

# VICTOR OVERCOMES HIS FEAR

A Hunter Syndrome Story





Hunter syndrome, also known as mucopolysaccharidosis II (MPS II), is a rare genetic disorder that primarily affects males and has widespread progressively worsening effects on various aspects of their health, including physical, cognitive, and overall well-being.

While our story may not encompass the experiences of all children with Hunter syndrome, we hope it serves as a means to illustrate some of the experiences they may face, as well as to educate and raise awareness of Hunter syndrome.

**This book is dedicated to all those out there whose lives have been touched by Hunter syndrome, be they patients, caregivers, or friends and family.**

**The support you provide each other is a constant inspiration.**

In a town called Sunnyside, where our big story begins, live Victor and Vanessa, a pair of siblings.

Victor and Vanessa go to school each day, Victor in a wheelchair that still lets him play.



Though sometimes they bicker, like all siblings do, Victor loves Vanessa and she loves him too.

Victor looks forward to seeing his friends at school, especially his best friend Noah, who is funny and cool.

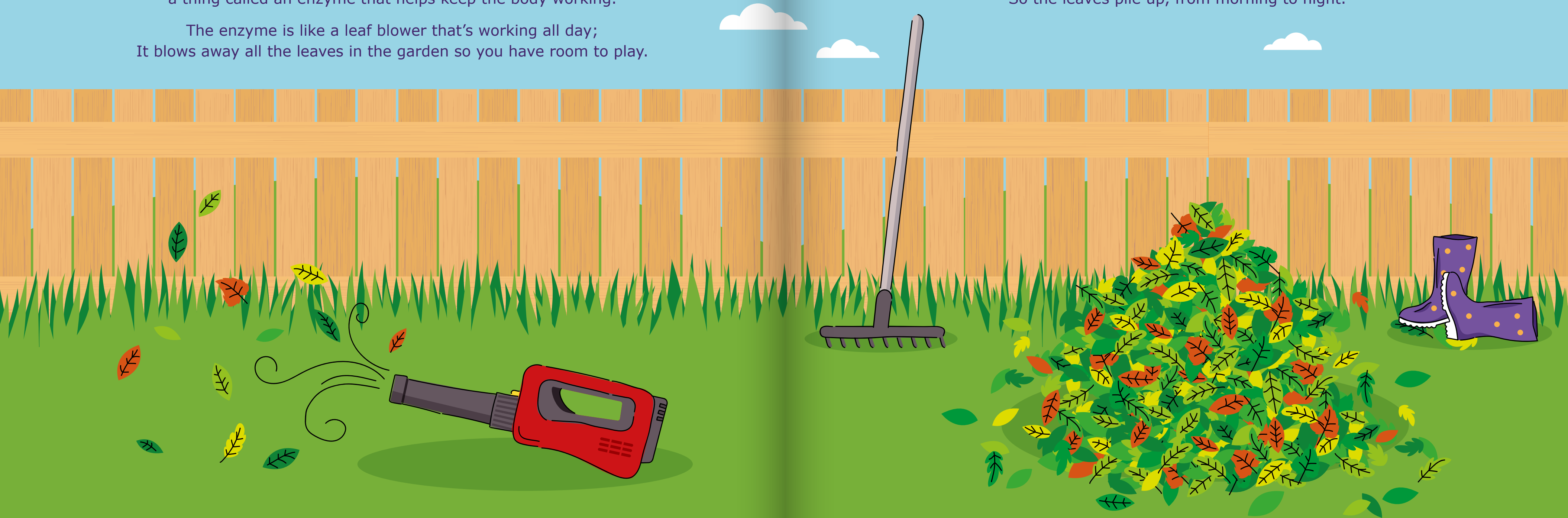
Victor also loves learning, most of all about space; yet sometimes at school he can feel out of place.



Victor is a boy who is bright, kind, and smart, and he has a condition called Hunter syndrome that sets him apart.

People with Hunter syndrome are missing something:  
a thing called an enzyme that helps keep the body working.

