

Hope it's in our genes
Our strategy 2019–2021

About the plan

The 2019-2021 strategy is the beginning of a new chapter in the development of the MPS Society. It is a clear statement of how we are going to change over the next few years whilst remaining true to the vision of our founder Christine Lavery MBE.

This strategy begins with a new vision and mission statement that reflects the changing lives of people with MPS, Fabry and related diseases. Development of new treatments and therapies together with improved clinical management of these rare diseases means that many within our community are living longer and having a better quality of life.

However with these improvements new and complex issues now face our families and individuals such as social isolation, difficulty in securing employment, relationship issues, problems with transition in to adulthood and complex care issues that are managed by new clinical teams to the patients and are sometimes delivered in an unfamiliar way.

The MPS Society has always been at the forefront of supporting patients and giving them a voice. We are considered a worldwide leader amongst patient organisations in the rare disease sector and we will continue to innovate and champion the needs and wishes of our patient community.

We are proud of our past achievements and excited about the future. We will be bold in our endeavours and collaborative in our approach putting the patient and their families at the centre of all that we do.

Bob Stevens
CEO

James Garthwaite
Chair

1982

Where we've come from

The Society for Mucopolysaccharide Diseases (MPS Society) was founded in May 1982, by our late CEO Christine Lavery MBE. It is the only registered UK charity providing professional support to individuals, families and professionals affected by Mucopolysaccharide (MPS), Fabry and related diseases throughout the UK

In the beginning we only had 40 families spread throughout the UK. In 2019 we now have over 1,500 people registered with us.

Since its inception Christine created, steered and developed the MPS Society to become a nationally and internationally respected charity that prides itself on providing the highest level of service to those affected by MPS, Fabry and related diseases.

Living with an ultra-rare disease is an isolating and lonely experience. Christine knew this and, by founding the MPS Society, threw a lifeline of compassion to those in desperate need.

She always put the advocacy support service at the heart of what we do and the specialist knowledge she has bred throughout the charity means that we are here for you whenever you need us and for whatever you need us for.

2019

What we have now

Our governance

The foundations of a good charity are always built upon good governance. Our Trustees are from a diverse range of backgrounds including family members of those with the diseases, clinicians, scientists and business people. Our Trustees receive regular training and play an active role at events and in setting the strategy.

Global collaboration

The MPS Society has become a world leading patient organisation within rare diseases both in the UK and internationally. We have played a leading role in setting up the UK Lysosomal Storage Diseases (LSD) Collaborative which represents and works on behalf of those with Lysosomal Storage Diseases, we are a founding member of MPS Europe and the International MPS Network (IMPSN). We also represent our Fabry community at the Fabry International Network.

MPS Commercial

Originally set up to provide logistical support to clinical trials worldwide within rare diseases our unique specialist knowledge has enabled MPS Commercial to expand. We now provide, logistics for patient access to clinical trial, support for patient advisory boards, research design and conduct, survey design and delivery, data interpretation and analysis and publications. All profits from MPS Commercial go directly back to our patient community to provide support and funding for innovative work and projects globally.

2021

Where we're going

The MPS Society undertook the biggest consultation with all key stakeholders in our 36 year history. The Vision Project, as it was named, involved patients, their families and support networks, clinical professionals, the pharmaceutical industry, education, social services and other key stakeholders. This collaborative project captured a wide range of views from all sections of our community and it has enabled us to plan for your future and the changing needs and wishes of those affected by Fabry, MPS and related diseases.

The project told us that the most important things we do are:

- Support
- Advocacy
- Research
- Information
- Awareness
- Connection

Our members also told us they wanted more opportunities to connect and more information in a way that suits them.

The results of the survey have formed the basis of our strategic plan so that in all we do we put the patient at the centre.



Our mission

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

Our vision

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

Our goals for 2019–2021

The future for the MPS Society is one where we put our members at the centre of everything we do in line with our vision for all people affected by our diseases to live the lives they want. In order to achieve this we have set ourselves six goals.

Our goals

1. Affected people know where to turn for specialist knowledge, support and advocacy
2. Provide the services that beneficiaries tell us they need, in a way that suits them
3. Take an active role in research
4. Families receive the fastest possible diagnosis
5. Champion new and existing treatments and therapies
6. Making it happen by investing in our future.

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

As the only charity supporting individuals and families affected by MPS and related diseases in the UK, we offer the specialist support, information and advocacy that our community needs to make informed decisions, whether about treatment, education or benefits. We enhance our services with personal experiences, access to a community of peer support and collaboration with healthcare professionals. Our goal over the next three years is to raise the profile of our organisation to ensure that every affected person in the UK can have easy access to our services.

