Suzanne and Amy (bottom left)
BOTH LIVING WITH HPP

A guide to understanding how ***hypophosphatasia (HPP) can affect the body and daily life***

HPP starts with *low ALP*

HPP happens when the body has **low levels of working alkaline phosphatase (ALP),** an important enzyme. It is an inherited, lifelong condition that can affect many parts of the body and may get worse over time.

Your body needs ALP to help it do important jobs, such as:

1. 

Build strong bones

2. 

Keep your brain healthy

3. 

Support muscle strength

That's why having low ALP may be linked to issues with your bones, brain, and muscles.

Low ALP over time means having 2 or more ALP levels below the normal range, measured at least 30 days apart.

Because HPP is linked to low ALP, understanding your ALP levels over time may help identify HPP.

Learn more about ***what causes HPP***

Click here or scan to get a better understanding of the disease.

Enzyme=a helper protein in the body that speeds up important processes so your body can work properly.

“

If I had known I had HPP when I was younger, I would’ve been able to stand up for myself at doctors’ offices.”

Amy (left)
LIVING WITH HPP

Click here or scan to watch Amy’s story

HPP symptoms may be felt in *different parts of the body*

HPP symptoms are not the same for everyone. Below are examples of how HPP symptoms may appear:

Can make it harder to build strong bones

People of all ages with HPP can be affected by unexpected bone fractures and bones that look weaker than normal on bone imaging. HPP can make bones more likely to break or fracture. In one study of people with HPP, 43% developed bone-related symptoms.

Can affect the brain

HPP can disrupt sleep, impact mood, and reduce quality of life. Patients may experience:

- Nerve pain and headaches
- "Brain fog," which may look like confusion and difficulty concentrating
- Problems with sleep
- Depression and anxiety

Can cause muscle weakness and fatigue

People with HPP may have extra difficulty doing daily activities such as standing up from a sitting position, walking, or running.

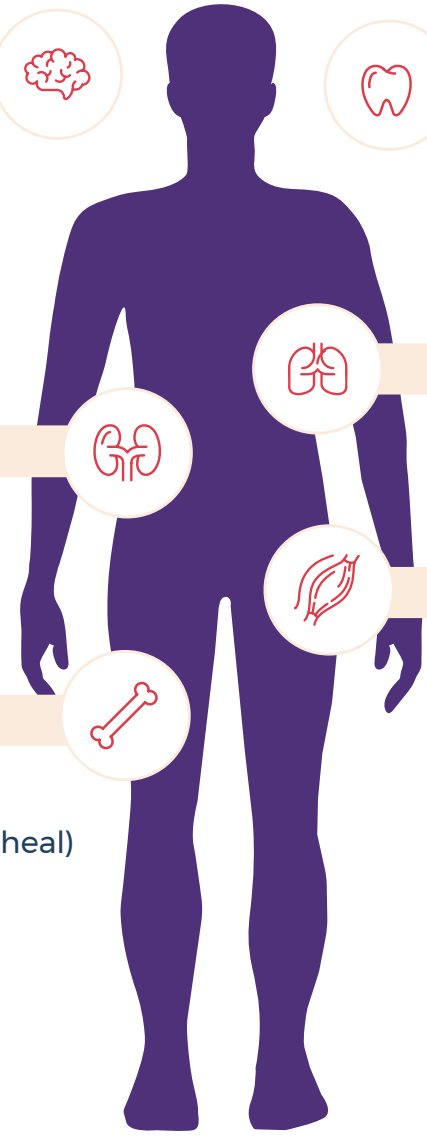
Fatigue may affect people throughout the day, making it harder to stay awake, focus, keep up with peers, or complete school or work responsibilities.

Sharing your or your loved one's full experience with a doctor can help provide a clearer picture of how symptoms may be connected or related to HPP.

Common symptoms *of HPP*

This diagram highlights some common symptoms that may be part of the HPP experience.

If any of these symptoms feel familiar, consider **circling them** and **bringing them to your/your child's doctor.**



Brain

- Brain fog
- Seizures*
- Headaches

Kidneys

- Kidney stones
- Kidney disease

Bones

- Pain
- Fractures (slow to heal)
- Rickets (weak/soft bones in children)
- Bowed legs

Teeth

- Early tooth loss
- Gum disease
- Cavities

Lungs†

- Breathing problems
- Pneumonia

Muscles/Joints

- Weakness
- Pain
- Muscle fatigue
- Joint swelling
- Missed growth or developmental milestones‡
- Mobility issues

Diagram shows symptoms seen in infants, children, and adults. This is not an exhaustive list of HPP signs and symptoms.

