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?

Heart Problems

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!
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.
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.
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?

BE KIND

Please don’t tease me; it makes me feel very sad.
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!
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
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.barthsindrome.org  Barth Syndrome Foundation (USA)
www.barthsindrome.org.uk  Barth Syndrome Trust (UK)
www.barthsindrome.ca  Barth Syndrome Foundation of Canada
www.syndromedebarth.fr  Association Syndrome de Barth France
www.barthitalia.org  Barth Italia Onlus