



Mike Swain
National Federation of Demolition Contractors
Regional Secretary
85 The Elms
Hertford
Herts
SG13 7UY
22/7/10

Dear Mike

I am writing to thank the NFDC for their donation to The Lily Foundation by giving Andy Turk a place to run in the London Marathon and raise his sponsorship for The Lily Foundation. Andy did a fantastic job, both in running the marathon in a great time, but also raising £6133.33. Thank you so much.

The Lily Foundation was set up in memory of my daughter Lily, who died aged just 8 months, to help fund research into Mitochondrial Diseases. Mitochondrial Disease is a genetic condition that prevents the 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. The gene testing programme – this will speed up diagnosis for patients which will enable supportive treatments to be administered in good time to make a difference. For families who have an affected child or have lost children it will lead to the possibility of pre-natal testing, testing of siblings and of course parents. The work on this is well underway. The technology has been designed, trials are coming to an end and testing on the mitochondria will be underway within the year. To date we have donated £158,000 to this project.
2. Training of specialised doctors and nurses – currently there is very little NHS funding for training in this field. The Lily Foundation supports training needs. To date we have donated £12,000 to this cause.
3. The Ronald McDonald House in London provides housing for families who have sick children in hospital. It enables parents and siblings to stay close by during these very difficult times. Last year we donated £3000 and we will soon be donating a further sum.

During the time in which The Lily Foundation has been involved in funding this research, the metabolic and genetic teams at The Evelina and Guys Hospitals have experienced a huge increase in patient referrals as they are now able to offer a diagnostic service, the first of its kind world wide. This means so much to those families just waiting for some answers.

We 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 heartbreaking disease.

Thank you once again for supporting The Lily Foundation.

Kind regards

Liz Curtis
The Lily Foundation and Lily's mum