

The logo consists of the letters 'XLH' in a bold, green, sans-serif font. The letters are slightly shadowed, giving them a 3D appearance as if they are floating above the text below.

X-linked Hypophosphatemia

explained for children

A booklet of the association "Phosphatdiabetes Austria" in cooperation
with Dr. Adalbert Raimann (Pediatric Endocrinology and Osteology AKH Vienna)

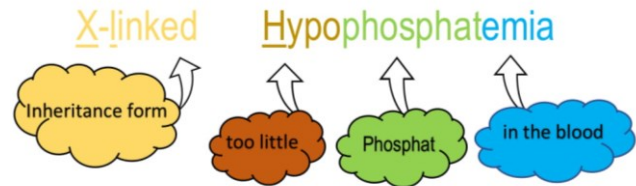
Hello, my name is Ben and I have

XLH



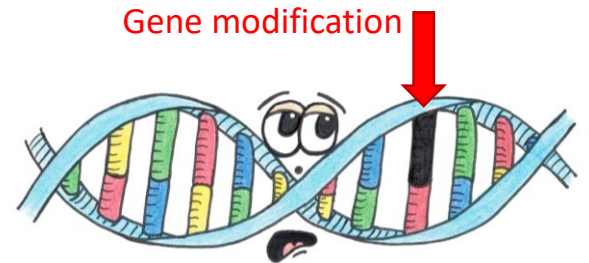
You have XLH too? Or know someone who has?

In this booklet, I explain everything you need to know about XLH.



Every human being has his or her own blueprint - the DNA code (deoxyribonucleic acid). The entire genetic material of us humans is stored in this DNA. It is responsible for the fact that we are all different. Our parents inherit this DNA to us, therefore we look alike and have many common behavioral patterns.

During the development of a human being, it sometimes happens that the code changes and thus processes in the body no longer function as they normally should.

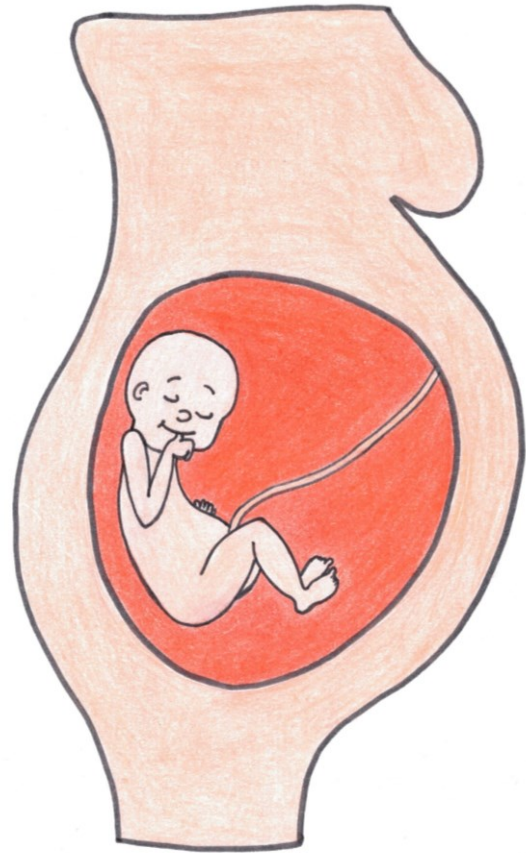


How did I get XLH?

I have had XLH since birth.

XLH is mostly inherited within the family.
I inherited XLH from my mom.

Unfortunately, sometimes it happens that you get XLH for the first time in your family due to a new DNA change. This was the case with my grandmother.

