

BBC Radio 4 Appeal on Sunday 27th June 2010

It was dawn on a North Essex beach. The sea was calm and rabbits were hopping about among the colourful beach huts.

In a nearby cottage hospital, a baby with red hair, called Joe, was born. His excited parents examined their beautiful little boy from head to toe. They were concerned to discover an extra digit on his left hand but the midwives reassured them that this could easily be removed at a later date.

Little did everyone know that this tiny little finger was the outward sign of a rare condition called the Laurence-Moon-Bardet-Biedl Syndrome, or LMBBS.

Joe's mother discovered the full facts of this syndrome while in the library, with Joe watching innocently from his pushchair... and sobbed. Tests had already indicated kidney disease, hypertension, obesity and delayed development. Diagnosis was finally confirmed when Joe was 10 months old and, soon after, the family were told the devastating news that he had a progressive eye condition that would lead to blindness.

Joe is my grandchild.

Luckily, Joe's parents soon discovered the Laurence-Moon-Bardet-Biedl Society, a support group for those with the syndrome, their families and carers.

The family were invited to the LMBBS Family Weekend and Conference. That was 12 years ago - they haven't missed one since.

The Family Weekend provides a stimulating break for parents and a fun-filled time for the children, who, for once in their lives, don't feel "different". Joe's Mum says: "...it feels like going home.....for just one weekend a year, we find true acceptance and peace."

I now volunteer as the charity's fundraising co-ordinator and raising money for this conference is a big challenge. But, if a thousand people were to donate £20, I can tell you - next year's weekend would be safe.

So please help us to continue providing these very special weekends for Joe and all the families who need them.

You can give now either online via the Radio 4 website or by calling 0800 404 8144. That's 0800 404 8144. Or you can write a cheque to LMBBS and send it to Freepost BBC Radio 4 Appeal. That's Freepost BBC Radio 4 Appeal. Please mark the back of your envelope 'LMBBS...and thank you.