The enzyme is like a leaf blower that's working all day;  
It blows away all the leaves in the garden so you have room to play.



If someone has Hunter syndrome, it doesn't work quite right,  
So the leaves pile up, from morning to night.

Victor's mom takes him to appointments each week,  
where he sees his older friend Jackson who is caring and sweet.

Jackson is there because he has Hunter syndrome too;  
They chat and play games until their sessions are through.



Although they don't experience Hunter syndrome the exact same way,  
they feel united and strengthened by what they go through each day.

When he goes to the clinic, another of his favorite parts  
is seeing Nurse Nancy with her kind smile and heart.



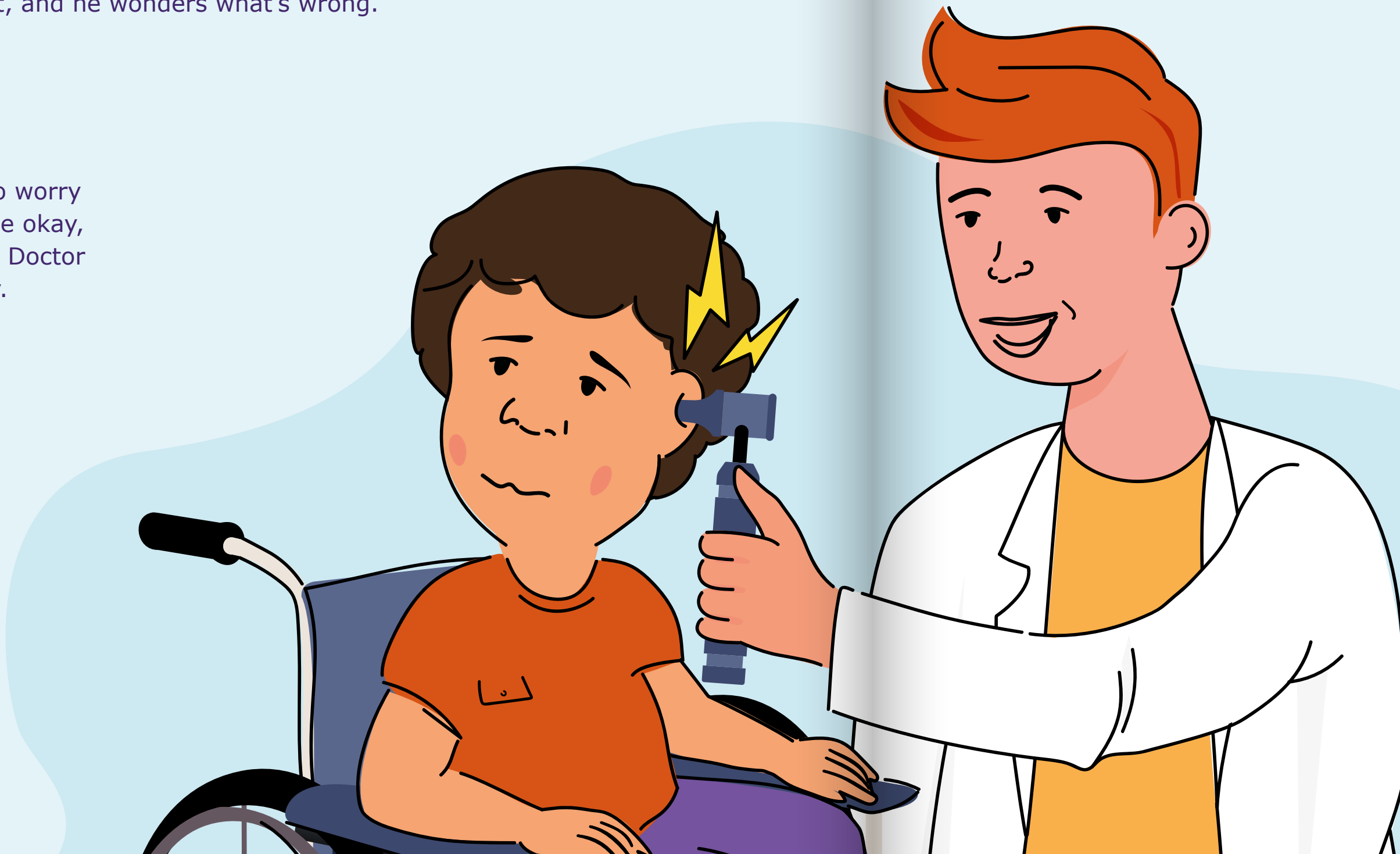
Seeing Doctor Dan is also lots of fun,  
especially the candy he gets when the appointment is done!



