SUPPORT | RESEARCH | AWARENESS

MPS Society
transforming lives through
support, research & awareness

Impact Report

2025

4188 PEOPLE SUBSCRIBED TO OUR MONTHLY EMAIL NEWSLETTERS

746 INCOMING CALLS RECEIVED

753 OUTGOING CALLS MADE

4057 MEMBERS CONTACTED

BOB STEVENS
GROUP CHIEF EXECUTIVE

We set out this year with a clear mission: to build a complete community so that anyone living with MPS, Fabry or a related condition feels there is a place for them, where they belong.

After a long gap, this year's conference gave us an opportunity to reconnect and reflect on what our community truly needs from coming together. I found myself thinking back to my first time attending as a dad, how nervous I felt, and how important it was to feel welcome. That sense of belonging shaped everything we aimed to deliver at the conference.

Our Support Team has significantly expanded its community offer, developing a supportive peer network. We now host 15 WhatsApp groups and a Facebook group, connecting around 500 members. These spaces allow support to be shared in a more informal, accessible and community-driven way.

We also built on the learning from the 2024 Fabry Matters conference, refining our approach to better support the Fabry community. Our focus was on connection, self-advocacy and resilience. Throughout 2025, the support team delivered a themed monthly education programme, helping individuals and families better understand and manage Fabry, while building confidence and knowledge.

Alongside this, we worked closely with a group of Adult Ambassadors who met regularly throughout the year. They have played a vital role in representing their peers, strengthening community engagement and raising awareness of MPS and related conditions.

We delivered seven events across the year, creating opportunities for our community to come together in ways that reflect the diversity of their experiences. From families and siblings to independently living young adults and bereaved families, we have aimed to support people at every stage of their journey.

For our professional community, we hosted our first joint meeting with the International MPS Network, focusing on the role of biomarkers in improving access to treatments. This brought together experts from around the world to deepen understanding and highlight the importance of integrating biomarkers into regulatory frameworks.

We were also proud to raise awareness more widely, with the support of Iwan Thomas through our BBC Lifeline appeal, and Robert Wilfort, who hosted our first Christmas carol concert. We even had a rising star in Ethan, who appeared on The BBC Children in Need Challenge Squad as The Greatest Showman.

With a brilliant team of employees and excellent trustees I know 2026 will be a year we can make an even bigger impact and for me in particular, change needs to happen so we can all experience **a rare life lived better**.

Warmest wishes
Bob

Supporting you

A strong community

A rare disease diagnosis can be isolating and needs the support of a community who understands. The informal peer network overseen by our Support and Communities Team grew this year to include:

- **15** private WhatsApp groups with **200** members between them
- **300** members in the private Facebook support hub
- **Weekly** staff-led engagement across all core groups
- Consistent **peer-to-peer interaction** in high-engagement communities
- Regular **virtual coffee mornings** and weekly peer support sessions delivered year-round

Members report feeling understood by people who "get it" which is not easily found outside the rare disease community.

Specialist emotional support

Last year **23** new clients accessed Rareminds counselling, delivering **214** specialist counselling sessions to adults living with rare disease or caring for someone who is.

Living with rare, progressive conditions brings significant psychological burden. Counselling data shows that members most commonly experience anxiety and fear about the future, uncertainty, worries about disease progression, stress linked to treatment, surgery and tests, parenting a child with a condition, and grief, loss and adjustment.

Rareminds provided safe, specialist-informed support tailored to these realities. Young adults particularly explored identity, isolation, self-esteem and medical anxiety – issues that are often under-recognised in rare disease.

Improved knowledge, confidence and self-advocacy

Access to clear, relevant information empowers better decision-making and reduces anxiety. We delivered:

Four specialist information evenings about Enzyme Replacement Therapy, gene therapy, research updates and physical wellbeing

A monthly Fabry education programme via WhatsApp covering pain, women's health, gastrointestinal issues, benefits, scripting for appointments and self-advocacy

Regular updates on clinical trials, treatment access and healthcare navigation

The impact of this was improved health literacy, increased confidence in treatment decisions, stronger self-advocacy skills, sustained peer discussion and shared learning, leaving members feeling better equipped to navigate complex systems in rare disease.

