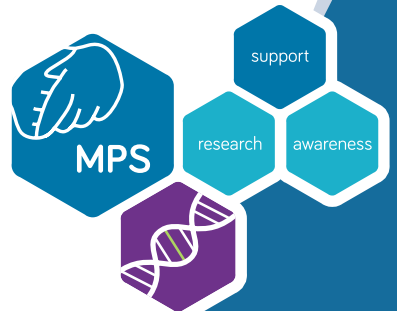


SUPPORT AND ADVOCACY TEAM

How we can support you





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.

Phone us on 0345 389 9901
Monday to Friday 9am–5pm

Outside these hours you can call us on 07712 653258
Monday to Friday 7am–9am and 5pm–10pm
Saturday and Sunday 7am–10pm

Email us at advocacy@mpssociety.org.uk

We also have a number of resources and lots of information available on our **website** at www.mpssociety.org.uk

Members in **Northern Ireland** can contact our Northern Ireland based advocacy worker on 07786 258336



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



Education Healthcare plans and school talks



Referrals to social care for services or respite



Independent living and transition support



Linking with specialist clinical centres and signposting for expert advice



Peer to peer befriending service



Support with end of life care, loss and bereavement

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.



Who we are?

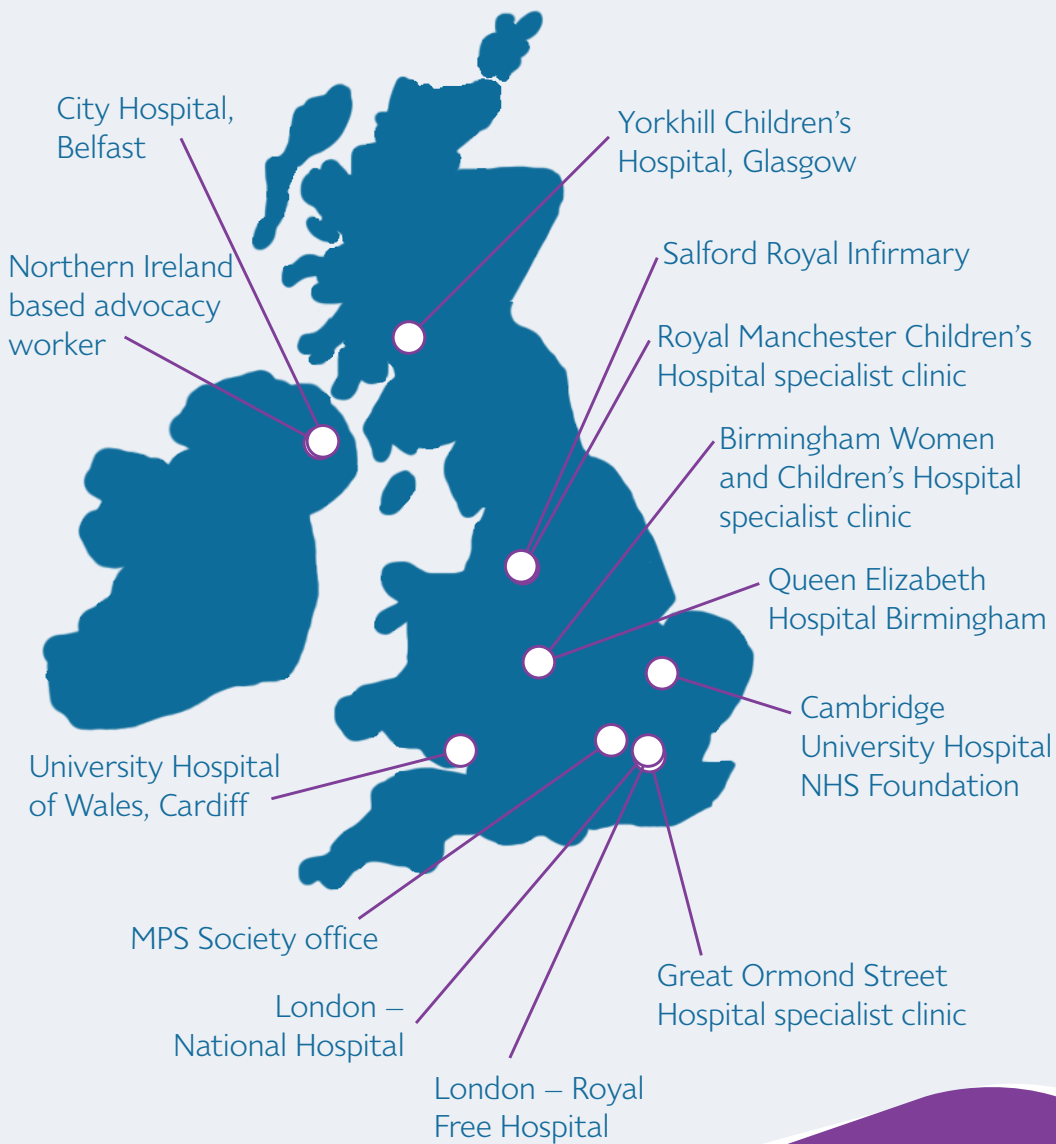
All our support officers are trained in MPS, Fabry and related diseases and are DBS checked.

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

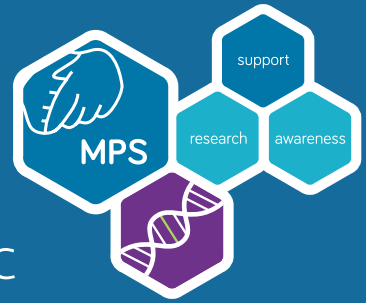


I can't thank you enough for your help. It was stressful, but without you I couldn't have done it. My heartfelt thanks.

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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White Lion Road, Amersham,
Buckinghamshire HP7 9LP
0345 389 9901

@MPSSocietyUK
fb.com/mpssociety
www.mpssociety.org.uk