Local families with bleeding disorders
Support for families, by families

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Family Stories Series

Henry's Story

Haemophilia A with inhibitors

9 year old Henry has a rare genetic blood disorder, he has severe Haemophilia A. His blood doesn't clot properly, he gets nasty bruises all over his body, but the worst are the internal bleeds into joints and muscles. If left untreated his condition could prove fatal. This disorder affects 1 in 10,000, mainly boys.
There is currently no cure.

However, Henry has an added problem making his condition even rarer. Henry's body see's this medication as a foreign body and a danger to him and produces an inhibitor (antibody) to Factor VIII to fight it off which gives him no protection to bleeds, meaning he is in constant danger of internal bleeding.

Since Henry was two, he has undergone several treatment plans just to get his body to except the vital Factor VIII needed to clot his blood. One of the treatments for this was to try and tolerise the body by injecting large amounts of Factor VIII daily, sometimes twice daily or more, in the hope his immune system tolerates the medication. He has endured two rounds of a immune suppressant (used in blood cancer's) that strips away part of the immune system in the hope that when the immune system grows back it will recognise the much-needed factor VIII. Unfortunately, this did not work either.

In the past he has spent weeks and months being carried or pushed about in a special pushchair. His joints swell up to the size of small football and it take weeks to get back to normal. Sometimes this may have been from a small knock or even just spontaneously.

He's a real trooper and takes it all in his stride, he has endured daily (often twice daily) injections. He has irreversible damage to his ankle joints which are always painful, and he has suffered from other painful joints. He has daily physio treatment and regular trips to the hospital.

In March 2017, Henry selected to take part in the ACE910 trial (now known as Hemlibra). He was one of only 7 boys in the country, 40 worldwide. It is a protein that manages to mimic factor VIII. It has changed our lives, although he still remains a haemophiliac. Having said all this, Henry doesn't let Haemophilia prevent him from doing things he loves, like playing football, riding his bike, swimming and fencing!

In Henry's words: "It's not that bad being a Haemophiliac with inhibitors, you get lots of attention! You get invited to fab fun days out and get lots of treats "

We would like to extend a special thank you to all the families who have contributed to this important series of experience-sharing stories, in particular, the children with haemophilia who have allowed their photo to be shared.
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