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

xlhbelgium@gmail.com

XLH Belgium

Achievements 2021

[1] Creating the association

[2] Communicate about the association

www.xlhbelgium.be/
Newsletter
Presentation leaflet

[3] Supporting patients and their relatives

[4] Give voice to the association and its members

Scientific articles
European survey
Contacts with pharmaceutical companies, the scientific world and associations close to XLH

Réalisations 2021

[1] Créer l'association

[2] Communiquer sur l'association

www.xlhbelgium.be/
Newsletter
Plaquette de presentation

[3] Soutenir les patients et leurs proches

[4] Porter la voix de l'association et de ses membres

Articles scientifiques
Enquête européenne
Contacts avec des entreprise pharmaceutiques, le monde scientifique et les associations proches du XLH (nationales et internationales)

Prestaties 2021

[1] Het creëren van de vereniging

[2] Communiceer over de vereniging

www.xlhbelgium.be/
Nieuwsbrief
Presentatie folder

[3] Ondersteuning van patiënten en hun familieleden

[4] Een stem geven aan de vereniging en haar leden

Wetenschappelijke artikelen
Europees onderzoek
Contacten met farmaceutische ondernemingen, de wetenschappelijke wereld en verenigingen die dicht bij XLH staan (nationaal en internationaal)

On 3 December 2020, the association is founded

Op 3 december 2020, de vereniging is opgericht

3 décembre 2020, l'association est fondée

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Volet B — Copie à publier aux annexes au Moniteur belge après dépôt de l'acte au greffe

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Déposé 03-12-2020

Greffe

07/12/2020 - Annexes du Moniteur belge

N° d'entreprise : 0759431509

Nom :

(en entier) : XLH Belgium

(en abrégé) :

Forme légale : Association sans but lucratif

Adresse du siège : Avenue des Sarcelles 35
1410 Waterloo
Belgique

Objet de l'acte : Constitution

Les fondateurs :
- Anna Koltunowska, domicilié(e) à Rue Belliard 162/3, 1040 Bruxelles,
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- Bernard Ramaekers, domicilié(e) à Rue du Bon Dié Cauwère 8, 5032 Bossière,
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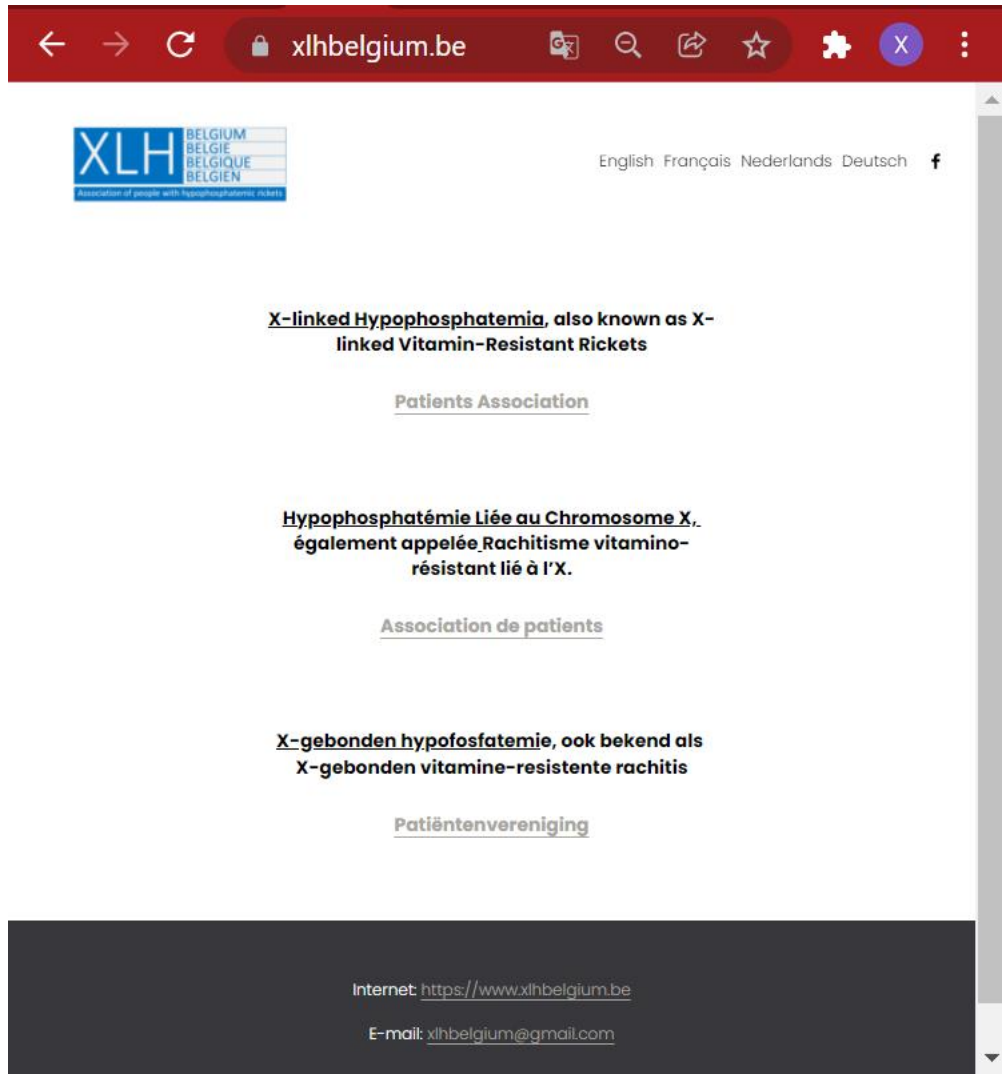

