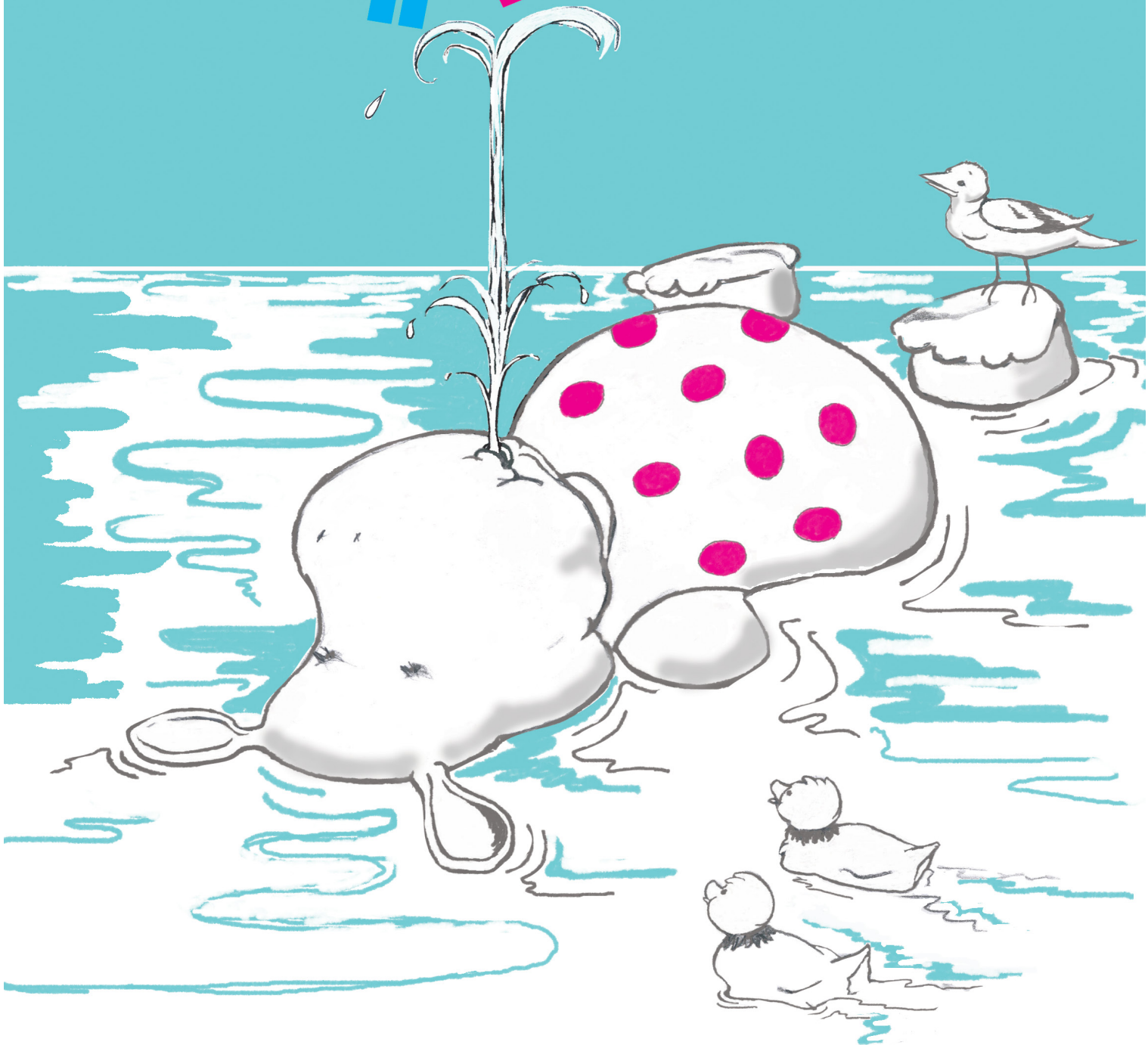


Journaling My

# HYPOPHOSPHATASIA

H P P

Written and Illustrated  
by Penne Wittner





Soft Bones, The US Hypophosphatasia Foundation, was formed in 2009 to provide information and a community to educate, empower and connect patients living with hypophosphatasia (HPP), their families and caregivers.

Hypophosphatasia is an inherited (genetic), ultra-rare, metabolic (chemical) bone disease of broad-ranging severity that causes life-threatening disease in approximately one per 100,000 live births.

