



HYPOPHOSPHATASIA (HPP)

Journal

For Tracking Symptoms, Observations,
Appointments, & Reflection



I have learned a lot
from HPP. I've learned
how to solve problems—
how to overcome
obstacles **to get where
I need to be.**

Amy

LIVING WITH HPP

HYPOPHOSPHATASIA (HPP)

A Journey

Use this journal as a two-month challenge to complete the following:

Tracking

Daily Review	4-43
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DAILY REVIEW *Example:*

DATE 01 / 01 / 22

MOOD



SLEEP

HOURS  

Last night's sleep was rough. I woke up a couple of times.

ACTIVITY

ENERGY  

Today I went to work and then the park, but now I'm tired.

I started feeling drowsy around 3 pm.

TODAY'S SYMPTOMS

*My shoulder started really hurting after I
got off work.*



CIRCLE SYMPTOM LOCATIONS

TODAY WAS A GOOD
DAY BECAUSE

*The weather was nice, and I
talked to my friend on
the phone.*

TODAY WAS A CHALLENGING
DAY BECAUSE

*Cooking dinner with a sore
shoulder was difficult.*

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TODAY'S SYMPTOMS



CIRCLE SYMPTOM LOCATIONS

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TODAY'S SYMPTOMS



CIRCLE SYMPTOM LOCATIONS

TODAY WAS A GOOD DAY BECAUSE

TODAY WAS A CHALLENGING DAY BECAUSE



We must let go of
the life we have
planned, so as to
accept the one that
is **waiting for us.**"

Joseph Campbell

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HPP can help you to be **compassionate**. When you see other people, you don't know what they may be going through."

Suzanne

LIVING WITH HPP

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Grounding Activity

Approaching each new day navigating a rare disease can be stressful, so sometimes taking a few deep breaths and grounding yourself may help relieve tension. If you find yourself anxious or overwhelmed, try this grounding activity to de-stress and clear your mind.

5 THINGS YOU CAN SEE



4 THINGS YOU CAN TOUCH



3 THINGS YOU CAN HEAR

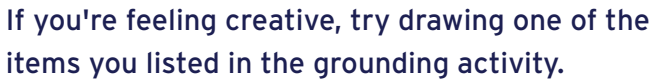


2 THINGS YOU CAN SMELL



1 THING YOU CAN TASTE



[illegible]

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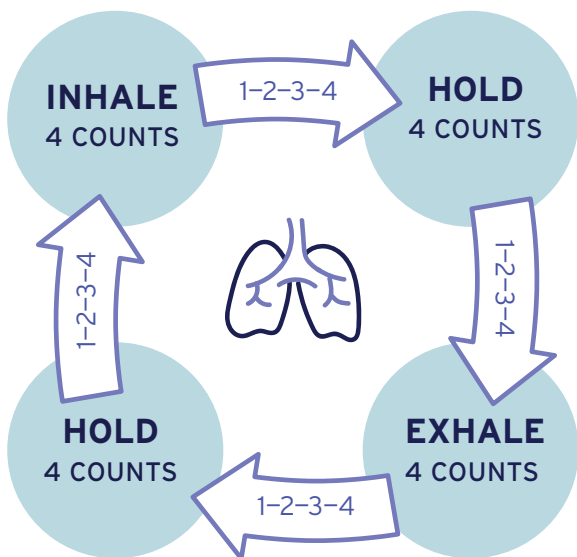
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Mindful Breathing

HPP can be overwhelming, but mindfulness activities may allow you to take charge of your thoughts instead of letting your thoughts take charge of you. One way to do that is to calm your body and your mind. Deep breathing may relax the nervous system, slow the heart rate, and increase oxygen in the blood.



Briefly describe how you are feeling after completing the mindful breathing activity:



Keep your face
always toward
the **sunshine**—
and shadows will
fall behind you.”

Walt Whitman

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HPP has helped me realize
what's important in life.
People are more important
than possessions.”

Amy

LIVING WITH HPP

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MONTHLY OVERVIEW

This section may be used to track appointments, meaningful occurrences, and activities over the course of the month.

MONTH:

YEAR:

SUN MON TUES WED THUR FRI SAT

NOTES

MONTHLY OVERVIEW

MOOD



1-4 Low, 5-6 Neutral, 7-10 High

PHYSICAL HEALTH



MENTAL WELLNESS



ABILITY TO ASK FOR HELP



OVERALL STRESS LEVEL



ACTIVITY LEVEL



WHERE I/MY LOVED ONE FELT DISCOMFORT THIS MONTH



CIRCLE SYMPTOM LOCATIONS

DO YOU FEEL THAT PROGRESS WAS MADE DURING THE PAST MONTH WITH OVERALL HEALTH?

WHAT WILL YOU DO IN THE NEXT MONTH FOR YOUR OVERALL HEALTH?

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Feel-Better Goals

Setting realistic goals is a great way to stay focused on creating a healthy lifestyle with HPP.

What **motivates** you to reach your goals? Consider how you **persist** when things become tough dealing with a rare disease. How do you keep showing up for your goals? Your **mindset** could be key. What actions have you taken in the past to reach a goal or milestone?