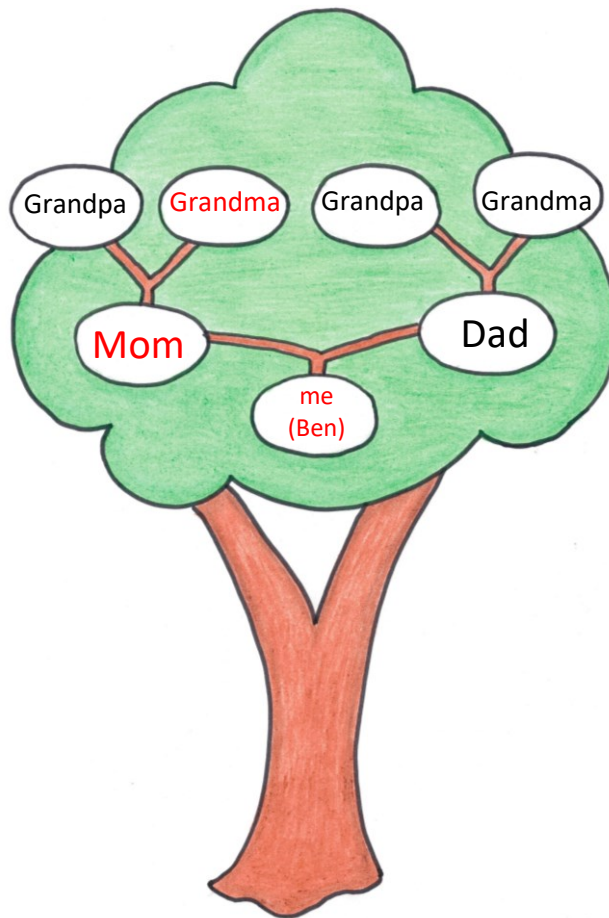


Here you can see who in my family has XLH. All family members written in red have the disease.

As you can see, men and women can get XLH.

Who in your family or circle of friends has XLH?

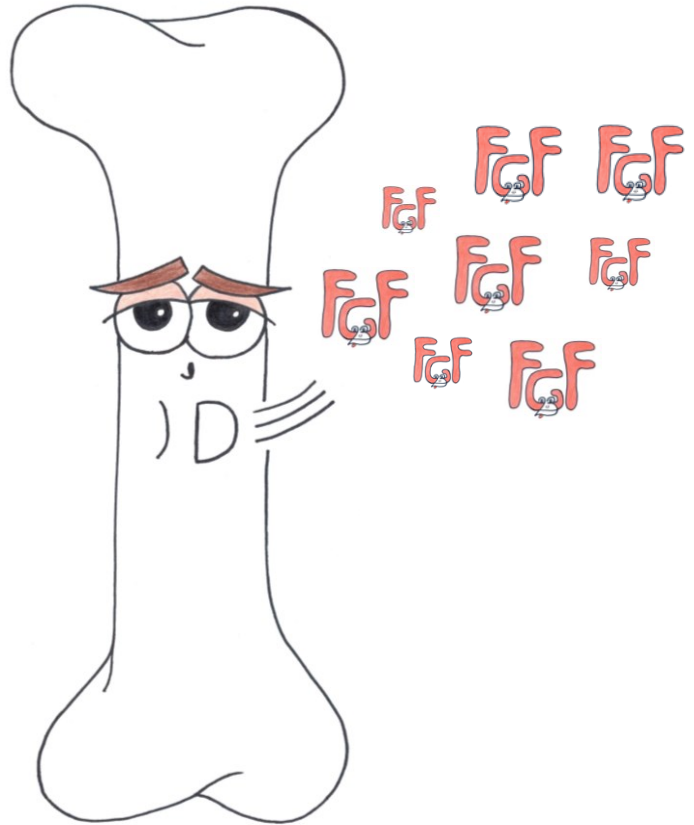
Maybe you want to draw your own family tree!

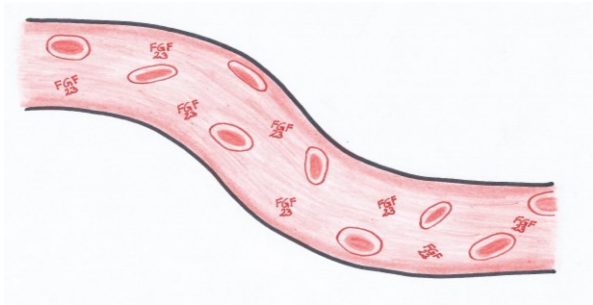


How does XLH affect my body and what can I do about it?