People with the condition have low levels of the enzyme alkaline phosphatase, which impairs the mineralization of bones. Normal mineralization is essential for hard and strong bones. Without it, bones become weak and soften and teeth may fall out prematurely. Depending on the severity of the skeletal disease, symptoms can include deformity of the limbs and chest, pneumonia, recurrent fractures, premature tooth loss and pain. While there is currently no cure for hypophosphatasia, treatment is directed towards preventing or correcting the symptoms or complications.

The Soft Bones Foundation catalyzes research of this rare bone disease through awareness, the CoRDS International Hypophosphatasia Contact Registry, and fundraising efforts. Soft Bones also advocates for access to treatment, educates lawmakers and brings attention to the needs and gaps in the care of patients affected by hypophosphatasia around the globe.

For more information visit [www.SoftBones.org](http://www.SoftBones.org).

This book was made possible, in part, through the support of:



This Book Belongs to:

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This book was made possible, in part, through the support of the following:



Sosforkids

## Introduction

Hypophosphatasia (HPP) is a rare condition and people living with HPP are rare, too. Some people learn about their HPP early in their lives or even before they are born, while still others learn about their HPP later on in life.

Either way, people with HPP have one thing in common. They have bones that are not as strong as most people's, so they need to choose their activities wisely. One symptom with HPP is that they lose their teeth (root and all) sooner than most people. This keeps the tooth fairy really busy!

People can't catch HPP like you can catch a cold. They have to be born with it. If you have HPP, you are rare.

Soft Bones would like to acknowledge the following kids for their thoughtful insight and suggestions.

Caleb	Blair	Evie	Cannon
Ana	Juliana	Grayson	Grace
Briley	Sophie	Micah	McKay
Maddox	Aubrey	Carson	Makenna
Esther	Abbey	Emery	Connor
Landon	Zooey	Addison	Zoey
Chett	Morgan	Avalon	Adeline

My name is Henrietta, and I have hypophosphatasia. It's a hard word to say and even harder to spell. Try spelling it below without looking.

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Most people just call hypophosphatasia HPP. HPP is a rare condition and people with HPP are rare, too. I am the only one in my school with HPP and even in my whole state!