> “It gave me the support and encouragement to acknowledge I was able to make changes...and speak to my family and friends about my concerns.

MEMBER WHO ACCESSED RAREMINDS COUNSELLING

19 RESOURCES AND PUBLICATIONS PRODUCED

59 NEW MEMBERS

500 MEMBERS ACROSS WHATSAPP AND FACEBOOK GROUPS

4 INFORMATION EVENINGS DELIVERED

15 WHATSAPP GROUPS

Support events

Throughout 2025 we held a variety of face-to-face support events for our families, tailored to their specific needs. This included opportunities for affected children, young people and their parents to come together as well as the bereaved community to share memories and experiences.

Our families were unanimous in expressing the positive impact of these events and sharing stories and experiences with other families.

Fairytale Farm Easter family day out

"Just a huge thank you for putting on the event. It is hard to put into words the impact of a day like that, it's one of the few days where we can truly relax without having to explain about MPS or justify why we feel stressed or worried, it's such a safe space where the other parents really understand."

Yorkshire Wildlife Park

"Loved the chance to catch up with another family who we hadn't seen for ages. It's wonderful being able to talk to someone who is in the same boat and knows the struggles you go through."

Paultons Park family day out

"Very grateful as we couldn't afford to take my whole family for day trips like this otherwise."

"It's a lovely setting to create unforgettable memories together, especially with the kids having so much fun."

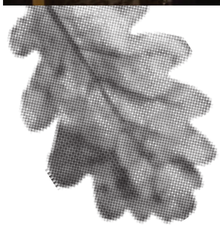
> "We think it's fantastic what you do to support families and we are so grateful.

Thanks to Sally and Marianne for organising these wonderful events.

Weekend of Remembrance – Thoresby Hall

“Very friendly, easy going atmosphere, and great staff members who attended.”

“We enjoyed seeing fellow members and the visit to the wood.”



Weekend of Remembrance – Planting

“I felt this day was well planned, it was nice to speak to other bereaved families, a lovely way to remember our loved ones. This will definitely be a place for our family to visit in the future and watch the tree planted in memory of my son flourish and grow.”

“The balance of feeling so welcome, cared for, supported, having some space to embrace the moments, so well catered for and that our father was so important was indescribable! A truly unique and precious experience.”

Odds Farm Park Christmas family day out

“Amazing day out, both babies really enjoyed themselves and the workers did an amazing job at organising it and making it so magical.”

Regional Independent Adult Get Together

“Sense of community. Connecting with peers with same condition – no expectations, no judgement, just pure understanding.”

> “It is hard to put into words the impact of a day like that, it’s one of the few days where we can truly relax.

7 FACE-TO-FACE SUPPORT EVENTS HELD

MPS Matters

After six years, our long-awaited family conference finally brought our community together again, something many of our members had been asking for. For individuals and families affected by rare conditions, the chance to meet others who truly understand their experiences is incredibly rare and deeply meaningful. We worked hard to create a warm, welcoming atmosphere across the weekend, making sure it felt supportive rather than overwhelming. The impact was clear in the feedback, with families describing a renewed sense of connection, belonging and confidence moving forward.

MPS Matters was made possible by a generous donation from The Gosling Foundation.

> “The conference was a lifeline, which we sorely missed. It made my daughter feel accepted by others; we also felt the lack of judgement from others, which means more than anything.
>
> PARENT

332 PEOPLE ATTENDED THE MPS MATTERS 2025 COMMUNITY WEEKEND INCLUDING:

143 COMMUNITY MEMBERS

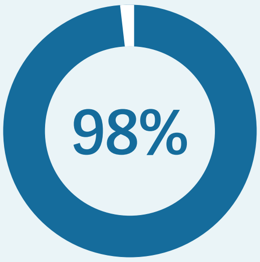
98 PROFESSIONALS

53 CHILDREN

20 VOLUNTEERS

THERE WERE THREE TRACKS

for parents/carers	(18 sessions)
for independent adults	(13 sessions)
for professionals	(7 sessions)



