



WORLD HPP DAY

WE ARE HPP

Media & Social Media Outreach Toolkit

Thank you for helping us spread the word about hypophosphatasia (HPP).

In recognition of World HPP Day on October 30. This year's campaign carries a simple but powerful message:

WE ARE HPP.

HPP is not represented by one age, one experience or one story. It includes people living with HPP, family members, caregivers, clinicians, researchers, advocates and partners. Each person is contributing their own perspectives to a fuller understanding of this rare condition.

Every voice helps make HPP more visible. By sharing your experience with your local community, you can help others recognize the signs of HPP, understand the significance of persistently low alkaline phosphatase (ALP) and see the real people behind a rare disease diagnosis. A local story can reach someone who has never heard of HPP.



Help Bring 'WE ARE HPP' to *Your* Community

We have created materials to help you share the campaign through local media and social media. Inside, you will find:

✉ [A customizable letter for pitching your story to local news outlets](#)

➡ [Ready-to-use social media posts](#)

💬 [Suggested language for sharing your experience](#)

💡 [Ideas for participating in the WE ARE HPP campaign](#)

Your story does not need to represent every HPP experience. It only needs to be yours. Together, our individual stories reveal the breadth, strength and humanity of this community. If you are interested in contacting your local media or would like help shaping your pitch, please email Info@SoftBones.org. Thank you for adding your voice and helping more people understand what it means when we say: **WE ARE HPP.**

Sincerely,

Deb, Denise, Jenn, Cindy, Sue, Jessica, Alex, and McKenna



World HPP Day Pitch

News Reporter Template:

Hello [REPORTER/EDITOR NAME],

My name is [FIRST AND LAST NAME], and I am a [CITY/REGION]-based resident living with hypophosphatasia (HPP), a rare inherited metabolic condition that affects bones, teeth and other parts of the body. In recognition of World HPP Day on October 30, 2026, I would welcome the opportunity to share my experience with your audience as part of this year's WE ARE HPP campaign.

