



Volunteer newsletter

Society for Mucopolysaccharide Diseases

www.mppsociety.org.uk

Welcome to the first MPS Society volunteer newsletter which is dedicated to all our wonderful volunteers who make a difference to the lives of those affected by MPS and related diseases.

We couldn't function without volunteers, whether it's packing envelopes or looking after children at our meetings and conferences, you are vital. Thanks to the support of volunteers we have increased awareness of MPS and related diseases, been able to fund research and supported individuals and families affected by these diseases through information days, outings and conferences.



But don't take our word for it. Here is what some of the families have said about our volunteers in the past:

“I would like to specially thank the volunteers for their time entertaining Zoha at the crèche. Without their support I don't think either of us would have been able to attend and gain as much as we learnt from this meeting.”

“I think it was Veronica and Helen who kept them busy and safe. Please pass on our thanks to them. The boys liked them both – probably because they let them loose on the pick & mix!”

So what's in it for you?

The benefits for us are obvious – helping us to provide support to individuals and families in need is invaluable – but what's in it for the volunteers?

Apart from being fun and rewarding, altruistic activities can give a sense of purpose and meaning in your life. It can help with an individual's ability to cope with mental illness and self-esteem.

Volunteering is also an opportunity to learn new skills and perfect ones you already have leading to better work prospects.

It also helps your community generally by enabling social change and breaking down barriers by providing the opportunity to socialise with people from different backgrounds.

About MPS

Mucopolysaccharide disease (MPS) and related Lysosomal Storage Diseases (LSDs) are caused by a faulty gene which prevents the correct production of an enzyme responsible for the break down and recycling of materials in the cells. This leads to storage of materials in almost every cell in the body and an increase in problems as time goes by which usually affect any or all of the major organs including heart, liver, kidneys and also the bones, eyes and skin and can lead to increasing neurological deterioration.

It's a devastating condition but thanks to generous fundraising, donations and volunteers we can support those living with these diseases to reach their full potential.

Know someone who might be interested in volunteering? Feel free to copy this newsletter and pass it on.



Simran's story

I became a volunteer as my family and I have been part of the MPS Society for many years, as I have MPS 1. As a child I attended the annual conferences on a few occasions. I was so grateful to the volunteers that helped me and looked after me that I decided it was something I would like to do, a way to give back.

I applied to be a volunteer at 18 and was accepted. I have helped look after children with MPS and their siblings during various conferences. It gives me great joy to see the children have fun. We have been to theme parks, bowling and Sea World. During the evenings the children party, watch films, play games and get creative.

I would encourage others to volunteer, as it is very fulfilling. You get the chance to meet new people, make friends, visit places and learn new skills. You feel a sense of belonging.

Ways you can volunteer with us:

- Childcare at conferences and meetings
- Magazine packing
- Write us a blog or a news article
- Promote MPS awareness on social media
- Volunteer to arrange a fundraising event
- Contact the schools in your area to get them involved in a Wear it Blue day

Get in touch for more information about volunteering.

Phone: 0345 389 9901

Email: mps@mpssociety.org.uk

2017 conference opportunity

The MPS Society is looking for childcare volunteers from the age of 16 years upwards for the 2017 national MPS society conference which takes place from 7–9 July in Coventry.

This conference will allow experts as well as adult individuals affected by MPS and related diseases to learn from and engage with one another. Our event programme is exciting and we rely on our childcare volunteers to keep the children and vulnerable adults safe whilst ensuring they have a happy and memorable time.

This is a wonderful opportunity to meet some amazing children and fellow volunteers where you will gain invaluable experience.

Successful applicants will undergo a full training provided by the Society.

All applicants should be physically fit, responsible, reliable, have good people skills, have a good understanding of confidentiality, be a good communicator, committed, enthusiastic, energetic and have experience of special needs/childcare. Applicants with a background in nursing, medicine or childcare are desired. You will be required to undergo an enhanced DBS check as the Society supports children and vulnerable adults. If you are a new volunteer we also require two references.

If you are interested in this opportunity please complete the form below indicating which training day you would prefer any what relevant skills you have

Name: _____

Address: _____

Post code: _____

Email: _____ Phone: _____

Please tick your preferred training day:

- Saturday 17 June at MPS House, Amersham
- Friday 7 July at the Hilton Hotel, Coventry

What professional skills qualifications relevant to childcare do you have? Please tick all relevant areas below giving details of qualifications, when attained and where relevant when these will expire in the space below.

- Childcare qualification
- Medical qualification (please specify what area)
- Teacher
- Special Educational Needs experience
- Child protection basic
- Child protection advance
- Safeguarding vulnerable adults
- Moving and handling training; including hoist training
- Gastrostomy /Enteral feeding
- Suctioning
- Tracheostomy care

