



WORLD HPP DAY

OCTOBER 30

Media & Social Media Outreach Toolkit

Introduction

Hello and thank you in advance for your help in spreading the word about HPP!

On this World HPP Day, our theme is Together We Can! Together, we can accomplish so much. And raising awareness through local media is one of the ways we can. Let's share our stories today to change the future of HPP.

We have created materials to help you reach out to your local media to share your story as well as suggestions for sharing through social media channels.

Below, you will find a templated letter that can be customize and used to pitch the local media to cover your story. Once finalized, you may then send your personalized pitch to a list of targeted media contacts, which will be provided by us, to potentially secure an interview. If a reporter expresses interest, we will provide a brief practice session ahead of your interview. In addition, we encourage you to share an image of yourself along with the pitch letter to visually tell your story.

Also below, you will find drafted social media posts customized for X, LinkedIn, and Facebook. If you choose to post the content on your personal social media pages, feel free to include an image of yourself to accompany the post as well as World HPP Day hashtags.

If you are interested in reaching out to the media, email info@softbones.org. Please let us know if you have any questions and thank you again for helping our HPP community make some noise to raise awareness!

Sincerely,

Deb, Denise, Sue, Cindy & Margaret

info@softbones.org

World HPP Day Pitch

Hello [INSERT REPORTER NAME HERE],

My name is [patient first and last name {link to patient social media page}], a [City]-based resident who lives with a rare bone disease called hypophosphatasia (HPP), pronounced hī-pō- fās-fə-'tā-zh(ē-)ə, and I would like an opportunity to share my experience as part of [World Hypophosphatasia Day](#) on October 30, 2024 to help bring much-needed awareness and attention to my disease.

I was diagnosed with HPP at the age of [age] and have lived with [insert main symptoms] for the past [number of years with HPP] years. I can describe my experience living with this disease as [insert quote from patient that provides an analogy or example of what it is like to live with HPP]. Despite having to deal with these difficult circumstances, I armed myself with the right information and resources to act and have fortunately been able to [insert an accomplishment / hobby / activity / milestone]. Because of this, and support from other HPP families and a patient advocacy group called [Soft Bones](#), I am determined to fight this disease and bring attention to its unmet medical needs.

HPP is a rare inherited bone disease that affects healthy development of bones and teeth, making bones softer and more prone to fracture. Others like myself who have HPP have trouble making an enzyme called alkaline phosphatase, or ALP. Without this important ALP enzyme, certain chemicals build up and prevent calcium and phosphorus from binding together and depositing in the bones. As a result, our bones can become soft, curved and fragile, and teeth may become loose or fall out prematurely. Along with [Soft Bones](#), I am sharing my story to help raise awareness for this year's World Hypophosphatasia Day.

If interested, I can connect with you to discuss my experience living with HPP and highlight the unmet medical need in this disease. I can also put you in touch with President and Founder of Soft Bones, Deborah Fowler, for more information on the disease and the organization's efforts to spread awareness.

Best,

[INSERT NAME AND CONTACT INFORMATION]

HELPFUL HINTS FOR CREATING IMPACTFUL SOCIAL MEDIA POSTS

- **Engage with Soft Bones!** Soft Bones will be posting frequently on our social media channels leading up to World HPP Day. We would love to see you commenting under posts, sharing the post with friends and family, or tagging your favorite celebrity or elected official under our posts. Your incredible efforts do not go unnoticed, and we rely on you to help bring awareness to the hypophosphatasia community.
- **Create your own post!** Keep it simple by sharing an image or HPP fact card. Use one of the assets that we've created OR get creative and share a video of yourself or your family to really connect with your friends and family!.
- **Tag your post to get more visibility.** Tagging followers, public figures, leaders, celebrities, and more will encourage additional participation and engagement. If you know someone who may be interested in World HPP Day, tag them, and spread the word. Use one/more of the hashtags #WorldHPPDay, #HPP, #HPPAware, #hypophosphatasia
- **Include a call to action!** If you can, include a call to action in your post. The best way to raise awareness is to spread the word and encourage others to join in. Make sure you use clear wording, so your followers know what you're asking them and how they can join in on the celebration.
- **Social media should be social!** Try to engage with your followers as much as you can. If you're getting questions and comments under your posts, respond and interact with them.
- **Be mindful of limitations.** A character limit is the maximum amount you can write in your post. Spaces, letters of the alphabet, numbers, and punctuation all count toward a character limit. Here is a quick character limit guide, though posts that are shorter tend to perform better:
 - **X**
 - **Regular Tweets:** 280 characters
 - **X Premium Subscribers:** 25,000 characters
 - **Facebook**
 - **Posts:** 63,206 characters
 - **Instagram**
 - **Captions:** 2,200 characters
 - **LinkedIn**
 - **Posts:** 3,000 characters
 - **TikTok**
 - **Captions (Video Description):** 2,200 characters
 - **YouTube**
 - **Video Title:** 100 characters
 - **Video Description:** 5,000 characters
 - **Snapchat**
 - **Snap Captions:** 80 characters

