



mps children's newsletter

Welcome!

Welcome to the first edition
of the MPS Children's Newsletter!

This is a Newsletter for children that are
affected by MPS and their brothers and sisters and
will be sent out alongside our main MPS Magazine
every Spring, Summer, Autumn and Winter.

We really want to hear all about you...

Do you or your brother or sister have MPS?
Tell us about them and your friends and let us know
why they are so special to you.

Do you have any stories, poems or drawings that you would like to send in to us?

Tell us all about your school and any after school clubs you're involved with.

We also want to hear about what you would like to see in the MPS Children's Newsletter
so ask your mum or dad if you can get in touch with us and let us know your ideas!
You can contact us at: newsletter@mpssociety.co.uk. Don't forget to ask permission first!

We hope that you like our new idea and look forward to hearing from you soon.



what's inside...

Zain's story - Zain's sister Ana has Sanfilippo. Zain writes about his family

What I did for my cousin - Elizabeth tells us about what she did at school to let everyone know about MPS

Living with Morquio - Josefine has Morquio and lives in Norway

Zain's story



Zain (aged 7), Ana (aged 5 who has Sanfilippo) and Haris (aged 6 months)

My Name is Zain. I am seven years old and I go to Burlington Junior School.

It is the best school ever! When I am at school I play "Thomas and Friends" with my friends Anjevan and Thavinan. They are both eight years old.

Sometimes we make up trains and their names and sometimes we just pretend to be like real steam or diesel engines.

Anjevan sits in front of me on my table and Thavinan is on the table behind me.

I have one after school club where I play chess. I really like Chess club because it is very exciting and fun. My favourite things are playing with my best friends and my toy train.

I have a younger brother who is called Haris and a younger sister who is called Ana.

My sister Ana is five years old and is special needs. She is hyperactive, determined and is a bit of a copycat. She broke my electric train! She also gets excited when we go on family walks.

Ana likes to watch television and dancing to some music. She loves to eat biscuits and we both like to eat pizza and chips together on Fridays.

Ana also likes playing with a ball in the park and bouncing on the bed. Ana goes to a special needs school and we help her by using sign language.

In the Easter Holidays I went to Shooting Stars House on a siblings day. Ana thought that she was going and got all excited. When she found out that it was just me that was going she started crying! But she got to go the next day.

Before my brother Haris was born, when we used to visit our family, we would stay in a hotel. I really like going there and so does Ana. I like having breakfast there and my mum likes watching the weather while we eat our Rice Crispies. My Dad normally has his breakfast first and brings back Ana's Coco Pops. Me and my mum go up next. Since Haris has been born we don't stay there but we did stay at my Granddad and Grandma's house.

When I grow up I want to be a train driver. If Ana could talk I think she would say that she would like to be a doctor because she is always playing with a stethoscope.

Written by Zain Adam Aged 7 who's little sister Ana is 5 years old and has MPS IIIB, Sanfilippo



Tell us all about it! The MPS Society's Sibling Breaks

The MPS Society organises Sibling breaks for children who have a brother or sister with an MPS or related disease. If you have been on one of our MPS Sibling breaks why not write in & tell us all about it & you could have your story in the next MPS Children's Newsletter!

What i did for my cousin

I was four years old when my cousin Hannah was born. Before she was 2 years old we were told that she had Mucopolysaccharide disease. My Uncle & Auntie (Hannah's mum & dad) were told about the MPS Society & we got in touch with them so that we could find out more about the condition.

Mucopolysaccharide is a long word to read & to say but I practiced saying it so I could tell my friends & teachers all about it. Each time the MPS magazine arrives I enjoy reading it & seeing how people raise money & I decided I wanted to raise money myself.

I started to plan a PowerPoint Presentation & used information I found from the MPS website & magazine. I made lots of PowerPoint Presentations & pretended that I was going to show them in an assembly at school but this was just a game as I knew I would be too nervous to get up & say anything! Then I had an idea of how I could raise some money. Every term at my school we have a "Wear What You Want Day" when everyone pays £1 to wear their favourite clothes instead of school uniform.

