



CARE-NMD project

Dissemination and Implementation of the Standards of Care for DMD in Europe

TREAT-NMD Patients' Voices Workshop Milano Sept 2010

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DMD - Current treatment situation

- Consensus guidelines have recently been published
(Bushby et al. The Diagnosis and Management of Duchenne Muscular Dystrophy. Lancet Neurol.2010;9(1)77-93 and Lancet Neurol.2010;9(2)177-189)
- However, many patients do not receive recommended treatment for many reasons:
 - Knowledge?
 - Access (to information, to reference centres)?
 - Economic?, Cultural?
- Life expectancy varies significantly, probably also “Quality of Life”
- Urgent need to improve treatment!

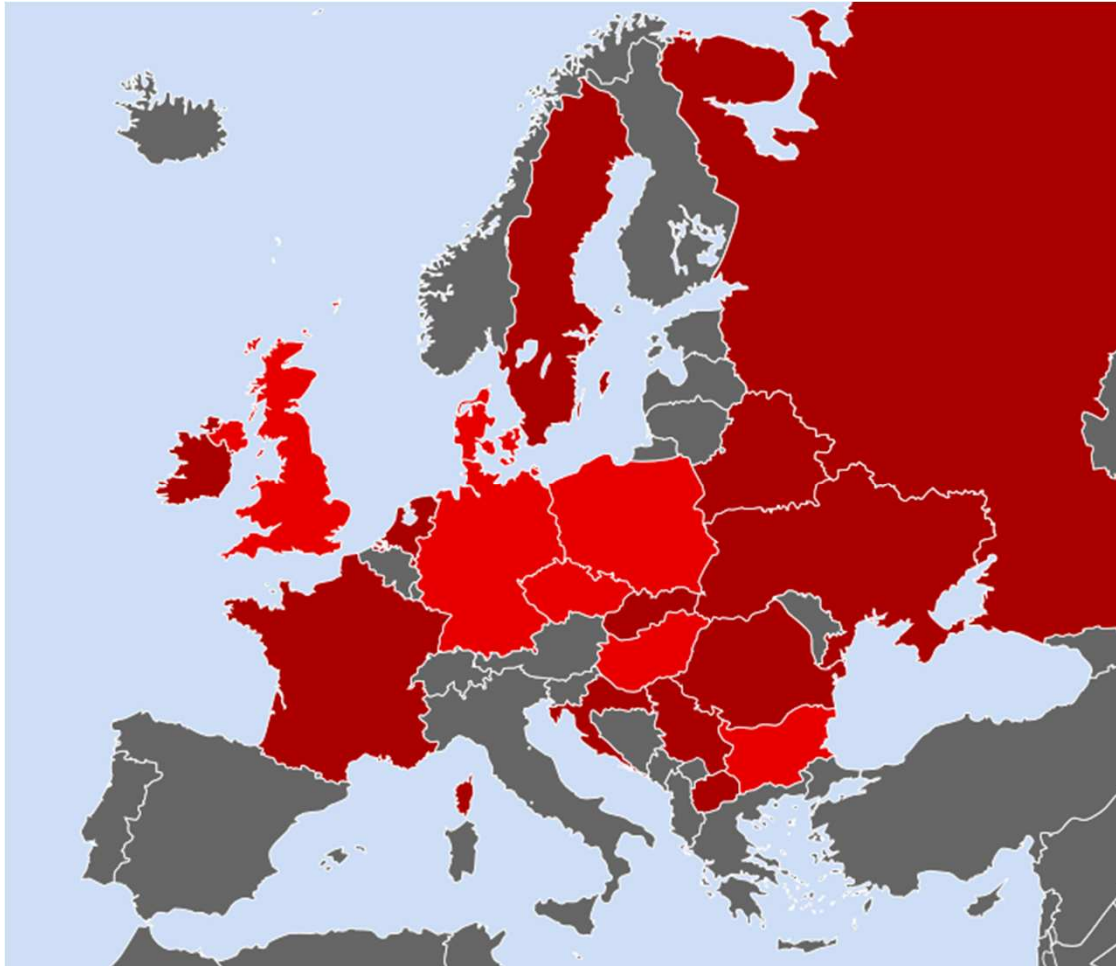
CARE-NMD - funding

- EU health program



- Application for grant of the EU in may 2009
- Selected for funding out of 257 applicants
- Duration: 3 years
- 1.6 M € (60% EU, 40% own resources)
- Official start of CARE-NMD: may 2010

