

JULY 2023

Welcome to the first edition of the KD-UK newsletter. The plan is to publish a newsletter approximately every 3 months subject to there being something meaningful to say!

It's been busy at KD-UK. We are partnering with UCL to deliver the first ever London international KD conference in November and the conference will replace the KDA conference this year. With a fantastic line up of presenters, the conference will be an outstanding opportunity for people living with KD, carers, and carriers to be brought up to date on all the latest guidance, and on the latest research into the illness. There will also be an update on the current ongoing clinical trials from the researchers who are carrying them out. Although the key presentations will be broadcast over the internet, please do try to attend the conference in person as interaction between attendees adds hugely to the value.



Future plans for KD-UK include creating a grant programme to help cover the cost of travel for people living with KD, with limited means, to make the journey to London for their annual review. We are also looking at finding ways to make it easier to access treatment locally rather than always having to rely on the specialist clinic in London. We will keep you updated as these plans progress. We are also strengthening our links with the international KD community on the basis that if we work together we can achieve more. Our first joint programme with KDA is to create some information factsheets on managing the disease. These will be published on our website over the coming months.

For those of you looking for a mobility scooter, or powered wheelchair, we have negotiated a 10% discount with the very well established [TGA mobility](#). When you order, simply say you are a person living with KD and the discount will be applied. I have one of their scooters and so far so good! We hope to expand the number of companies that will offer discounts over the coming months.



MEDICAL TEAM

We are delighted to report that our new KD research physio, Louie Lee, has now started at UCLH and many of you will meet him when you make your trek to London for your annual review. Louie is being funded by KD-UK; initially for 2 years.

More information can be found [here](#).

A WARM WELCOME

Sam has also joined the team at KD-UK to give us some much needed admin and comms support.

Sam works for us 1 day a week and can be contacted at sam@kd-uk.com.



Two interesting documents have been published so far this year. One was the study by Professor Pietro Fratta into disease frequency that confirms that many more people have the KD gene defect than first thought (about 5 times as many!!) and the other is 'The Voice of the Patient' report that was put together by the KDA. Both these documents can be accessed through the KD-UK website [here](#).



FUNDRAISING FOR KD

There have been some fundraising events this year, and we have persuaded some ageing cyclists to pedal over the alps from Chamonix to Nice in support of KD-UK. Please support by clicking [here](#).

Please do also contact KD-UK if you have your own fundraising ideas. We are always happy to advise and support.

FOR A FUTURE WITHOUT KD

University College London and KD-UK are organising the first ever London International Kennedy Disease Conference from 4-7 November 2023. The conference will also incorporate the KDA annual conference.

 Date: Nov 4th-7th

 Time: Starts at 11 AM on Nov 4th

 20 Bedford Way, London, WC1H 0A

The first two days of the conference (4-5 November) are entirely focused on people living with Kennedy Disease, carriers, carers and for people wishing to learn more about the disease.

The conference is free to attend, both in person and online. The conference banquet is free for everyone who is attending the conference in person. Additional tickets can be purchased for friends and family at a cost of £60 per ticket.

KD CONFERENCE

The conference banquet on the evening of Saturday 4 November at The Royal National Hotel is free for all live attendees and includes some excellent live entertainment.

Please register for the conference by [clicking here](#).



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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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