Click here or scan to learn more about how HPP affects different parts of the body.

*Primarily observed in babies with HPP.
†Lung and breathing problems are most common in babies with HPP, especially before birth, soon after birth, or in early infancy.
‡Observed in some children with HPP.

HPP can have a *big impact on daily life*

HPP can affect:

Bones | Joints | Teeth | Lungs* | Brain | Muscles

HPP can make routine activities more difficult, which may affect:

Work | School | Relationships | Everyday tasks

Here's how this may show up in daily life:

Common activities and everyday tasks can be difficult for people with HPP, such as running, walking, and activities of everyday living such as using the stairs, carrying groceries, or caring for yourself or your children.

HPP may also affect your **work, relationships, or everyday activities.**

Managing the symptoms of HPP and navigating their impact each day **can take an emotional toll.**

Understanding how symptoms affect daily life can support more informed conversations with a doctor.

*Lung and breathing problems are most common in babies with HPP, especially before birth, soon after birth, or in early infancy.

HPP had a big impact on my life as a child. HPP has affected me as an adult in the same exact manner."

Carol
LIVING WITH HPP

Click here or scan to watch Carol's story

Help your doctor understand ***how symptoms affect daily life***

Use this space to note experiences, challenges, or changes that may be important to discuss during a doctor visit.

HPP Symptom Discussion Guide

Click here or scan to request a printed resource to further explore symptoms and their impact on your life to help guide a conversation with your doctor.

HPP can show up *at any point in life*

HPP may **show up at any age and can get worse over time,** so it's important to share your experience with your doctor.

Why do many people remain undiagnosed?

HPP can take time to be diagnosed because it can look like other conditions.


Fibromyalgia


Osteoporosis


Arthritis


Pseudogout

Keep track of how symptoms may change over time and talk to your doctor about any new or worsening symptoms—and whether similar symptoms are present in your family.

HPP is a *lifelong condition* that is *passed down through families*

HPP is caused by a genetic variant in the *ALPL* gene. While not required for diagnosis, receiving genetic testing can give you information about your specific mutation and how it was inherited. Because it's in your genes, HPP can be passed on to your children, but it is not contagious.

However, every person with HPP is different, and symptoms can look different, affect different parts of the body, or have varying levels of severity between family members—even siblings.

Click here or scan to download the HPP Symptom Discussion Guide to help your family explore their symptoms.

When our boys were about two months old, we noticed that we could hold one son standing up, but we could not hold the other one. He could not stretch his legs out."

Elizabeth
CAREGIVER OF SON
LIVING WITH HPP

Click here or scan to watch Elizabeth's story

Getting an official diagnosis is really validating. Looking back, you realize that all these things that happened throughout the years—there was a reason for it."

Amy
LIVING WITH HPP

How HPP *is identified*

A diagnosis of HPP is based on 2 things:

Low ALP levels over time

Experts identify low ALP over time as a hallmark of HPP—your doctor can order a simple blood test to track your ALP level.

Symptoms of HPP

HPP symptoms can affect different parts of the body. If symptoms are present along with low ALP over time, HPP can be confirmed.

Low ALP over time means 2 or more ALP levels below the normal range at least 30 days apart. Your doctor may also perform other tests to get insight, help confirm a diagnosis, or support your care.

Looking at both ALP levels over time and symptoms can help provide a clearer picture of HPP and guide conversations with a doctor.

