



This group is for informal and casual conversation to support one another, share stories, and connect with other patients or caregivers. Never use Facebook or any social media as your first and final source of information regarding your health. Always visit a doctor to discuss any concerns about your health.

Guidelines/Group Rules:

1. Be Kind and Courteous

- Everyone is at a different place in their HPP journey. Keep interactions positive, supportive and respectful.
- Make sure everyone feels safe and welcome. Bullying, profanity and hate speech of any kind is strictly prohibited. No comments about race, religion, culture, sexual orientation, politics, or gender will be tolerated.

2. Share Your Personal Experiences

- HPP has a wide spectrum of symptoms, some which are not well-understood or studied. Many patients also have multiple diagnoses. When sharing advice, please provide personal experiences only and avoid prescriptive recommendations.

**Always consult your own medical team before making any changes to your care plan.*

3. No Promotions or Spam

- No selling of products or services is allowed unless prior approval from Soft Bones Moderators. Fundraisers to benefit Soft Bones may be shared in this group without approval needed. Fundraisers to benefit any other organization or group are not permitted.

4. Respect Everyone's Privacy

- Photos or content shared in this group is prohibited from being downloaded, copied, or reshared unless authorized by the original creator.
- Before sending a private message to an individual group member, ask them for permission first. If you are receiving unwanted private messages please notify an Admin or Moderator.
- It is not recommended to share medical documents, genetic testing, lab results or health records on social media. For any discussions around test results or personal information,

we recommend joining the Soft Bones community forum HPP AND ME. Contact Cindy at Cindy@SoftBones.org with any questions.

5. Promotion of other groups, pages, or publications.

- Promotion of external groups/pages/websites, including other HPP organizations outside of Soft Bones, is permitted as long as you state its relevance to hypophosphatasia and does not violate any other group rules. If you are unsure, reach out to the Admin or Moderator for clarification.
- Scientific publications have copyright laws and as such are not permitted on Facebook. If you have any type of scientific discussion please go to HPP AND ME and join the HPP Huddle forum.

6. Keep it casual and social

- Discussions relating to medical questions, lab results or scientific publications can be posted in the appropriate forum on HPP AND ME.
- All posts providing prescriptive or medical recommendations will be removed.

If a post does not comply with any of the rules or is disrespectful to other members it will be removed by an Admin or Moderator. Multiple offenses will lead to revoking posting privileges or removal from the group.

NOTE: An important reminder that posts and comments in this group are not endorsed by Soft Bones. Personal experiences and advice given by patients may or may not be based on current research or best practices in the treatment of HPP. While we understand intentions are always positive, there can be unintended negative consequences. We caution everyone to contact their healthcare provider before taking healthcare advice offered here or in any social media.

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