



Parley

Parents And Relatives
Listening and Empathising
with You

Kelly's Story

Reuben was officially diagnosed with Hereditary Multiple Exostoses when he was a baby – I found his first lump when he was 6 months old. He inherited this condition from his father (who didn't know he could pass it on) it manifests itself as mostly large and often painful benign bone tumours all over his body, Reuben has these lumps on his arms, legs, knees, fingers, toes, ribs, spine, hips and collar bone. Thankfully it doesn't affect the head/face as the bone in the skull is different from the rest of the skeleton.

As well as being unsightly and uncomfortable HME interferes with normal bone growth so suffers experience joint/rotation problems and even restricted growth, a common characteristic is very short arms. Reuben has limited mobility in his wrists/arms/pelvis and is facing surgery this year to straighten his arm which is twisting. He has had several operations already to remove some of the more problematic growths and will require further surgery throughout his childhood. Other lumps he has learnt to live with. I treat his pain with ordinary childrens' over the counter pain killer remedies, massage and occasional chiropractic treatments.

Normally the condition stabilises in adulthood when the child stops growing, the growths also stop forming but in some cases some adults find that their lumps and bumps continue to be a problem and require treatment. As they get older, HME sufferers are also at greater risk of arthritis and certain types of bone cancer. The risk of inheriting HME is 50% and severity varies between family members, it affects roughly 1 in every 100,000 people. My son is worse affected than his father unfortunately. At the moment there is no cure but genes responsible for the condition have been isolated so there is ongoing gene therapy work going on to try and come up with a cure/prevention. At the moment the only way to avoid passing it on is embryonic screening.

Reuben's mental health is unaffected and for the most part he/we live a normal life and he joins in as much as he can with all the normal activities that boys his age enjoy. There are times when he needs to use a

wheelchair if he's in pain and/or experiencing limited mobility/fatigue but he copes with these difficult periods with remarkable stoicism. The nature of his condition means that you can never be quite sure what each year of his childhood/growing up will bring but he remains very upbeat and positive and even seems to enjoy a lot of the special attention he gets when he goes to hospital. (We travel from Brighton to Edinburgh for this as the only specialist in the country is based there. The condition is so rare the specialist takes self referrals which is what I did). Reuben is now quite scarred as a result of numerous surgeries but he is still a very beautiful and courageous child and I am very proud of him.

The most informative and helpful website for people suffering from HME in this country is: <http://www.hmesg.org.uk/> This is the official website for the HME support group and has lots of useful information about the condition as well as providing a space for sufferers and their families to chat etc. They hold regular conferences and AGMs and fundraising events some of which I have attended and do their best to publicise this little known condition. They can also provide advice to newly diagnosed families and offer advice on hospital referrals etc.

The HME website is affiliated to the contact a family website which is also useful for families with kids with rare disorders:
<http://www.cafamily.org.uk/index.php?section=861>

There is an American website specifically aimed at children with HME that is also quite useful is: <http://www.mheandme.com/> (note that in the US this condition is known as MHE).

At a more local level I've had a lot of help and advice from Brighton based disabled children's charity Amaze:
<http://www.amazebrighton.org.uk/> They are able to help with things like DLA advice and school statements etc as well as providing more general support and advice – one of the best things they do is the compass card please see website for more details if you're unfamiliar with this scheme.