which is free to attendees, will include a performance by the highly talented Hank Grey Country Band who have featured on many occasions on the TV. Debbie Hadley from UCLH has worked tirelessly to bring the conference together. KD-UK has been hugely grateful for all the work she has done on behalf of the entire KD community.



A SHORT MESSAGE FROM LOUIE LEE AT UCL

My exciting new role is split into two main areas:
clinical and research.

Clinical: I will be providing physiotherapy input in the national Kennedy's Disease clinic in London. I will be offering the option of video follow up sessions to support people with their exercise and balance training, this will be particularly helpful for those who do not live in London.

Research: The focus of my research is building our understanding of balance and falls in Kennedy's disease. We hope to use this research to help us to develop specific approaches to balance assessment, rehabilitation, and training.

We are looking for fund raising opportunities for 2024 so please do put your thinking caps on and help to raise the funds we need to keep the research programmes going. We rely entirely on donations/events to fund the invaluable work of Luca, Louie and the doctors in London.

RESEARCH UPDATE BY DR HELEN DEVINE

To get closer to a treatment for KD it is important that there is a wide range of research covering different aspects of the disease from investigating the mechanisms of disease using basic science in the lab, to exploring the early clinical features of the disease, identifying biomarkers which can show whether a treatment is working and clinical trials to test possible therapeutic agents. In the past year there has been research progress around the world in all these areas in KD. Here is a whistlestop tour of some of the research in KD that has been published over the last year:

An unexpected finding from studying genetic sequencing data from the 100,000 genome project suggested that the CAG repeat expansion in the androgen receptor gene (the genetic cause of KD) is present in 1:6887 males which is four times more frequent than previously thought!

Understanding the mechanisms of disease is crucial to identifying potential therapeutic targets. Work in international labs have found further evidence of mitochondrial dysfunction (mitochondria provide the energy for the cell) and promising results for targeting androgen receptor aggregates and metabolic pathways can improve motor function in SBMA mice. These lab findings require further studies before they can be translated into human treatments.

Clinically characteristics of disease in different international patient groups have been reported as well as work looking at clinical and neurophysiological changes in early-stage male patients which is particularly relevant in the event of a potential drug which can be used to slow or stop progression of the disease.

There is also new evidence that virtual telehealth clinical assessments for patients with KD are effective and reliable which is important especially when people have limited mobility and may not be able to travel long distances to a specialist appointment. An interesting report of a single case gait treatment with a cyborg assisted limb showed benefit in maintaining gait during disease progression but more research is needed in this area. Finally, the use of mexiletine as a symptomatic therapy for the worsening of muscular weakness under cold conditions which can be a common feature of KD was tested in a randomised control trial of a small group of patients in Japan. Unfortunately, it did not show an improvement in this study.

Scientific experts in KD will meet in November at the International KD conference in London to discuss their latest research findings.

FOR A FUTURE WITHOUT KD

We have commissioned and printed a Kennedy Disease Christmas Card this year. A friend of KD very kindly painted a winter scene of Queen Square Gardens and the National Hospital of Neurology and Neurosurgery for us. The cards are very high quality and are matt laminated.

Cards are priced at £5 for a pack of 6 cards and envelopes. Three packs (18 cards) are £12.50. Postage and packing is £3.50 regardless of number ordered.

Please E-Mail kim@kd-uk.com to order your cards. You will then be sent an invoice that allows you to pay by credit/debit card online.

Cards will be on sale at the upcoming London International Kennedy Disease Conference.



Find out how you can help us today.

Do reach out if you feel that KD-UK can help you in anyway. We can be contacted at hello@kd-uk.com.

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