

# PAUL AND POMPE DISEASE



Pompe disease is a rare genetic disorder which can cause a range of health issues. The most common symptom is muscle weakness which deteriorates with time if the disease is left untreated.

This brochure explains in simple terms the cause of Pompe disease and which symptoms may arise at a young age.



# PAUL AND POMPE DISEASE

Hi, my name is PAUL and I am 8 years old!

I live on a farm with my parents  
and little brother, PETER.

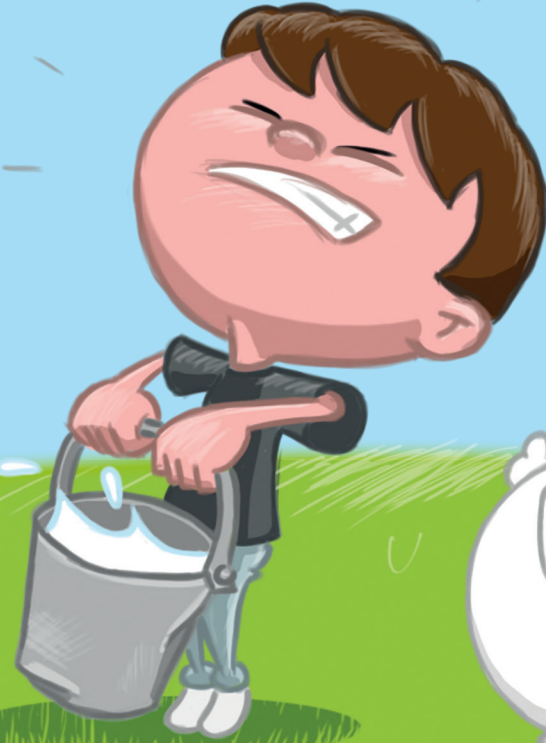
WE HAVE LOTS OF COWS,  
CHICKENS AND OTHER ANIMALS



During the summer holidays,  
I like to help my mum and dad with  
taking care of the animals.

I sometimes find it hard to carry heavy  
things because my arms  
DON'T FEEL STRONG ENOUGH.

MY MUM SAYS THAT'S  
BECAUSE I'M STILL VERY YOUNG





Just two more weeks and I'll be going back  
to **SCHOOL!**

I'm going to be in year 4 this year which  
means that I will be one of the big kids at  
school now.



But for now, I get to play in the HAYLOFT  
with my little brother, Peter.

Except I have trouble  
climbing the ladder

BECAUSE IT'S SO TIRING



My legs also feel so TIRED

when I take the cows out to the fields.

SO MY DAD HAS TO CARRY ME  
THE REST OF THE WAY



I feel so weak and tire so quickly that my parents are starting to worry about me. So we went to visit the doctor in the village.

We spoke to the doctor and he did a couple of tests.



He said that I was probably run down from helping at the farm all day.

I just needed to slow down a little and get some rest and I would be fine.

But, when I was back home  
I tripped over a stone while I was gathering eggs.

I had TROUBLE GETTING BACK UP

and I had to support my hands on my legs  
to be able to stand up again.

My dad came running to help me.

ALL THE EGGS WERE BROKEN,  
and I was really upset.



School's started again  
but I'm too tired to go  
to school all day.



I HAVE TO STAY AT HOME NOW

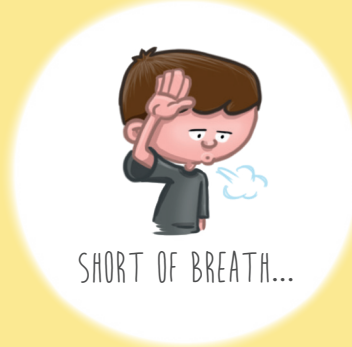


My parents don't believe that  
I'm just worn out and  
my mum went and  
looked on the internet to see  
what else it could be.