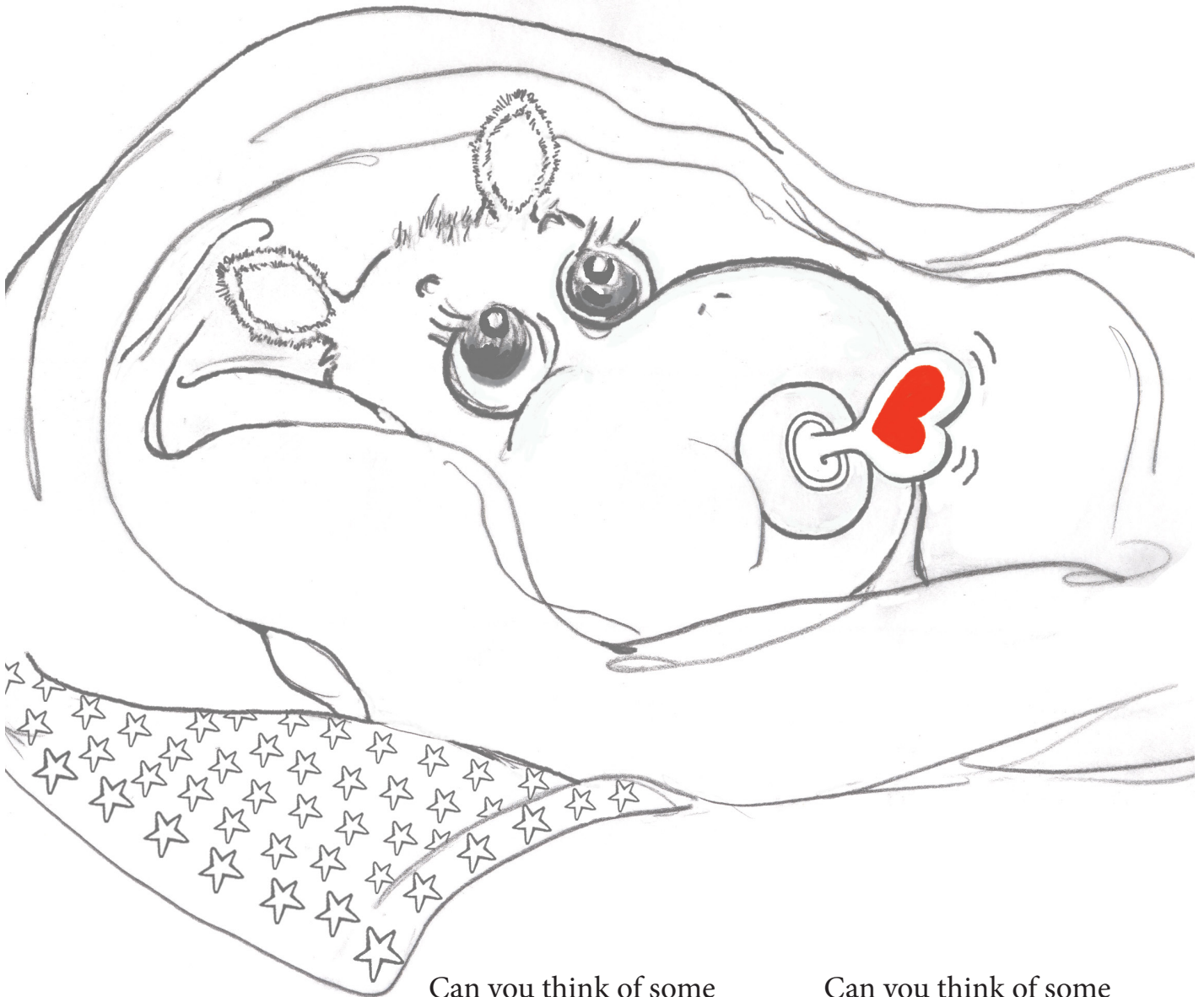


I have HPP, but I also have a super imagination and it helps me when I have bad days with my HPP. For example, the word “hypophosphatasia” reminds me of a hippopotamus and I LOVE hippos! Sometimes I like to imagine I am a hippo because they are strong and powerful! They are also different from the way they look. They are so big that you would think that they would be slow-moving, but they run really fast.

If you would like, I could take you inside my hippo imagination to tell you a little about my HPP.

When I was just a baby, things were pretty good, I suppose. At least I think they were because I really don't remember much about my baby days. But as I grew older, I started to remember things like my favorite foods, such as bacon or hot dogs or hamburgers with french fries!

I also remembered things that I did **not** like, such as shots.



Can you think of some things that you like?

Can you think of some things that you don't like?

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Not everyone with HPP gets shots,  
but I do.