Burden of disease associated with X-linked hypophosphataemia in adults: a systematic literature review

L Seefried [1], M Smyth [2], R Keen [3], P Harvengt [4]

Affiliations + expand

PMID: 32710160 PMCID: PMC7755619 DOI: 10.1007/s00198-020-05548-0

Free PMC article

Abstract

This systematic review collated evidence on the burden of XLH in adults. Data captured highlight the substantial ongoing burden of XLH in adulthood and identified unmet needs. Greater awareness and understanding of the impact of XLH in adulthood are needed to improve care and outcomes in adults with XLH.

Introduction: X-linked hypophosphataemia (XLH) is a rare metabolic bone disease characterized by renal phosphate wasting and musculoskeletal manifestations. Whilst the disease's impact in children is well documented, information on the effects of this progressive, debilitating condition on adults is lacking. This systematic review aimed to collate existing evidence on the burden of XLH in adulthood to identify unmet needs.

Methods: MEDLINE, Embase and Cochrane Library databases and recent congress reports were

Consensus Recommendations for the Diagnosis and Management of X-Linked Hypophosphatemia in Belgium

Michaël R Laurent, Jean De Schepper, Dominique Trouet, Nathalie Godefroid, Emese Boros, Claudine Heinrichs, Bert Bravenboer, Brigitte Velkeniers, Johan Lammens, Pol Harvengt, Etienne Cavalier, Jean-François Kaux, Jacques Lombet, Kathleen De Waele, Charlotte Verroken, Koenraad van Hoeck, Geert R Mortier, Elena Levtchenko, Johan Vande Walle

Mental Health and Wellbeing research group, Clinical sciences, Biology of the Testis, Pediatrics, Clinical Pharmacology and Pharmacotherapy, Gerontology, Geriatrics, Internal medicine, Internal Medicine

Research output: Contribution to journal › Article

Overview Fingerprint

Abstract

X-linked hypophosphatemia (XLH) is the most common genetic form of hypophosphatemic rickets and osteomalacia. In this disease, mutations in the PHEX gene lead to elevated levels of the hormone fibroblast growth factor 23 (FGF23), resulting in renal phosphate wasting and impaired skeletal and dental mineralization. Recently, international guidelines for the diagnosis and treatment of this condition have been published. However, more specific recommendations are needed to provide guidance at the national level, considering resource availability and health economic aspects. A national multidisciplinary group of Belgian experts convened to discuss translation of international best available evidence into locally feasible consensus

- Burden of disease associated with X-linked hypophosphataemia in adults: a systematic literature review. https://pubmed.ncbi.nlm.nih.gov/32710160/
- Consensus Recommendations for the Diagnosis and Management of X-Linked Hypophosphatemia in Belgium. https://pubmed.ncbi.nlm.nih.gov/33815294/
- X-linked hypophosphatemia: The medical expert's challenges and the patient's concerns on their journey with the disease. https://pubmed.ncbi.nlm.nih.gov/34593293/