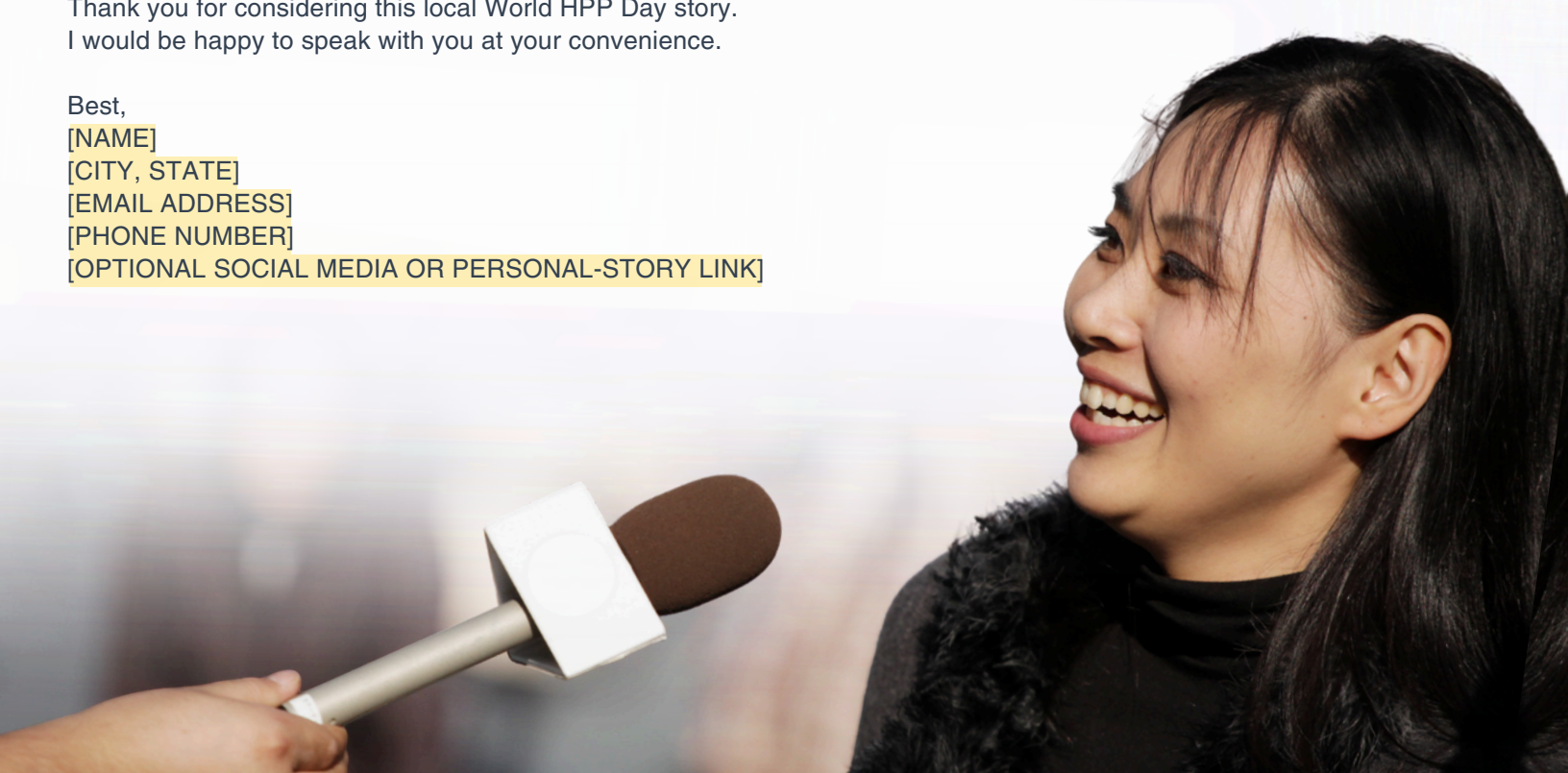
I was diagnosed with HPP at age [AGE] and experienced [INSERT MAIN SYMPTOMS]. I describe living with HPP as "[INSERT A SHORT PERSONAL QUOTE OR COMPARISON]." With information, resources and support from other HPP families and Soft Bones, I have been able to [INSERT AN ACCOMPLISHMENT, ACTIVITY OR MILESTONE]. I am sharing my story to help others understand both the challenges of HPP and the lives being lived beyond the diagnosis. HPP is associated with low activity of an enzyme called alkaline phosphatase, or ALP, which is important to healthy bone and tooth mineralization. Its effects vary widely and may include soft or fragile bones, fractures, pain and premature tooth loss.

The WE ARE HPP campaign recognizes that no single story represents the full HPP experience. Patients, families, caregivers, clinicians, researchers, advocates and partners each contribute to a broader understanding of this rare condition. By sharing my experience, I hope to help your audience see beyond the letters & meet the person behind the diagnosis.

I would be glad to discuss my path to diagnosis, how HPP affects my daily life, the role of community and advocacy, and why greater awareness and continued research matter. I can also connect you with Deborah Fowler, Chairman of the Board and Founder of Soft Bones, Inc., for additional information.

Thank you for considering this local World HPP Day story.
I would be happy to speak with you at your convenience.

Best,
[NAME]
[CITY, STATE]
[EMAIL ADDRESS]
[PHONE NUMBER]
[OPTIONAL SOCIAL MEDIA OR PERSONAL-STORY LINK]





Helpful Hints for Creating Impactful Social Media Posts



Engage with Soft Bones!

Soft Bones will post frequently on our social media channels leading up to World HPP Day. Follow us on: [Facebook](#), [Instagram](#), [Twitter/X](#), and [LinkedIn](#)!



Comment on a post



Share on your social media



React with emojis



Tag your favorite celebrity or elected official under our posts.



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.



Social media should be social!

Engage with your followers as much as you can. If you're getting questions and comments under your posts, respond and interact with them.



Tag your post for 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:

#SoftBonesHPP #WeAreHPP #WorldHPPDay, #HPP, #HPPAware, #hypophosphatasia



Include a call to action!

The best way to raise awareness is to spread the word and encourage others to join. Consider adding a call to action to your post. Make sure you use clear wording, so your followers know what you're asking them and how they can join in on the celebration. Here are some suggestions below:

1. Donate to Soft Bones,
an organization that means a lot to me
2. Shop for a cause to support patients living with HPP
3. Share my story and help me spread the word



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 count toward a character limit. Here is a quick character limit guide, though shorter posts tend to perform better:



Instagram: 2,200 characters



Twitter/X: 280 characters



Facebook: 5,000 characters



LinkedIn: 3,000 characters



Help amplify the 2026 campaign message: WE ARE HPP.

