

# BARTH SYNDROME



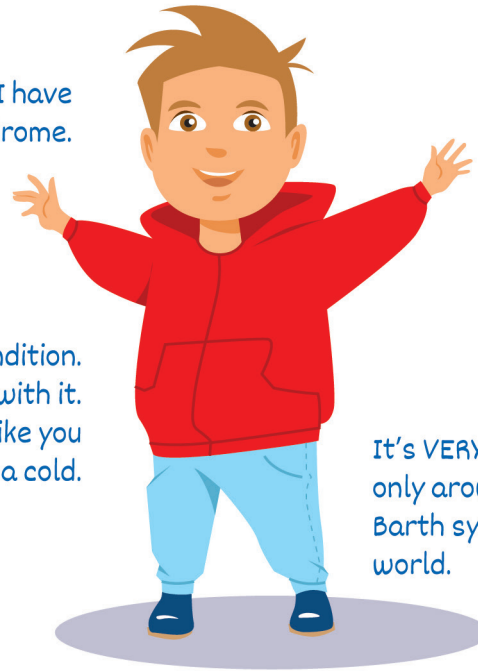
A little book for children

Florence Mannes / Zoé illustratrice

## Barth syndrome ? What's THAT ?

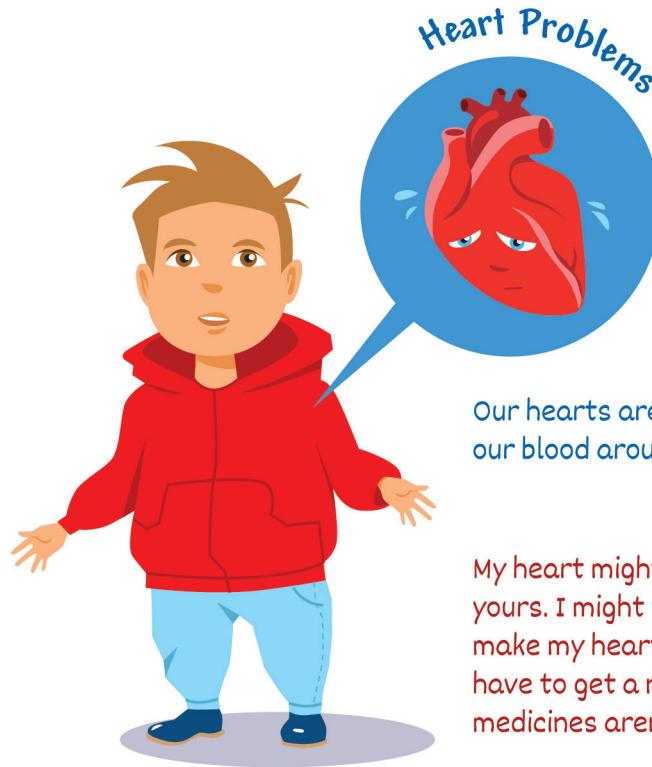
My name is Sam and I have  
Barth syndrome.

It 's a GENETIC condition.  
That means I was born with it.  
You can't catch Barth syndrome like you  
might catch a cold.



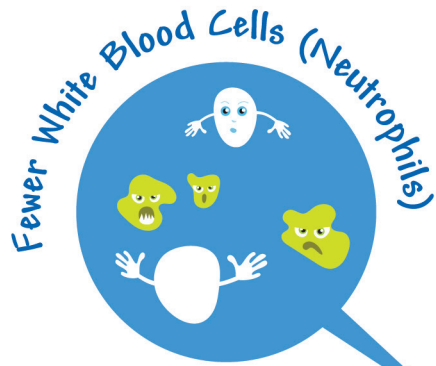
It's VERY rare and there are  
only around 200 of us with  
Barth syndrome in the whole  
world.

What does it do ?



Our hearts are pumps that move our blood around our body.

My heart might not pump as well as yours. I might take medicines to make my heart work better. I might have to get a new heart if the medicines aren't enough to help me.



WHITE BLOOD CELLS are in your blood and they fight germs and infections.

I SOMETIMES HAVE A LOT LESS OF THESE BLOOD CELLS THAN YOU DO. I might take medicines or have injections to help my body make more white blood cells. I can get sick quickly and might miss school. I'd prefer to be with my friends though!