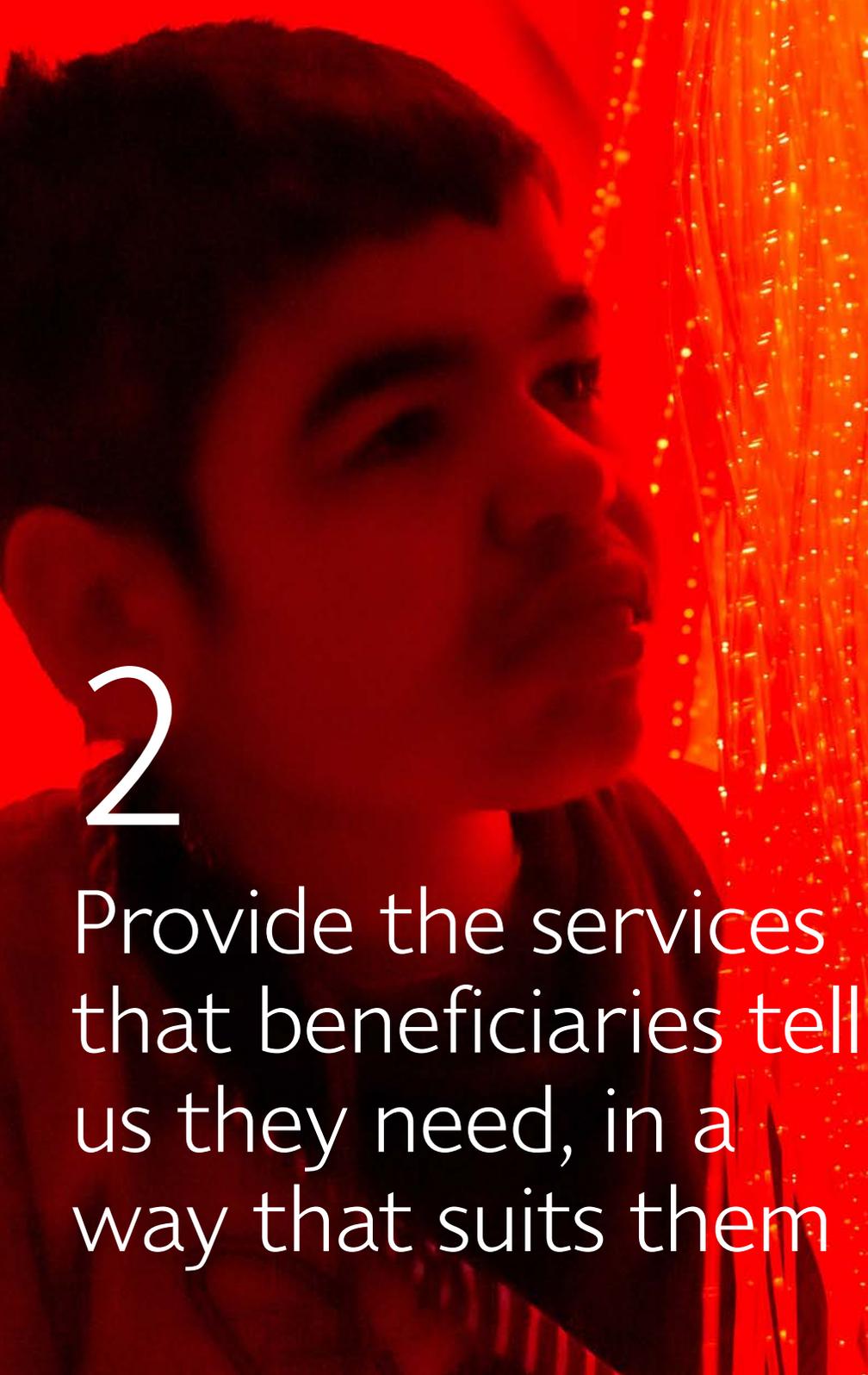
We will do this by:

- Expanding our patient services and advocacy team to meet the increasing demand of our 1,500 members
- Investing in our digital and social communications to reach more people, developing a user-friendly website with key online materials that are easy to read and easily accessible for all
- Highlighting specialist knowledge and sharing patient stories through video content
- Improving and updating our disease specific literature and information resources
- Promoting our support and advocacy service to the wider public

- Ensuring all specialist centres across the UK have our key literature available to share with affected individuals and families
- Adapting and developing our literature and information for different audiences including for children of all ages, resources for young people, adult resources and information in different languages
- Raising awareness of MPS and related diseases and the charity's support through local and national media, press, television and events.