HPP is more than an acronym. It is made up of people living with HPP, caregivers and families, clinicians, researchers, advocates and partners—each bringing a different experience to our shared understanding of this rare condition.

Choose the message that reflects your connection to HPP, personalize it and share it with a photo or one of the WE ARE HPP campaign graphics.



For someone living with HPP

WE ARE HPP. I have HPP.

HPP is part of my life, but three letters cannot tell you who I am or capture everything my experience has taught me. This [#WorldHPPDay](#), I'm sharing my story so more people can see beyond the letters and understand the people behind the diagnosis.

[ADD ONE OR TWO SENTENCES ABOUT YOUR EXPERIENCE.]



For a family member or caregiver

WE ARE HPP.

I care for someone living with HPP.

HPP affects more than one person. It can shape the lives of families and caregivers who learn, adapt, advocate and stand beside the people they love. This [#WorldHPPDay](#), I'm adding my voice to the story of HPP.

[ADD WHAT YOU WOULD LIKE OTHERS TO UNDERSTAND ABOUT YOUR EXPERIENCE.]



For a healthcare provider

WE ARE HPP.

I am working toward greater understanding.

Progress in HPP begins with listening—to the evidence, to emerging research and to the people who live with this condition every day. This [#WorldHPPDay](#), I stand with the HPP community in working toward greater recognition, understanding and progress.



For an advocate, partner or supporter

WE ARE HPP. I stand with the HPP community.

Every person who listens, learns and shares helps make HPP more visible. This [#WorldHPPDay](#), I'm helping bring greater attention to the people and experiences behind this rare condition.



Short option for any participant

WE ARE HPP.

We are patients, families, caregivers, clinicians, researchers, advocates and partners. Different experiences. Different perspectives. One community working toward greater understanding and progress. This [#WorldHPPDay](#), see beyond the letters. See the person.

[WORLD HPP DAY LINK]



Posts for Facebook, Instagram, & LinkedIn



Leading up to Rare Disease Day:

On #WorldHPPDay, I will be raising awareness for the #hypophosphatasia community. On October 30th, join the celebration. Together, we can learn to be **#HPPAware**:

<https://softbones.org/world-hpp-day-2026/>

#WorldHPPDay is just around the corner!

[I/my family/organization] will be making some noise to raise awareness for **#hypophosphatasia**. Join us. Together, we can learn to be **#HPPAware**:

<https://softbones.org/world-hpp-day-2026/>



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

[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!

<https://softbones.org/world-hpp-day-2026/>

[Share a photo of yourself with the HPP sign]

Today, join me in support of people like me, who live with **#hypophosphatasia** 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>

My HPP journey is unique! I have hypophosphatasia, and I am making some noise for **#WorldHPPDay**.

Together we can learn to be **#HPPAware**:

<https://softbones.org/world-hpp-day-2026/>

2026 marks the 78th anniversary of the discovery of #hypophosphatasia. 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 together we can learn to be **#HPPAware**! Learn how to get involved:

<https://softbones.org/world-hpp-day-2026/>

[Share a photo of you/your family/organization holding an HPP sign]

On this year's **#WorldHPPDay**, I join the Soft Bones Community in spreading awareness around hypophosphatasia (HPP) and in support of others living with this disease, just like me. I was diagnosed with HPP [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 control my life. For more information on HPP, click here: <https://softbones.org>



Posts for Twitter/X



Leading up to Rare Disease Day:

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/>

#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-2026/>

It's almost time to come together 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-2026/> @SoftBonesHPP



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

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.]

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-2026/> [Share a photo of you holding an HPP sign]

Since 2008, **#SoftBones** has created a community 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-2026/>

Since 2008, **#SoftBones** has created a community 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-2026/>

2026 marks the 78th 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 (ALP) in our bodies. Join [me/my family/organization] and be **#HPPAware**! Learn how to get involved: <https://softbones.org/world-hpp-day-2026/> [Share photo of you/ your family/organization holding an HPP sign]