## GETTING SICK

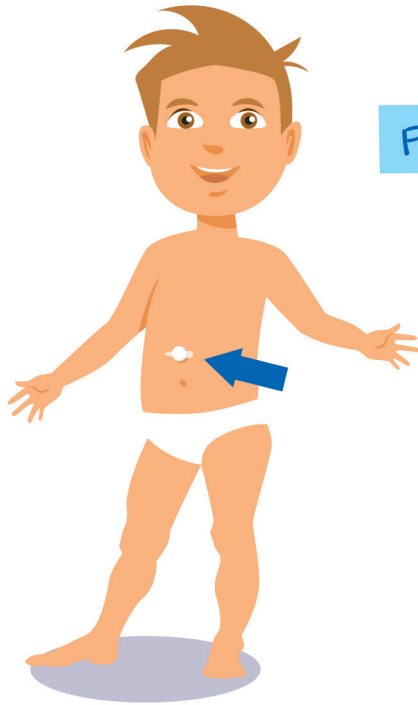
A tummy bug or a cough or cold isn't fun for anyone. But if I catch one I might have to go to hospital for a few days.

If a lot of people are sick at school, I might have to stay home or wear a mask at school to keep me safe. My friends who are sick often stay away from me until they are better so that I can stay healthy.

## Feeding troubles



I might need to have lots of snacks to help my energy. I might take a long time to eat or I might not eat very much because my chewing muscles get tired.

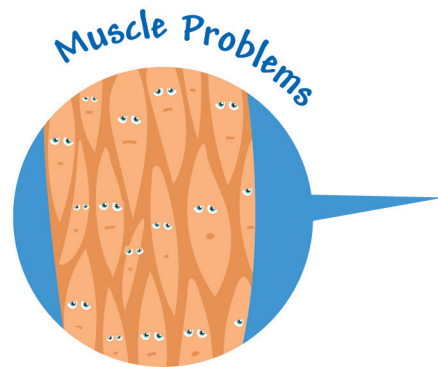


## FEEDING TUBE



You have to eat a lot to make your body grow and work properly. Sometimes it can be hard to eat enough when you're tired so some of us with Barth syndrome have a tube in our nose that goes down to our tummy or a special button on our tummy.

A special milkshake can be put through these to fill us up. It doesn't hurt at all!



Sometimes my muscles get tired and I need  
a little rest. I might not run as fast as you  
but I still love to join in games.  
If I have to walk far, I might need a wheelchair  
or buggy so that I can save my energy  
for when we get there!







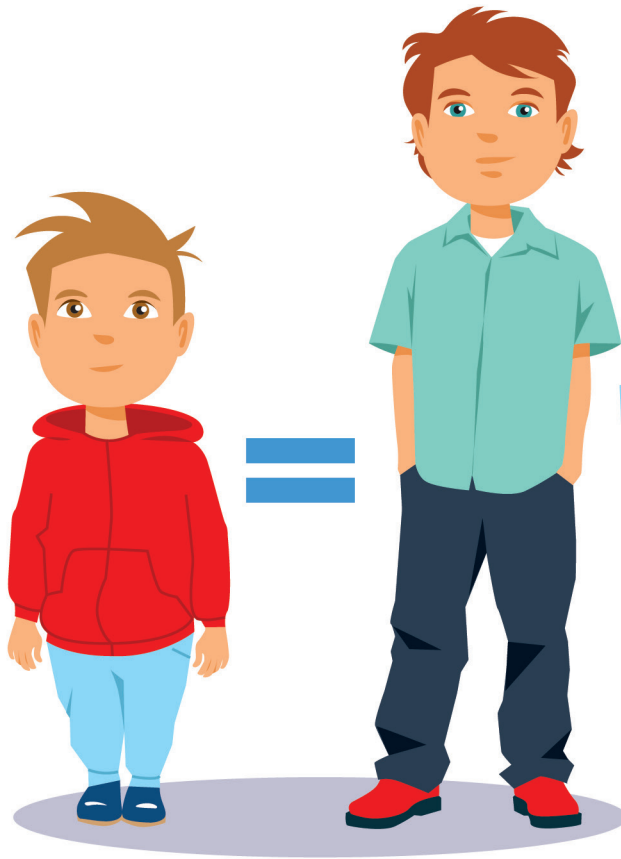
## DAY TO DAY LIFE

Easy things like walking, running, jumping, writing or carrying my book bag can sometimes be VERY difficult for me. I might need to rest every now and then. I might even have a grown up who helps me at school.