98%

of respondents thought the conference was well organised (out of 41 responses)

28 PRESENTATIONS

9 WORKSHOPS

1 EXPERT MEETING

And a research-focused Dragon’s Den style feature and poster session

> “Meeting other families and having our own time. The childcare was amazing.
>
> PARENT

Thank you to our wonderful volunteers

Spread the word

MPS Awareness Week

This year's MPS Awareness Week campaign raised over £29,000. Thank you to all the schools, community groups and individuals who organised events throughout the week and made this total possible. It is because of you that we are able to support families and individuals affected by MPS, Fabry and related conditions throughout the year. We thoroughly enjoyed seeing all your pictures from your Wear it Blue events, bakes sales and awareness activities.

IN MAY... **119K** TOTAL IMPRESSIONS

5300 WEBSITE VISITS

942 BBC LIFELINE DONATIONS

FABRY AWARENESS MONTH

Throughout April we shared insights from the Fabry Matters conference which highlighted how patients are usually diagnosed with Fabry, symptoms which have the biggest impact on patients and the emotional journey of a Fabry patient.

We celebrated International Fabry Women's Day with an insightful interview from Liz Dudeney who received her Fabry diagnosis after her dad had been admitted to hospital. She told us about the symptoms she experiences, how peer support has made her feel less alone, managing her mental health, talking to her family about the condition and running the London Marathon.

BBC Lifeline appeal

We were fortunate enough to be selected for the BBC Lifeline appeal in May. The production team created an emotional film which shared the stories of Tillie Mae, Leah and Henry all presented by the splendid Iwan Thomas. The appeal raised over £22,000 towards our family events and awareness amongst the public as well as causing a buzz in our community seeing people with MPS and related conditions on screen.

MPS Awareness Day event

We held an MPS Awareness Day event in London and invited our community, supporters, donors, service users and other stakeholders to learn more about our work. The night hosted speakers, who shared their experience of living with a rare condition, talks from our support team and an opportunity to mingle.

Patient-centred progress

SOPHIE THOMAS,
SENIOR HEAD OF
PATIENT SERVICES AND
CLINICAL LIAISONS

Throughout 2025, my work focused on improving care pathways for people with Lysosomal Storage Diseases (LSDs), strengthening national policy and clinical decision making and ensuring the voices of patients and caregivers remained central to every discussion.

A key part of my role was bringing specialists, families, policymakers and international partners together to create meaningful and lasting change across the system.

A major area of progress this year was the **MPS Airway Project** (MAP). We continued pushing for joint funding and established the clinical groups needed to begin developing new multidisciplinary airway guidance for people with MPS. As the year progressed, ear nose and throat (ENT), respiratory, paediatric and adult teams came together to agree a shared approach. By late 2025, authorship teams had been confirmed and the structure for two publications was agreed, representing one of the most collaborative clinical projects in the MPS field.

Alongside this, I coordinated the **development of the Emergency Airway Passport**, working with clinical teams, NHS England Highly Specialised Services, ENT and anaesthetics teams across the UK to prepare drafts and plan consultations. This important tool will help ensure safer, more consistent emergency care for people with complex airway needs from 2026 onward.

I also played a key role in **newborn screening advocacy**. After the National Screening Committee concluded there was "weak evidence" for including Metachromatic Leukodystrophy (MLD) in the screening programme, I helped coordinate a strong, united response across patient organisations, clinicians, diagnostics experts and scientists. This included challenging inaccuracies in the review and supporting wider engagement with MPs, the media and national steering groups, ensuring families had a clear and influential voice at a crucial moment.

Collaboration continued across the UK and internationally. I coordinated the **UK & Europe Biomarker Meeting**, which brought together regulators alongside clinicians, researchers, industry and patient groups. Over 50 people attended in person, with hundreds joining online, and feedback was overwhelmingly positive. I also led the MPS Expert Meeting, supported transition pathway work and represented the community at international newborn screening and MPS family meetings in Taiwan.

