

**[Organisation’s name/fundraiser’s name] to hold [type of event] for national charity the MPS Society**

[Organisation’s name/fundraiser’s name] from [location] will be holding a fundraising event on [date] to help raise vital funds for the MPS Society, a fantastic charity which provides support for children and families affected by one of 25 rare, life-limiting genetic conditions.

The MPS Society has been helping those affected by rare genetic conditions for the past 40 years and is the only charity in the UK which focusses on MPS (Mucopolysaccharide), Fabry and related disorders which can cause a range of progressive and life-limiting disabilities. Every 8 days, a baby born in the UK is diagnosed with MPS or a related disease so this wonderful charity strives to transform lives through specialist knowledge, support, advocacy and research.

[Organisation’s name/fundraiser’s name] would like to invite the local community to come along to join in the fun. [Add more info about the event here, including name, times of event, activities etc].

As a small charity, the MPS Society is entirely reliant on donations and fundraising. Rare diseases can be isolating and lonely so the MPS Society’s Advocacy Team works closely with those affected by providing an active listening service and helpline. They also provide help with accessing disability benefits, housing, home adaptations, education, referrals to social care, signposting, befriending, bereavement and more. They organise fun events for their members and hold national conferences and expert meetings.

**Anna Featherstone, Head of Fundraising and Communications at MPS Society, said:** “We really appreciate any donation that you give to the MPS Society, whether big or small. We are passionate about ensuring families receive the fastest possible diagnosis and championing new and existing treatments and therapies. By donating just £6, you could pay for a newly diagnosed family to receive a disease-specific information booklet.”

[Organisation’s name/fundraiser’s name] is looking forward to seeing you on [date]. For more information about fundraising for the MPS Society, please visit mpssociety.org.uk/fundraise or email fundraising@mpssociety.org.uk

**-ENDS-**

**Notes to Editors:**

For press opportunities or more information about the MPS Society, please contact the Communications team on 0345 389 9901 or email communications@mpssociety.org.uk.

**About MPS Society**

Founded in 1982, by Christine Lavery, MBE, the Society for Mucopolysaccharide Diseases, or MPS Society, are the only registered charity providing professional support to individuals and families affected by rare, life-limiting genetic diseases such as MPS, Fabry or related disease in the UK.

MPS Society is transforming the lives of those affected by MPS, Fabry and related diseases and reach over 1,500 people per year.

**About MPS**

Mucopolysaccharide (MPS) diseases are a family of rare, life-limiting lysosomal storage disorders that can affect both children and adults. Mucopolysaccharides are long chains of sugar molecules used in the building of bones, cartilage, skin, tendons and many other tissues in the body. Usually, there is a continuous recycling process of building new mucopolysaccharides and breaking down old ones.

For people with MPS diseases, there is not enough of a particular enzyme to break down used mucopolysaccharides which means they build up and store in the cells in the body which causes progressive damage.

**About Fabry**

Fabry disease is closely related to mucopolysaccharidoses and is one of the lysosomal storage diseases. It was first described in 1898 by William Anderson and Johannes Fabry and is also referred to by some as Anderson–Fabry disease.

**About related diseases**

The MPS Society supports 25 MPS and related diseases including the Mucolipidoses, other ‘storage diseases’ and the following diseases which are similar to Mucopolysaccharide Diseases.

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Symptoms can vary greatly but all forms are characterised by a degree of neurodegeneration and cognitive impairment. More information about the diseases can be found here <https://www.mpssociety.org.uk/related-diseases>