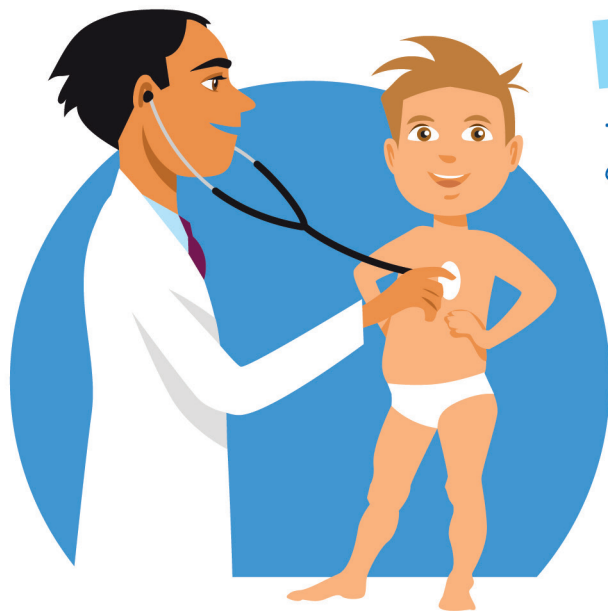
## PLAYTIME AND SPORT

I love to play and run around and play sport with my friends. I might just need a break now and then; I need to be careful not to do too much or I might run out of energy for the rest of the week!



## BEING SMALLER

I grow slower than you do and I might LOOK younger than you but I'm the same age as you are! When I'm a grown-up, I'll probably be the same size as you since I'll do all my growing when I'm older.



## HOSPITAL VISITS

To make sure I stay healthy, I visit the doctors at the hospital quite often.

I might see:

A Cardiologist (a heart doctor)

A Haematologist (blood doctor)

An Endocrinologist (to check my growth)

A Dietician (to help me with eating)

A Physiotherapist (to help with my muscles)

An Occupational Therapist (to help me do the things I want to do like getting around by myself)

I sometimes have to have my blood taken or have injections.  
I might need special shoes or a wheelchair to help me get around.



HOW CAN YOU HELP ME?



Please don't tease me; it makes me feel very sad.



## HELP

I find climbing stairs or carrying a heavy book bag very hard...

So if you're around and you can help me that would be great!



## ILLNESS

When I get sick, it takes me a LOT longer to get better. So, if you stay home when you're sick, that would stop everyone else in the class getting sick too.

If you're only a little sick and are coming to school, please tell my parents or your teacher so that we can keep apart just for a while!



## PLAYING

I can't always join in some games that are too tiring or that involve a lot of running but...

If we tweak the rules a little, we can have a lot of fun together!

Some of the games we could play are:

- What's the time Mr Wolf?
- Card games: Snap, Black sheep, Go fish
- Simon says
- Duck, duck, goose
- Come a little closer
- Marbles
- Marco Polo
- Chinese Whispers



Notes

Notes

## BARTH SYNDROME

Barth syndrome families from around the world are all working TOGETHER to help families and to help doctors find a treatment and a cure.

I hope this booklet helps you understand better what my life is like. See you soon!

You can find lots of information on our websites.

[www.barthsyndrome.org](http://www.barthsyndrome.org)

[www.barthsyndrome.org.uk](http://www.barthsyndrome.org.uk)

[www.barthsyndrome.ca](http://www.barthsyndrome.ca)

[www.syndromedebarth.fr](http://www.syndromedebarth.fr)

[www.barthitalia.org](http://www.barthitalia.org)

Barth Syndrome Foundation (USA)

Barth Syndrome Trust (UK)

Barth Syndrome Foundation of Canada

Association Syndrome de Barth France

Barth Italia Onlus

