



World HPP Day Media Outreach Toolkit

Introduction

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

October 30th is World HPP Day! This year, our theme is **“Let’s all be heard!”** For some, HPP can be a very visual disease but for others, HPP can be invisible. In the spirit of “being heard”, 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 you can customize and use 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 four drafted social media posts customized for Twitter, 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. Please note, Twitter has a maximum character limit of 280 characters.

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 lending your voice so we can ALL BE HEARD!

Sincerely,

Deb, Denise & Sue

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-fē-tā-zh(ē-)ə, and I would like an opportunity to share my experience as part of [World Hypophosphatasia Day](#) on October 30, 2021 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 organizations efforts to spread awareness.

Best,

[INSERT NAME AND CONTACT INFORMATION]