



A Guide to Your Best Doctor's Visit

Living with hypophosphatasia (HPP) means navigating a medical system where many doctors and other healthcare providers have never seen—let alone treated—this rare condition. Every appointment carries a mix of hope, vulnerability, and the desire to simply be heard. Whether you are seeking a diagnosis, meeting a new doctor, or following up with someone who knows your story, it's natural to want clarity, validation, partnership, and trust.

A productive doctor's visit doesn't require solving everything in one day. What matters is feeling respected, understood, and leaving with a clear next step. This guide was created with input from HPP patients and physicians to help you prepare for those conversations with confidence. No matter who sits across from you—an HPP expert or someone learning alongside you—you can make each visit more effective, less stressful, and more collaborative.

What Makes a Good Visit?

The best visits aren't defined by a perfect diagnosis or neat answers. HPP affects many systems in the body and progress often happens in layers.

Patients and doctors consistently share that a "good visit" includes:

-  Leaving with a clear plan, even if it's small or interim
-  Feeling respected as a partner in care, & developing trust over time
-  Being well-prepared for the appointment
-  Recognition that HPP has many pieces and no one has all the answers
-  Efficient use of the doctor's time
-  Setting realistic expectations about what can be accomplished in one visit
-  Hypophosphatasia is difficult to diagnose as symptoms can suggest many other medical conditions



Preparing for a Productive Appointment: What Patients Say Really Works

Many HPP patients share that the most successful doctor visits happen when they spend a little time preparing beforehand. Here are the strategies patients say make the biggest difference:



Bring Your Key Records

Come with recent test results, labs, & imaging so your doctor has all the data in one place.



Share a Summary of Your Care Team

Bring a short list of the specialists you see (e.g., endocrinology, neurology, dentistry, pain management, orthopedics). This helps your doctor understand your full picture and makes care coordination easier.



Determine Your Top Priority, the Questions to Help Support Getting an Answer

It's completely okay — even helpful — to say at the start of your appointment: *"I have one main concern that I would like to cover and some questions to help us address it."* This helps your doctor understand your main goal & keeps the visit focused.



Use Tools to Track Symptoms

Patients and doctors say *the myHPP app*, which helps track bodily systems, makes it easier to document what's been happening in between visits. The MyHealthReport feature on the app summarizes all symptoms and can be printed out in an easy way to share with your doctor.



Prepare a Brief Narrative

A simple, one-paragraph summary of why you're here today and your number one concern is incredibly useful. We have included [a template](#) that you can use to help you write your story. This gives your doctor instant context and helps keep the visit on track.

Communicating With Confidence

Tone, Approach, and Partnering With Your Doctor

Navigating conversations about HPP can feel overwhelming — especially when you're still learning about the condition yourself. The good news: the way you approach the conversation can make a big difference in how productive and supportive your visit becomes. **Here are practical techniques HPP patients say they have found helpful when working with their doctors:**

1 Use a Partnership Approach, Not a Command Approach

Patients say in their experience, doctors respond best when patients invite collaboration rather than making demands. Try language such as:

✓ **These phrases communicate respect while still advocating for yourself.**

Examples:

“Can we partner on this to rule out HPP?”

“Can you help me understand whether these symptoms fit with HPP?”

“For my peace of mind, could you check my vitamin B6?”

2 Bring Information, but Frame it Thoughtfully

If you've read something valuable:

- Print out a copy of the journal article instead of saying, “I Googled it.”
- Frame it as a resource and an opportunity to educate the doctor.

✓ **This demonstrates that you've taken time to prepare and be informed.**

Example:

“I came across this study and wondered if you could help me understand how it might apply to my situation.”

3 Stay Calm and Even-Keeled

It's normal to feel anxious, frustrated, or scared. But staying steady helps the physician stay open & attentive.