SUGGESTED POSTS

Facebook/Instagram/LinkedIn:

Leading up to Rare Disease Day:

1. On #WorldHPPDay I will be raising awareness for the #HPP community. Learn how you can be #HPPAware: <https://softbones.org/world-hpp-day-2024/>
2. #WorldHPPDay is just around the corner! [I/my family/organization] are coming together to raise awareness for #hypophosphatasia. Join us and be #HPPAware: <https://softbones.org/world-hpp-day-2024/>

The Week of / Day of World HPP Day (October 30th):

1. [Today is/October 30th is] #WorldHPPDay and I am a proud [member/supporter] of the #SoftBones community. Get involved and help us spread the word by going to [this link](https://softbones.org/world-hpp-day-2024/). <https://softbones.org/world-hpp-day-2024/>. [Share a photo of yourself with the HPP sign]
2. On this #WorldHPPDay, we celebrate what we can accomplish by coming together as an HPP community. Together, we can raise awareness, but we need more research to understand the impact of low alkaline phosphatase on the body. Join [me/my family/organization] and be #HPPAware! Learn how to get involved: <https://softbones.org/world-hpp-day-2024/> [Share a photo of you/your family/organization holding HPP sign]
3. Today, join me in support of people, like me, who live with #HPP on #WorldHPPDay. Despite having to deal with the many symptoms that come with this disease, I am determined to spread awareness #HPPAware and bring attention to the needs of our community. For more information on #HPP, click here: <https://softbones.org>
4. On this year's #WorldHPPDay, I join the Soft Bones Community in spreading awareness around #HPP and in support of others living with this disease just like me. I was diagnosed with #hypophosphatasia [insert how many years since diagnosis] years ago and have learned to cope with the many symptoms I deal with every day to not let my disease shape my life. For more information on #HPP, click here: <https://softbones.org>
5. Today, I spread awareness about my rare disease #hypophosphatasia on this #WorldHPPDay. Learn how you can be #HPPAware: <https://softbones.org/world-hpp-day-2024/>

X:

Leading up to World HPP Day:

1. Mark your calendars, it's almost #WorldHPPDay! On October 30, [I/my family/my organization] will be joining the #WorldHPPDay movement in support of the #hypophosphatasia community. Learn more on @SoftBonesHPP website: <https://softbones.org/>
2. #WorldHPPDay is right around the corner and, [I/my family/my organization] will be spreading awareness about #HPP. For more information on how you can be #HPPAware, visit @SoftBonesHPP website: <https://softbones.org/world-hpp-day-2024/>
3. It's almost time to make some noise for #WorldHPPDay! [I/my family/my organization] will be wearing #WorldHPPDay swag to show support for those impacted by #HPP. Learn how you can get involved: <https://softbones.org/world-hpp-day-2024/> @SoftBonesHPP

The Week of / Day of World HPP Day:

1. Today is #WorldHPPDay and I am a proud [member/supporter] of the #SoftBones community. Be #HPPAware and show your support for those living with #hypophosphatasia today: <https://softbones.org/>. [Share a photo of yourself.]
2. Are you making some noise for #WorldHPPDay? Join [me/my family/my organization] and @SoftBonesHPP and spread the word about #HPPAware . You can raise support for the #HPP community by getting involved now: <https://softbones.org/world-hpp-day-2024/> [Share a photo of you or your family/ organization holding an HPP sign]
3. Today, [share what you or your family/organization is doing for World HPP Day] for #WorldHPPDay! What are you doing to raise HPP awareness?! #HPPAware [Share a photo of you/your family/ organization holding an HPP sign]
4. Since 2008, #SoftBones has created an #HPP community that comes together to raise awareness for those affected by #hypophosphatasia. Join [me/my family/ organization] and @SoftBonesHPP to celebrate the HPP community. Get involved: <https://softbones.org/world-hpp-day-2024/>
5. 2024 marks the 75th anniversary of the discovery of #HPP. On this #WorldHPPDay, we celebrate how far we've come, but also recognize how far we still have to go to understand the impact of low alkaline phosphatase in the body. Join [me/my family/organization] and be #HPPAware! Learn how to get involved: <https://softbones.org/world-hpp-day-2024/> [Share photo of you/ your family/organization holding an HPP sign]