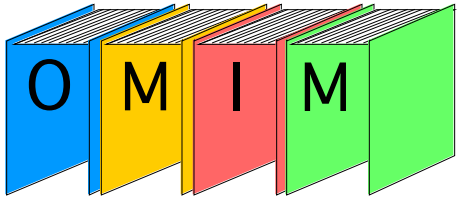
THERE IS A LOT OF SCIENTIFIC LITERATURE
ON
X-LINKED HYPOPHOSPHATEMIA

An excellent overview is presented in this recent research article:

New perspectives on the biology and treatment of X-linked hypophosphatemic rickets.
Carpenter Thomas O.,
Pediatric Clinics of North America
44(2): 443-466 (1997)

For an exhaustive review of the scientific literature, see the XLH entry in the Online Mendelian Inheritance in Man (OMIM) database on the web.

http://www3.ncbi.nlm.nih.gov/htbinpost/Omim/dispmim?307800



We are each of us precious human beings who happen to be affected by a rare genetic disorder. Please do contact us if you would like to meet others who share the same problems and concerns of living with this condition. Get information on diagnosis, treatment, research, and everyday concerns. And help us to reach more families and do what we can to push forward research on XLH and related genetic diseases of bone development. We all continue to hope for a better approach to the root cause of these syndromes, and one day a cure.

WE HOPE THAT THIS FLYER WILLBRING A SMALL LIGHT OF CHEER INTO THE LIVES OF EVERYONE WHO MAY READ IT, AND WE WISH YOU ALL THE BEST ALONG YOUR LIFE'S JOURNEY.

The XLH NETWORK

Would you like to find out even more about XLH? Have you been frustrated in trying to get information or just dealing with it day-to-day? Just knowing others who have long-term personal experience with XLH can be so helpful. Unfortunately, until now most of those affected with XLH would never meet others with the disorder outside of their families, and thus felt very much alone dealing with the disease. In addition, the feeling of isolation is increased because it can be difficult to find specialists with adequate knowledge of the disorder.

THE XLH NETWORK IS TRYING TO CHANGE ALL OF THAT

Begun in November 1996, this network is an international volunteer group of people affected by or interested in XLH and other associated diseases. Growing daily, the XLH Network now links almost 400 members around the world with up-to-date information on diagnosis and treatment, knowledgeable clinicians, and active researchers.

You can easily reach us if you have access to the INTERNET. Our website is always available:

www.xlhnetwork.org

Here you will find a growing body of public information on XLH, and a link to a private webspace, exhaustive archives of our activities, and a chatroom for network members.

The free internet-based discussion list, called F-HYPDRR, is currently our primary means of connecting to each other. You can join by sending an email to either of the Subscriptions Coordinators:

Larry @ XLHNetwork.org
Joan @ XLHNetwork.org

No Internet Connection? Then WRITE to us:

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Elpha Green Cottage
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We are looking forward to hearing from you!

[V1.12 October 2003]

THE XLH NETWORK

X-linked Hypophosphatemia (XLH)
X-Linked Hypophosphatemic Rickets
Familial Hypophosphatemia
Vitamin D-Resistant Rickets

These are some names for a relatively rare disease that affects about 1 in every 20,000 people. The name used by professionals is the first one listed, and is generally referred to by its acronym: XLH. XLH is a genetic disorder that is passed from one generation to the next. It is carried on the X chromosome; hence the 'X-linked' in the name. The rest of the name identifies the primary and key sign of XLH, which is a low level of phosphorus in the blood; this is called hypophosphatemia. Another sign, which doesn't always occur or can be mild to severe when it does, is bone disease where the legs can become knock-kneed or bowed; this is called rickets. There are also other genetic bone diseases causing hypophosphatemia which are called 'autosomal' -- not X-Linked. While different in subtle ways, these other diseases and XLH can have effects that are very similar.

If someone you know, your family, or you, are touched by congenital hypophosphatemia, please read on for more information.