



*FLIP FOR MORE INFORMATION
FOR ADULTS LIVING WITH HPP*



Talking About Hypophosphatasia (HPP)

ADVOCATING FOR YOUR CHILD

When a child is living with a rare metabolic disorder such as HPP, their caregiver becomes their first advocate and their example in learning how to advocate for themselves. In time, your child may learn to become their own advocate, but until then, you can be the voice that helps them understand how this will impact them and ensure their needs are met at school, in social situations, and even at doctors' offices.

Talking to People at Your Child's School

People at your child's school may not know anything about HPP. You can start by providing a written document that outlines your child's needs. It is often helpful to request a meeting with the school guidance office, the school nurse, your child's teacher, and any other specialists at school who assist with student accommodations. Work with the school staff to figure out a plan for your child's day-to-day activities.

Be sure the school has an accurate record of the following:

- A written request from your child's healthcare provider for accommodations
- Assistive mobility devices, such as wheelchairs, walkers, or canes
- Any medication or administration instructions in case the school nurse needs to provide care
- Possible situations that could arise and how to handle them
- Instructions on whom to contact in case of an HPP-related emergency
- Your pediatrician's and specialist's names and numbers



Meeting Your Child's Daily Needs at School

Consider what type of accommodations your child might need at school or elsewhere. HPP may make walking difficult, so extra time to travel from class to class or an elevator pass could be necessary. During recess and gym, participation in alternative activities or opting out early could be helpful. Chronic fatigue may require extra time for assignments or take-home/virtual work. Don't hesitate to request these accommodations and more.

Any individuals who will be spending time with your child during the day should be aware of their needs. In addition to open and honest conversations about HPP, you may also want to speak with your child's teachers about whether they should explain HPP to curious classmates—and if so, how. Your child's teacher can be an invaluable resource for normalizing differences among students. The teacher will be able to understand that HPP is a rare, progressive, inherited metabolic disorder that can affect growth and development.

Explaining it to students in simplified terms can encourage understanding and empathy. Keeping it simple such as "bones may be hurt more easily than others" is often effective.

What you choose to share about HPP is a personal decision, but educating the staff and teachers at your child's school may help school remain a safe place to learn and grow.



Clubs, Extracurriculars, and Explaining HPP

Other children may have very pointed questions about your child's illness. Remember that children are curious, and it is natural for them to ask direct questions. Simplify the explanation to adjust for developmental age, be matter-of-fact, and know that your own child is listening. Allow your child to opt out of activities as needed. Help other adults who care for your child to understand that physical sports may not be appropriate activities for your child. As your child grows, they may become more comfortable asking to have their needs met based on the example you have set for them, and working with them to establish a way of explaining HPP may be helpful as well.

Help your child learn to set limits with their friends. Give your child age-appropriate language to explain HPP, should they choose to disclose it. This may be as detailed as they wish, and may include something similar to "My bones are weaker than others" or "Sometimes I get tired and have a hard time focusing because of my HPP." Encourage your child to be honest about their limitations and to ask for accommodations when appropriate.





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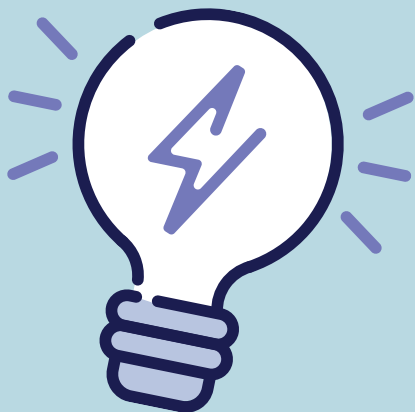
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TAKING CHARGE OF YOUR HEALTH

When it comes to living with HPP, in time, you learn to become your own advocate. Part of taking charge of your own health is letting people know how you are feeling and what your limitations may be. You may have to be frank in telling others what you need. It may help to think about the complications of HPP when making plans so that you can prepare for any situation in which you need to explain HPP or ask for accommodations, such as requesting mobility devices or alternative transportation.



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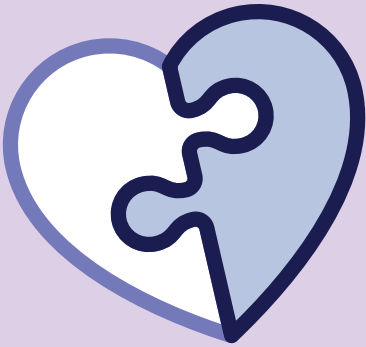


The Power of Educational Opportunities

As a person living with HPP, you may find yourself becoming somewhat of a spokesperson to help bring awareness to others. Consider it a chance to be honest about your condition and share with those around you how your symptoms affect you. This could be an opportunity for others to learn about HPP and what it might mean for you.

HPP is a rare, inherited metabolic disorder that impacts bone formation, but it can also affect other areas of the body, such as the brain and kidneys. It's important to understand your personal picture of HPP so that you can talk to others about it and advocate for yourself.

Because HPP is a progressive disease, it can worsen over time. Symptoms can change with age and have a profound effect on managing daily activities. Living with a chronic, rare disease can have its own unique challenges. Taking a proactive role in your healthcare journey may lead to a greater understanding and empowerment over your health and well-being. Remember, it's okay to share only what you are comfortable with.



Having Honest Conversations

You may have a loved one with HPP in your family. Since HPP is a genetic disorder passed down from one or both parents, you may have a family member who is affected. It is possible that sharing your own story may help others put the puzzle of their own symptoms together. When you determine who you want to have conversations about this rare disease diagnosis with, you may want to consider the impact of the genetic connection of HPP in families. Be aware that different people may respond in various ways to the conversation when disclosing conditions that are hereditary. Although HPP is a condition passed down through DNA, that does not mean that all family members are carriers of the mutated *ALPL* gene.

If no one else in your family has been diagnosed with HPP (parents, siblings, grandparents, aunts, uncles, or cousins), it is still helpful for them to be aware of it, what causes HPP, and its common symptoms. Recognizing any of the variable signs and symptoms of the disease could potentially result in an important discussion with their doctor.



Asking for Help

Asking for help can be one of the hardest parts of a chronic, progressive disease. Letting people know what you might need allows others to be there for you.

Keys to asking for help:

- Take the risk of asking
- Be specific
- Don't apologize
- Make it personal, not transactional
- Share your gratitude

Remember that people generally want to help but sometimes just don't know how. **Here are some ideas of how others can help you:**

- Transportation
- House or yard work
- Grocery shopping
- Mobility assistance during travel
- Flexible work hours

Planning and anticipating your own needs might make it easier to navigate social/work-related situations, travel, and common day-to-day activities. You don't have to navigate this condition on your own.