Benefits for registered sites

- Increase publicity of your neuromuscular centre among patients, clinicians and industry
- Potential participation in clinical trials and research projects
- Participation in an international network of neuromuscular centres
- Receive information about care recommendations and new developments

Benefits for industry and researchers

- Use an existing network for your research project
- Use the CTSR as a single point of access for feasibility information
- Improve recruitment through a combination of trial sites and patient registry data

How to register as a neuromuscular centre

The CTSR is a password protected database. Registration is free of charge and you can specify for what purpose your data is used. Once you have provided your data it is easy to log-in later and update your information as needed.

To sign up, please go to:
www.treat-nmd.eu/ctsr

By clicking on the “sign up for a new account” link, you can start your registration process.

For technical issues or if you are not sure if your centre has already registered, please contact:
ctsr-info@uniklinik-freiburg.de

Contact

For more general information about TREAT-NMD please visit: www.treat-nmd.eu

For matters concerning the CTSR:

PD Dr. Jan Kirschner
TREAT-NMD Care and Trial Sites Registry
Division of Neuropediatrics and Muscle Disorders
University Medical Centre Freiburg
Mathildenstrasse 1
79106 Freiburg, Germany
janbernd.kirschner@uniklinik-freiburg.de
tel: +49 (0)761-270-43440
fax: +49 (0)761-270-44460

Care and Trial Site Registry (CTSR)

A worldwide database of neuromuscular centres

TREAT-NMD Neuromuscular Network

[Image of a network and contact information]
Background

One of the major organisational hurdles to overcome before initiating a clinical trial is identifying those trial sites capable of recruiting enough patients and offering a specific standard of care and experience in clinical trials. The concept of establishing a Trial Site Registry providing information on personnel, facilities and patient population was born to help pharmaceutical industry and clinical investigators select trial sites.

The CTSR was established in 2007 as one branch of TREAT-NMD, an EU-funded “network of excellence” whose goal it is to improve treatments and find cures for patients with neuromuscular disorders (www.treat-nmd.eu).

As a partner of TREAT-NMD one of Germany’s leading Departments of Neuropaediatrics and Muscle Disorders at the University Medical Centre Freiburg set up the CTSR.

The CTSR is a flexible database and has been continuously expanded with more items and is now also functioning as a database of care centres providing information to health professionals and patients seeking specialised centres worldwide.

CTSR today

As of January 2012, 274 centres in 46 countries have joined the registry. Originally planned as a registry of potential sites for multi-centre clinical trials (see background section), the database has attracted significant interest from industry and academic institutions. Nine official requests for site identification, often in combination with TREAT-NMD patient registry information, were received between 2009 and 2011.

In addition to this primary function, the CTSR has become a valuable resource as an international network of centres treating many types of neuromuscular disorders. It can also be used to disseminate therapy recommendations and to evaluate current clinical practice on a national or international basis. This is currently underway as part of the EU-funded CARE-NMD project (www.care-nmd.eu).

For this purpose, we have expanded the database to include additional questions concerning care settings and clinical research activities, as well as a specific section addressing DMD treatment activities of each of the registered centres. This will also help to identify centres which are able to provide a defined level of care.

Content of the CTSR

General Site Information
- Name of institution, potential principal investigator and contact details

Patient Cohort
- Patient population (disease and age specific)
- Available diagnostic tools

Care Settings
- Members of interdisciplinary team
- Arrangements for transition from paediatric to adult care
- Pulmonary and cardiology care

Duchenne care (examples)
- Types and frequency of assessments
- Current practice concerning steroid treatment
- Availability of non-invasive ventilation

Research and Education
- Participation in clinical trials
- Peer-reviewed publications
- Training activities

Clinical Trial Infrastructure
- Personnel and experience
- GCP training
- Equipment

A complete list of items can be found in the information chart under www.treat-nmd.eu/ctsr