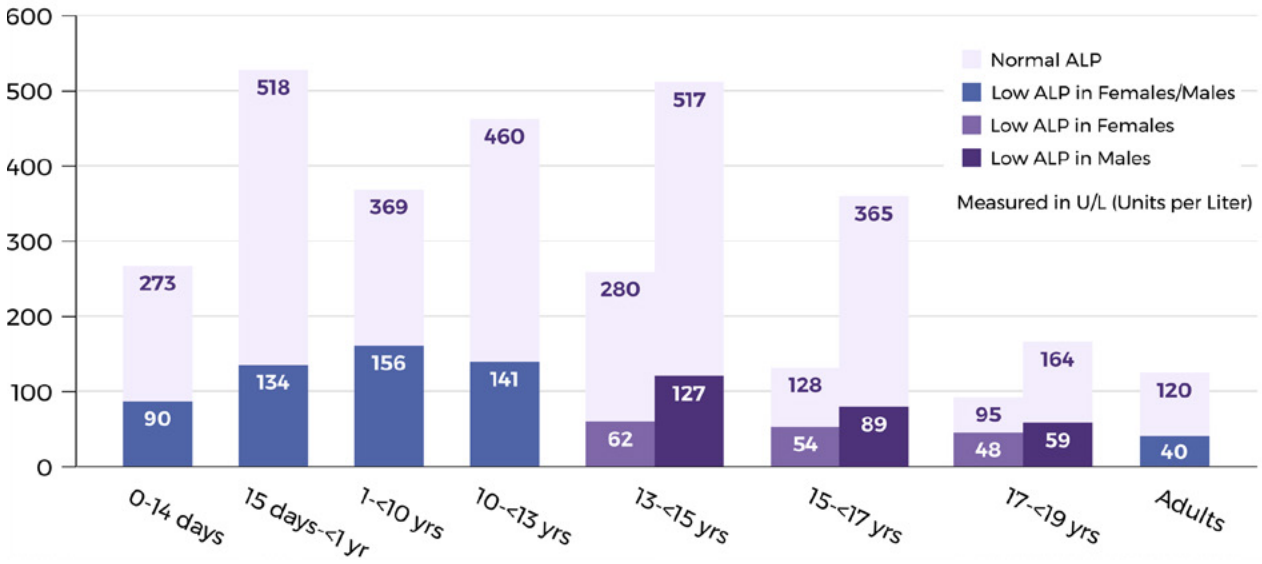
Learn more about *HPP diagnosis*

Click here or scan to see what doctors look for when diagnosing HPP.

Where to find *ALP levels*

ALP is part of a common blood test that may already be in your/your child's medical files, so talk to your doctor if you have any questions about your ALP levels. This test is called a comprehensive metabolic panel, or CMP. You may see ALP in the results as "alk phos" or "alkaline phosphatase."

Normal ALP levels vary by age and sex



0-<19 yrs values were adapted from the Canadian Laboratory Initiative on Pediatric Reference Intervals (CALIPER) project (Adeli et al, 2017). Adult values were adapted from the ARUP Laboratories Test Directory. No variation in ALP based on ethnic differences was observed. CALIPER reference intervals were established on the Abbott ARCHITECT C8000 analyzer.

Check with your doctor for the appropriate age- and sex-adjusted reference range. Low ALP is not conclusive for diagnosis of HPP. Patients should be evaluated for other symptoms of HPP, and differential diagnosis should be ruled out.

Use this space to note your ALP test results and bring them to your next doctor's visit.

ALP level: _____

Date: _____

Explore ALP levels

Click here or scan to better understand what your ALP levels may mean.

You are not alone *in navigating HPP*

There are organizations and resources available for additional support and education. Engaging with the HPP community, advocacy groups, and trusted resources can help build understanding and connection.

Direct support programs for HPP

Programs that connect you with people, information, and personalized support to help navigate life with HPP.

OneSource® Personalized Patient Support from Alexion

Personalized patient support from Alexion, with dedicated Case Managers who provide information on HPP, treatment options, and insurance support.

PEER CONNECTS

Connect by phone with an HPP STAR to hear real experiences and get answers to HPP questions.

HPP STARS

Hear from people impacted by HPP who share their stories to educate, inspire, and support the community.

Advocacy and community resources

Organizations that offer education, community, and tools to help support awareness and self-advocacy.

Soft Bones Finding the Key to HPP

Offers education, support, and connection for people, families, and caregivers living with HPP.

The AVALON Foundation kidscaringforkids.org

Provides emotional and mental support for children with HPP and their families.

Global Genes® Allies in Rare Disease

Builds awareness and connects people to resources and support across the rare disease community.