✓ **A calm tone supports clearer thinking and better outcomes for both of you.**

4 Manage Expectations, Progress Often Takes Time

HPP is complex. It may take more than one visit, multiple tests, and careful symptom review to reach a proper diagnosis or build a treatment plan. Remind yourself that:

- **Not every symptom may be from HPP or documented in research. Doctors are trained to base their care on case studies and published data.**
- **You can be assertive *and* kind.**
- **You can be confident *and* collaborative.**
- **Not everything can be resolved in one appointment. Retesting is often necessary.**
- **Small steps with each visit add up.**

✓ **The goal is not to “convince” your doctor, but to work together to reach clarity and ensure your symptoms and concerns are fully considered.**

When Doctor Visits Don't Meet Expectations

Setting Realistic Expectations & Navigating Challenges

Even with preparation and the best intentions, **not every medical appointment goes smoothly — especially when navigating a rare disease like HPP.** Understanding the common factors that can make a visit challenging can help you stay grounded, reduce frustration, and approach your care with more clarity and patience.

This isn't about blaming an individual. It's about recognizing the realities of our healthcare system and learning how to advocate for yourself within it.

Time Constraints Can Be Real

Doctors often have limited time for each appointment. This can make it hard to cover everything you'd like to discuss, especially with a complex condition like HPP. This does not mean your concerns aren't important — but it does mean you may need multiple visits, or additional communications through a portal with the medical team, to get the attention and answers you deserve.



A Good Doctor Should Have the Right Chemistry

Some doctors are exceptional diagnosticians but less strong in communication or bedside manner. A clinician can be highly skilled and still fall short in tone, empathy, or listening. **While differences in personality or style don't automatically mean a doctor can't help you medically, you still deserve a provider you trust and feel comfortable with**—someone you can speak openly with and share important information without hesitation.



HPP is Rare: Many Physicians Have Never Encountered It

Some clinicians may dismiss unfamiliar symptoms or rely strictly on textbook cases rather than the real-world variability of HPP, or may simply feel more comfortable referring to another specialist. **If a physician isn't giving you what you need, you may need a second opinion.**

When Doctor Visits Don't Meet Expectations (Cont.)



The Understanding of HPP is Still Evolving

You're not expected to know everything about HPP — and neither is your doctor. That's because our understanding of HPP is evolving and there are still many unanswered questions that even the experts have about HPP. Compounding this, many patients are also dealing with other competing diagnoses, which can further complicate treatment. Understanding this can help set realistic expectations and create space for shared learning.



□● HPP Varies Widely ◆▲ Between Patients

The wide range of symptoms — and how differently HPP looks from person to person and at different ages can make diagnosis and management **challenging**. This is especially true when patients within the same family can experience HPP in very different ways. Even well-trained clinicians may struggle when symptoms don't fit a clear pattern. It's okay to gently remind your doctor that variability is part of the disease.



System Pressures Affect Care

Doctors often balance patient care with:

- administrative burdens
- documentation requirements
- high patient loads
- insurance barriers
- referral delays
- large institutional policies

These pressures can limit the time, attention, and flexibility they can offer — even when they want to do more. **Remember: the problem is often the system, not the doctor.**

For more information, please contact the Soft Bones Foundation

☎ (866) 827-9937 – Toll Free ☎ (973) 453-3093 – Direct Line

📍 141 Hawkins Place, #267 Boonton, NJ 07005 🌐 www.SoftBones.org

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Use this form to help you build your narrative to prepare for your visit.

When did you first feel something was wrong?

Text input area with three horizontal lines.

How have your symptoms changed over time?

Text input area with three horizontal lines.

“I was healthy until... then I began to experience...”

Text input area with three horizontal lines.

Childhood:

Text input area with four horizontal lines.

Teen Years:

Text input area with four horizontal lines.

20s/Early Adulthood:

Text input area with four horizontal lines.

Recent Years / Today:

Text input area with three horizontal lines.

Final Summary (2-3 sentences total):

Text input area with three horizontal lines.