

RESEARCH | AWARENESS | SUPPORT



MPS Society

Strategy 2023-2026

Our previous strategy

In 2019 we launched our previous three-year strategy based on the work we carried out through the Vision survey. The strategy signalled a new chapter in the development of the MPS Society and was a clear statement of how we intended to change to better support our evolving community whilst remaining true to the vision of our founder, Christine Lavery MBE.

The many ways we support patients were changing and issues such as social isolation, relationship issues, securing employment, transition into adulthood and complex care issues were still our priority. However, Covid introduced and reinforced issues that were not initially our strategic priority, forcing us to find better solutions for the mental health and wellbeing support our families needed.

Affected people know where to turn for specialist knowledge, support and advocacy

To meet those needs we introduced our mental health and wellbeing programme. This included partnering with Rareminds to offer a specialist counselling service for rare disease patients. Following its success, we extended this pilot to include younger age groups. We offered online mindfulness courses and workshops for siblings, parents and individuals. We continued to share your stories to share the experiences of those we support, told through their own words. We expanded our patient services team, bringing different skills into the team, including bereavement specialists and offered new resources about the diseases we cover including new-look booklets and animations all of which were tested with the people that use them.

Provide the services that beneficiaries tell us they need, in a way that suits them

We offered online expert meetings and social hang outs and, when we could, face-to-face events. We introduced a young person's advisory board - Rare Voices - which continued to meet throughout lockdown and still meet regularly. We introduced GriefChat, a web-based chat both for those dealing with bereavement, and organised visits to the newly-refurbished Wood of Remembrance and Hope.

Take a active role in research

The Clinical and Scientific Advisory Committee was established to oversee applications and allocate funds to relevant research projects. We used existing data to develop patient resources and promoted research surveys and trials to our members to encourage participation in research.

Families receive the fastest possible diagnosis

We provided disease specific expert meetings for Fabry disease treatments and about vaccines for patients with an inherited metabolic diseases and collaborated with other patient organisations to champion newborn screening tests for our diseases.

Champion new and existing treatments and therapies

We worked with other patient organisations, pharmaceutical companies and healthcare professionals to secure NHS funding for treatments including for MLD and MPS IVA Morquio.

Making it happen by investing in our future

We moved to a hybrid working pattern, moving to a modern office environment which has increased the productivity of our staff. We kept our systems relevant and invested in ways to improve our effectiveness. As well as this we worked on diversifying our income sources to broaden our ability to generate sustainable income.

About this strategy

This strategy sees the focus of our support on mental health and wellbeing. We continue to put our members at the centre of everything we do but we now look to do this with a more proactive approach – rather than purely needs-led we hope to anticipate those needs and be ready with support.

We will continue to focus on early diagnosis, through newborn screening and other diagnostic tools that become available and aim to embed standards across the specialist centres that our members turn to. We will also work with stakeholders to make sure there is equitable access to effective treatments for our community.

To achieve this, we distilled our previous six goals into three clear and easy to understand goals, working to ensure all our community have access to: exceptional support and advice, world-class clinical care and effective treatments.

Bob Stevens
Group CEO

Judith Evans
Chair



The background features three overlapping circles. The top-left circle is orange and contains the text 'Our vision'. The bottom circle is blue and contains the text 'Our mission'. The right side of the image is partially covered by a purple circle.

Our vision

For all people affected by
our diseases to live the
lives they want

Our mission

To transform lives through
specialist knowledge,
support and advocacy
and research

Our goals

We are working to ensure all our community have access to:

- exceptional support and advice
- world-class clinical care
- effective treatments



1 Exceptional support and advice

Our goal for the next three years is for our support and advocacy service to meet the needs of our members today by constantly listening, anticipating and testing new approaches so future needs are quickly addressed.

We will do this through:

Community connection and engagement

- Identifying, listening and responding to the needs of the community
- Expanding our individual and family events, face to face and online
- Providing learning opportunities for members
- Connecting the membership with each other
- Increasing our engagement through social media and online presence

Mental health services and support

- Developing and expanding our counselling services
- Consulting with stakeholders and gathering feedback to inform service development
- Developing resources
- Supporting events and learning opportunities

Support and advocacy

- Developing our team
- Developing resources and online content
- Consulting with stakeholders to inform and develop support services
- Providing direct support and contact with our membership



2 World class clinical care

Over the next three years we will work to make sure MPS, Fabry and related lysosomal diseases are diagnosed rapidly and that services provided by the NHS to meet the needs of our membership are world class.

We will do this through:

Engaging with key partners and stakeholders

- Working with key partners (NHS, Pharmaceutical, etc) to make sure patients have an effective patient journey.
- Leading and collaborating with LSD partners to formalise the proposed Patient Professional Partnership Network (PPPN), continuing to represent the patient voice on patient boards.
- Aligning with NHS partners and the LSD collaborative, undertaking audits of clinical centres, reviewing performance, issues and changes in the environment.

Research and innovation

- Continuing to identify and support areas of research, innovation and education that increases disease awareness, improves clinical practice and supports best practice and standards of care.
- Using our own resources to fund research into relevant areas and engage future generations to.
- Supporting earlier diagnosis through education, awareness, production, sharing of resources and materials and monitoring how this will be implemented through the UK Rare Disease Action Plan.
- Advocating for change to newborn screening, aligning with other organisations with similar aims.





3 Effective treatments

All our members have access to the best treatments and therapies licenced anywhere in the world, and in a timely manner.

We will do this through:

Access to treatments

- Supporting key stakeholders, implementing policy and process to ensure equitable access to treatments.

Research and clinical trials

- Actively engaging with pharmaceutical companies, horizon scanning and undertaking resource reviews.
- Keeping patients informed of potential clinical trials available.
- Publishing material that informs research and progression of disease areas.

Political influencing

- Using our international and external expertise as part of the broader landscape to influence and develop relationships to achieve our goals.
- Engaging with NHS and Health Technology Assessments (HTA) decision makers to ensure new and existing treatments are evaluated equitably and fairly, ensuring the patient voice is included and valued throughout.

4 Operational Excellence

MPS Society and Rare Disease Research Partners (RDRP) operate with effective processes both at the Board and within the staff teams, adopting a 'member-centric' approach.

We will do this by:

- Delivering a financial performance in line with budget and planning cycle.
- RDRP undertaking activities in line with the objectives and principles of the Society, to generate a gift to the Society.
- Carrying out an internal health check and investing in staff development.
- Clearly defining our core identity and making sure our purpose, mission, vision and values are in line with the needs to the people we serve.
- Ensuring the organisation is operating in line with all relevant guidance and regulations







Through all our work we will uphold our core values

People first

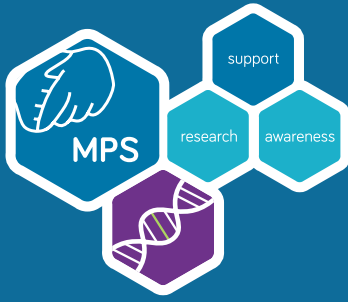
We will always put the people we support at the centre of what we do

Open and transparent

We will always be open and transparent in the way we work

Speak out

We will always speak out on issues that affect our community



Together we can transform lives

We need you now more than ever before. In order for our work to become a reality please consider supporting us, through a regular gift, taking part in one of our many challenge events, getting your company involved or volunteering your time.

Contact us for more information:

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