XLH BELGIUM BELGIE BELGIQUE BELGIEN

Association of patients with hypophosphatemic rickets

X-Linked Hypophosphatemia (XLH) is a rare genetic disorder that affects about one in 20,000 people. The key characteristic of XLH is a low level of phosphate in the blood, called Hypophosphatemia. When a person is affected by XLH, their kidneys do not properly handle Vitamin D and phosphate. This causes a variety of symptoms and disorders that usually affect their bones and teeth.

Source: Learn About XLH (xlhnetwork.org)

Our association is called XLH Belgium, and aims to contribute to the well-being of people with XLH and their relatives. It pursues the following actions:

Gathering information and explanations about XLH, the treatments and therapies recommended, and all the available means of help.

Communicating and sharing this information and explanations with people with the disease

Form a national and international support network

Representing patients and their families to medical, political, social security and other authorities.

Partners and other associations:

RadiOrg *Umbrella organisation for patient organisations concerning rare disease - www.radiorg.be*

Orphanet *The portal for rare diseases and orphan drugs - www.orpha.net*

International XLH Alliance *Alliance of international patient groups for people affected by X-linked hypophosphatemia and related disorders.- xlhalliance.org*

www.xlhbelgium.be

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