



**MPS Society**

transforming lives through  
support, research & awareness

FABRY AWARENESS MONTH, APRIL 2026

# Review

## Fabry Education and Resilience Project 2025

70

members took part,  
sharing experiences,  
advice, raising questions

52

resources shared, including medical  
papers, trial updates, research  
summaries, practical guides

### ABOUT THE PROJECT

Throughout 2025, the *Fabry Education and Resilience Project* brought together the UK Fabry community to share knowledge, ask questions and support one another.

The project created multiple opportunities for member engagement via our WhatsApp group, coffee mornings, webinars and Q&A sessions. It also offered a safe space to explore the practical and personal challenges of living with Fabry disease.

We collated and shared various resources, including medical papers, clinical trial updates, research summaries and guides specifically tailored to our members' needs. Content was also published in our e-news and is now accessible via the MPS Society website.

Discover more 

4

webinars and Q&A  
sessions addressing  
specific themes

11

coffee mornings offering  
informal peer support  
and specialist input



[mpssociety.org.uk](https://mpssociety.org.uk)

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## UNDERSTANDING FABRY

We began the year by building a foundation of understanding.

Conversations focused on the basics:

- how Fabry disease presents
- the role of genetics
- treatment options available in the UK

Members shared their experiences of symptom variability and the difficulties of discussing a genetic condition within families.

This early discussion set the tone for the project, combining clinical knowledge with lived experience and highlighting that Fabry is highly individual.

As members of the Patient Professional Partnership Network (PPPN), we helped develop clinical standards for diagnosing, assessing, monitoring and treating Fabry.

[BIMDG treatment guidelines](#)

## PHYSICAL ACTIVITY

We explored how members can remain active despite Fabry-related fatigue, pain or heat intolerance.

Members also reflected on the psychological and social benefits of staying active, noting that even small movements throughout the day helped maintain mobility, circulation and mental well-being.

Tracking progress with logs, diaries or smart watches was encouraged to support self-advocacy and inform clinical reviews.

Dr Sarah Gosling shared insights from her research.

[Q&A with Dr Sarah Gosling](#)

The findings underscored the importance of pacing, gradual progression and adapting activities to individual tolerance. Activities ranged from seated stretches to hydrotherapy, pilates and Tai Chi.



## EXPLORING PAIN AND NEUROLOGICAL SYMPTOMS

Fabry-related pain is often misunderstood or under-recognised. Members described neuropathic pain, acroparesthesia and the unpredictability of daily discomfort.

Discussions emphasised the personal nature of pain and explored practical strategies to manage it.

Some members described keeping symptom diaries, others shared pacing techniques, while a number highlighted mind-body approaches such as breathing exercises or gentle stretching.

Specialist input reinforced the need for a multidisciplinary approach, combining symptom management with mental well-being support.



[Fabry UK Consensus](#)

## DIGESTIVE HEALTH AND NUTRITION

Gastrointestinal (GI) symptoms were identified as a major concern by many members.

GI issues affect over half of people with Fabry and can include:

- abdominal pain
- diarrhoea
- constipation
- nausea
- bloating



Members described the frustration of symptoms appearing suddenly or changing over time, sometimes in connection with lactose or gluten sensitivity, hormonal changes or stress.

The community shared tips for dietary management and our support team highlighted approaches such as low-FODMAP or anti-inflammatory diets, always emphasising the need for guidance from a dietitian or specialist.

While diet alone may not resolve symptoms, Fabry-related nerve involvement and Gb3 accumulation in the gut can contribute. Small changes, tracking and specialist advice were repeatedly reported as beneficial.

[Dr Seema Kanwal on Fabry and nutrition](#)

## SELF-ADVOCACY AND FAMILY COMMUNICATION

A recurring theme throughout the year was the value of having a clear way to explain Fabry disease to others.

Many members found that creating a short, tailored Fabry script can be extremely useful.

[Ask us for help with your script](#)

A script can highlight the aspects of Fabry that matter most to you and explain the accommodations or support you may need. Adapted for different audiences, for example in school, work or education settings, they help explain the need for rest breaks or flexible arrangements.



With friends and family, they offer a way to describe symptoms like fatigue, pain or gastrointestinal issues. In healthcare appointments or public spaces, a concise script ensures your priorities are understood without pressure to over-explain.

Having a prepared script aids confident and consistent communication, reduces stress and ensures needs are heard.

Our discussions also emphasised the importance of self-advocacy, keeping symptom logs, preparing questions and clearly stating priorities.

These can make a real difference when engaging with healthcare teams or requesting adjustments in daily life.

## SOCIAL AND FINANCIAL REALITIES

One of the wider challenges of living with Fabry disease are social and financial considerations.

Many members shared experiences of navigating work, benefits and healthcare.

One tangible outcome was the development of the Fabry PIP tool, now regularly used by the MPS Society support team to assist members with benefit applications.

Discussions also highlighted the importance of both formal and informal support networks, reminding members that they are not alone in managing these challenges.

[Access the PIP tool](#)



## WOMEN'S HEALTH

Many members felt that women's health issues deserved greater attention.

Conversations covered:

- menstrual and menopausal symptoms
- hormone replacement therapy
- contraception
- pregnancy planning
- urinary tract health

Members shared experiences of heavy periods, painful cramps and concerns about fertility, while specialists provided guidance on risk assessment, multidisciplinary care and proactive management.

The discussions emphasised that Fabry symptoms can overlap with gynaecological issues.

Careful evaluation and collaboration between metabolic and gynaecology teams were key.



[Share your experiences with us](#)

## AGEING AND GENERAL WELL-BEING

Living longer with Fabry has brought new conversations about ageing and overall well-being.

Beyond organ-specific care, members discussed challenges, including:

- mobility
- fatigue
- mental health
- maintaining independence

Holistic approaches, proactive planning and pacing energy emerged as key strategies. Social connections, manageable physical activity and mental health support were repeatedly mentioned as central to day-to-day quality of life.

Coordination across specialists ensures care reflects the whole person, highlighting that living with Fabry is about more than monitoring organs, it's about resilience, autonomy and well-being.



[Fabry well-being tips](#)

## CONCLUSION

Members reported an improved understanding of Fabry disease, increased confidence in managing symptoms, greater awareness of social and financial support and stronger connections within the community.

By listening to our members, opening up conversations and sharing evidence-based guidance, we aim to support people with Fabry to manage the condition with confidence and access the resources they need to live well.

We invited our Fabry community to anonymously submit their big, complex and personal questions. These are just a few examples:

Is it normal to feel resentful that Fabry was passed on to me?

How do I cope with the guilt of passing on a genetic condition?

My mental health is very low, where can I get help?

Is Fabry impacting my fertility?

What if I don't feel sick enough to ask for help?

## LOOKING AHEAD

The *Fabry Education and Resilience Project* grew from the conversations, learning and connections established at our Fabry Matters conference in 2024.

Building on that foundation, we are looking forward to bringing Fabry Matters back in the future, giving our community the chance to come together face-to-face once again.

Our goal is to ensure that these events and all the services we provide are member-led and reflect the priorities, questions and experiences of people living with Fabry.

We encourage members to complete our conference survey and share their ideas about what topics, speakers and practical support they want to see.

This feedback will help us shape future events and resources so that they are truly responsive to the needs of the Fabry community.

[Join the conversation](#)

#WeAreHere

[Take part in the survey](#)