First of all I spoke to the Deputy Head, Mrs. Williams & asked her if we could have a "Wear What You Want Day" for MPS. She knew all about MPS as she'd taught me & I'd told her lots about Hannah. I spoke to my best mate who is on the school council & they agreed we could fundraise for MPS! I was really pleased but very worried as Mrs. Williams asked if I'd talk about MPS in assembly! I copied my PowerPoint on to a memory stick & gave it to Mrs. Williams. I was SO NERVOUS & felt really scared & I really wanted Mrs. Williams to read it for me but when the day came she was on a school trip!

If you would like to do something at your school to tell your friends and teachers about MPS, please ask your parents or teacher to get in touch with us.

We can send you a
School Fundraising Pack
to get you started!
Email fundraising@mpssociety.co.uk



Elizabeth with her cousin,
Hannah, who has MPS

My friends kept telling me I would be ok & after I had done the assembly they kept hugging me. I felt really pleased that I'd managed to tell everyone about Hannah & MPS because I love her so much & wanted everyone to see that even though she has MPS she's still a great cousin & I love spending time with her & her little brother Ben.

When we had the 'Wear what you Want' day we raised over £140 for the MPS society! It's great when Hannah comes to stay & shares my room as we love playing.

Written by Elizabeth Cartright

In the next edition:

More of your stories and photos
Information and resources for siblings
Sources of support

What else would you like to see
in these pages?

Email us at newsletter@mpssociety.co.uk
with your ideas

Living with morquio

My name is Josefine and I live in Norway. I have four siblings & I have Morquio syndrome. I like spending time with my friends, listening to music, playing sports & computer games, going to the cinema, different types of art and craft & cheerleading & I really like to go downhill skiing with friends & family. I have skis & I am quite good at it. Last winter my father & I almost had an accident when we flew three metres up in the air before landing with a big bang in the ski hill. We use helmets.

When I was little & went to kindergarten I stumbled & fell a lot. My carer talked to my parents & they took me to a doctor at the hospital. It took about two years before I was diagnosed with Morquio because the Norwegian doctors were not quite sure what was wrong with me. When I met Dr. Ed Wraith from Manchester when I was five years old he confirmed that I have Morquio. I do not have the most severe form of the disease, but I have already had surgery on my hips. Sometimes I have pain in my wrists & in my legs, especially if I have been very physically active during the day.

The bad things about having Morquio are that I can't jump on our trampoline & do gymnastics as my siblings do and sometimes people treat me as if I am six or seven years old because I have short stature. I also often get a bit angry & sad because I move much more slowly than my friends.

I enjoy school & have a lot of good friends. The subjects I like the best are mathematics, gymnastics, cooking & health, craft & English. The name of my gymnastics teacher is Harriet. She is a very good teacher. She has borrowed five wheelchairs so all the pupils in my class can learn how to use them. When we have races I always win. Another person who means a lot to me is Bodil. She is my physiotherapist. She has known me since I was little & she supports me when I need it.



would you like to be a penpal?

This article by Josefine first appeared in our Winter 2009 MPS Magazine. Aaryanna, who lives in Northern Ireland has MPS I Hurler Scheie, and loves reading the MPS magazine. She saw Josefine's story and felt an amazing connection with what Josefine had written about living with MPS. Josefine was looking for a pen pal in the UK and attached her email address.

Within seconds of reading her story, Aaryanna was on her computer in order to invite Josefine to be her pen pal. Two days later she received the email response she was desperately awaiting. Josefine was delighted to have received an email from Aaryanna and is very happy to have someone she can chat to who, like her, has lifelong membership of the really rare club - MPS.

Aaryanna has asked her Mum to say a huge 'Thankyou' for printing the article on Josefine.

If you would like a pen pal, please write us a short story about yourself and include your email address. We will then print it so that others can read your story. *Please do ask permission from your parents first!*