MOTIVATION

PERSISTENCE

MINDSET/ACTION



Consider some small milestones on your HPP goal journey and what actions you can take to achieve each milestone.

GOAL #1

ACTIONS & MILESTONES

_____	○ 1.	_____
_____	● 	_____
_____	○ 2.	_____
_____	● 	_____
_____	↓ 3.	_____

GOAL #2

ACTIONS & MILESTONES

_____	○ 1.	_____
_____	● 	_____
_____	○ 2.	_____
_____	● 	_____
_____	↓ 3.	_____



What actions did you take to meet your goals and milestones? Is there anything you want to improve?

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**Being strong is being
my own advocate and
believing in myself.”**

Carol

LIVING WITH HPP

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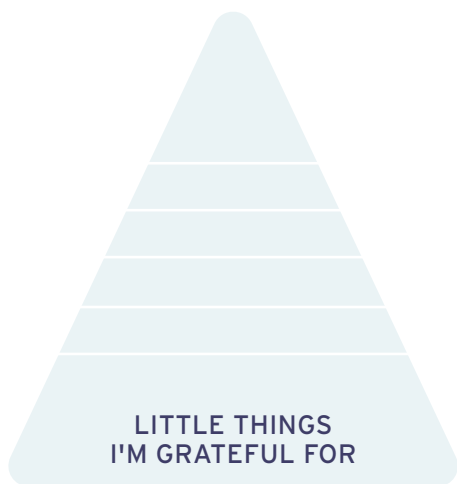
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Gratitude Is an Attitude

Sometimes it's easy to be overwhelmed by the complications that may come when living with HPP. Think about all the things that you are grateful for and imagine filling your life with gratitude. What are some of the things you appreciate right now?





In order to succeed,
we must first believe
that **we can.**"

Nikos Kazantzakis

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We know what we
are but know not
what we may be.”

William Shakespeare

Self-care Is an Act of Love

Managing HPP is a full-time effort, but taking time for self-care is important too. Self-care is about taking a deliberate approach to your own mental, physical, and emotional well-being. The self-care umbrella includes a combination of healthy sleep, alone time, quality time with loved ones, eating well, exercise, and anything that you feel nourishes your body, mind, and well-being.

Check off activities that appeal to you, or write in your own:

- | | |
|--|--|
| ☐ Sleep in | ☐ Listen to music |
| ☐ Look at the clouds or stars | ☐ Watch the sunrise or sunset |
| ☐ Gentle yoga | ☐ Take a nap |
| ☐ Read a book | ☐ Take a bath |
| ☐ Call a friend | ☐ Go to bed early |
| ☐ Eat a favorite meal | ☐ Watch your favorite movie |
| ☐ Practice mindful breathing | ☐ Write a list of compliments to yourself |
| ☐ De-stress with art | ☐ _____ |



Journal about your experience with a self-care activity below:

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I think the best advice for a
care partner is just be there.
Do what you can.”

Bill

HUSBAND TO CAROL,
CAROL, LIVING WITH HPP

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MON

TUES

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THUR

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MONTHLY OVERVIEW

MOOD



1-4 Low, 5-6 Neutral, 7-10 High

PHYSICAL HEALTH



MENTAL WELLNESS



ABILITY TO ASK FOR HELP



OVERALL STRESS LEVEL



ACTIVITY LEVEL



WHERE I/MY LOVED ONE FELT DISCOMFORT THIS MONTH



CIRCLE SYMPTOM LOCATIONS

DO YOU FEEL THAT PROGRESS WAS MADE DURING THE PAST MONTH WITH OVERALL HEALTH?

WHAT WILL YOU DO IN THE NEXT MONTH FOR YOUR OVERALL HEALTH?

Dear Hypophosphatasia

Write a second letter to HPP. Consider how your perspective on this rare condition may have changed since your first letter and write everything that you wish you could say.



You may not control
all the events that
happen to you, but you
**can decide not to be
reduced by them.”**

Maya Angelou

Healthcare Team

NAME _____

LOCATION _____

SPECIALTY _____

NOTES _____

CONTACT INFORMATION _____

NAME _____

LOCATION _____

SPECIALTY _____

NOTES _____

CONTACT INFORMATION _____

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LOCATION _____

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CONTACT INFORMATION _____

NAME _____

LOCATION _____

SPECIALTY _____

NOTES _____

CONTACT INFORMATION _____

Support System

Include everyone on this list who helps you or your loved one along the HPP journey.

NAME _____

RELATIONSHIP _____

CONTACT INFORMATION _____

NOTES _____

NAME

RELATIONSHIP _____

CONTACT INFORMATION _____

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NAME

RELATIONSHIP _____

CONTACT INFORMATION _____

NOTES _____

Labs

Use this space to track alkaline phosphatase (ALP) levels and other important lab values over time. Fill in the blank columns below with the values you would like to record.

LAB NAME	TEST RESULT	DATE

NOTES TO DISCUSS WITH DOCTOR



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