



MPS Society

Job Title: Senior Support Officer (with special interest in neurology)

Reporting to: Head of Support

Hours: Full time 35 hours per week (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

Join our team at the MPS Society, one of the leading rare genetic disease charities in the UK aiming to transform the lives of individuals and their families affected by MPS, Fabry and other related lysosomal diseases. This is a rare opportunity to join our Support & Communities teams who provide direct support, practical guidance and other patient focused activities to over 1500 members and their families, UK-wide.

We are looking for someone with ability and enthusiasm who will enjoy working as part of a small, dedicated team providing a UK-wide service that offers information, advice, support and advocacy in areas including clinical management, social care, housing, education, transition, independent living, palliative care and bereavement. You will need to have excellent written and oral communication skills, upholding best practice, challenging poor policy and inappropriate decisions. Ensuring that the individual or family remain at the centre of support is a key element of the post. A positive attitude and willingness to work with and support the Head of Support in the development of the team is essential.

You will work collaboratively with both internal departments and externally to raise awareness, advocate for our membership, as well as supporting the delivery and development of services for the MPS Society community.

Applicants for this role must ideally be a qualified to degree level or equivalent in a relevant field, for example health, social care or education. Prior knowledge of MPS and related conditions is not required as in-depth support and training will be provided. You will be required to develop expertise in MPS and related conditions, and the needs of those affected by these progressive, life-limiting conditions.

We offer flexibility in working hours, free on-site parking, a competitive salary, 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 to find out more about us and the community we serve.

For an informal discussion about the role or the work of the MPS Society, please contact Bethanie Pentecost on 0345 389 9901 or b.pentecost@mpsociety.org.uk

Key Responsibilities:

Management support

- To take a lead role in monitoring and keeping up to date with all appropriate legislation, knowledge and skills required to ensure the advocacy team are kept up to date and informed.
- To be a deputy lead safeguarding officer for both children and vulnerable adults, taking the lead in the absence of the Head of Support, Head of Projects & Communities and/or Senior Head of Patient Services and Clinical Liaisons. Online safeguarding concerns are managed by the Head of Projects & Communities and/or Head of Communications.
- To take an active role in team meetings; providing updates and training to the rest of the team where appropriate.
- To act as a mentor and where appropriate line manager of new recruits; as directed by the Head of Support.

Patient support services

- Have a good knowledge and understanding of MPS and related diseases with expertise to work as the named worker for a designated group of conditions.
- Follow legislation and best practice relevant to supporting people with disabilities.
- Provide an individual needs led service to members, their families and carers by providing support, information and guidance in areas such as, new diagnosis, education, social care, welfare benefits and home adaptations when requested.
- Support 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 during palliative care, end of life, bereavement and post bereavement.
- Provide a telephone helpline service to all service users.
- Maintain accurate individual member records on the MPS Society's database at all times.
- Undertake UK wide travel as required to attend meetings, visit families and attend regional hospital clinics.
- Support the preparation and organisation of the MPS Society's regional, national and online events, attending as required. This will include assessing need and risk to develop care plans for members attending.
- Work with colleagues to undertake research opportunities as the opportunity presents itself.
- Provide a support service to members of our LSD Collaborative partners as required.

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 when required.
- Promote awareness of MPS diseases and the work of the MPS Society by giving talks and presentations to outside organisations, professionals and the general public.

Continuous professional development

- Maintain a high level of professional conduct, ensuring clear professional boundaries when representing the Society.
- Maintain professional development through training and supervision to meet changing demands of the job.
- Maintain own professional registration with relevant bodies.
- To undertake such other duties, training and/or hours of work that may be reasonably required, and which are consistent with general levels of responsibility for the job.

General Responsibilities

- Participate in appropriate team and organisational meetings.
- Adopt a positive approach to personal and professional development, engaging in regular one-to-one meetings and an annual performance review with line manager.
- Attend training events relevant to the specific responsibilities of the role.
- Attend occasional UK and international conferences and events out of hours where required.
- Carry out any other reasonable duties as requested by your line manager.

Changes to key responsibilities

If for any reason it is necessary to make changes to the responsibilities in this job description this will be discussed in advance between the post holder and the supervising line manager.

Essential requirements:

- Eligibility to work in the UK.
- 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 and willing to drive UK wide as required.

- **Disclosure & Barring Check (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 through our dedicated support and advocacy service, telephone helpline, clinical research, online activities and forums, annual events, patient expert meetings, focus groups and conferences. MPS staff, trustees and volunteers may be asked to be involved in the delivery of its regulated services and activities.

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 an enhanced DBS check as part of the recruitment process and for this to be reviewed on a regular basis.

Further information:

Location and working hours:

This post is primarily based in our Amersham office, however 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.

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

Person specification:

As the ideal candidate, you will be a team player who enjoys working as part of a small, dedicated team and have:

- Eligibility to work in the UK.
- GCSE grade 5+ (A-C) or equivalent in English, Maths and Science.
- 2 years' experience of working with individuals with neurological disabilities in a direct support role within health and social care, education or related field.
- Demonstrable experience and knowledge of health & social care, education and relevant assessment processes.
- Expertise of the needs of individuals with disabilities and their families; and an awareness of Equality, Diversity, and Inclusion.
- Knowledge of palliative care and end of life.
- Experience in multi-agency working.
- Awareness of health provisions to promote access to appropriate clinical management and support.
- Exceptional verbal, written and IT skills to produce clear and accurate reports, correspondences, case records and presentations.
- Experience of working across teams to provide a high-quality service.
- Good organisational, time management and prioritisation skills with a strong attention to detail.

- Good analytic and assessment skills to inform and improve outcomes for individuals and families.
- Ability and willingness to proactively support other team members, including new recruits by providing mentoring and training.
- Ability and willingness to support the team manager and to deputise as required.
- Ability to work flexibly to meet the demands of the role, managing own workload and work using own initiative.
- Effective communication and interpersonal skills at all levels.
- Effectively challenge poor policies and practices and uphold the rights of the individual.
- Tact, discretion, and respect for confidentiality.
- Self-motivated with a positive and flexible attitude.
- A caring, compassionate, empathetic, and supportive nature, with a genuine interest in supporting others.
- Ability to evaluate and reflect on own professional practice and identify when training is needed.
- Confidence and ability to act in a representational role for the organisation.
- Be a team player.
- A current UK driver's licence, with no more than 6 points, access to a car and be able and willing to travel UK wide as required.
- Passionate about the MPS Society's mission and aims.

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

Next steps:

Applications:

Applications should be made to HR@mpssociety.org.uk

Please provide your CV and a supporting statement (maximum 750 words) outlining your understanding of how rare, complex and progressive conditions such as Mucopolysaccharidoses (MPS), including their neurological impacts, can affect individuals and families across the life course. In your response, please describe the experience, skills and approaches you have developed that would support you to carry out the Senior Support Officer role, including (where relevant) supporting people with complex needs, working across health, education and social care systems, and providing advice, advocacy or casework support.

Kindly note, applications received without a supporting statement will not be considered.

Closing Date: Whilst we have an initial closing date of 20th March, we reserve the right to close this vacancy early if we receive enough suitable applications to take forward to interview and assessment.

1st interviews: Initial virtual interviews will be held end March/early April.

2nd interviews: Final face-to-face interviews and assessments will be held on 16th & 17th April at MPS House, Amersham.