

MARCH 2023

As ever, we have been busy at KD-UK over the past months.

KD-UK has continued to provide financial support to the clinical team at UCLH. Both Luca Zampredi and Louie Lee, who provide outstanding clinical support to KD patients and carers are not NHS funded. As it stands, they are entirely funded by KD-UK or by research funding.

We have launched a campaign to raise awareness of Kennedy Disease by Neurologists, and thanks to the pro bono support of the marketing company Marketwise we are in the process of e-mailing all UK Neurologists with details on how to recognise Kennedy Disease symptoms. This campaign will be followed up by a much larger campaign with General Practitioners. Recent research at UCL suggests that it is likely that every GP practice in the UK will have at least one patient with the gene defect that causes Kennedy Disease, and that the illness is being massively under diagnosed.

We have started work on creating a new and more interactive KD-UK website. Target date for the launch of the new website is late summer 2024.

Many thanks to Anita Edwards-Symons for organising the Boscastle Sea Shanty Festival, and also to Julian Gadd who is bravely jumping out of an aeroplane next month. These events have raised significant and much needed funds for the charity. Please keep your fundraising ideas and donations going. All the money that we raise is very wisely spent.

Finally, if you would like to help with the running of KD-UK please contact me at kim@kd-uk.com. We are always on the lookout for new Trustees.

JULIAN GADD FUNDRAISING SKYDIVE

Julian was finally diagnosed with Kennedy's Disease last year and has been a supporter of KD-UK ever since. Shortly after his diagnosis his wife, Jen, was diagnosed with breast cancer. This April, Julian will soar to new heights in a tandem skydive with the Red Devils at Netheravon.

Julian is fundraising for three causes close to his heart, KD-UK, St Richard's Hospice and Worcestershire Breast Care Haven.

"I, for some reason which I cannot put my finger on, always wanted to do a parachute jump, but for many reasons failed to make it happen in the last 50 years," says Julian.

"So, I created an opportunity and it is going to happen. To be clear it is only going to happen once and I will not be doing it again!"

So far, he has raised more than £1,600, split between the three charities. Julian added: "Becoming ill is a frightening thing when it happens, but I have found there are so many fantastic people and charities out there to help, we just need to make everyone aware."

We send our heartfelt thanks to Julian for taking on this skydive to support our care!

www.justgiving.com/crowdfunding/JulesAndJen



KD Drug Trial

It is hoped that the drug trial by Nido Biosciences will get underway soon in the UK. There are still some regulatory and funding issues to overcome but good progress is being made. Updates will be published on the KD-UK website as and when they become available.

STRONGER LINKS WITH THE MNDA

KD-UK is working with the Motor Neurone Disease Association to help KD patients with access to local support.

The well-funded MNDA has a well-established regional support network and is also able to give grants to KD patients who are struggling to afford equipment or struggle financially to get up to London for their clinic appointments.

One of the goals of KD-UK is to help patients with accessing more local support as we are very aware that travel to London is very difficult for many.

Details of how KD patients, and carers, will be able to access the services offered by the MNDA will be published on our website over the coming weeks. Details of some of the services they offer are in the MNDA presentation that was presented at the Kennedy Disease International Conference in London last November. Click [here](#) to link to the presentation.

UPDATE FROM LOUIE LEE

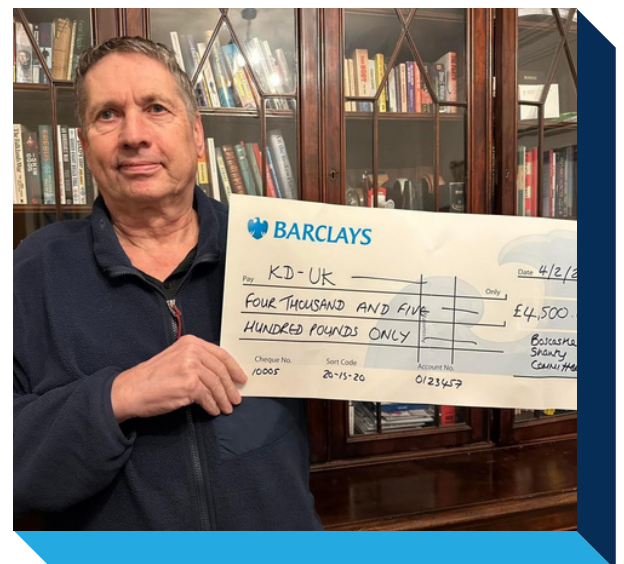
Over the past few months, I have been enjoying providing physiotherapy for patients attending the national KD clinic in London. As part of my role, I have recently set up a remote video clinic that our patients will be able to access once every 6 months, so that they can receive physiotherapy and exercise advice without having to travel into London. From a research perspective, I am in the process of setting up two studies exploring balance and falls in people living with KD. The data from these studies will be used to inform the design and delivery of future balance interventions.

Finally, I have been in contact with physiotherapists at the NIH in the USA, with a view to arranging a future collaboration. It's shaping up to be an exciting year!

FOR A FUTURE WITHOUT KD

Many thanks to Anita Symons-Edwards and the team behind the Boscastle Shanty Festival for the exceptional £4,500 donated to KD-UK.

The money is being ring fenced, along with money raised by Eric Mager last November, for a KD awareness campaign for regional Neurologists.



Find out how you can help us today

[LEARN MORE](#)



Facebook
E-mail
Website
Twitter

[Kennedy's Disease UK](#)
hello@kd-uk.com
www.kd-uk.com
[@UkKennedys](https://twitter.com/UkKennedys)

