RESEARCH | AWARENESS | SUPPORT

SUPPORT AND ADVOCACY TEAM

How we can support you

MPS Society

transforming lives through support, research & awareness

Thank you to the support and advocacy team for everything that you all do.
It makes a massive difference to have your support.

Member feedback

The MPS Society's support and advocacy team is at the core of everything the charity delivers. It provides a unique, flexible and wide-ranging support service to its members from the point of diagnosis.

The rarity of MPS, Fabry and related diseases means affected individuals and their families often experience difficulties accessing support services in their local areas.

Our experienced and skilled team works closely with individuals and their families as well as with health, social care and educational professionals to make sure the needs of our members always come first.

How to get in touch

We are here for you whenever you need us. Here's how to get in touch.

You can phone us on **0345 389 9901** or email us at **advocacy@mpssociety.org.uk**. Our office opening hours are Monday to Friday, 9am-5pm.

Our out-of-hours support line is open Monday to Friday, 5pm-10pm, and on weekends and bank holidays from 9am-5pm. Call **07712 653258**.

Members in Northern Ireland and Scotland can contact their Support and Advocacy Officer on **07786 258 336**.

Or visit **mpssociety.org.uk/support-we-offer** to find out more about our support.

How we can support you

From point of contact we provide emotional support, practical advice, information and guidance and signposting where needed. Our specialist knowledge of the MPS, Fabry and related diseases and our social work experience means we can help in any stage of your journey.

Active listening service and telephone helpline

Help accessing disability benefits

Information on housing, home adaptations and specialist equipment

Peer to peer befriending service

Education Healthcare plans and school talks

Support with end of life care, loss and bereavement

Referrals to social care for services or respite

Events

We also organise regional events for families, siblings and individuals which are a chance to get together with others living with MPS, Fabry and related diseases. These are held throughout the year and all over the UK.

The MPS national conference and expert meetings are a highlight for families and health professionals and are an opportunity to learn as much as possible about the individual diseases and what it is like to live with them.

Independent living and transition support

Linking with specialist clinical centres and signposting for expert advice

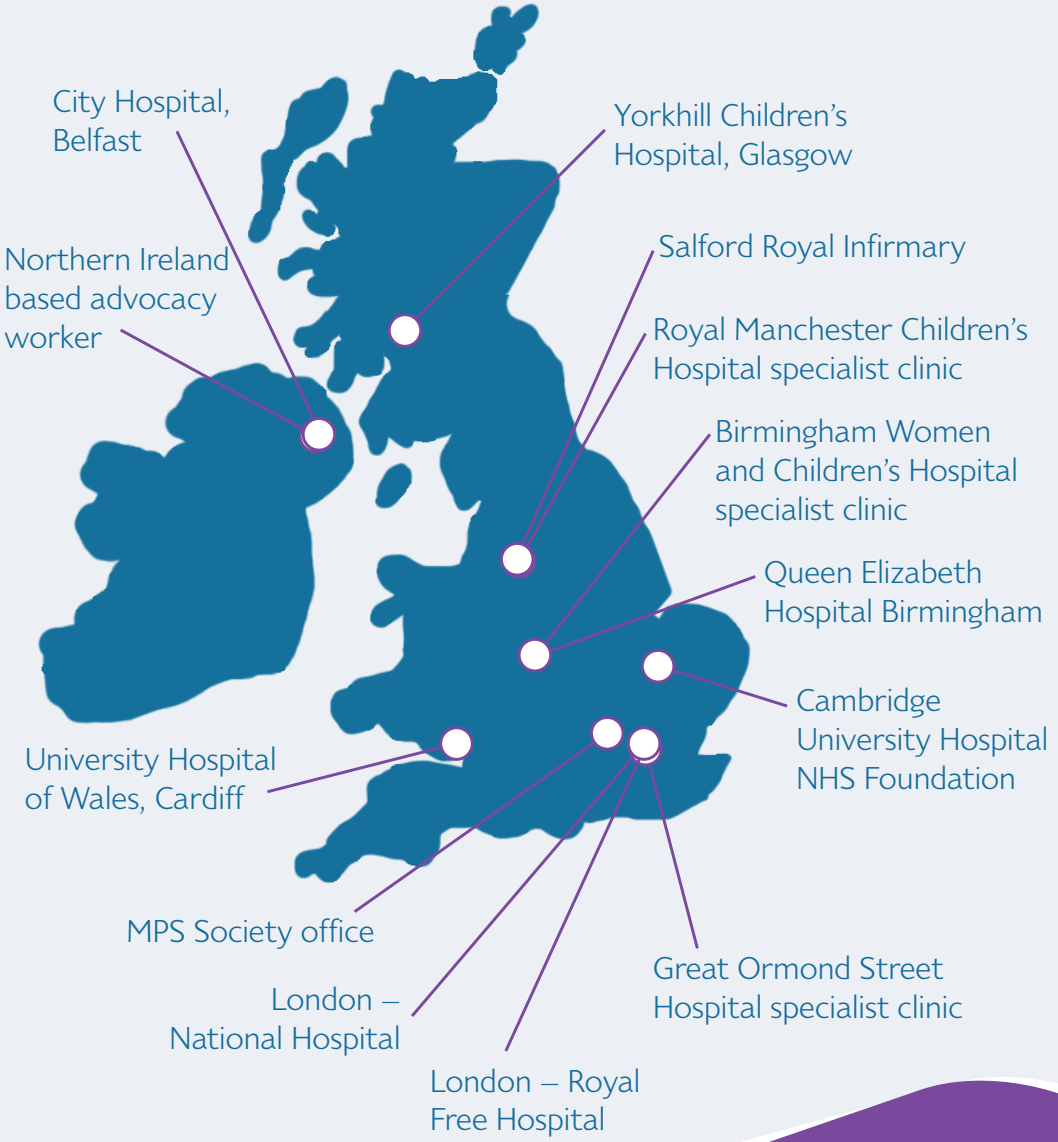
Who we are?

All our support officers are trained in MPS, Fabry and related diseases and are DBS checked.

Please see the MPS Society's website for details on individual advocacy support officers and the specific disease groups they support.

"I can't thank you enough for your help. It was stressful, but without you I couldn't have done it. My heartfelt thanks.

Member feedback



Specialist centres

I met a family at a clinic recently and they were very complimentary of the support provided and have found it invaluable. Thank you for your support and all that you have done and continue to do for this family.

Nurse practitioner feedback

Confidentiality and safeguarding

With the nature of the work we undertake we often need to share sensitive and personal information. We take our responsibilities in relation to confidentiality seriously and are careful that we only share information where consent has been given. The only exception to this is where a safeguarding issue has been raised about a child, young person or adult at risk. In these instances we will always ask an individual or inform a parent or guardian before sharing information.

Get in touch

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