WORLD HYPOPHOSPHATASIA DAY 2020 TOOLKIT
Customized World HPP Day Logo For General Use

World Hypophosphatasia Day
hpp together
OCTOBER 30, 2020

Logo Variations For Posting

Cover Image For Social Media Posting
Facebook Frame Image For Profile Picture

Your profile picture goes on top, with the logo at the bottom of your image.

Suggested Hashtags For Awareness and Engagement
#HPPTogether, #SoftBones #HPPAware, #WorldHPPDay, #Hypophosphatasia

When posting your awareness picture or pictures, we suggest using no more than three to four of the hashtags listed above.

Limited-Release World Hyposphosphatasia Day 2020 T-Shirt

Our HPP Together t-shirts are now available for purchase. Please use the link provided below or visit www.inktothepeople.com and choose the fundraiser for Soft Bones. T-shirts must be purchased by October 8 to ensure delivery before October 30.

CLICK HERE to Purchase Your World HPP Day 2020 T-Shirt
Suggested Activities for Social Media and Online Engagement

1. Instagram
   a. Post an image of our customized logo.
   b. Be sure to use the hashtags listed above.
   c. Post a photo on your feed wearing our World HPP Day t-shirt.
   d. Spread awareness through the “Fun”draiser StoryBoard:
      Post our World HPP Day StoryBoard to your Instagram story. Your followers will be able to “purchase” one or more of the squares listed, and will donate the amount listed through Venmo. Once a donation is received, use the Instagram Story tools to mark off the squares that have been purchased bingo-style. If you have questions about the fundraiser StoryBoard, please email: sue@softbones.org
For instructions, please see video tutorial on how to post the Instagram Fundraiser StoryBoard on www.worldhppday.org.

2. Facebook
   a. Post an image of our customized logo or use the World HPP Frame. To use the Soft Bones Frame, follow these steps:
      ■ Click on your Facebook profile image. Select Update Profile Picture.
      ■ Select “Add Frame” tab at top.
      ■ In search box, type in Soft Bones World HPP Day.
      ■ Select frame and position photo using the + - feature under the photo.
      ■ When finished, click “Use as profile picture” button at bottom left to save.
   b. Be sure to use the hashtags listed above.
   c. Post a photo on your feed wearing our World HPP Day t-shirt.
   d. Change your cover photo to one of our **HPP Together World HPP Day graphics** (listed above). The customized World HPP Day Graphic will highlight the importance of engagement and being involved in advocacy. It will show your family, friends, and Facebook followers the strong community here at Soft Bones.
   e. **Host a Facebook Fundraiser** - Create a Facebook fundraiser a few days prior to World HPP Day so that your followers will be able to donate to your cause. It’s quick and easy!
      - Click ❤️ Fundraisers in the left menu of your News Feed. You may need to click See More. You can also click this link
      - Click + Raise Money.
      - Select Nonprofit or Charity.
      - Select a charitable organization, fill in the fundraiser details and choose photo.
      - Click Create.

**Suggested Fundraiser Titles**
- Hope for Hypophosphatasia: The U.S. Soft Bones Foundation fundraiser
- Hypophosphatasia: The U.S. Soft Bones Foundation fundraiser
- World Hypophosphatasia Day: The U.S. Soft Bones Foundation fundraiser
- Hypophosphatasia Fundraiser: World Hypophosphatasia Day October 30

Commented [DF1]: Might not need this – I finally understand how it works. LOL
**Suggested Fundraiser Description**
World Hypophosphatiasis Day is October 30. Your support can help the U.S. Soft Bones Foundation to make an impact, whether you donate $5 or $500. Your gift will raise awareness of hypophosphatiasis (HPP) within the healthcare community and among patients. In rare diseases, many patients have never met another patient who has their disease. Soft Bones offers travel grants to allow HPP patients to connect with one another and become better advocates for their health, as well as connect with healthcare specialists to oversee the many aspects of their treatment. The Foundation also drives research for HPP, including gene therapy, to fuel hope for tomorrow. Thank you for your support. We've included information about Soft Bones below, but you can also visit the website at www.SoftBones.org

The mission of Soft Bones, Inc. is to provide valuable information, education and support for people living with hypophosphatiasis (HPP), their families and caregivers. The Foundation promotes research of this rare bone disease through awareness and fundraising efforts.

3. **Twitter**
   a. Post an image of our customized logo.
   b. Be sure to use the hashtags listed above.
   c. Post a photo on your feed wearing our World HPP Day t-shirt.
   d. Tweet about World HPP Day and encourage others to follow @SoftBonesHPP on twitter. Please re-share any content you see on the Soft Bones twitter account to increase awareness on World HPP Day.

4. **HPP Together Official Video**
   a. Our World HPP Day video will be highlighting two pivotal aspects:
      1. To reinforce and support that Together -We are Stronger.
      2. To reinforce and educate the public about the importance of engagement and patient advocacy.
   b. The video will be 2-3 minutes long, which will include short clips submitted by patients, family members, friends, doctors, etc. It will be shared through social media, as well as the Soft Bones website.
   c. If you are interested in participating, please email bonnie@softbones.org for more information.
5. Wellness Webinar
There will be a wellness webinar on 10/30 at 2pm (ET) with Today Show correspondent Dr. Jen Hartstein (https://www.drjen.com). Dr. Jen is a nationally recognized child, adolescent and family psychologist based in New York City. She is a frequent contributor on NBC’s The Today Show and a core expert on The Dr. Oz Show. During this webinar, Dr. Jen will discuss how to manage emotional and mental health while living with a chronic disease. This webinar will include tools to cope during uncertain times, such as COVID-19, self-care strategies, such as journaling, and much more! More information and registration details to come.

6. Soft Bones Hippo Squad
As a means of engaging children with HPP and their siblings, Soft Bones offers a membership group known as the Hippo Squad, where “cool” kids connect. The squad offers children living with this rare disease an opportunity to connect to a community of others just like them, while educating them on their disease through activity boxes mailed to their home throughout the year. To further demonstrate the theme of HPP Together, families are encouraged to learn more about this program and register their child(ren) at: bit.ly/SBHippoSquadandBookOrder.

All registrants will receive a copy of the first storybook of its kind for children with HPP created by Soft Bones, “Journaling My Hypophosphatasia.”

7. Media Outreach
We are always looking for patients who are interested in sharing their story with the media. If you are interested in telling your story, or know of a media contact who would like to feature content on World HPP Day, hypophosphatasia or Soft Bones, Inc., please email bonnie@softbones.org for more information.

To learn more about World Hypophosphatasia Day and HPP, please visit:
www.worldhppday.org
www.worldhypophosphatasiaday.org

Soft Bones
Finding the Key to HPP

(866) 827-9937 info@softbones.org www.softbones.org