

WHEN LIFE CHANGED WITH INHIBITORS

Christopher's Story

Belinda and Paul are parents of Christopher, aged 7, who has haemophilia and inhibitors.

They talked to HFA about the enormous change a new and effective treatment for inhibitors has made in his life.



Christopher now.

'I don't want to have haemophilia anymore.'

Belinda and Paul heard this time and time again from their son, Christopher.

When he was 10 months old, Christopher had his first bleed in his left elbow. Although he had factor replacement therapy, when he was 18 months old he had a bleed into his elbow that wouldn't stop. His body had developed inhibitors; antibodies which prevented his factor replacement therapy from working.

Christopher was not able to do the things most children take for granted - it put his life at risk. Haemophilia tested the family's courage and resilience: it felt to his parents like a very long journey, fraught with fear and anxiety. For Belinda, these times were 'always waiting for something bad to happen'.

By the time Christopher had reached his sixth birthday, Paul and Belinda had grown to fear the childhood milestones we often celebrate. Belinda recalled, 'when he lost his two front teeth, he ended up in hospital for weeks both times because we couldn't stop the bleeding.'

Christopher had suffered significant joint damage in both ankles and one elbow as a result of uncontrolled, spontaneous bleeds. He had to use a wheelchair at school and wear braces to support those joints.

As an active young boy who loved the outdoors, Christopher grew frustrated as his severe haemophilia stopped him from doing many of the things he enjoyed.

A typical day for Christopher involved getting up early, putting numbing cream around the port site in preparation for treatment, which had to be infused into a vein carefully



Christopher as a baby.



and slowly. Once treatment was completed, Belinda put Christopher's splints on before going to school. This whole process could sometimes take up to two hours a day.

At night, Christopher would sleep in the same room as his parents. Belinda explained, 'I could hear him groaning in pain. This is how I would pick up he was bleeding again.'

The opportunity to use a new treatment product late last year made an amazing difference to Christopher's health and wellbeing.

From having a bleed monthly – sometimes even weekly – he now hasn't had a bleed in months. He no longer has to cope with daily intravenous infusions or have hospital stays. Christopher can have physiotherapy on his damaged joints without the fear of causing more bleeds – and without the wheelchair, the leg and elbow splints.

He can now spend his free time being the active boy he always wanted to be, playing with his friends and going camping with his family. This is a welcome change - camping used to be impossible as Christopher's daily infusions had to be carried out in a sterile environment to avoid infections.

For his parents as well as Christopher, the impact has been life-changing. 'We feel as if we've won the lottery. We are able to enjoy life with our son and the normal everyday things,' said Belinda and Paul.

This is a new type of treatment and Christopher's parents are desperately hoping it will continue to work well for Christopher and allow him to grow into a confident, healthy young adult. Christopher doesn't complain about life with haemophilia anymore. He's too busy enjoying all the things he couldn't do before and going to school full-time. ■