



**Job Title:** Support and Advocacy Officer

**Reporting to:** Head of Support and Advocacy

**Hours:** Full time post however part time with a minimum of 28 hours may be considered for the right candidate

**Location:** Amersham, hybrid working with a minimum of two days in the office each week

At the MPS Society we aim to transform the lives of people affected by MPS, Fabry and related lysosomal diseases through specialist knowledge, support and advocacy, and research.

As a Support and Advocacy Officer you will join a skilled team who collectively provide a unique UK-wide support and advocacy service to over 1500 members. You will primarily provide direct support and practical guidance to our Fabry members. This patient group is largely adult focused but there will be elements of family and child support. You will raise awareness within both the Fabry community and external agencies; and contribute to the development of resources, to promote self-advocacy within the patient group. A key objective of the role will be to build a sense of community and identity for our Fabry membership. You will also have the opportunity to facilitate and contribute to project work within our organisation such as youth engagement, advisory boards, and support groups.

In addition to supporting the Fabry community there will also be a requirement to provide support to those affected by other conditions under our umbrella.

**What is Fabry Disease?** Fabry is a rare genetic condition with symptoms similar to other more common conditions such as cardiomyopathy, kidney disease, mental health issues, stroke, and chronic pain.

The ideal candidate will have ability and enthusiasm and will not only enjoy working as part of a small, dedicated team; but also, collaboratively with stakeholders, to raise awareness and advocate for our membership. You will have the ability to communicate accurately, concisely and with clarity with a high attention to detail; uphold best practice, challenge poor policy and support decision making, while ensuring that the individual (or family) remain at the centre of support. You will be highly organised, juggling many strands of work and have the creativity and passion to work with us to develop the service and support we provide to our Fabry community, engaging with them to drive the service forward.

Prior knowledge of Fabry Disease is not required as in-depth support and training will be provided. Regular supervision and a supportive work culture will help you to expand your knowledge and become an expert in the work you are undertaking.

We value our staff, their skills, experience and commitment therefore in addition to a competitive salary, we offer pension contributions, life assurance (subject to the conditions of the scheme), 5 weeks annual leave (increasing after 5 years' service), extra leave between Christmas and New Year and an Employee Assistance Programme.

We encourage candidates to view our website and ask that you please download the job description to see the full role responsibilities.

For an informal discussion about the role or the work of the MPS Society, please contact Steve Cotterell on 0345 389 9901 or [steve.cotterell@mppsociety.org.uk](mailto:steve.cotterell@mppsociety.org.uk)

**To apply:**

Applications should be made to [HR@mpssociety.org.uk](mailto:HR@mpssociety.org.uk) Please provide your CV and a covering letter explaining how your previous roles and experiences make you the candidate we are looking for.

**Closing Date:** Interviews and assessment will be held following receipt of suitable applications.

**Skills and experience:**

We welcome applications from those who have a minimum of two years' experience of working with individuals with disabilities within health and social care, education, or related field. Experience of project management and service development would be an advantage.

**Key Responsibilities:**

- Develop a good overall knowledge and understanding of MPS and related conditions and expertise in Fabry disease as the named worker for this condition.
- Develop knowledge of legislation and best practice relevant to supporting people with life-long conditions.
- Provide a support service to individuals, their families, and carers by providing emotional support, information, and guidance in areas such as diagnosis, disease awareness, health and social care, and disability benefits.
- Support individuals and families to access best possible clinical management and care; and to inform them of developments in clinical trials and treatment options, signposting as appropriate.
- Work collaboratively with other professionals to ensure that assessment and provision of services are based on an accurate understanding and identification of individual needs.
- Support individuals and families through their Fabry journey including bereavement.
- Support, signpost and direct people towards mental health and psychological support as required.
- Maintain accurate individual records on the MPS Society's database at all times.
- Undertake UK wide travel to attend meetings, visit individuals and families, and to attend regional events.
- Support the preparation, organisation, and delivery of the MPS Society's regional, national, and online events. This will include assessing need and risk to develop care plans for those attending.
- Work with colleagues to support research opportunities.