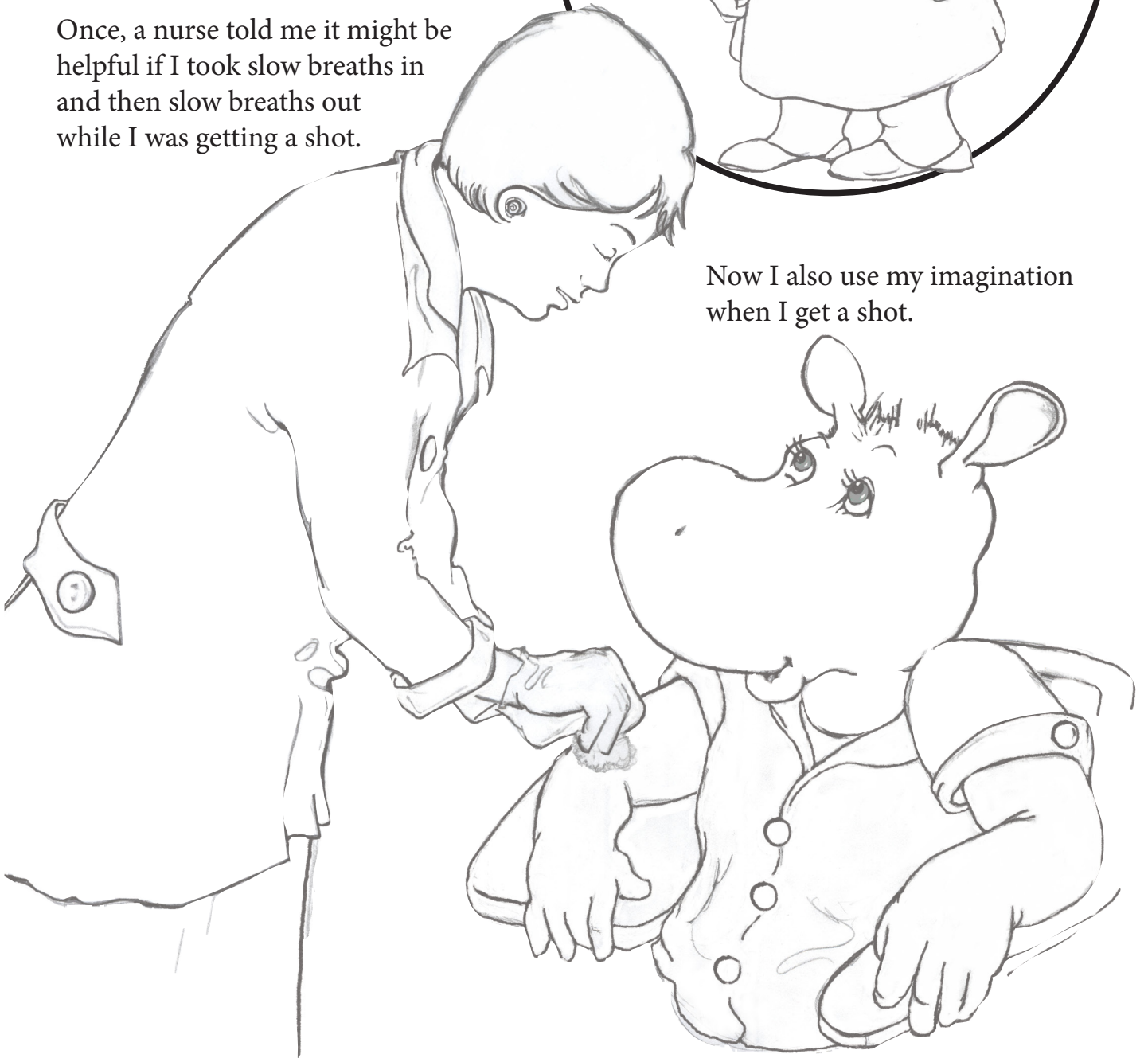
**I  
REALLY do not like  
shots!**

Now that I am older, I understand that  
shots help my bones get stronger and that  
helps me feel better.

Once, a nurse told me it might be  
