



Waiting for a smile



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by Gil Lightfoot, Chester Chronicle

Isaac Hughes is a contented, gurgling little boy, playing in the garden with his mum. But the happiness he feels inside will never show on his face – because he cannot smile.

AN incredibly rare syndrome, which affects only 200 people in the UK, means Isaac Hughes will never smile, blink or show facial expression.

The 11-month-old delights in the company of his elder brother, Theo, aged 4, and laughs at his antics, but that joy is never expressed on his face.

For the past few months his life has been an endless round of appointments with consultants as his parents, former Chester residents, Ceri and Philip Hughes, now of Mold, seek advice on the syndrome, Moebius. It is so rare that there is no specialist consultant available and no research programme being undertaken.

Now Ceri is hoping to help change that by joining with the families of other sufferers nationwide to raise £250,000 to fund research which may identify the cause of the condition and pinpoint possible treatments.

As soon as he was born, Ceri knew that Isaac had problems because he was unable to feed properly. Breastfeeding was impossible because he was unable to suck so he was fed intravenously in intensive care. Eventually Ceri was able to take him home and bottle-fed him every hour. Even though she used tiny teats she still had to physically hold his mouth closed around them to make sure he fed properly.

Because no-one knew why Isaac was having such problems feeding, a series of genetics tests for a range of ailments was carried out and it was two agonising weeks before the results came back.

"We cried with relief when those tests came back negative," said Ceri. "However, the relief was short-lived. Isaac was feeding slightly better, but I still felt instinctively that something was wrong.

"Over the next few months Isaac developed well but his eyes were extremely turned in and did not move outwards. We all thought the reason we were still waiting to see his first smile was because he had poor eyesight.

"Every day I hoped to see a smile from Isaac but, despite trying all the usual peek-a-boo games, there was not even a flicker of a smile. He had chuckled a few times and even laughed, although it sounded a bit strange, but no smile lit up his face.

"Every parent wants their child to be a happy, smiley person and when we were choosing names we settled on Isaac because it means 'he laughs' in Hebrew. How ironic that has turned out to be."

At Isaac's eight month check-up his paediatrician at the Countess of Chester Hospital dropped the bombshell that Isaac was suffering from Moebius syndrome – and there was no known cure.

Ceri, who is well-known in the Chester business community having set up and run the Prowl networking group for professional women while working as the marketing manager for Allwoods accountants in the city, was determined to find out all she could about the syndrome.

"In our search to find answers one thing was evident," said Ceri, "and that was that there was very little
http://iccheshireonline.icnetwork.co.uk/printable_version.cfm?objectid=2061988... 23/03/2008

likelihood of finding a consultant who specialised in Moebius as there were too few cases of the syndrome spread throughout the country and there has been no research into the condition because of its rarity.

"The best source of information has come from other parents and people with the syndrome that I have met through the Moebius Research Trust (MRT)."

Ceri and Philip, an accountant, have come to rely on the Trust as a vital source on information.

"Isaac can't blink but he can close his eyes to sleep which is apparently very rare," said Ceri. "Most sufferers have to sleep with their eyes open.

"Also because he can't blink the sun and the wind affect his eyes badly so we have bought him a tiny pair of sunglasses to wear when he is outside."

Every sufferer is affected differently, explains Ceri. Isaac can only look forwards and not to the side. He has a squint and focuses with only one eye at a time.

He is now facing the first of what could be a series of eye operations to try to help with some of these problems. Later on he will have plastic surgery to correct a slight webbing of some of his fingers which is another recognised symptom of the syndrome.

So far Isaac has seen a plastic surgeon, a paediatric consultant, a paediatric community doctor, an ophthalmic surgeon, a speech therapist, a speech therapist specialising in feeding issues, a hand plastic surgeon and a consultant paediatric neurologist, at hospitals in Chester. Wrexham and Liverpool.

Although he has just learned to close his own mouth sufficiently for bottle feeding he still has problems eating and is prone to choking.

Despite all his problems Ceri says that Isaac is happy and content.

"The syndrome may mean that he is slower to crawl and walk than other babies but he will get there in the end," said Ceri. "He is very interactive and simply adores his brother. There is apparently a higher rate of autism with babies with this condition but we have seen no signs of that.

"It has been a real journey for me to accept that Isaac is as he is," said Ceri.

Ceri, who now runs the Clarity networking group for women, believes so passionately that research is vital she is voluntarily helping the trust raise its profile.

To kick-start the fundraising two members of MRT from Scotland are preparing for a gruelling motorcycle ride across the US covering 3,000 miles in 10 days this summer.

They are hoping to raise funds through corporate sponsorship. If you would like to sponsor them, visit [www.kiltsacrossamerica .co.uk](http://www.kiltsacrossamerica.co.uk)

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