

# Eradicating MLD

(Metachromatic Leukodystrophy)

**Ideas and Information for  
Fundraisers and Supporters**





**If you have been affected by MLD or know a family that has and would like to make a donation, volunteer or fundraise for us, this leaflet will point you in the right direction.**

## **Why every £ raised can make a difference**

MLD (Metachromatic Leukodystrophy) is a rare genetic condition, but when it strikes it brings devastation to the entire family. Because it is rare, many health professionals will have little experience of either the symptoms or the progression of the disease. We can help affected families in the UK by making them aware of the experience of other families and alert them to the likely progress of the disease and its effect on family members.

## **Donations and Volunteers**

We urgently need donations so that we can support families and also help to find a cure for MLD. There are many ways in which you could help us – perhaps you have a special skill which could help us promote the charity and help raise funds. Some examples are shown opposite of imaginative ways that some of our supporters have used. If golf, sky diving or abseiling are not your thing then we are just as happy to receive donations large and small through Just Giving. If you are looking to volunteer, please contact us at [\*\*admin@mldsupportuk.org.uk\*\*](mailto:admin@mldsupportuk.org.uk).

## Fundraising for us

Are you planning a sponsored walk, run, swim, cycle ride, quiz, karaoke or golf day? Or if you like the idea of fundraising for us but need a few tips and some inspiration, meet some of the heroes who have already supported our cause. Whatever you decide, we are here to offer advice and moral support.

### Elliott and Leanne Whittingham

#### Event: Epsom Golf Charity Day

Elliott and Leanne Whittingham, Denise Hodgson, Amy, Gail and Chris organised an all-day Golf Event at the Epsom Golf Club. Their family had suffered two bereavements from Adult-Onset MLD and organised this day in their loved ones' honour. They gathered together almost 60 golfers who took part in the challenge, which was followed by a Raffle. Altogether, they raised £4,000 for the Charity.



### Abdul Shaded

#### Event: Tandem Sky Dive

Hamzah, my cousin, is a 3-year old boy who suffers from Late-Infantile MLD. I decided to do the skydive because I have always been afraid of heights and I felt if I could overcome my fear by jumping 15,000ft out of a plane, I can somewhat overcome my fear of eventually losing Hamzah. We may not be able to change Hamzah's fate, but together we can help give other children like him a brighter future. With my supporters we raised £2,740.



### Chantelle Bond

#### Event: Charity Bike Ride in Canterbury

Chantelle Bond attended an event put on by the National Citizen Service in Kent to raise awareness of MLD Support Association UK and the work we do to support sufferers and their families. She wanted to help us and signed up for a Charity Bike Ride in Canterbury to raise funds for our charity on JustGiving. Well done Chantelle, who raised £125.



### Kieren Martin

#### Event: Abseiling the ArcelorMittal Orbit

Keiren Martin is planning to Abseil from the ArcelorMittal Orbit in August 2019. He regularly takes on challenges for charity, and this time has chosen us. Let's all wish him luck.



## Paul Warrington

**Event: London Marathon 2019**

Paul has known Scott Clark (sufferer of Adult-Onset MLD) for over 25 years. He is a designer who created the brand identity and website for MLD Support Association UK. He is also involved with regular updates of our marketing materials. Thank you Paul for undertaking such a gruelling run for our Charity.



## Erica Tyrrell

**Event: London Landmarks Half Marathon April 2022**

Erica is a good friend of Vivienne Clark, Chair of MLD Support Association UK and has known Scott (sufferer of Adult-Onset MLD) for a number of years. Erica also volunteers her time to help with the administration of the charity. At the remarkable age of 74, Erica is running the London Landmarks Half Marathon – go amazing Erica!



## What is MLD?

MLD is an acronym for Metachromatic Leukodystrophy. MLD is an autosomal recessive genetic disorder, directly caused by a deficiency of the enzyme Arylsulfatase-A. Without this enzyme sulfatides build up, eventually destroying the myelin sheath of the nervous system. The myelin sheath is a fatty covering that protects nerve fibres. Without the sheath, the nerves in the brain and the peripheral nerves cease to function properly. At the moment the only treatment approved by the NHS is Gene Therapy, but this is not available for all forms of MLD.

## About us

MLD Support Association UK was set up to bring hope to families in the fight to eradicate MLD (Metachromatic Leukodystrophy).

Our aim is to provide support to families, personally, through our Website and Facebook group and at annual Family Conferences and Fun Days.

To find out more about our work and the disease, see our **Living with MLD** and **Understanding MLD** leaflets, or visit our website.

## Contact us

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