helpful if I took slow breaths in  
and then slow breaths out  
while I was getting a shot.



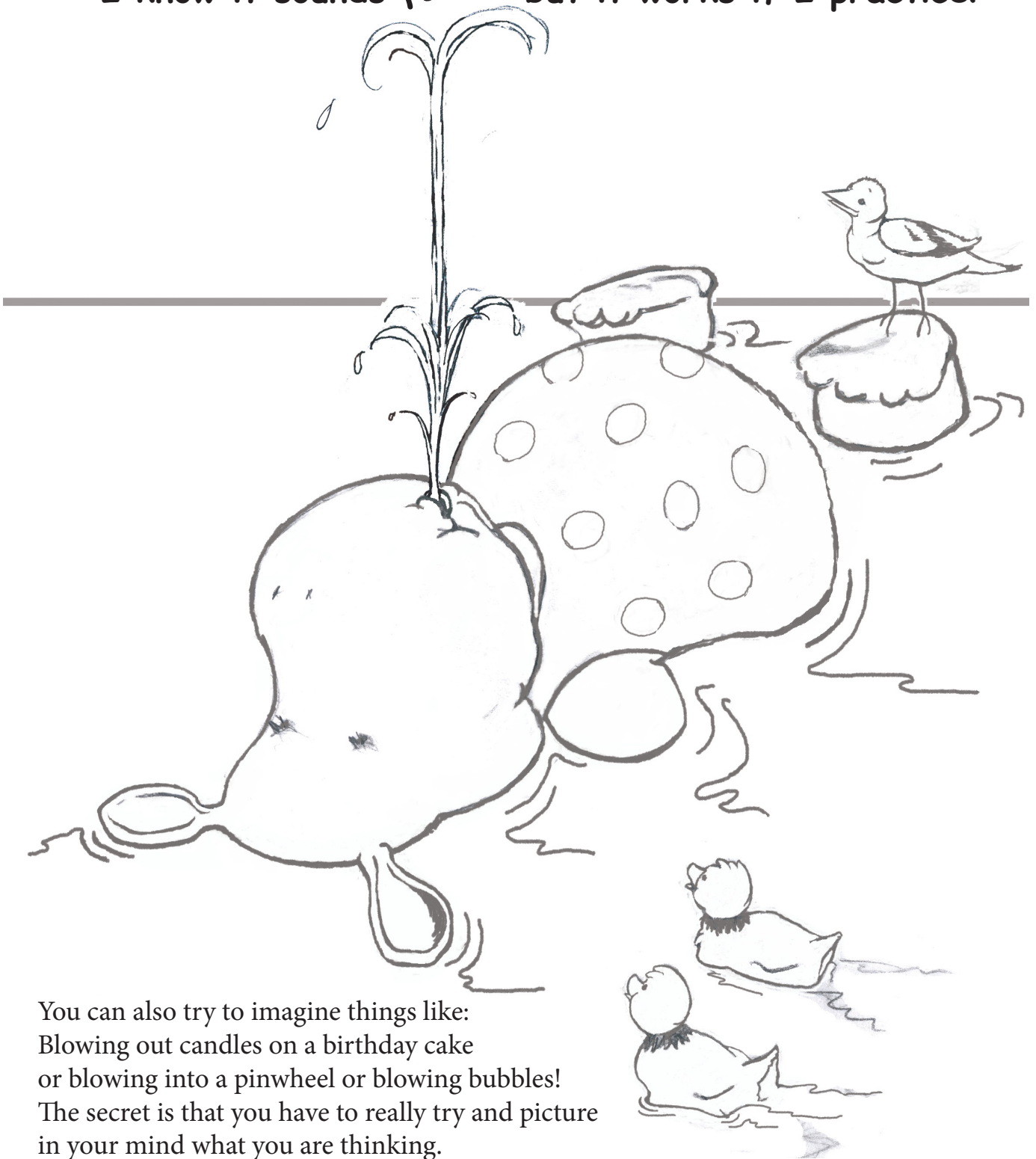
Now I also use my imagination  
when I get a shot.





