



Sent via email to: [timiccm@btinternet.com](mailto:timiccm@btinternet.com)

19th October 2017

Dear Trevor Robinson

I am writing to acknowledge and say a huge thank you for the donation of £5000.00 that we received today from Kevin Pilkington of Croydon Crematorium, as beneficiaries of the ICCM Recycling of Metals Scheme. As a relatively small charity we were thrilled to be nominated and delighted to be chosen to receive the cheque. We are in the early stages of planning an emotional support based residential weekend for parents whose child has been diagnosed with or have passed away from a Mitochondrial Disease, we are hoping to use this donation to help towards the costs of the weekend. I will let you know how the plans go! Thank you.

The Lily Foundation was set up in memory of my daughter Lily to help fund research into Mitochondrial Disease. Mitochondrial Disease is a genetic condition that prevents cells in the body from producing enough energy for the body to survive. It can affect any part of the body, for example the heart, brain, muscles, eyes, hearing, stomach or kidneys.

The Lily Foundation has three main aims:

1. **Diagnosis and Treatment** – To date we have invested over £1,000,000 on research. Through funding Research Projects and Medical Staff, we aim to improve diagnosis, develop treatments and ultimately find a cure for Mitochondrial Disease. We currently fund a diagnostic project which is a collaboration of all the Mitochondrial Research Centres in UK, Great Ormond Street Hospital, The Evelina Children's Hospital at Guys and St Thomas, The John Radcliff Oxford and Newcastle University, supporting patients from all over the UK. This year we have expanded our research strategy to fund research focussed on finding treatments for Mitochondrial Disease. A very exciting time for us and the world of Mitochondrial Disease.
2. **Raising Awareness** - We work hard to raise the awareness of Mitochondrial Disease and of The Lily Foundation amongst the general public and medical profession. We believe that the actual figure of diagnosed cases in the UK is just the tip of the iceberg. For every race run or cycled, every cake baked, every t-shirt worn you are doing your bit to help us to raise the profile of Mitochondrial disease.
3. **Supporting Families** - The Lily Foundation supports families who have lost a child or have children or family members suffering from Mitochondrial Disease. We sponsor rooms in accommodation attached all the hospitals we support enabling families to stay close to their loved ones while in hospital. We send families with sick children on a family breaks to Center Parcs to give them memories to last forever. We fund specialist nurses, and part fund specialist equipment. Finally, we are always there at the end of the phone to answer a call from a parent who just needs to talk.

We are so proud of what we have achieved and with your help we will continue to strive to support those families facing the daily challenges of Mitochondrial Disease and to find some answers for those who have lost their loved ones to this heart - breaking disease.

Thank you so much for your support x

Kind regards

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Liz Curtis

The Lily Foundation and Lily's mum x

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