

## 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 gain access to consultants who have specialist 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 well over 100 affected families 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. The free internet-based discussion list, called F-HYPDRR, is currently our primary means of connecting to each other. You can join by sending email to any of the coordinators:



Larry Winger (Larry.Winger@ncl.ac.uk)  
Elaine Jacobson (emj@super.org)  
Colin Steeksma (Colin\_Steeksma@telus.net)



If you have access to a WEB BROWSER, take a look at our public website:

<http://georgia.ncl.ac.uk/VitaminD/vitaminD.html>

where you will find a growing body of information on XLH, and a link to a private webspace for F-HYPDRR list members. If you join our list you will learn how to access this special area for members, but much of the information is available to all at the web address above.

### No internet connection? Then WRITE to us:

Larry Winger	Colin Steeksma	Elaine Jacobson
Elpha Green Cottage	34640 Devon Crescent	3517 Mase Lane
Sparty Lea, Allendale	Abbotsford,	Bowie,
Hexham,	British Columbia	Maryland
Northumberland	V2S 2X6	20715
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United Kingdom		

We are looking forward to hearing from you!



Information presented in this XLH NETWORK brochure is provided solely for educational purposes. All patients should consult with their respective doctors and specialists to get the best possible medical advice concerning their own individual specific condition and treatment. The effect of each family's mutation may be different and unique.

[V1.11 March 2000]

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

An excellent overview is presented in this recent research article:

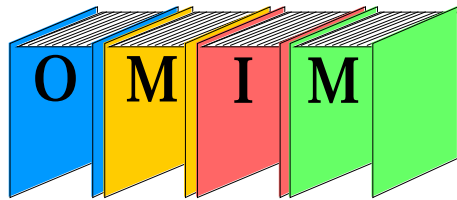
New perspectives on the biology and treatment of  
X-linked hypophosphatemic rickets.

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/>

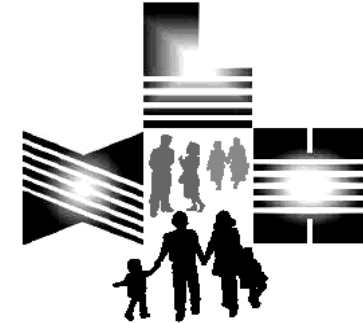
[htbin-post/Omim/dispim?307800](http://www3.ncbi.nlm.nih.gov/htbin-post/Omim/dispim?307800)



We are each of us important and valuable 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 THIS BROCHURE HAS BEEN HELPFUL. HOWEVER YOU HAPPEN TO HAVE READ IT, WE'D LIKE TO TAKE THIS OPPORTUNITY TO WISH YOU ALL THE BEST.

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## 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 typically 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.