Now, I imagine that I am floating in a cool lake with the sun shining brightly. I take a slow breath in, and then I imagine that I am blowing a waterspout out of my mouth.

**I know it sounds funny, but it works if I practice!**



You can also try to imagine things like:  
Blowing out candles on a birthday cake  
or blowing into a pinwheel or blowing bubbles!  
The secret is that you have to really try and picture  
in your mind what you are thinking.

I use my imagination at other times, too, like when I feel extra achy and can't get to sleep or when I just feel bored. All I have to do is to keep picturing things I would rather be doing like:

Ziplining or driving a go-cart or riding a pony!

Can you name some things you really like to do?

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At school, the teacher said Randy would be my playground buddy. I told Randy I didn't want him to have to miss out on playing with the other kids during recess. But he told me he really didn't mind at all. He actually liked quieter activities.

Randy and I became good friends. We have so much fun playing board games during recess and laugh so much that sometimes some of the other kids want to join us.



Some days, Randy and I just like to read. Randy likes anything to do with stars. I do, too, but I also like to read about hippos...of course!

Sometimes, I have to miss school. Last year, I had surgery and I missed so much school that I made a calendar to keep track of how many days I missed. I even rated each day from a number one, which meant I had a very bad day, to a number ten, which meant I had a very good day.

Randy told me he wouldn't mind getting out of going to school sometimes, but not for surgery. He would rather miss school to go fishing!

I would rather go fishing, too.

# MY 1-10 RATING CALENDAR

1= A Very Bad Day

10= A Very Good Day

Write the number for the kind of day you are having.


More calendars can be found in "My Journal" at the end of the book.

One day, when I got home from school, my mom told me we needed to pack our suitcases for a special trip. We were not going to a hospital. Instead, we were going to an HPP patient meeting where we would meet other kids and families affected by HPP!

I couldn't wait to go. Mom was excited, too. I packed some of my favorite things to take with me.

What are some of the things you would pack for a trip?