One day in Sunnyside, while he's just rolling along,  
Victor's ear begins to hurt, and he wonders what's wrong.

His parents tell him not to worry  
and that everything will be okay,  
but they should go to see Doctor  
Dan without further delay.

Doctor Dan looks  
carefully at Victor's ear  
and tells him he'll need  
surgery to help him  
hear clear.



He explains to Victor, with the kindest of smiles,  
that even though it's scary it will all be worthwhile.

"To feel much better, my  
little friend, you'll need to  
sleep through surgery from  
start to end."

"Through dreams and rest,  
your pain will mend, and  
you'll be back to causing  
mischief by next weekend!"

All of a sudden Victor feels scared,  
As he realizes that he feels unprepared!

Although he's had surgery,  
He's never had to sleep through it!  
How would he find the courage to do it?

At his next appointment, Jackson sees his friend's frown.  
Something is wrong, he can tell his friend is feeling down.

Then Jackson shares his own story, in a calming tone.  
"Everything will be alright, and you won't be alone."

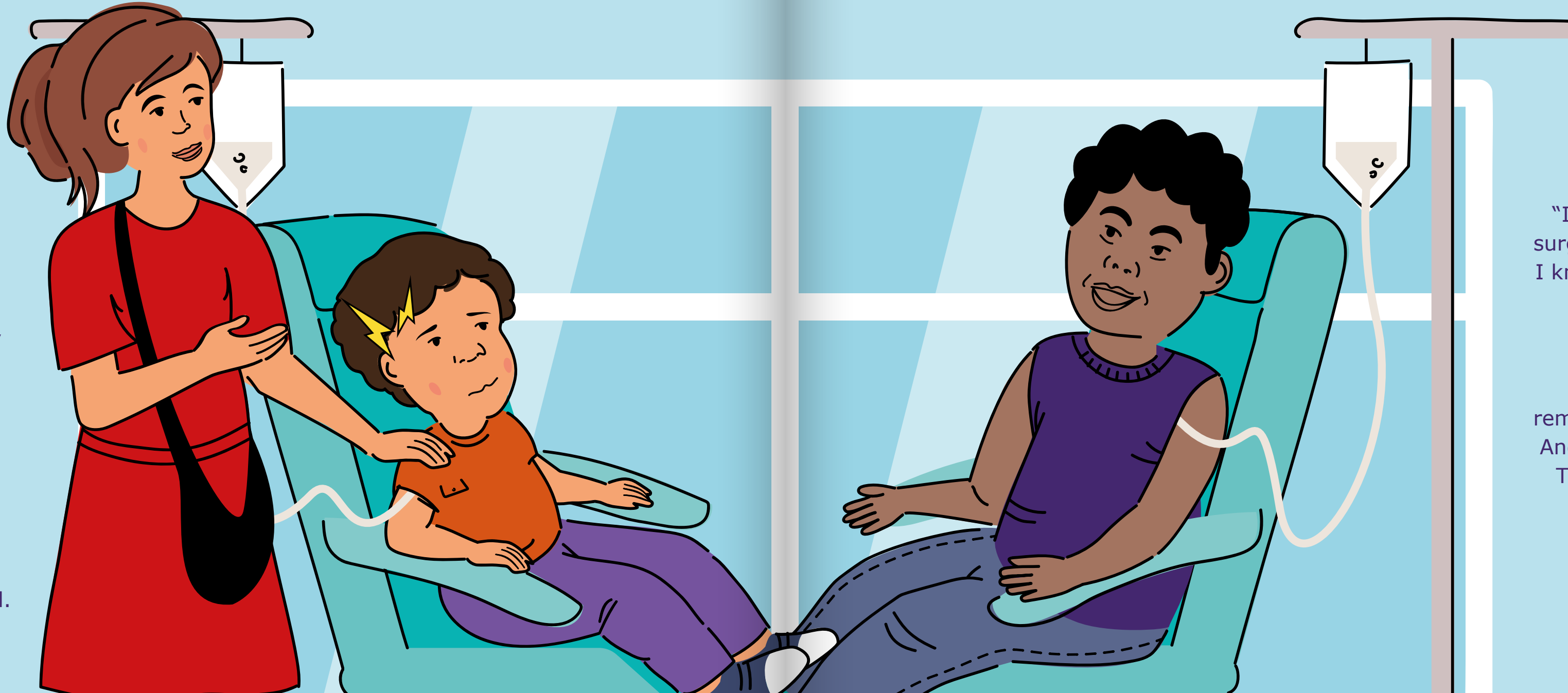
"What's wrong?"  
Jackson asks, with  
a voice full of worry.