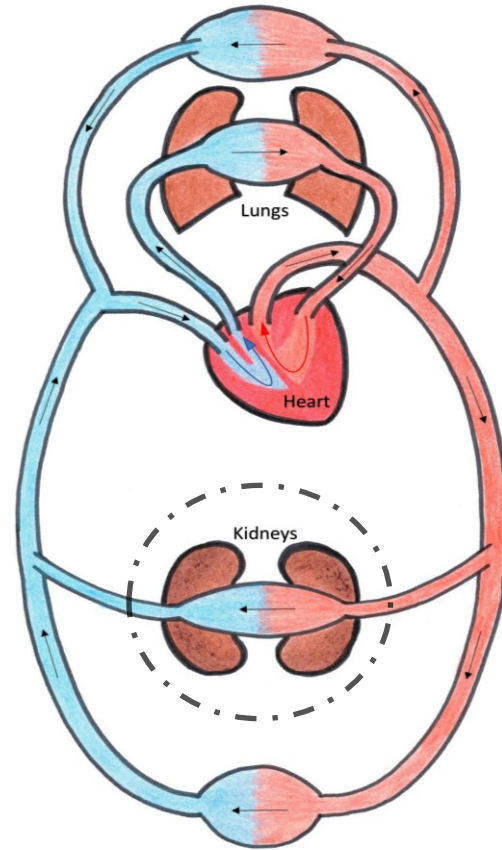
Due to the change in DNA, my bones produce too much FGF23, which is a hormone.

Hormones are messenger substances that distribute information in the body.



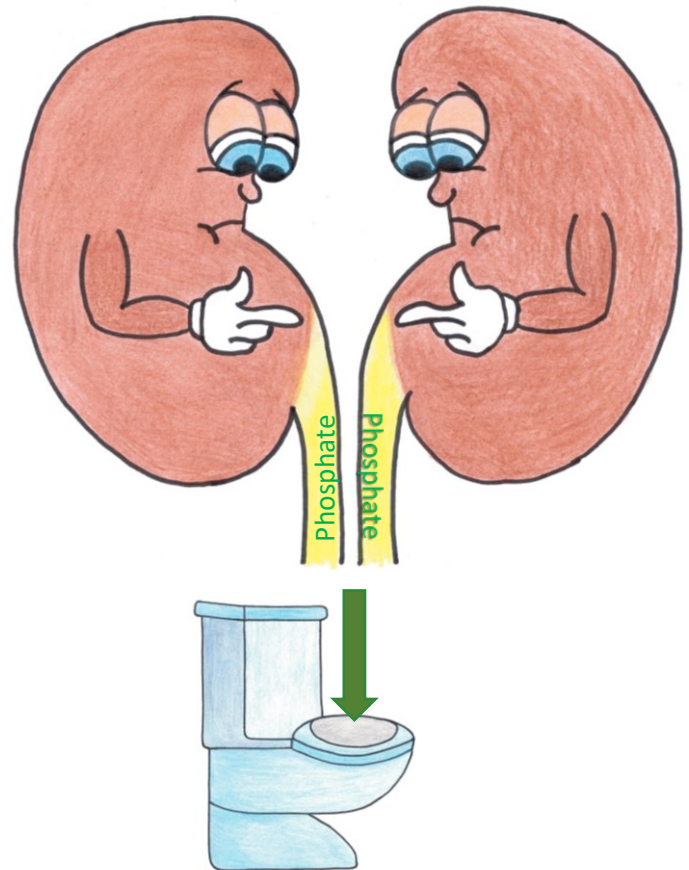


Together with other important messenger substances, the hormone FGF23 floats to the kidneys via the bloodstream.



The kidneys are excretory organs. Most substances that the body does not need are excreted through the urine.

Phosphate also floats in the blood. The hormone FGF23, however, informs the kidneys to eliminate this important building material of bone from my body via the urinary bladder.



But my skeletal bones need the phosphate to stay hard and strong.

Due to the loss of phosphate, my bones become soft and bend. The legs are most often affected by this.