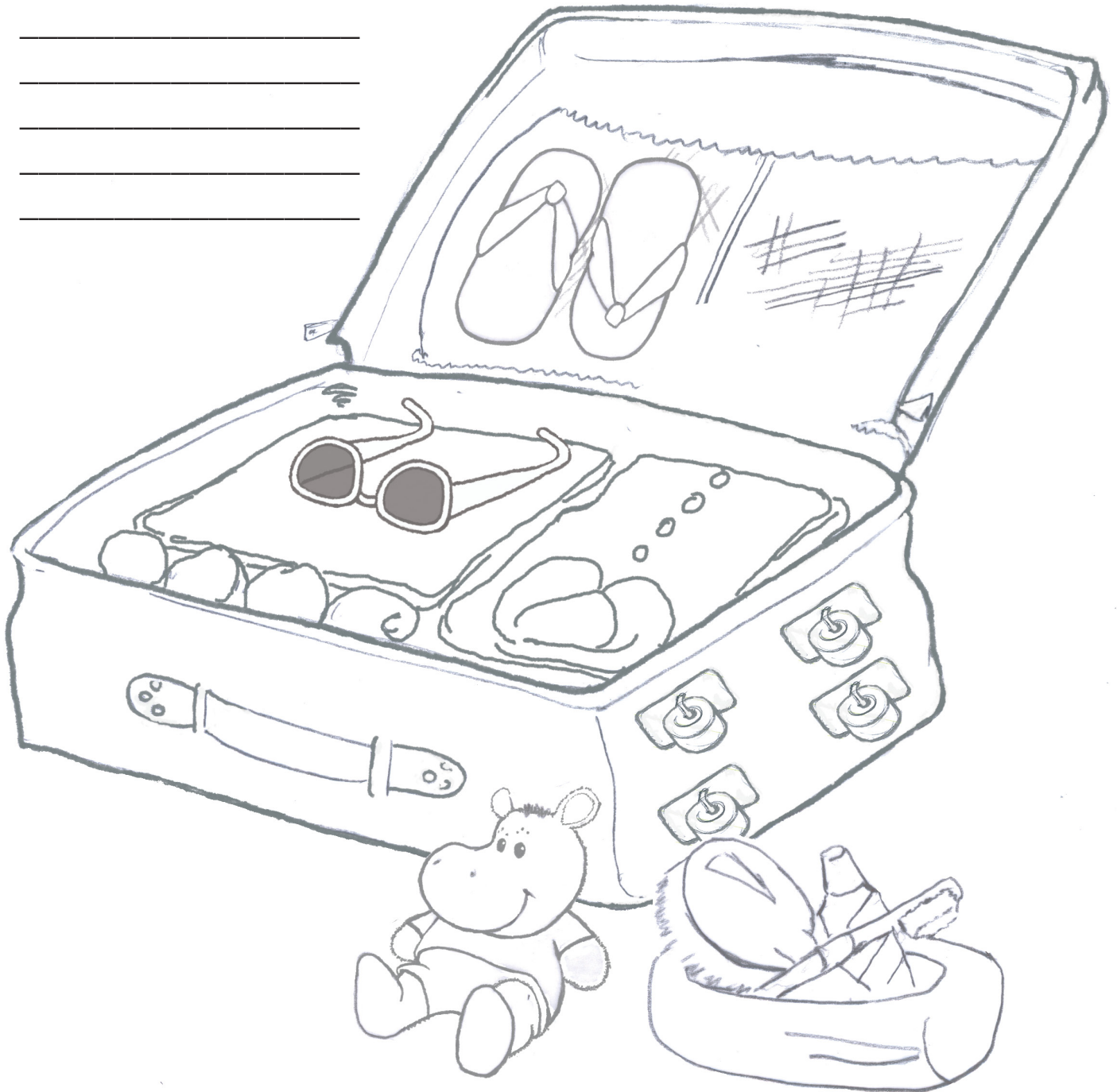
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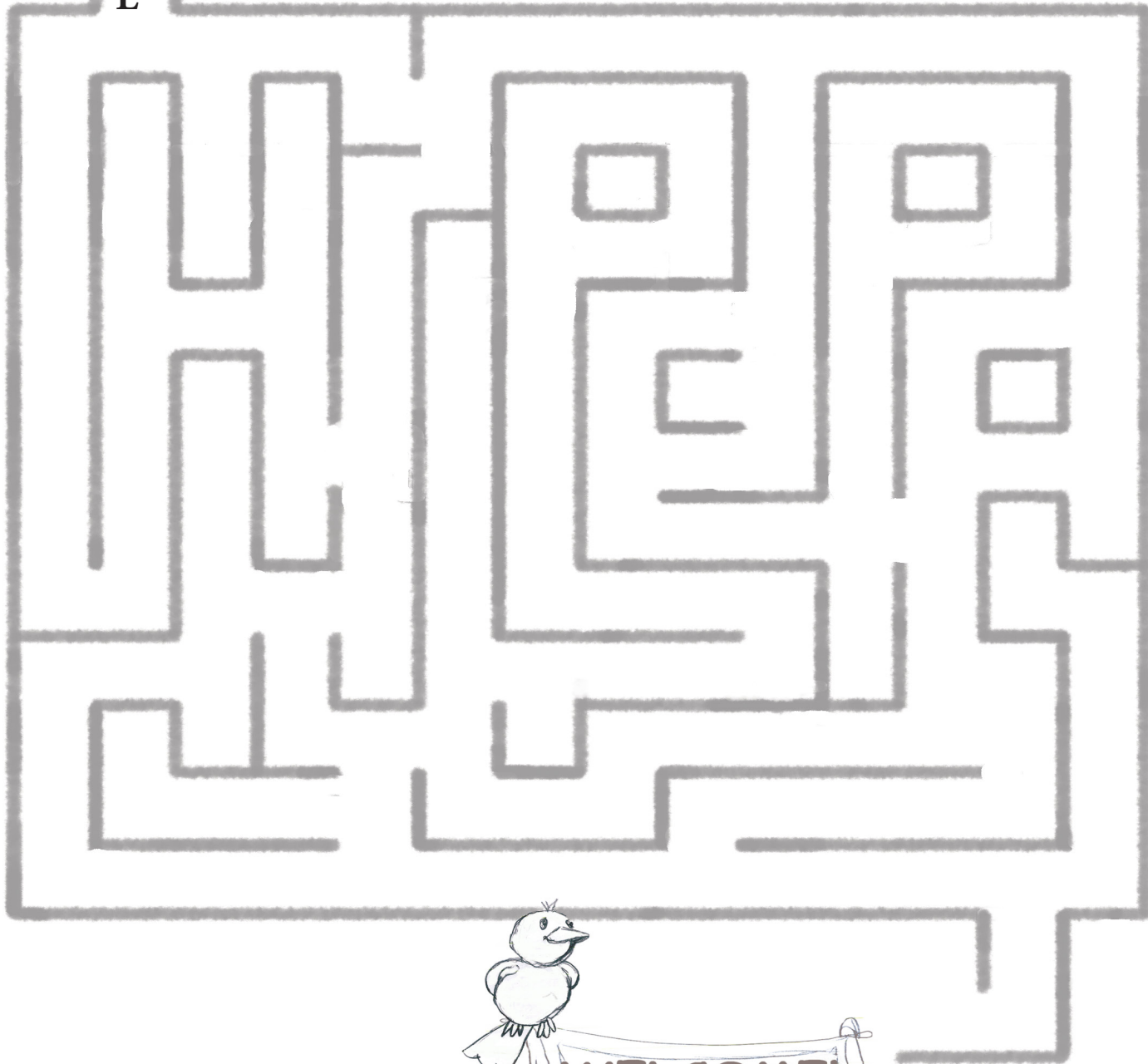


