

Lennie's story

Three-year old Lennie suffers from side effects from the medication he takes for a rare and potentially fatal condition, but our research has helped lessen the impact of his treatment on his body so that he can feel like other boys his age.

Our son Lennie is three and a half years old and he's just like any other little boy in Manchester. He loves swimming, playing football and going to pre-school with his friends.

What no one can see from the outside is that Lennie suffers from a rare condition called congenital hyperinsulinism, which means his blood sugar levels fall extremely low because his body produces too much insulin. We have to monitor his blood sugar levels throughout the day and always make sure we carry snacks in case his blood sugar drops too far.

He was diagnosed with the condition at just 7 months after he had a seizure and was rushed to hospital. The doctors took some of Lennie's blood to be tested, and when they came back they told us his blood sugar level was dangerously low, and it was due to a rare disease. We had no idea what congenital hyperinsulinism was and we were anxious about how it would affect his life.

Fortunately, there are good medications for congenital hyperinsulinism and Lennie was put on one called diazoxide, which has stabilised his blood sugar levels so he can run around and play just like any other little boy of his age.

But diazoxide comes with a horrible side effect - excessive hair growth. At first the hair on Lennie's head started to grow very quickly and became very thick. This wasn't too bad, but when the hair started to sprout on his arms and lower back, it was really stressful not just for Lennie but for the rest of the family too. We were worried about how unusual the hair looked on such a young boy and what it would be like if more hair grew over time.

We want him to feel just like everybody else.

We went to Lennie's consultants and explained our worries to them. We were relieved to hear that researchers were also interested in reducing the side effects of diazoxide and that Lennie's doctors were themselves running a study into fish oil extracts, which they thought might help Lennie. Taking the fish oil extracts helps to manage blood sugar levels, which means you can take less diazoxide and still get the same impact - that is, with fewer side effects.

Around the same time, family and friends saw an article in the local newspaper about a little girl with congenital hyperinsulinism, who had been on the study, and had seen a reduction in hair growth. That cemented our decision to let Lennie try it too.

We started to give him the fish oil supplement alongside his medication in September 2013 and the results have been great. Not only has his hair growth lessened, but we have been able to reduce Lennie's diazoxide dosage 0.5ml a day, as the fish oils are maintaining his sugar levels so well. No parents want to see their child on lots of medication so we're thrilled with the outcome.

Research like this is so important to the NHS and to improving people's quality of life.

Not only does it lead to the development of better treatments and medicine, it also helps raise awareness of rare disorders like congenital hyperinsulinism.

Learn more about clinical research at [The Royal Manchester Children's Hospital](#) and [how you can get involved with research](#).