

MARCH 2025



KD-UK is continuing to work on its new website which will contain lots of information for people living with the disease; be they patients, carers or carriers. We plan on launching the website in May,

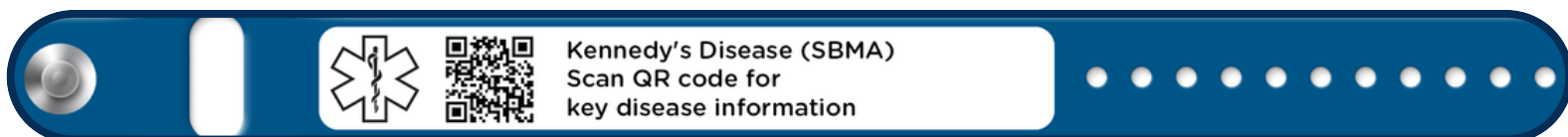
We continue to strengthen our links with the international KD community. We are working with KD advocacy organisations in the USA, Italy, France, Japan and Australia to ensure that information is shared and disseminated.

We have also greatly strengthened our links with the MND Association who have a remit to support people who are living with KD. Please do visit their website as KD patients are able to access their grant programmes and local support groups.

The launch of the KD wristband has been a massive success with wristbands now being taken up and worn across the world.

Work is also ongoing to give people living with KD, who have difficulty getting to the London Clinic, greater clarity on how they can access medical support across the UK.

The challenge of fundraising is ever present. Please do reach out to us if you have ideas for a fundraiser event. We need as much support as possible from the KD community if the charity is to fulfil its ambitious plans.



WRISTBANDS

There has been an excellent take up of the new KD wristband which provides advice to A&E, and emergency rooms, on the specific challenges of treating KD patients.

This is important as it is highly unlikely that any A&E doctors have any understanding of the disease and could give inappropriate treatment or make wrong diagnoses. A&E doctors simply have to scan the QR code on the wristband to access information on the illness. We already have a report of a KD patient whose heart attack diagnosis was changed after A&E read the information that was accessed from the wristband.

KD-UK is sending out wristbands free of charge to patients in the UK and Europe. A large batch of the bands has also been sent to the KDA in the United States. To order your wristband please [click here](#).

Find out how you can help us today by visiting our website.

DRUG TRIALS

Drug trials continue to be carried out by [AnnJi in the USA](#) and [NIDO in Europe](#). Although there are absolutely no guarantees, it is hoped that these drugs could lead to an effective treatment for the disease in the coming years. Initial results from the trials will be published later this year or early in 2026. It's not a quick process!

MNDA GROUPS AND SUPPORT

The MNDA has many branches and groups throughout the UK. Please [click here](#) to access the list. These groups welcome KD patients, carers, and carriers.

Apart from being enjoyable social events with people who understand the illness they are also an excellent place to pick up tips on how to access specialist care within your region. Feedback from KD patients who have attended MNDA regional meetings has been universally positive.

THE GREAT BIKE RIDE – SIGN UP!

The Great Bike Ride from London to Paris is scheduled to take place from 11–15 September. The cost of the ride, which includes ferries, hotels, food, bike transport etc. is a very reasonable £975 and this cost can be covered from your fundraising provided at least 50% of the monies you raise goes to the charity.

If the trip is to go ahead, we do need more riders. Please encourage friends, family and colleagues to sign up. You can [sign up here](#).

INTERNATIONAL CONFERENCE

The next International KD Conference will be in Orlando, USA in late February/early March 2026. The conference will follow the London format with 2 patient days and 2 days for the research community.

People living with KD in the UK will be warmly welcomed at the conference. Full details will be published in the coming weeks on both the KD-UK website and the KDA website.

BATH HALF MARATHON

Kennedy's Disease may be a predominately male illness, but it was girl power that was most evident at the Bath Half Marathon this March. Claire Reid and Charlotte Beare both put in exceptional performances and raised over £2,500 for KD-UK. A big thank you to both of them.



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