Victor's mom  
explains calmly,  
without any hurry.

"Victor will need surgery  
to fix his painful ear.  
But the idea of sleeping  
through it has brought  
him lots of fear."

All of a sudden, Victor  
shouts, "I'm scared!"

So he can tell his friend  
that he feels unprepared.



"I've had to sleep through  
surgery in the past too, and  
I know the doctors will take  
good care of you."

"The doctors had to  
remove a lump on my belly,  
And although I was scared,  
They were all so friendly."

"The doctors will give you medicine, and it will help you to doze.  
It's called anesthesia, it will relax you from your head to your toes."

"Through a tiny tube  
or mask, they'll deliver  
it just right."

"You will fall asleep  
gently, just like any  
normal night."



"While you rest, they'll  
watch over you with care,  
and make sure all goes  
well with your repair."

"As you awaken slowly,  
you might feel a bit dazed.  
But there's no need to worry  
as this will quickly fade."

After this chat, Victor feels  
calm and collected, his  
friend's words in his head  
making him feel strong  
and protected.



On the day of the surgery, the staff are extra kind,  
which puts his mind at ease, and helps him unwind.



He heads into surgery with his head held high,  
gives his parents a big hug and then waves them goodbye.

The doctors prepare the  
medicine to help Victor sleep,  
which will let him settle  
into a slumber so deep.



