

400+ boys

Over 400 boys around the world have been diagnosed with XLP. It is believed that there are many more.

XLP has been described as 'the silent killer' - few will make it into and through their teen years.

Currently the only cure is a bone marrow transplant - but many of these boys do not have this as a viable option.

The XLP Research Trust exists to fund vital research into this rare genetic disease — with the belief that a genetic cure is just around the corner.....

Can you help make this reality?



Finding a cure for X-Linked Lymphoproliferative Syndrome

www.XLPTrust.org

The XLP Research Trust

60 Winchester Road
Romsey
Hampshire
SO51 8JA
United Kingdom

Phone: +44 (0)1794 521077
Email: davidh@XLPResearchTrust.org
Web Site: www.XLPTrust.org

What is XLP?



X-Linked Lymphoproliferative Syndrome (XLP), which is also known as Duncan's Syndrome, is a rare, always fatal disease that only affects boys.

To date over 100 families with 400+ boys have been diagnosed worldwide. It is likely, however, that there are many more cases where the correct diagnosis has not yet been made.

XLP can have many symptoms including: severe glandular fever, cancer of the blood (lymphoma) the inability to fight off infections and sometimes severe anaemia. 70% of individuals with XLP die by the age of 10 years without treatment. The cause of the condition was only found in 1998, so there is still a lot to learn.

The best 'prevention' is: regular top-ups of anti-viral medicines, immunoglobulin therapy or steroids – but these are not a cure. Today the only possible cure is a bone marrow transplant – in effect replacing the faulty immune system.

However with advances in genetics, a potential cure may now only be a few years away.

Introducing the XLP Research Trust

The XLP Research Trust exists to:-

- ◇ Promote and fund research into the cause, management, symptoms and cure for XLP
- ◇ Provide a point of contact and support for those families affected by XLP
- ◇ Raise the awareness of XLP amongst the medical profession and the general public

History of the XLP Research Trust



David and Allison Hartley established the XLP Research Trust after their four sons were diagnosed with XLP in 2003.

In the London based Institute of Child Health Research Report 2004, there was a comprehensive feature on XLP and the Hartley boys. This suggested that a genetic cure would be possible in the next few years if funding was available—this brought about the birth of the XLP Research Trust.

The Hartleys are under no illusion that a genetic cure will be of any help to their sons who are currently going through the long process of bone marrow transplantation. Their hope is however that no one else should walk the dark valley that

XLP casts in the future – by that a safe genetic cure will be available.

Please join with us to win the battle with XLP, so that one day we will have that all important cure and moreover, that it will be available worldwide.

How you can help

The XLP Research Trust depends entirely on voluntary donations to fund our work. Whilst being based in the United Kingdom, the role of the XLP Research Trust is truly global and we are delighted to accept donations from anywhere in the world.

If you would like to make a donation please send cheques made payable to 'The XLP Research Trust' to the address below. The Trust is in the process of applying for charitable status with the Charity Commission of England and Wales.

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