Partners (associated and collaborating)



Associated partners:

University Medical Center
Freiburg, Germany

University of Newcastle,
United Kingdom

Sofia Medical University,
Bulgaria

University Hospital Brno,
Czech Republic

Hungarian Institute of
Environmental Health,
Hungary

Medical University of
Warsaw, Poland

The National Danish
Rehabilitation Centre for
Neuromuscular Diseases,
Denmark

Partners (associated and collaborating)



Reteaua Nationala de Medicina Legală

MEDICINA DVX AVXILIVMQVE IVSTITIAE



United Parent Projects
Muscular Dystrophy

Parent Project
Muscular Dystrophy

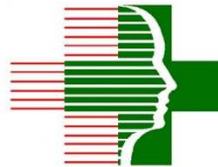
LEADING THE FIGHT TO END DUCHENNE



Deutsche Gesellschaft
für Muskelkranke e.V.



Muskelsvindfonden



Kick-off meeting May 2010



CARE-NMD - Work packages

Management activities

- WP1: Project coordination
- WP2: Project dissemination
- WP3: Project evaluation

Content-related activities

- WP4: Enhancing registration of patients and care providers
- WP5: Evaluation of care practices for DMD
- WP6: Establishing a reference network for DMD treatment
- WP7: Assessing and improving quality of life for boys with DMD

CARE-NMD objective and approach

Standardisation and amelioration of treatment of DMD through

Improvement of

- Knowledge
- Access
- (Resources)

approach

- Assessment of status quo
 - questionnaires
- Implementation of SoC
- Provide information
- Reference network
- Increased awareness and education

Knowledge - Dissemination & Implementation of SoC

- Workshops in participating countries
 - According to country-specific needs
 - Focussing on issues relevant for QoL
- Publish translations of the consensus guidelines (Lancet Neurology) on the websites of CARE-NMD and TREAT-NMD
- Interactive webpage with online discussion forum for professionals

National vs. International Approach

- To reach as many patients and families and professionals we have to respect and use existing national infrastructures
- CARE-NMD aims to use a coordinated multinational approach and provides a toolkit for national implementation of the project
- National implementation workshops are planned in each country involving project partners, professional organizations, patients groups etc.

Collaboration with TREAT-NMD Registries

CARE-NMD aims to

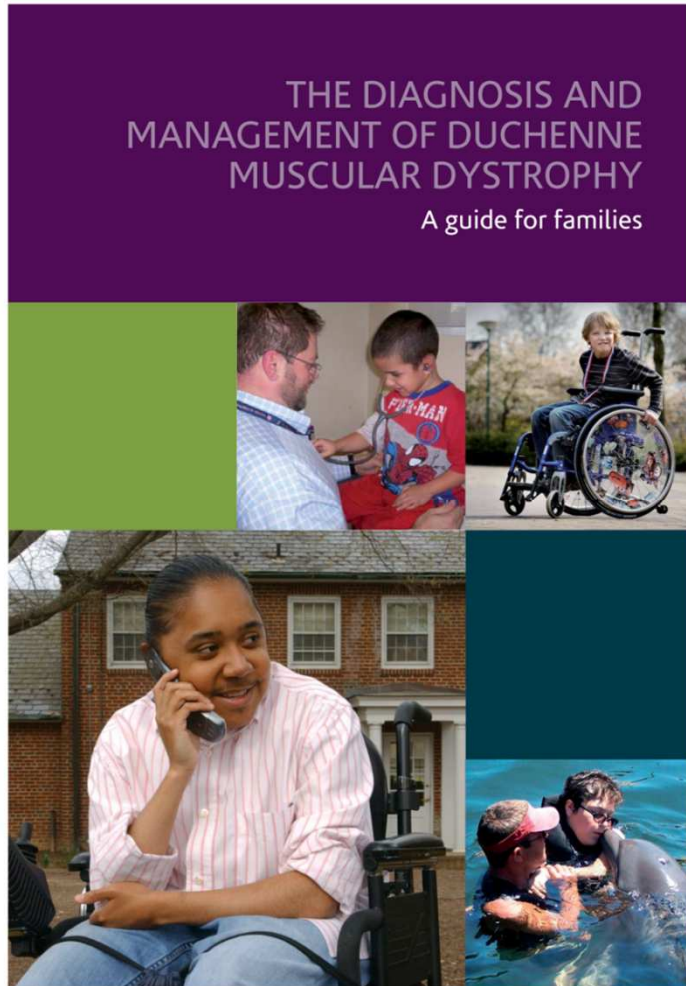
- Increase Registration of Patients and Care sites
- Reach out to patients/professionals through Registries
 - Distribution of Information about the CARE-NMD project
 - Distribution of Questionnaires
 - Distribution of the translated Family guide
 - Information about CARE-NMD activities (e.g. workshops)