Our information will enable people to be more informed about their condition and where to go for support.





2

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

The MPS Society's members are at the heart of all we do. We want to ensure that we can offer support in the way it is most needed from a family with a newly diagnosed young child to the transition to adulthood and beyond. Our priority for the next strategic stage of our organisation is to keep listening to our community and ensure that we provide a tailored, people-led service by:

- Ensuring that we hold expert support events and conferences that are designed and based on stakeholder feedback
- Introducing a Young Persons Advisory Board, comprising young people affected by MPS and related diseases
- Adapting to the changing needs of our community
- Identifying future support needs and how we can collaborate with other services to deliver these
- Consult with patients and professionals throughout, adapting services to meet beneficiary-led needs
- Sharing learning with other charities and professionals to act as a voice for the MPS affected community, representing the key issues that affect them
- Supporting siblings affected by MPS, Fabry and related diseases by facilitating dedicated sibling events
- Exploring end-of-life and post-bereavement support through organising a bereavement support weekend and assessing the availability of end-of-life training across all specialities
- Finding new and innovative ways of engaging and continuing to listen to our community that is appropriate to each audience, including video consultations, focus groups and social media.

We will focus on funding and collaborating on innovative, world-class research that could make a positive impact on the lives of those affected by an MPS or related disease.

Over the next three years we will:

- Identify our community's unmet research needs and respond by securing funding and inviting applications from leading researchers in the field
- Use existing data to develop more appropriate and relevant Patient Reported Outcomes
- Support others to carry out innovative research through the clinical and scientific advisory committee
- Signpost patients, where appropriate to available research surveys
- Promote latest research through media, with quarterly press releases to local and national media
- Communicate key research news and findings in understandable language that is accessible to all, sharing research e-shots on social media twice per quarter
- Allocate funds to be used across research grants approved by our new Scientific Advisory Board comprising trustees and representatives from patient services
- Continue to work with pharmaceutical companies on clinical trials and develop new partnerships to facilitate new research opportunities.



3

Take an active role
in research

4 Families receive the fastest possible diagnosis

The earlier a family can receive a diagnosis, the sooner the child or young adult can receive treatment. The family will feel less isolation, confusion and the whole family will be able to join the rare disease community, where they can find support, advice and people with shared experiences.

We will:

- Share information to help identify early symptoms, as reported by patients
- Create a working forum with key professionals to identify possibilities or new diagnostic initiatives
- Provide disease specific expert meetings
- Work with key industry stakeholders to diagnose patients earlier through specific projects
- Raise awareness and collaborate with other organisations exploring earlier diagnoses
- Liaise with the specialist centres to create a diagnostic pathway, standardising the process for every new patient in the UK
- Support considerations of potential new-born screening tests
- Continue to support people through the process of diagnosis with information, advice and advocacy.



5

Champion new and existing treatments and therapies

Currently there is no cure for MPS and related diseases but by championing new and existing treatments we can ensure that lives are lived to their fullest.

Over the next 3 years we will:

- Engage with the relevant regulatory organisations to ensure that patients are put first
- Collaborate with other organisations and stakeholders to ensure a unified voice
- Ensure that rare diseases stay on the health and economic agenda by working closely with other MPS, LSD and rare disease organisations
- Organise a joint conference with the LSD Collaborative
- Work in collaboration globally to promote fair and equitable access to effective treatments for everyone
- Engage politically to inform and influence policy decision making.



6

Making it happen,
by investing in
our future

By investing in our people we will

- Ensure all members of the MPS Society team have the skills and resources they need
- Keep our systems relevant and improve effectiveness
- Develop monitoring and evaluation framework
- Identify suitable paid roles and employ people with MPS and related diseases
- Introduce annual disease awareness training for all Trustees and Senior Management team
- Invest in resources to deliver the strategy and ensure long-term growth
- Engage additional support to increase fundraising capacity, focussing on long-term trusts and grants
- Broaden our ability to generate sustainable income by diversifying our sources of funding.

Through all our work we will uphold our core values

Patient
first

We will always put
the patient first

Open and
transparent

We will always be
open and transparent

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:
0345 389 9901
fundraising@mpsociety.org.uk
www.mpsociety.org.uk



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White Lion Road, Amersham, Buckinghamshire, HP7 9LP
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