



Fighting Mitochondrial Disease through research, awareness and support

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Dear Parents, Carers and Guardians,

Before half term, the school was visited by Liz Curtis from The Lily Foundation Charity, which was set up in memory of my daughter Lily who died of Mitochondrial Disease aged 8 months old.

When she was diagnosed, we had never heard of Mitochondrial Disease so we searched the internet for information and advice but found none. We decided to change this by forming The Lily Foundation to raise money and support for other families like us.



The purpose of today's visit was to introduce our charity to the school community and to increase awareness of Mitochondrial Disease.

The children were shown a short animation called 'What's Mitochondrial Disease' which you can watch by following the link. <http://www.thelilyfoundation.org.uk/animation/>

### So, what is Mitochondrial Disease?

Mitochondria are the batteries in our cells and they produce the energy our body needs to survive. When a person has Mitochondrial Disease their batteries do not work properly and the cells die, which can lead to organ failure and often death. There is currently no treatment and no cure.

Mitochondrial Disease can affect anyone, and is often first noticed in babies and young children who may show symptoms like slow weight gain, excessive tiredness, seizures or heart problems. For children with the disease it can be debilitating, and their lives can be cut tragically short.

### Is it common?

Although on paper Mitochondrial Disease is considered rare, doctors believe that many cases of this disease remain undiagnosed due to lack of awareness and understanding of the condition.

We already know that faulty mitochondria are responsible for common conditions such as Diabetes, Alzheimer's, Parkinson's, Epilepsy and some forms of Cancer and could also be an explanation for sudden infant death syndrome, otherwise known as cot death. We need to learn more about this.

### What do we do?

The money we raise funds vital medical research which improves diagnosis, we increase awareness of the condition and help support families living with the disease or those who have lost a child.

For more information about Mitochondrial Disease or how you can help, please visit

[www.thelilyfoundation.org.uk](http://www.thelilyfoundation.org.uk). Thank you **Liz Curtis - Lily's Mum**

## Please help us make a difference



[www.thelilyfoundation.org.uk](http://www.thelilyfoundation.org.uk)



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