This year also saw continued growth in the **international alpha-mannosidosis community**, working jointly with teams from Germany and Spain to plan meetings and strengthen shared learning.

My advocacy extended through the **Childhood Dementia Action Group**, contributing to policy engagement in Scotland, national reports, global reviews and parliamentary preparations to ensure that the needs of children with neurodegenerative rare diseases remain visible and prioritised.

One of the most significant achievements of the year was **chairing the Patient, Professional and Partnership Network (PPPN)**. Through this role, I guided the network in finalising and publishing 10 national clinical guidelines across conditions including MPS I, II, III, IVA, VI, alpha-mannosidosis, Fabry, Wolman Disease, late onset Pompe Disease and Niemann-Pick Type C, representing a major step forward in ensuring consistency in care across the UK.

Two projects were selected for **presentation at WORLD*Symposium* 2026**: one showcasing the PPPN's collaborative approach to clinical guideline development, and the other highlighting mental health pressures experienced by patients and caregivers, reinforcing the importance of emotional and psychological support within care pathways.

2025 marked a year of deepened collaboration, stronger clinical pathways and significant progress toward patient-centred change across the LSD community.

Funding research

FIONA STEWART, CHAIR OF THE CLINICAL SCIENTIFIC ADVISORY COMMITTEE

CSAC is the MPS Society's Clinical Scientific Advisory Committee. Its Chair, Fiona Stewart, reflects on a productive and eventful year, highlighting the exciting research initiatives the committee has supported.

The past 12 months have been an exceptionally busy and rewarding period for CSAC. A particular highlight was the MPS Matters 2025 family conference, where we were delighted by the outstanding quality of research submissions to both the **Dragon's Den and poster competitions**. It is especially encouraging to see such a strong cohort of dedicated and talented early-career researchers engaging in this field.

In this year's funding round, CSAC approved support for three distinct research projects focusing on exercise, respiratory function and urinary biomarkers. We are grateful to the trustees for allocating additional funding, which enabled all three high-quality and diverse projects to proceed. These investments reflect our commitment to advancing knowledge across multiple areas that have meaningful implications for patient care. We look forward to sharing the outcomes of this work in due course.

Over the year, CSAC has also contributed its expertise through a series of online meetings with pharmaceutical companies, providing scientific and clinical advice on a range of initiatives. It is encouraging to see the committee's insight increasingly recognised and valued within the wider research and industry community.

In October, Bob and I attended an **Aspire event** in London, which brings together patient organisations with unmet needs and biotechnology and pharmaceutical companies seeking to address them. This provided a valuable opportunity to present our priorities and engage directly with potential partners. We are now actively following up on several promising leads arising from these discussions.

£129,766

PAID OUT TO GRANTS BY CSAC IN 2025

Rare Disease Research Partners

2025 was a successful year for RDRP, marked by the establishment of new clinical trial and research project contracts. RDRP also expanded its role in research recruitment, collaborating with market research agencies working on behalf of pharmaceutical companies. RDRP was awarded the British Healthcare Business Intelligence Association (BHBIA) Bobi Award for Best Use of Innovation in recognition of its inclusive, patient-centric approach to insight gathering at the Fabry Matters Conference 2024. Collectively, these achievements have enabled RDRP to make its annual gift to the MPS Society of £156,680.

£156,680

GIFTED TO THE MPS SOCIETY

Thanks to you

31 AWARENESS WEEK FUNDRAISERS

RAISED **£29K**

Scarlett's Active April Challenge

Thank you and well done to Scarlett who cycled 50km around the Collier's Trail for Active April raising a whopping £1,510. This was all in honour of her friend Luna who has an MPS condition.

We can't thank you enough Scarlett for your sheer strength and determination to raise funds and awareness for the MPS Society. You are a true MPS superhero!