NORD® National Organization for Rare Disorders

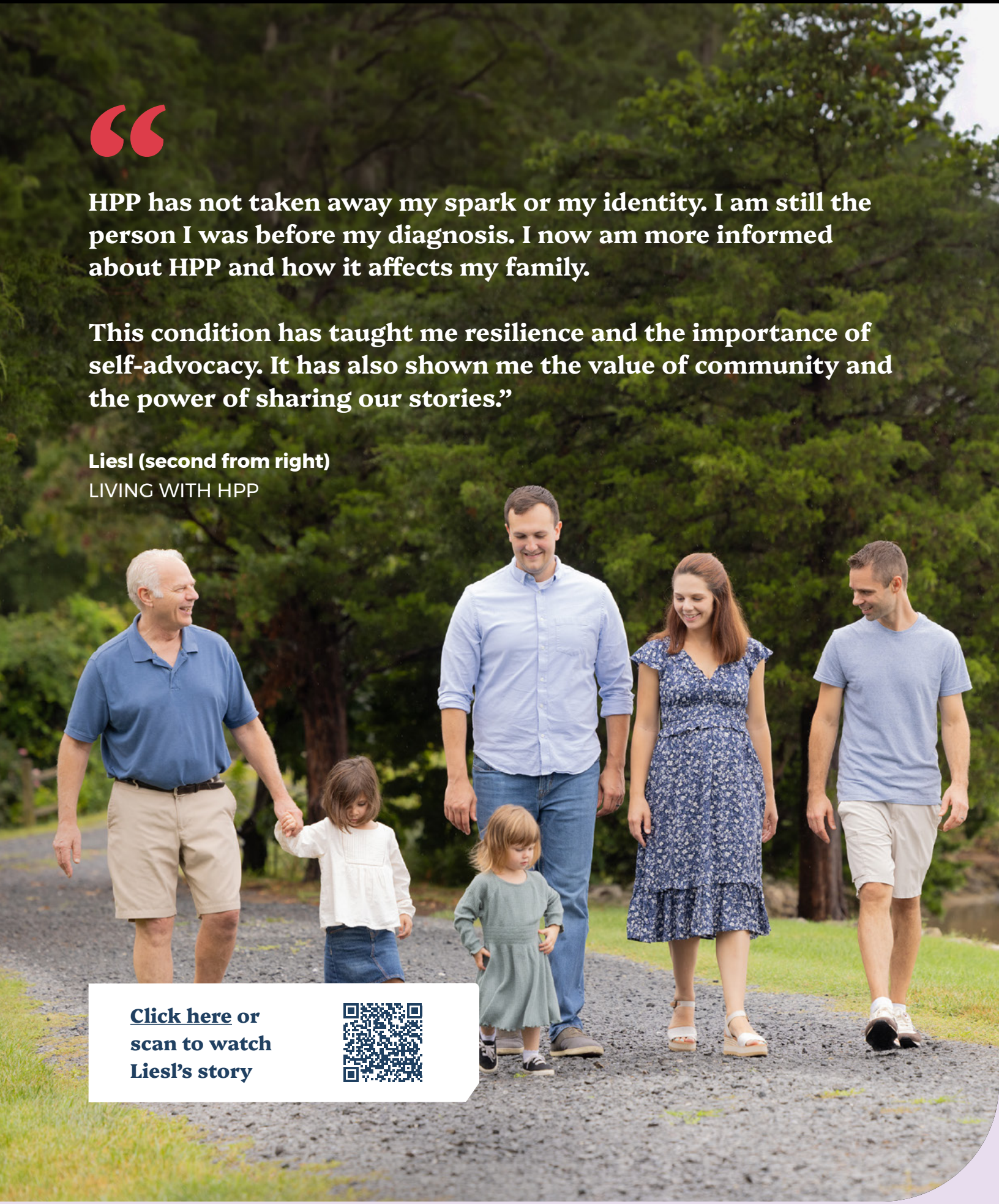
Offers education, advocacy, research, and patient support for those affected by rare diseases.

Get *HPP support*

Click here or scan the QR code to explore these programs and resources.

Want to *continue learning about HPP?*

Join a virtual program and/or explore on-demand learning to deepen your understanding by hearing real stories from those living with HPP, insights from doctors caring for those with HPP, and learn more about available support from OneSource™.



HPP has not taken away my spark or my identity. I am still the person I was before my diagnosis. I now am more informed about HPP and how it affects my family.

This condition has taught me resilience and the importance of self-advocacy. It has also shown me the value of community and the power of sharing our stories."

Liesl (second from right)
LIVING WITH HPP

Click here or scan to watch Liesl's story

Feeling *held back by HPP?*

Not an actual patient.

HPP happens when the body has low levels of working ALP, an enzyme that does several important jobs.

HPP can have a **big impact on daily life, affect different parts of the body,** and **get worse over time** if not addressed.

You're not alone.

Click here or scan to learn more about HPP and find helpful resources.

ALEXION®
AstraZeneca Rare Disease