SLMSR Sylvia Lawry Centre for
Multiple Sclerosis Research

multiple sclerosis
international federation

UNIQUE MS PATIENT DATABASE NOW WIDELY AVAILABLE

Since 2001, the Sylvia Lawry Centre for MS Research has been building the world’s largest database of patient information – from 20,000+ patients and 81,000+ patient years. This comprises virtually all the MS patients who participated in the placebo arms of the major clinical trials conducted over the past 20 years. Additional data, including active arm data, is routinely incorporated as it becomes available.

This has been the bedrock of the work on statistical analysis of the disease undertaken by the Centre, with the support of the Multiple Sclerosis International Federation (MSIF). Now the two bodies have entered into a contract to widen access to this unique database to clinicians and researchers in the field worldwide.

With this invaluable tool, we hope to enable researchers to plot the way this mysterious disease develops in patients and find effective ways of treating it. We need to tackle the very unpredictability of the course of the disease to be able to understand it.

There are more than 2.5 million people in the world with MS and most were diagnosed between the ages of 20 and 40, although MS is becoming apparent in even younger people, including children. By widening access to the database, we have a real opportunity to involve the whole MS community in striving for these aims.

The database was supplied to the Sylvia Lawry Centre by pharmaceutical companies, universities, clinicians and researchers. It comprises 45 databases containing placebo arms from clinical trials and from academic research centres. There are a total of 15,000 combinations available for exploring MS data.

The Sylvia Lawry Centre is using the database as part of its major research programme and new developments planned include:

- the addition of more datasets as they become available
- the inclusion of treatment data
- the inclusion of patient history
- the extension of this work to a tool for disease management in MS.

The Centre is hoping to improve and accelerate the evaluation of potential new therapies by applying advanced statistical evaluation methodologies. It also hopes to identify those people with MS who might benefit most or who are in urgent need of treatment, by developing a predictive model which can be applied to the individual.

By applying to the Sylvia Lawry Centre, and on signature of a Provision of Data Agreement, authorised researchers worldwide are able to access:

- Synthetic data sets that can be manipulated with sophisticated Online Analytic Processing (OLAP) tools or with your own preferred statistical software packages from your own desktop. The synthetic data sets are constructed with methods developed at the SLC in such a way that they typically reflect all the important statistical properties of the entire database, and can be used to develop stable and robust statistical models, explore hypotheses, check the plausibility of research findings published by other research groups and confirm the stability of published results.

  Synthetic data sets and the rights and obligations laid out in the corresponding Provision of Data Agreement have been developed in such a way that the delivery of these data sets to individual researchers is compatible with the restrictions from the individual data donors.

- The “open” part of the database, from your own desktops, with OLAP tools that will give you the same research opportunities.

If you are already involved in research in this exciting field, or you want to use your clinical or scientific skills to best effect, you can access the database by contacting:

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