



Society for
Mucopolysaccharide
Diseases

MPS GROUP EVENTS

MPS Diseases

Founded in 1982, the Society for Mucopolysaccharide Diseases (the MPS Society) is the only national charity specialising in MPS and Related Diseases in the UK, representing and supporting over 1200 affected children and adults, their families, carers and professionals. At present there is no cure for these devastating diseases, only treatment for the symptoms as they arise.

'This year's Sibling Weekend was filled with loads of fun and continuous laughs, from canoeing to archery to giant swing. The weekend was one certainly to remember. It was an action-packed experience. Thank you MPS and keep up the great work.' Vishal (volunteer)

MPS Events

The idea of families coming together on holiday is to share support, to give support and to enjoy each other's company. The idea was first conceived in 1986 and by 1987 it became a reality. Every year since then, the Society has had the privilege to offer families and individuals the opportunity to support each other in this way.

'Thank you for inviting me on the adult weekend trip to London. I had a fantastic time and have to admit that seeing the theatre production 'Wicked' and travelling on the London Eye have been the highlights of my year. Going on the trip has given me the confidence to venture out on my own without the support of my family.' Lois (MPS member)



Why are they so important?

Many individuals and families suffer isolation when a rare condition like one of the MPS or related diseases is diagnosed. They can often feel shut off and very much alone. Imagine for one moment telling someone your child has MPS or Fabry disease, the normal response is a total blank, confusion or even embarrassment. The result can be isolation. MPS Society events for families and individuals affected by MPS and related diseases break down the isolation, enables experiences to be exchanged, bring understanding, care and support and for many, the development of lasting friendships.

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What sort of events?

Given the range and diversity of needs of those affected by MPS and related diseases we aim to hold a variety of different events including weekends for young adults aided by volunteers and sibling activity weekends for the brothers and sisters of those affected. We also organise family get togethers and days out where whole families can come together to swap stories and experiences.



MPS receives many letters and emails from our members thanking us for the events that we arrange.

'We really enjoyed the Alton Towers family weekend, the volunteers put their heart and soul into helping the children have a happy time.'

How are they organised?

This depends on the type of event but generally they follow a schedule of activities which allow plenty of time for families and individuals the opportunity to get to know each other in a friendly and relaxing atmosphere. Our sibling weekends often have an action-packed programme of fun to entertain the children, whilst the adult weekends, for example, make the most of the sights and sounds of London along with plenty of time to relax and chat. The MPS Society will provide volunteers as necessary to ensure the safety and care needs of our participants are upheld at all times. All volunteers are checked for references, fully trained in moving and handling and are subject to an Enhanced Disclosure check with the Criminal Records Bureau.



How are they financed?

Our events are financed by fundraising and donations from companies and trusts. However, we do ask individuals and families for a token payment towards the costs involved.

We would like to take the opportunity to acknowledge the contributions from the many individuals, companies and trusts who support the MPS Society. Their help is invaluable.

Society for Mucopolysaccharide Diseases

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