While there are visible signs of HPP for some, others often hear from doctors, family members and friends that they “don’t look sick”. This makes patients feel as if their feelings and challenges are dismissed or don’t matter. On World HPP Day, patients and caregivers were asked to take time to share their untold stories and—"Let’s all be heard!" They clearly understood the assignment, displaying their support while sharing their successes and challenges through an array of activities, summarized below.

Here is how the HPP community made an impact this past October, culminating on October 30 (World HPP Day):

- The HundredX Causes fundraising program encouraged our community to provide feedback on popular retailers and businesses, earning $2 for each survey completed. We are still awaiting a grand total, but have already raised over $3,000 during this campaign.

- The Soft Bones Teen Advisory Council (TAC) created an Instagram bingo board fundraiser held on October 30th, raising over $400! Fundraisers like this are a fun and easy way to support Soft Bones. See their sample bingo board [here](#).

- Official World HPP Day merchandise was added to the Soft Bones swag shop, where a portion of proceeds from item sales will be donated back to our organization. Apparel is still available [here](#).

It's not too late to support World HPP Day! Make a donation by visiting this [link](#). For more information, contact us at info@SoftBones.org or (866) 827-9937.
More than 248 people changed their Facebook profile photo to include the official World HPP Day frame.

Multiple virtual education meetings and support meet-ups were held throughout the U.S. to help community members stay informed and connect to their community.

A Halloween virtual meetup was held for our youngest HPP patients and families.

Houston, TX celebrated World HPP Day by illuminating two landmarks, the IAH Airport Entrance at JFK and the Montrose Bridges.
"I'm a Survivor before doctors knew what HPP was. Even with a double mutation and if I added up all my hospital stay it would equal 2/3rds of my life. But that is what it’s all about when you have a rare disease, never let it win over your will to succeed to do your bucket list. Life is too short to let your rare disease define you as a person. Yes I have HPP but it’s not who am or what I can do!" - Sue

I was diagnosed with Hypophosphatasia one year ago, and my journey has not been easy. In this piece, I wanted to portray not only the fragility of my bones through their depiction as a skeleton but the fragility of my feelings during this tough and uncertain time in my life. Three of the bones seen in the painting I have broken. The ribbon-like structures represent alkaline phosphatase, and I painted it as though I could not grasp nor control the chaotically scattered enzymes, which parallels the lack of control I have over my condition.

- Holly
"I'm a Survivor before doctors new what HPP was. Even with a double mutation and if I added up all my hospital stay it would equal 2/3rds of my life. But that is what it's all about when you have a rare disease, never let it win over your will to succeed to do your bucket list. Life is too short to let your rare disease define you as a person. Yes I have HPP but it's not who am or what I can do!"

"My picture is dedicated to all who lost the fight, who couldn't get help. Who live in countries where they can't get treatment. Who never find a doctor who knows what HPP is. Who's insurance fight them tooth and nail. Those who's doctors tell them to go home, or belittle, or shame them. It's for my grandma who died never knowing what was wrong with her and for my daughter who cried for a year and a half and no doctor could find out why. It's for the clumsy little kids dressed in red and blue with dysautonomia & dyslexia & who can't run right and can't see right and who can't hear right. It's for the babies in hospitals and the kids with “just” growing pains. It’s for the tired, depressed ones. It’s for the ones with brain fog and neuropathy and migraines. It’s for the ones in pain every single day. It’s for the “complicated” ones.

At times we feel hopeless but let’s don’t put down our brushes yet…. There are good people working on this. They have cured HPP in mice.” -Amy
"HPP is this never ending waterfall of pain. It's a pummeling and swirling barrage of emotions. It's drowning in trying to find information and doctors who can help. But in the midst of all of that, there is a rainbow of hope for a cure."

Josh & Kristina

"This fall Doug and I decided we would take a now or never trip to the mountains, spent 5 weeks camping in our minivan, exploring remote places, meeting amazing people, and enjoying every minute of it. I didn't break anything along the way even though we were prepared with all the aids I might need. On the way home I was able to capture this picture. A clear reminder that every day we can choose to focus on the mountain or we can focus on the rainbow."

Heather & Doug
"I'm a Survivor before doctors knew what HPP was. Even with a double mutation and if I added up all my hospital stay it would equal 2/3rds of my life. But that is what it's all about when you have a rare disease, never let it win over your will to succeed to do your bucket list. Life is too short to let your rare disease define you as a person. Yes I have HPP but it's not who am or what I can do!" - Sue

"When you hear the sound of hooves, think horses, not zebras." We ARE the zebras - this photo is composed of all of the verbiage that defines our family's journey with HPP. These are our stripes.

- Laiken
"This drawing represents our journey with HPP. It starts off with two lines, a red one and a blue one, because I was 'the red twin' and my sister was 'the blue twin'. The first dip in the lines is when she was hospitalized for a month with pneumonia as an infant. She cried too much when my mother visited, so my mother didn't visit. In reality I should have started with lines before ours, to represent our mother and grandma, who taught us not to tell doctors our weird symptoms, because, "You'll just start a wild goose chase." Our experience with doctors, like there's, is that they don't help, but they belittle, and can make you feel crazy, or hopeless, or worse. I've added our mother's and grandma's colored lines into the mix on the right, with our older sister, and our children and grandchildren. We've put years of effort into finding out what is wrong with us, and we finally have a diagnosis!! and found Soft Bones!!, but the fight to get treatment seems never ending, and sometimes impossible. Today happens to be a discouraging day. There have been many. This is represented in the black shadow at the bottom of the drawing. We still have hope though. And we keep trying to get help. We are so thankful for other HPPers - their support, encouragement, and insight. We are not alone." - Suzannah
"We just passed our 2-year HPP diagnosis anniversary. We have learned so much about ourselves and others like us in this time. We have been very fortunate to start treatment this year, which allowed us to go further and higher than ever before. We are stronger than we've ever been and are looking forward to taking more trips, exploring, and scaling more rocks in the future." - Sara & Iris

"This captures both the good and bad times of having HPP. The needle shows the medicine, and the pain that comes with the disease, but the rose symbolizes what the medicine does for a patient, and becoming stronger both physically and mentally." - Grace