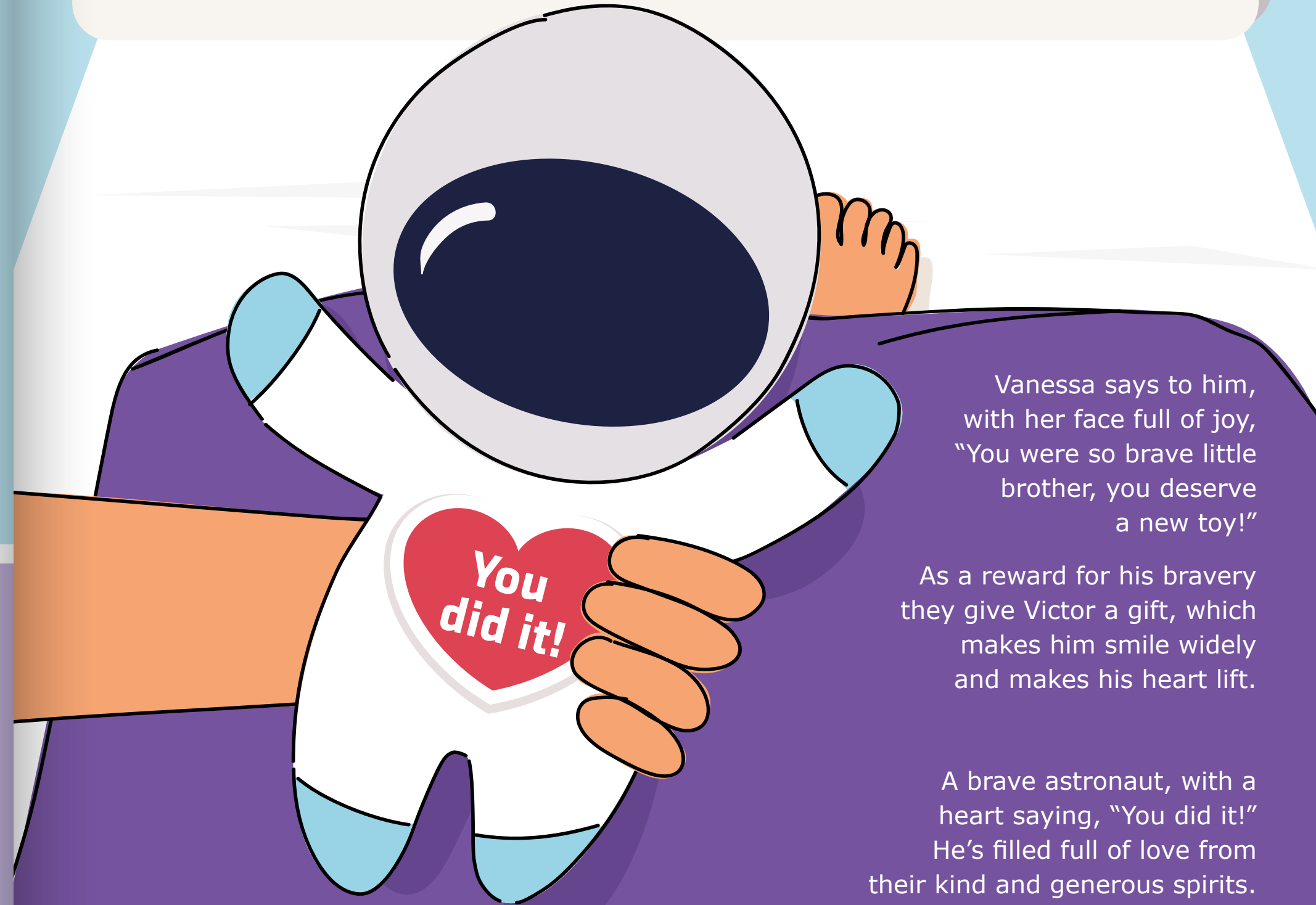
He begins to feel  
oh so tired and so slow,  
and before he knows it  
the dreams freely flow.

When his surgery is over and he begins to stir, Victor opens his eyes and by his side he sees her.

His sister Vanessa, with Jackson, and Noah!



They've all been there waiting for his eyes to open.



Vanessa says to him, with her face full of joy, "You were so brave little brother, you deserve a new toy!"

As a reward for his bravery they give Victor a gift, which makes him smile widely and makes his heart lift.

A brave astronaut, with a heart saying, "You did it!" He's filled full of love from their kind and generous spirits.

Victor is suddenly filled with an overwhelming pride,  
with his family and friends all there by his side.



Knowing he overcame  
what made him so scared,  
he felt ever so grateful for  
what his friend shared.

# Section for Grown-ups

We hope that you enjoyed reading this story with your loved one who is living with Hunter syndrome. We know that caregivers can have a lot to juggle, so spending quality time with your child to read a book together is a special time.

This story can also be used to spark conversations with your child—for example, exploring their feelings about their condition or thinking about ways to help them better understand it.



## SOME DISCUSSION POINTS YOU MIGHT LIKE TO CONSIDER:

- ☐ What was your favorite part of the story?
- ☐ How did it make you feel when Victor was worried about surgery?
- ☐ Is there anything you find scary about going to hospitals or appointments?
- ☐ Who are the people you'd want to be there for you when you're down?
- ☐ What would you do if you felt an unexpected pain like Victor does in the story?
- ☐ What are some things you do that make you feel brave?







Click [here](#) for more resources about Hunter syndrome.





Follow the stories of Victor and Jackson,  
As they learn new ways to cope on their Hunter syndrome journeys.



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