MPS Commercial

Specialists in the provision of patient focussed, rare disease services to the pharmaceutical industry

With our combined experience of over 35 years we can offer you bespoke solutions

- Clinical trial logistics
- Patient focussed research
- Managed Access programme support
- Medical communications

MPS Commercial

Logistical services for your clinical trial patients

We provide worldwide logistical support to patients with MPS and other rare conditions. Our services were developed in response to the complex requirements of patients with rare conditions. Often patients will need to travel long distances to attend their clinical trial centre and may even need to relocate for the duration of the trial. Through in-depth knowledge of the needs of these patients and their families we are able to provide the support they need to access and remain on your clinical trial.

- We are experts in the ultra-rare diseases field, providing fully managed logistics to ensure patients can access clinical trials
- Our service includes out of hours support, which can be accessed by non-English speaking families
- We provide a patient-led service and are experienced in finding solutions to unique challenges

The needs of patients can vary hugely from country to country. Poor literacy levels and no access to emails, bank accounts or identification documents can be a reality for many, so we have created a flexible approach to meet these demands.

Collection of patient reported outcomes to support reimbursement

The first Managed Access Agreement (MAA) of its kind was established to provide individuals with Morquio A (MPS IVA) access to enzyme replacement therapy in England. Since the establishment of the MAA in December 2015, MPS Commercial has been responsible for collecting the quality of life (QoL) data from patients and reporting the outcomes to clinicians, NHS England, NICE and the Market Authorisation Holder.

We pride ourselves on the quality, accuracy and completeness of the data collected. This is achieved through the establishment of an in-house team who conduct patient interviews to our defined and consistent methodology.

Our experience in meeting the unique demands of an MAA means that we are able to offer our services in support of future MAAs for rare diseases. We can provide:

- advice on the collection of QoL data
- experienced in-house staff with Good Clinical Practice and Pharmacovigilance training to collect patient reported outcomes, including home visits where necessary
- provision of translators and interpreters for non-English speaking patients and their families
- secure systems for recording and reporting data
- established relationships with expert clinical centres, NHS England and NICE
- publication support

Why we are unique

We understand the challenges of working in rare diseases

From the difficulties faced by a family wanting their child to participate in a clinical trial taking place hundreds of miles from their home, to the need to provide additional data to support reimbursement post approval; we have a thorough knowledge of the issues faced by companies working in the rare disease arena and the expertise and experience to support you.

We have direct access to patients

When you need the disease insight that can only be gathered through talking directly to patients and their families, we are in the unparalleled position of having direct access to those with Fabry, mucopolysaccharide (MPS) and related lysosomal storage diseases in the UK. Our established connections with international patient organisations and networks allows us to conduct your research multi-nationally, if required.

We fund research and patient support services

As a not for profit subsidiary of the MPS Society UK, we are a company which strives to improve the lives of patients with MPS and related lysosomal disorders through research and access to medicines. We reinvest any profits for the purposes of education, enhancing advocacy support, quality of life research and scientific research.

Specialist rare disease medical communications

We can help you publish the results of studies we have conducted on your behalf, or your own research. We can also develop disease awareness and patient directed materials, ensuring the content and language are suitable for the target group. We can offer:

- in-house medical writers, communications and information specialists
- in-depth knowledge of MPS and related rare diseases

Bespoke research

There is often a lack of published information on the natural history and impact of rare diseases. Through the membership of the MPS Society UK, we have access to 1300 patients with MPS and related lysosomal storage diseases; and our close working partnerships with international rare disease networks and individual patient organisations allows us to conduct studies across patient populations.

We can design and conduct a bespoke study specifically designed to address your information needs and offer:

- a highly qualified and experienced team to create a bespoke solution to answer your research question
- a custom study to meet your needs including postal and on-line questionnaires, patient interviews and focus groups
- multi-national studies through our extensive network of patient organisations
- full analysis, reporting and publication of your study

MPS Commercial

MPS Commercial was formalised as a company in 2011 to support patients with ultra-rare conditions taking part in clinical trials. As our business continues to grow, we have been able to extend our services to provide patient focussed research and communications.

Non-profit status

MPS Commercial is a wholly owned, not for profit subsidiary of the Society for Mucopolysaccharide Diseases (MPS Society) which is a registered charity.

Our social objectives are to invest any profits into the MPS community for the purposes of education, enhancing needs-led advocacy support, quality of life research and scientific research.

Supporting the MPS Society

As the not for profit subsidiary of the MPS Society, we are proud of the contribution we are able to make to the work of the charity. Recent grants awarded include:

- an in-depth characterisation of Fabry patients with cardiac devices to predict risk of malignant arrhythmia and sudden cardiac death – Queen Elizabeth Hospital, Birmingham; Royal Free Hospital, University College London; Salford Royal NHS Foundation Trust, Manchester
- a pilot study into the value of portable technologies in recording day-to-day patient monitored information in children and young people with Fabry disease – Royal Free Hospital, University College London
- assessing the bioavailability of Genistein in patients with MPS II, MPS IVA and MPS VI – Salford Royal NHS Foundation Trust, Manchester
- genotype-phenotype relationships in Fabry disease to stratify severity and understand heterogeneity using extended family pedigrees – Royal Free Hospital, University College London

Working together

We are always happy to talk through your future projects and how we may be able to help. Please contact us for an informal discussion.

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