

Parents' joy as FOUR sons are saved by life-saving bone marrow transplants

By JAMES MILLS Last updated at 08:34am on 25th March 2008

For five years they lived under the shadow of a rare condition that threatened to kill their four sons before they left their teens.

But David and Allison Hartley can at last put the nightmare behind them after the final bone marrow transplant which means each boy can now enjoy a normal life.

The youngest, eight-year-old Luke, had his operation in November at Great Ormond Street children's hospital and is now home and healthy.



Happy and healthy: Mr and Mrs Hartley with, from left, Joshua, Nathan, Luke and Daniel

Brothers Joshua, 16, Nathan, 14, and Daniel, 11, had already received their transplants.

"We are so relieved," said Mr Hartley, 44, a company director from Romsey, Hampshire.

His 40-year-old wife added: "All the boys can now go on and lead normal lives. It's fantastic."

The brothers were diagnosed with the rare genetic disorder X-Linked Lymphoproliferative syndrome (XLP), or Duncan's Syndrome, in November 2003.

Affecting only boys, the disease attacks the immune system and leaves victims vulnerable to cancer and fatal infections.

Only 100 families worldwide are affected.

Most sufferers do not survive beyond their teens, but can have their life expectancy restored to normal by a bone marrow transplant.

When the Daily Mail highlighted their plight in March 2004, more than 1,000 volunteers came forward for tests as possible bone marrow donors.



Appeal for donors: The Hartley family pictured in 2004

Mrs Hartley had already been matched as a donor for Joshua, who had a successful operation in June 2004.

Seven months later, Daniel had an operation thanks to an anonymous donor located through the Anthony Nolan Trust.

Another donor was found for Nathan, who had his operation in October 2005.

Nathan was then eligible to be a match for Luke, who went into hospital for his operation last May.

The operation was unsuccessful but the setback was only temporary as another, anonymous donor was found.

Although all the boys are now cured of Duncan's Syndrome and have healthy immune systems, Joshua has Graft Versus Host Disease (GVHD) which is common after bone marrow transplants.

This is caused by the immune cells of the donor marrow attacking the body of the recipient.

However, doctors are confident that with treatment he will be free of the disease within the next year.

Daniel and Nathan have both made good recoveries and have no complications.

Luke hopes to return to school before the summer holidays.

"The last five years has been like going through a dark tunnel," said their mother.

"It really was like a very long nightmare. But throughout it all, the boys were very positive and everyone comments on how normal and well adjusted they are."

Mr and Mrs Hartley set up their own charity two years ago - the XLP Research Trust - which has so far provided £150,000 for investigations into the condition that nearly destroyed their family.

Mr Hartley said: "When we were first told that the boys had Duncan's Syndrome there was no organisation there to support us.

"There are charities to help families coping with a lot of other diseases, but this one is so rare that most people hadn't even heard of it.

"We're delighted that our boys have all pulled through, but we want to carry on helping other families."