X-Linked Lymphoproliferative Syndrome

# Having Children



The XLP Research Trust 60 Winchester Road Romsey, SO51 8JA United Kingdom

+44 (0)1794 521077 info@xlpresearchtrust.org www.xlpresearchtrust.org



DISCLAIMER: This fact sheet is designed for educational purposes only and is not intended to serve as medical advice. The information provided here should not be used for diagnosing or treating a health problem or disease. It is not a substitute for professional care.

Published July 2008



Registered Charity Number 1111075

#### Introduction

X-linked lymphoproliferative syndrome (XLP) is a rare inherited condition that can be passed from one generation to another. However, there are also cases where a new XLP suffer is discovered without a previous family history of XLP.

The purpose of this leaflet is to explain the likelihood of XLP affected individuals passing on XLP to future generations.

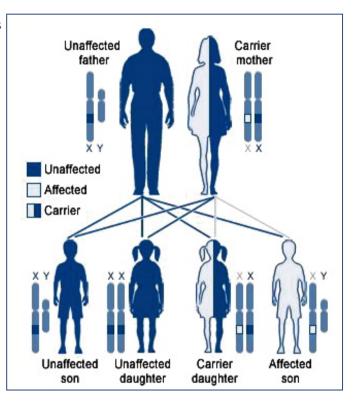
#### Female carriers of XLP

*Q.* My daughter is a carrier of XLP. What are the chances of her having a child with XLP?

A. If your daughter has children with a partner who is not affected genetically by XLP then: -

For each pregnancy there is a 1 in 4 chance that they will have:

- A boy with XLP.
- A boy who does not have XLP and who will not pass on the condition to his children.
- A girl unaffected by XLP but who will be a carrier of the gene.
- A girl who will be unaffected by XLP and is not a carrier of the XLP gene.



*Summary.* For female carriers of XLP there is a 50% chance of having a child with XLP. There is a 25% chance of having a boy affected by XLP and a 25% chance of having a girl who is a carrier.

### Males affected by XLP

*Q.* My son has XLP. What are the chances of him having affected children?

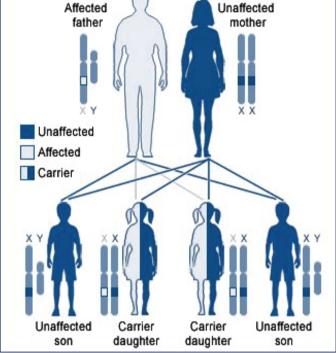
A. A striking characteristic of x-linked conditions is that fathers cannot pass X-linked traits to their sons, no maleto-male transmission.

If your son has children with a partner who is not a carrier of XLP then:

 Boys will not be affected by the condition and they will not pass on the XLP gene to their children.
All the girls will

be carriers of

XLP and will



potentially pass the XLP gene on to their off-spring.

An XLP affected male who has been through a bone marrow transplantation as a cure for XLP may however be infertile due to the associated chemotherapy. You should seek medical advice from your doctor who will be able to arrange fertility tests.

## **Genetic Testing**

With recent advances in medical science it is now possible to screen for XLP prior to pregnancy. Preimplantation genetic testing is a process which involves testing the genetic makeup of embryos created using assisted reproductive technology (ART) such as *in vitro* fertilisation (IVF), and selecting specific embryos to transfer, which are not affected by XLP, to a woman before her pregnancy begins. Please seek medical advice on this.