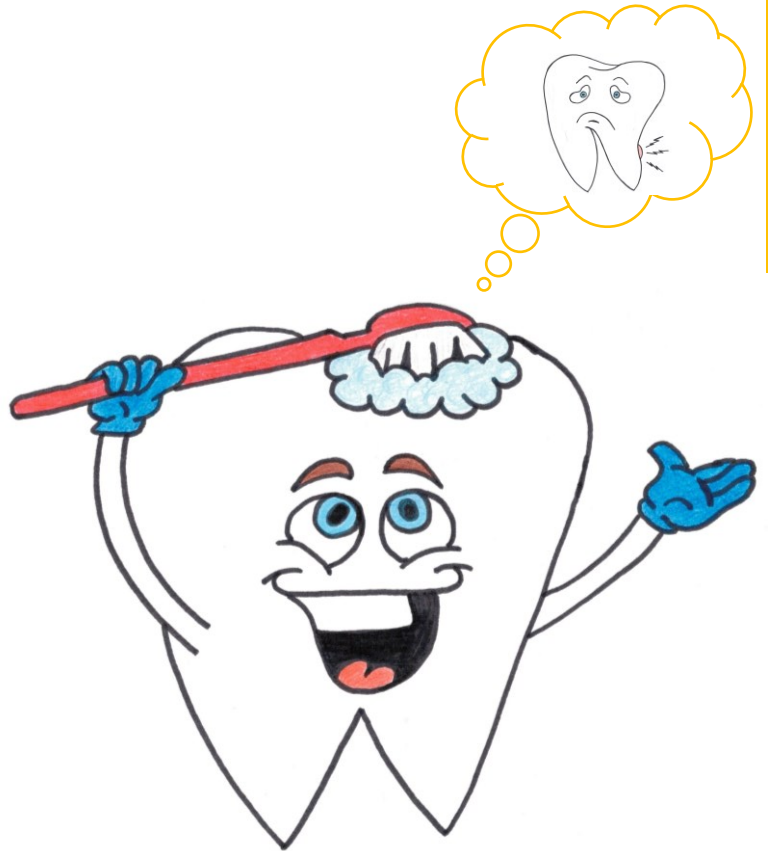
My other skeletal bones also cannot grow as well as a result. I am therefore smaller than other children.



My teeth are also weakened by the constant loss of phosphate and can sometimes cause problems.

By brushing your teeth several times a day and cleaning the spaces between your teeth with dental floss, you can often avoid cavities and pain.

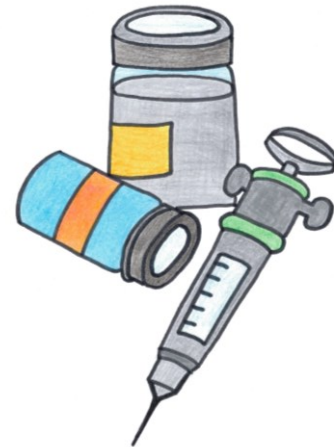
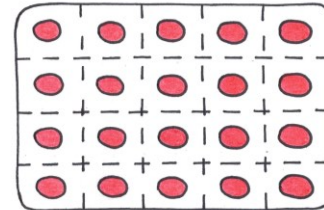
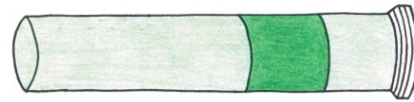
Furthermore, one should have professional oral hygiene performed by a dentist several times a year.



To ensure that there is enough phosphate in my body despite the excretion and that my bones do not become soft, the following medications are available to me:

- several times a day phosphate as effervescent tablets and additionally special vitamin D capsules to cover the phosphate requirement or
- every two weeks a small injection under the skin, which inhibits the messenger substance FGF23, so that the kidneys no longer excrete so much phosphate.

Both strengthen my bones.

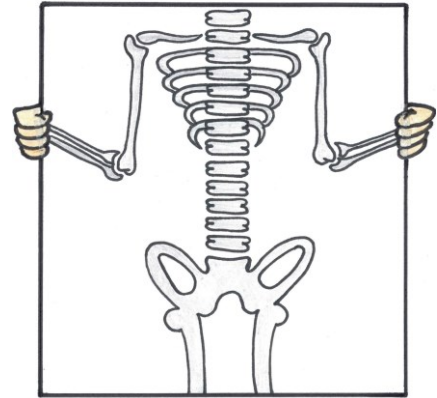


Because of the medication I take, a doctor has to check my blood every 3 to 6 months.