**START**

At home, I am the only person I know with HPP. But at the patient meeting, I learned that there are lots of other kids and even adults with HPP. It was AMAZING!

**H  
E  
R  
E**

Can you find how many ways there are to the patient meeting in the maze below?



Can you find the letters  
“HPP” in the maze above?



I also learned that there are different ways people with HPP might get around. Some were in wheelchairs some of the time like me, and others got around in other ways.

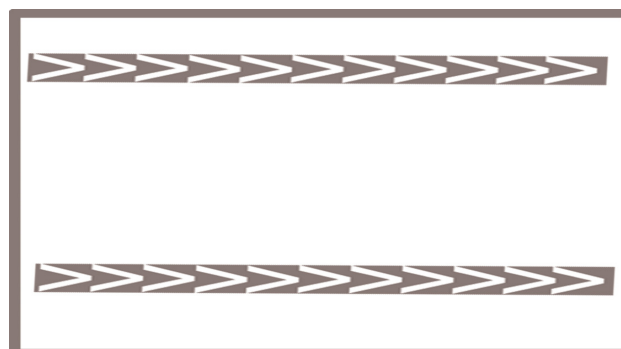
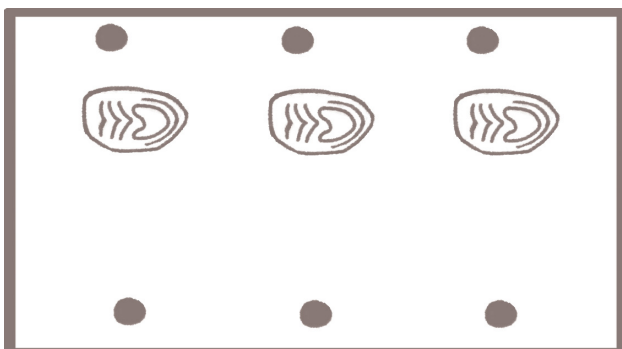
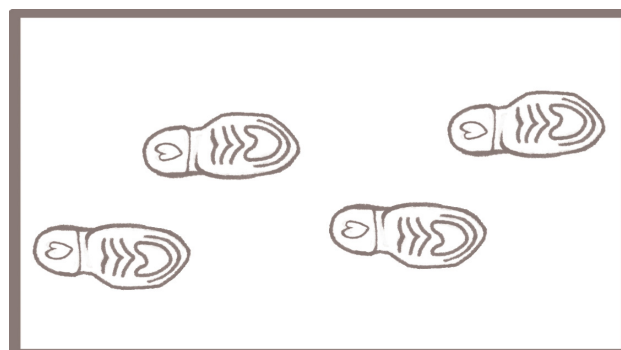
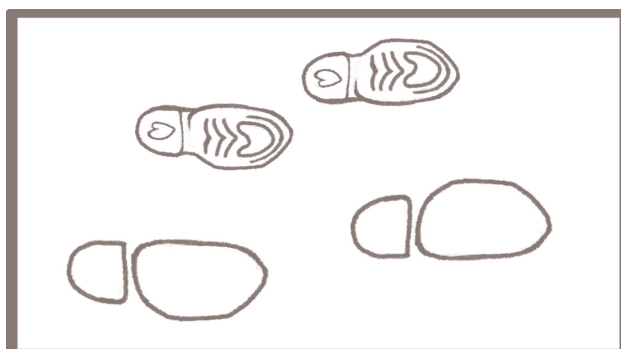
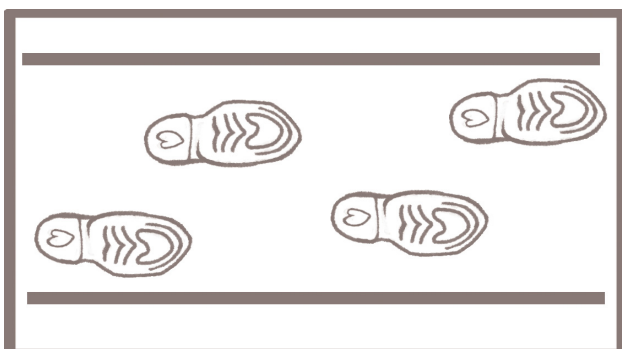
It didn't really matter how we got around because it was like we were all just one big family, and we all helped each other out. We had so much fun and made lasting friendships, too.

### You Be The Detective

Can you match the words with the pictures below?

**Walking alone    Walking with a helper    Wheelchairs**

**Crutches    Walker    Knee scooter**





I even made a special friend at the patient meeting. Her name is Pamela. She plays the guitar, but doesn't like to sing. So I sing while she plays guitar. We were even in a concert together, and we won a prize! Now we are pen pals and BFF's. We write each other as often as we can.

We understand each other in a special way because we both have HPP.



I have learned that when most people understand even just a little about HPP they may want to help. That makes me feel good. I just don't want anyone to feel sorry for me. If I had a choice, I would not have HPP. But since I don't have a choice, I am really okay with my HPP.

One Halloween, my neighbor Mary heard that I could not go out trick or treating because my ankles were too swollen. She went out with some other kids and took an extra bag just for me. Later, they came to my house and gave me a big bag of treats. Then Dad lit a jack-o'-lantern, and we all told ghost stories. We had a great time and we all agreed that this was one of the best Halloweens ever!



I can't go to most gym classes with HPP, but there are lots of things I can do. One thing I really like to do is help the teacher organize workbooks and papers during gym class. I am a good helper at school and at home.

I may have HPP, but there is so much more that makes me who I am.

**I am:**

**A swimmer**

**A reader**

**A writer**

**An artist**

**A singer**

**A star gazer**

**A helper**

**A good friend**

**A gamer**

**A musician**

You may want to list some things that make you who YOU are.

**I am a** \_\_\_\_\_

**I am a** \_\_\_\_\_

**I am a** \_\_\_\_\_

**I am a** \_\_\_\_\_

**I am a** \_\_\_\_\_

My name is Henrietta, and I have HPP. But that is not who I am!  
When I am with my family and my friends, I don't have to imagine I am  
a hippo or anyone else other than

**MYSELF!**



Hi again!

I hope you have enjoyed my journal.

You may write a journal about yourself on the following pages if you would like. Journaling is not about pictures or words being perfect. It is about showing how you are feeling on paper. There are no rules! So don't get too hung up on trying to make it look perfect.

You can just put a line like a frown



or

a line like a smile if you want.



It's just about you for you alone. Or to share if you want. Just have fun!

Your friend always,

Henrietta



# My Journal

Personal Property Of

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# My Journal

Date \_\_\_\_\_



# My Journal

Date \_\_\_\_\_

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My notes \_\_\_\_\_

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