Dating and Relationships

If you are starting to date, are dating, or are in a relationship, you may be wondering when – and how – to talk to your partner about XLH. As someone living with a rare disease, you've likely told people close to you – family, friends, and possibly colleagues – about your condition. But it may feel different to talk to a romantic interest or partner. It's common to wonder how they'll react or whether they'll change their perception of you.

There's no right answer; it all depends on what makes you feel most comfortable. Take some time to think about your hopes and expectations for the relationship. Everyone is different, but these tips might help you decide what's best for you:

- Talk to other people with XLH about their dating experiences or ask for their advice.
- Decide in advance how much you want to share and how you want to tell your story, so you feel in control of the conversation.
- Develop an "elevator pitch" — a clear and concise way to explain XLH that's easily understood and lasts about as long as an elevator ride.

SAMPLE ELEVATOR PITCH:

"I have a genetic, chronic condition called XLH. My body doesn't retain enough phosphorus, which affects my bones and makes them weak. I manage it through treatment, but it still affects me daily, and some days are worse than others. I can have trouble walking and getting around. I have a lot of pain, and I can be exhausted very easily so I have to be careful how I plan my days."

- Practice in front of the mirror until you feel comfortable.
- Like most serious conversations, it's best to have this one in person.
- Give people time to process the information and let them ask questions.
- Have information or resources ready, in case they would like to read or research more on their own.
- Recognize that they may be uncomfortable talking about it at first. Be patient.

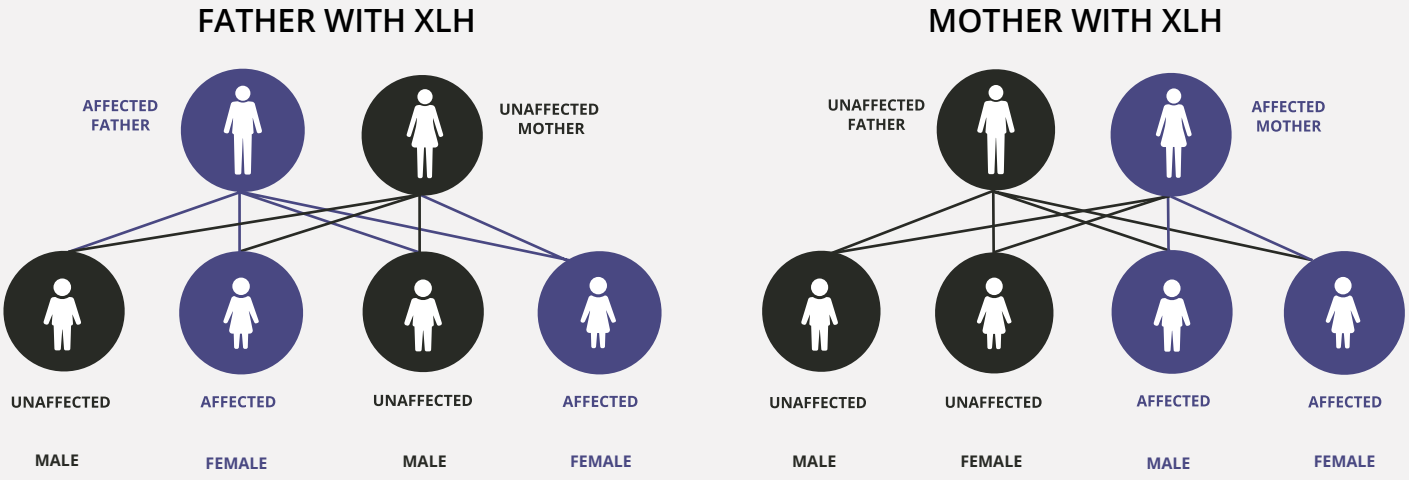
THINKING ABOUT STARTING A FAMILY

At some point, you may consider starting a family. This is an exciting milestone, but one that can present unique challenges for someone with XLH. **If you decide to have a child, it is a deeply personal decision,** and you may consider options like in vitro fertilization (IVF), sperm or egg donation, surrogacy, or adoption.

If you are a woman with XLH considering pregnancy, consult an obstetrician to discuss any potential health risks to you. Also, it's important to understand how XLH can be passed down in families. **XLH is an inherited disease**, which means that an affected parent may pass it down to his or her children. The "X" in XLH stands for "X-linked" because the disease results from a mutation on the X chromosome. Females have two X chromosomes and males have both an X and a Y chromosome.[1]

A male with XLH passes down his X chromosome to his female children and his Y chromosome to his male children, which means all of his female children will have XLH. If a female has XLH, each of her children, regardless of sex, has a 50% chance of having XLH. The chance of having an affected child is the same for each pregnancy regardless of what has happened in a previous pregnancy.

XLH INHERITANCE PATTERN



In some cases, people with XLH will have unaffected children. For example, a woman with XLH (whose partner does not have XLH) has a 50 percent chance of having a child (male or female) without XLH. A man with XLH (whose partner does not have XLH) could have male children without XLH.

Sometimes children can have XLH, even if neither parent is affected. This is called a **spontaneous case,** and it happens in about one-third (30%) of XLH cases.[1] Once a person has XLH, they can pass it down to their children, following the X-linked inheritance pattern.

If you decide to have a child, consulting a **genetic counselor** can help you:

- Understand the XLH inheritance pattern.
- Learn about your reproductive options.
- Decide what's best for you.

Hospitals and health systems often have genetic counselors on staff. If you go to a hospital for your XLH care, ask your specialist to refer you. You may also find it helpful to talk to people with XLH who've had experience with pregnancy or have made a decision about family planning.

Elizabeth and her son, Simon, living with XLH

To learn more about genetic counseling, or to find a counselor near you, visit the National Society of Genetic Counselors at aboutgeneticcounselors.com.

XLH AND PREGNANCY

When you become pregnant, you'll likely see an obstetrician, midwife, or doula in addition to your primary care physician or XLH specialist. It's important to **talk to all your healthcare providers about how XLH affects your body** and to keep careful records that include your medical history, test results, all medications, and any symptoms you experience. It's also important for your healthcare providers to talk to each other to ensure coordination of care.

Be diligent about prenatal care, proper nutrition, and rest. Pregnancy can be more challenging for women with XLH because they may already have joint stiffness, pain, and fatigue. You will also need to discuss whether you can continue your XLH treatment and any other medications you take while pregnant, and possibly while breastfeeding.

To learn more about managing pregnancy with a rare condition see the Global Genes toolkit "Women with Rare Disease: The Reproductive Years."

Remember, people may have opinions, but whether or how you start a family is your choice, and you should choose what is best for you.

REFERENCES

1. Gaucher C, Walrant-Debray O, Nguyen TM, Esterle L, Garabedian M, Jehan F. PHEX analysis in 118 pedigrees reveals new genetic clues in hypophosphatemic rickets. *Hum Genet*. 2009;125:401-411.