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# Strategic Plan

## for 2017–2019

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### About the MPS Society

Founded in 1982, the Society for Mucopolysaccharide and related Lysosomal Storage Diseases (the MPS Society) is the only national charity specialising in 25 very rare Mucopolysaccharide (MPS) and related Lysosomal Storage Diseases (LSDs) in the UK. It represents and supports over 1,250 children and adults suffering from these diseases, their families, carers and professionals. MPS and related LSDs affect 1:25,000 live births in the UK. One baby born every eight days is diagnosed with one of these multi-organ storage diseases which cause progressive physical disability and, in many cases, severe degenerative neurological deterioration resulting in death in childhood.

#### Our vision

A world where all children and adults affected by these diseases is no more.

#### Our mission

To transform the lives of children and adults affected by MPS and related lysosomal diseases by providing support and advocacy, investing in research and raising awareness.

### Our values

**Collaborative** – working with others to maximise our impact, respect diversity and respond to individual needs.

**Empowering** – promoting self-determination and empowering individuals to help them reach their full potential.

**Equitable** – acting with integrity and transparency in the support and advocacy we provide and the research we fund.

**Always improving** – continuously seeking to improve our services by learning, consulting and reflecting on our actions.

**Respectful** – treating everyone with dignity and respect.

**Accountable** – to those whose lives we hope to see transformed, to those we work with and those who support us.

**Courageous** – inspiring and bold in our words and actions, and highly motivated in our determination to pursue our mission.

## Our objectives

### Support and advocacy

To advocate for everyone affected by these diseases to ensure they have access to expert clinical management and treatment, reimbursed therapies and advocacy support.

### Research

To play a leading role with clinicians, scientists and other healthcare professionals in initiating and funding innovative research projects which may have therapeutic benefit for those affected by MPS and related diseases.

### Communication and awareness

To raise awareness to help with faster diagnoses and to communicate effectively with our members so they are aware of how we can support them to be active members of society reaching their full potential.

To deliver our objectives we need to invest in ourselves as a charity over the next three years. This means understanding the needs of our beneficiaries, supporting our employees' professional development, maximising income innovation and fundraising.

## How we plan to do this through

### Support and advocacy

Through our dedicated Advocacy Team we plan to work in partnership with affected children and adults, their families, caregivers health and social care professionals. Our Advocacy Team will continue to provide a vital needs-led individual service to all those affected by MPS, Fabry and related LSDs while working on the following key objectives over the next three years:

- a) Improve our UK-wide specialised person-centred advocacy service by offering information on mental capacity, guardianship, deprivation of liberties (DOLs), changes to the education system and implementation of Education Healthcare Plans (EHPs) whilst maintaining the already high quality service we offer.
- d) Continue to provide an advocacy support service across the whole of Ireland, through the MPS Society's advocacy worker based in Belfast, and take a leading role in securing equitable access to enzyme replacement therapy in the Republic of Ireland.

- c) Develop our advocacy support service for teenagers and young adults by providing focused support to this cohort as they transition and adjust to the challenges of adult life. Including organising teenage/young adult social events, developing information resources for this age group and seeking their views and engaging them in the future direction of the MPS Society and other services for their age group.
- d) Input and participate in at least three technology appraisals for treatments across the UK and Ireland.
- e) Following completion of the study on pregnancy, the MPS Society will develop a series of leaflets, sharing personal experiences, practical advice and useful hints and tips from our members.
- f) Attend our National Conference held every two years to support and facilitate individual/family participation; managing both the childcare and volunteer programmes.

### Research

- a) Collaborate with expert clinicians and partners in the pharmaceutical industry to support children and adults with MPS and related diseases to access natural history studies, clinical trials and quality of life studies.
- b) Support research initiatives that may lead to therapeutic benefits for those affected by MPS and related diseases, as funds allow.

### Communication and awareness

- a) Create a budgeted plan and identify funding to restructure the current website making information as accessible and clear as possible.
- b) Increase our reach on social media focussing on Twitter and Facebook.
- c) Use the MPS Society fundraising campaigns to increase engagement with our existing supporters and reach out to new audiences to broaden our current supporter base.
- d) Review and develop content for the on and offline quarterly MPS Magazine to encourage engagement within our diverse supporter base.
- e) Ensure maximum impact for MPS Awareness Day, held annually on 15 May, to engage with existing and potential new supporters through the 'Wear It Blue' campaign building on the success of previous years.
- f) Promote use of the fundraising toolkit for supporters to use to promote their fundraising and awareness activities to help ensure maximum impact and consistency of message.

- g) Continue to evaluate and monitor the effectiveness of our communications using online tools to measure engagement.
- h) Develop a series of easy to read booklets for young adults with learning disabilities to help them understand their disease and enable them to self-advocate and talk independently about their condition and how it affects them.
- i) Enhance and keep up to date the information we offer about clinical trial opportunities to those affected with MPS and related LSDs through the MPS website, MPS quarterly magazine and individual communications with members.
- e) Continue to support and promote community fundraising, sharing success stories across social media platforms to thank and to inspire.
- f) Continue to develop the MPS Society's involvement in established events and identify new opportunities for event participation by recruiting supporters for involvement.
- g) Continue to work proactively with current active supporters and identify new fundraising opportunities.
- h) Implement a full cost recovery strategy for all restricted grant applications sought and awarded.
- i) Promote the capability for supporters to direct donations to specific campaigns (such as the Sanfilippo Genistein fundraising clinical trial) via the Society's website.

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## Investing in ourselves

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- a) Use the versatility of the Society's brand to create new fundraising initiatives to broaden our appeal and generate unrestricted income.
- b) Maximise income generated around the opportunities created by MPS Awareness Days.
- c) Demonstrate to our donors how the MPS Society uses the funds that are raised.
- d) Increase income with existing and new supporters, particularly schools, university RAG committees and businesses to secure new Charity of the Year opportunities.
- j) Continue to invest in our employees personal and professional development with a focus on maintaining motivation and retention.
- k) Increase the number and diversity of the Board of Trustees and continue to invest in excellence in governance ensuring best practice is upheld.
- l) Deliver a consistent message through the MPS brand, campaigns and social media ensuring our values are reflected in all we do.