Collaboration with Patients' Groups

- UPPMD has been involved in grant application
- ENMC is involved through Jes Rehbek and others
- Many national and international patients' organizations are collaborative partners
- Financial support during the application period through patient organizations from UK, Ireland, Denmark, and Germany
- Continuous involvement of patients during the project (national implementation workshop, training sessions)
- Discussion of care and QoL questionnaires with patients' representatives

Access and knowledge



- Distribution of translated „family guide“
 - On the internet
 - Printed
- Creation of network of national reference centres

English
Deutsch
Български
Dansk
Polski
Čeština
Magyar

CARE-NMD

CARE-NMD is an EU-funded project to implement best-practice standards of care for Duchenne muscular dystrophy across Europe, by bringing together a network of leading care centres.

The project will evaluate existing treatment practices, implement newly agreed international consensus care recommendations, and evaluate their impact on patients' quality of life.

By adopting an inclusive networking approach, targeting both care providers and patients, CARE-NMD will improve accessibility to best-practice care for Duchenne muscular dystrophy patients throughout Europe.

For more information about the project, please contact info@care-nmd.eu.

Standards of Care for DMD

A major international consensus document on best-practice care of Duchenne muscular dystrophy was published in the Lancet Neurology journal in January and February 2010.


The publication of these guidelines, which followed an extensive review process by 84 international experts in Duchenne diagnosis and care, represents a unique opportunity to implement the highest quality care for Duchenne patients across Europe. The guidelines themselves can be viewed at the [TREAT-NMD website](#).

About DMD

Duchenne muscular dystrophy is the most common childhood neuromuscular disorder, affecting approximately one in 3500 to 6000 male births. Caused by a mutation in the X chromosome, it leads to progressive muscle weakness and wasting. Most patients require a wheelchair at the age of 10, and if untreated, the condition leads to death by the age of 20.

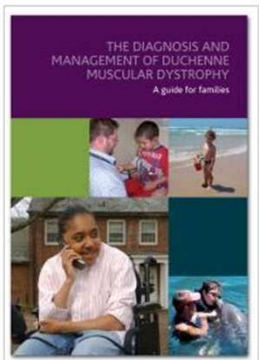
Although there is currently no cure for DMD, a multidisciplinary approach to care can significantly improve both patients' quality of life and life expectancy.

Partners



- [Universitätsklinikum Freiburg](#)
- [BGNMDS](#)
- [Fakultní nemocnice Brno](#)
- [RehabiliteringsCenter for Muskelsvind](#)
- [NIEH](#)
- [Warszawski Uniwersytet Medyczny](#)
- [Newcastle University](#)

[more partners](#)





About TREAT-NMD

- News
- Meetings & Events
- Partners
- TACT

Neuromuscular Diseases

- DMD
- SMA
- Patient Care
- Patient Registries

Research

- Pre-clinical
- Outcome Measures
- BioBank
- Job Opportunities

Industry

- Service Overview
- Trial Sites
- Scientific Advisory
- Study Support

Websites

- TREAT-NMD
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- Registry of Outcome Measures

Projects

- NMD-CHIP
- BIO-NMD
- CARE-NMD
- the ART of TREAT-NMD

CARE-NMD perspectives

- Funding of the CARE-NMD project by the EC is a unique possibility to evaluate and improve care for patients with DMD and their families throughout Europe
- Active involvement of patient representatives, academic institutions, and public organizations is essential
- Participation of collaborative partners will help to disseminate beyond the countries of associated partners
- Aim to reach as many families and professionals as possible, inclusive approach - no exclusivity
- Focus and final goal is the quality of life of patients

www.care-nmd.eu




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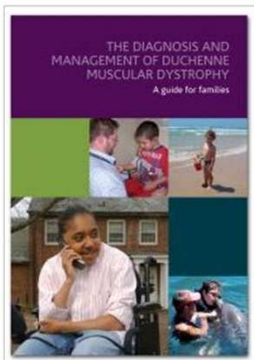
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Thank you!



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