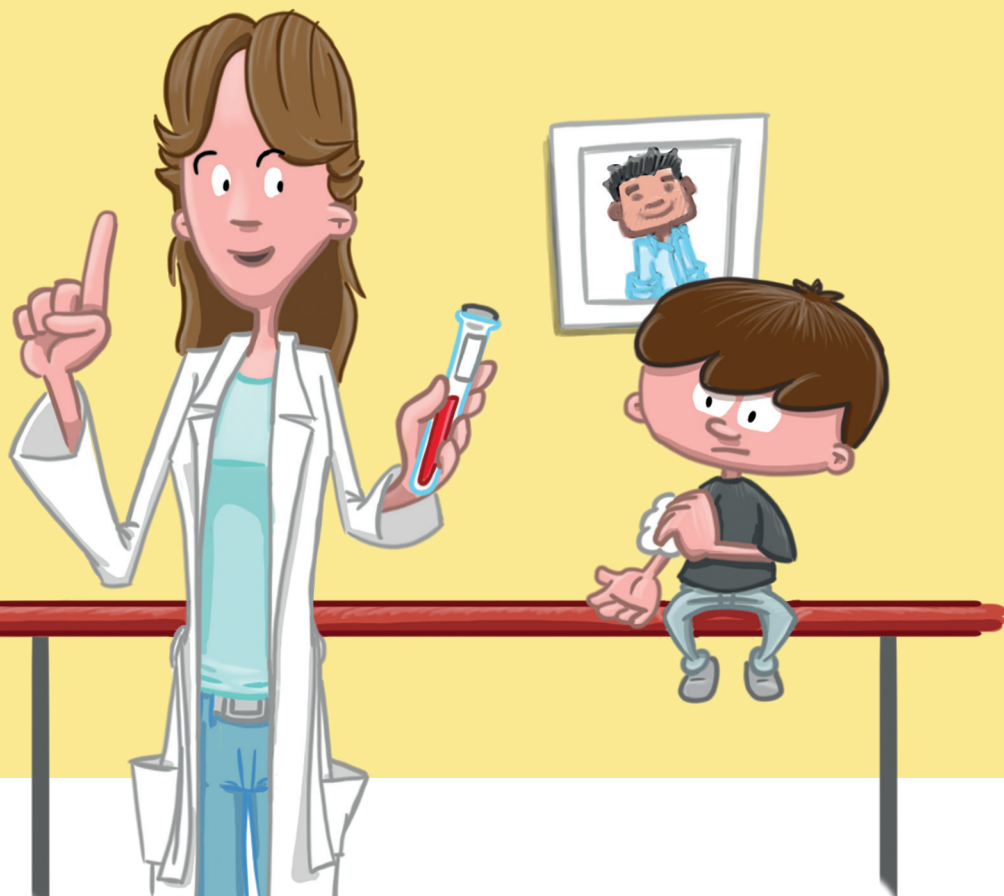
We called the doctor again  
and we made an appointment  
with the paediatrician –  
that's a long word for a doctor  
who treats children.



When we saw the doctor at the hospital,  
I told her all the things I had been having trouble with:



The paediatrician also saw that  
MY SPINE WAS BENT



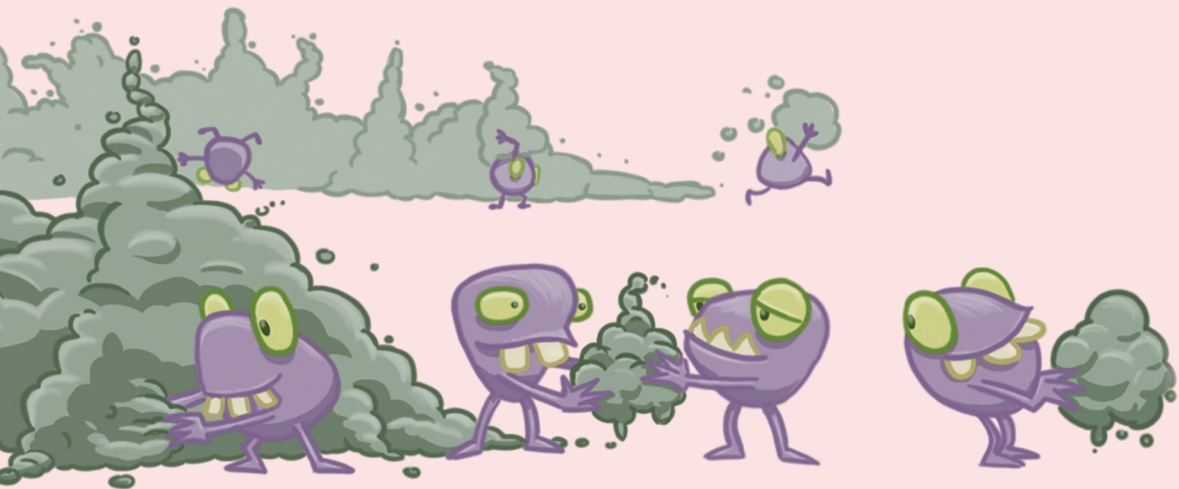
She said that she thought she knew  
what the problem was.

THE DOCTOR CALLED US AS SOON  
AS SHE HAD THE RESULTS

We went back to the hospital  
for the results.

The doctor told us  
that I had **POMPE DISEASE** and  
explained to us what this disease is.





My body is just like my room:

WHEN IT GETS MESSY,  
IT NEEDS TO BE CLEANED



The problem is that my body  
doesn't have enough 'CLEANERS' so  
the 'MESS' piles up and causes all the  
problems I've been having.

Some people even have so few 'CLEANERS' that they have trouble with this disease when they're only a baby.



The doctor said to me:

'You will need to come to the hospital regularly for check ups. By visiting us, it means we can help you to

**MANAGE THE DISEASE.'**

There are other children with this disease who are also being treated in this hospital.





When we got back home,  
my parents were relieved  
that the doctors knew  
what was wrong and were

ABLE TO SUPPORT ME

