Hunter Syndrome Stories

Hunter Syndrome Stories



This book is dedicated to people living with Hunter syndrome and their caregivers

Everyone is different...



This is Isaiah, he has curly brown hair and stickers on his chair. This is Diego, he has a round belly and likes wearing cool clothes.





This is Hannah, she wears green glasses and has red hair.



...for many different reasons! 4

...and this is Max, he wears a hearing aid and a big smile!

Isaiah, Diego and Max all have Hunter syndrome.

Isaiah





Max

Everyone with Hunter syndrome is special and unique, just like you!

People with Hunter syndrome are missing something in their body called an enzyme.

The enzyme is like a garbage truck.

In most people, the garbage truck comes by and takes away the trash. But for people with Hunter syndrome, the garbage truck does not come, so the trash builds up.

Some children with Hunter syndrome take medicines for their condition.

Isaiah goes to the hospital every week for his medicines.

At the hospital, he is taken care of by Doctor Henry.

Isaiah was scared at first, but Doctor Henry was very kind.

Isaiah's mom plays his favorite music quietly and tells him a story. He gets lots of cuddles! Max is also given his medicines at the hospital. This takes a while, so Max spends his time playing and drawing!

Max is very brave! He's also brought his favorite toy with him.

Ra)



This is Doctor Ana. She is very friendly.

Diego is given his medicines at home. He doesn't like sitting still, but he does look forward to giving his dog, Spot, a big hug afterwards!

Nurse Tanya keeps Diego company and makes sure he is comfortable. They talk about all sorts of fun things! Having Hunter syndrome might mean that you're not able to do some of the things that your friends can...





... but it also means that you meet lots ... Nurse Tanya... of nice people like Doctor Henry...

... Doctor Ana...



... and all of their friends too!

Caregiver Tips

Page 4/5

This page provides an opportunity to explain to your child how people are different. Can you spot any other differences between children?

Page 6/7

You may like to discuss how your child is special and unique, and perhaps how other people in your family are too?

Page 8/9

Can you think of any other examples like the garbage truck?

Page 10/11

This could be an opportunity to discuss Hunter syndrome and what it means to the child you are caring for.









Page 12/13

What is your child's favorite song? Playing music can help calm your child while he is receiving treatment.

Page 14/15

What is your child's favorite toy? Bringing this with him to the hospital may make the experience easier for him.

Page 16/17

You may wish to use this page to talk about what he would like to do after receiving his treatment, and to talk about how it may make your child feel.

Page 22

Turn the page for a mini game!









Spot has been hiding toys in the garden. Can you find them all? How many apples can you see in the tree?

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