Sophie McCance Davis

Many of you will know Sophie, Henry and James. They have been sending Henry's smiles across the world, raising funds and awareness for Henry who has MPS II and the MPS Society. These are badges that people have been wearing and capturing in photos wherever they are. Friends, family and local businesses have all been on board to help raise these funds. We are so proud to announce that they have smashed the £10,000 mark and are currently on £12,571! Sophie has said:

> "We are not stopping here! We will keep adding as much as we can."

Towersey Morris and Haddenham Mummers

A huge thank you to the Towersey Horseshoe Morris who donated £500 from their summer events. The team attended the Bunkfest weekend of dance at Watlington and the Swanage weekend of dance where they danced on Swanage Pier. They continued to raise awareness and funds with the Haddenham Mummers Christmas shows raising a further £550. Thank you so much for your continued support over the last 40 years!

Little Bus Big Ride

To celebrate their family business turning 100 years old, three brothers, Andrew, James and Will Emerton from Nantwich, decided to embark on the adventure of a lifetime. Their goal was to raise vital funds for three charities close to their hearts by driving a 1940s miniature bus 1000 miles from Lands End to John O'Groats. The journey was predicted to take eight days at an average speed of around 12mph. Despite some challenges along the way, the three brothers smashed it, raising an incredible total of £32,165 which was shared between Hope House Children's Hospice, The Children's Society and MPS Society.

London Marathon 2025

A huge thank you to our 2025 London Marathon team including Ashley, Emily P, Emily V, Josie, Liz, Phil, Richard, Ruth, Tom and James who have been our absolute heroes. They ran their hearts out for their own personal reasons and raised a phenomenal amount for the MPS Society. Their team total was over £31,500! A massive thank you to all the cheer squads who supported our runners on the day and to every single person who donated. To our 2025 team, congratulations for completing the TCS London Marathon 2025.

Richard Cooling

A big thank you to Richard Cooling who has been an amazing fundraiser for us this year. He began the year taking on the London Marathon raising £2,660. We give thanks as well to him, his friends and family for raising an incredible £3,007 for their annual football match in honour of his brother Jonathan who has an MPS condition. It was a wonderful day which saw sparkly MPS Society logo face paints, raffles and of course the beautiful game! Thank you so much to everyone who was involved and who donated, we are so grateful.

MPS Society employees running for rare in April

Noah Varey in memory fundraiser

Thank you to Shauna and Ste Varey for raising an incredible £3,806.11 in memory of their son Noah for this years Wear it Blue campaign. Thank you to Ste and Tim for taking on a 171 mile cycle challenge in May and thank you to Autograph Care for your amazing fundraising! Shauna said:

> "We also had football cards, cake sales and a raffle and combined with last years fundraising, we've managed to raise £8,145.11 for the MPS Society which is just so, so incredible."

The Thistleton Family

In MPS Awareness Week the Thistleton family raised funds in honour of Tilly who has an MPS condition. Stuart, Tilly's dad, along with a group of family and friends took on the National Three Peaks challenge raising a fab £6,830. A big thank you to Kingswood Park Primary School who held a Wear it Blue Day and raised £628 putting the total up to almost £7,500.

And thanks to all our sporty fundraisers – epic work!

London Landmark's Half Marathon team – Alison, Lianne, Sandra, Frances, Morgan, Claire and The Helens – raised £5,155.

Great North Run runners – Craig, James, Emily, Damian, Dale and Stuart – raised £3,613.

Great Scottish Run 10kers, Nicola, Heather, Ange and Lynsey, and half marathoner, Fin, together raised over £1,400.

Royal Parks Half Marathon team – Elle, Pete, Lianne, Jon, Matt, Sam and The Helens – raised £3,409.

Together we can transform lives

Thank you...

...to the trusts and grant-making organisations who have supported us in 2025

...to our corporate funders who have contributed to the work we have done this year

...to all the regular donations we receive including those from anonymous donors, we don't know who you are but we are so grateful for your support

...to everyone who has left a legacy in their will to help support families with MPS and related conditions in the future.

Your support makes such a difference. Find out more about how we use your donations to transform lives at www.mpssociety.org.uk/our-impact

Contact us for more information:
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mpssociety.org.uk/donate

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