*Resources and awareness:*

- Provide information to assist in the development of the Society's information and guidance resources.
- Support the provision of online support and advice via social media channels.
- Promote awareness of Fabry, MPS and related conditions and the work of the MPS Society by giving talks and presentations to outside organisations, professionals, and the general public.

**General Responsibilities:**

- Adopt a positive approach to personal and professional development, identifying and attending relevant training, engaging in regular one-to-one meetings and an annual performance review with line manager.
- All members of staff are expected to participate in appropriate team meetings.
- Attend occasional UK and international conferences and events with some out of hours working.
- Carry out any other reasonable duties as requested by your line manager.

**Further information:****Location and working hours:**

This post is primarily based in our Amersham office, however the MPS Society recognises the importance of flexible working and support our staff to achieve a good work-life balance.

As part of the role, UK wide travel is necessary. This may on occasion include early morning and/or evening working and sometimes overnight stays. You may also occasionally be required to attend evening or weekend conferences and events. We have policies in place to ensure that any unsociable hours worked are fairly compensated.

This is an essential car user post. The applicant must hold a current UK driver's licence, with no more than 6 points and be able to drive UK wide as required.

The Support and Advocacy Team operates an out of hours advice service 5pm to 10pm weekdays and 9am to 5pm weekends, bank holidays and at times of office closure. This responsibility is shared between the team as fairly as possible, with time off in lieu granted for bank holiday cover.

The successful candidate must be eligible to work in the UK.

Salary will be agreed according to experience and pro-rata for part time hours.

### **Disclosure & Barring Service (DBS)**

The MPS Society is a charity that provides a range of care, support and activities for children and adults at risk throughout the UK. This is provided in a number of ways through our dedicated support and advocacy service, annual events, patient expert meetings and conferences. MPS staff, trustees and volunteers may be asked to be involved in the delivery of its regulated activities and therefore will require an enhanced DBS check during recruitment and for this to be reviewed on a regular basis.

***This post is exempt under the Rehabilitation of Offenders Act 1974. Due to the sensitive nature of the duties undertaking, the post holder will be expected to undertake a DBS check as part of the recruitment process.***

### **Person specification**

The successful candidate will have the following essential requirements:

- Eligibility to work in the UK.
- GCSE grade 5+ (A-C) or equivalent in English and Maths.
- 2 years' experience of working with individuals with disabilities within health and social care, education or related field including a knowledge of relevant assessment processes.
- Knowledge of the needs of individuals with disabilities and their families; and an awareness of Equality, Diversity, and Inclusion.
- Effective verbal and written communication with professional interpersonal skills.
- Excellent IT skills (Microsoft Office) to maintain accurate case recording and produce clear reports, correspondences, and presentations.
- Self-motivated with the ability to manage own diary, accept responsibility for own area of work, identify issues and pro-actively source solutions with minimum supervision.
- Highly detail-oriented and organised with a positive and flexible attitude, managing multiple cases simultaneously to meet the demands of the role.
- Tact, discretion, and respect for confidentiality.
- Ability to undertake a representational role, effectively challenging poor policies and practices and upholding the rights of the individual in a professional manner.
- Caring, compassionate, empathetic, and supportive, with a genuine interest in supporting others.
- Good analytic and assessment skills to inform and improve outcomes for individuals and families.
- Ability to evaluate and reflect on own professional practice and identify when training is needed.
- Team player as part of a small, dedicated team.
- Current valid UK driving licence with no more than 6 points and access to a car.

Whilst a relevant qualification within health & social care, education or a related field is desirable, other knowledge and work experiences are equally as valuable in this role. You may have experience working with and supporting mental health; the welfare benefits system; multi-agency working; knowledge of the needs of individuals affected by life limiting/ chronic diseases and their families; an awareness of health provisions to promote access to appropriate clinical management and support; or knowledge of palliative care and end of life.

We are also looking to expand and further develop our service therefore a proven ability to undertake project work, and a keen interest in supporting our online support and advice service via social media channels would be advantageous.