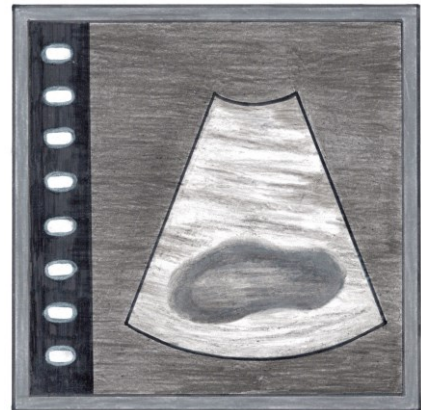
This is done by a small prick in the crook of the arm or by a finger prick.

My urine is also checked for increased phosphate excretion at every visit to the doctor.





Once or twice a year, my bones are examined with an X-ray and my kidneys with an ultrasound. You don't feel that at all - you just have to lie still.



What is my life like with XLH?

Together with my family I live in a house with a garden.

In my free time I play soccer. Even though I'm not the fastest, I still enjoy it very much.

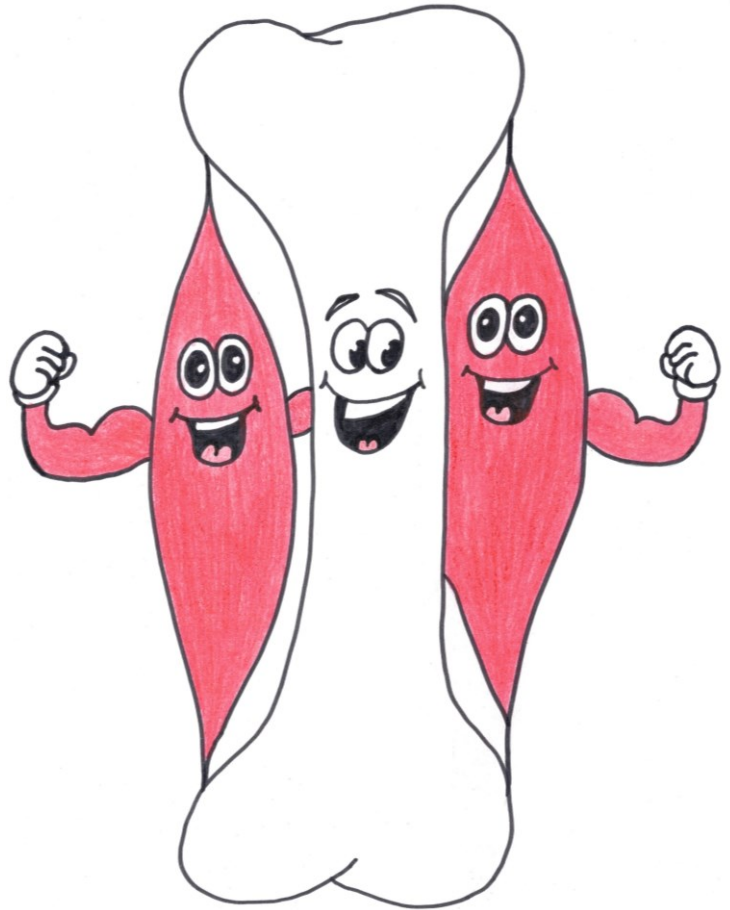
I also like to ride my bike and play table tennis. My illness does not play a role in these sports.



When you have XLH, it's important to do a lot of exercise to strengthen your muscles. This is because the muscles in the body support the bones.

In addition, I go to physical therapy regularly. My physical therapist shows me important exercises to strengthen my muscles.

With a lot of training, I can keep up well with other children in sports.



Hopefully, I was able to explain the disease XLH to you in more detail.

If you still have questions about XLH, you can ask your doctor.

Patient groups are also dedicated to answering your questions and addressing concerns.

All the best

your Ben

