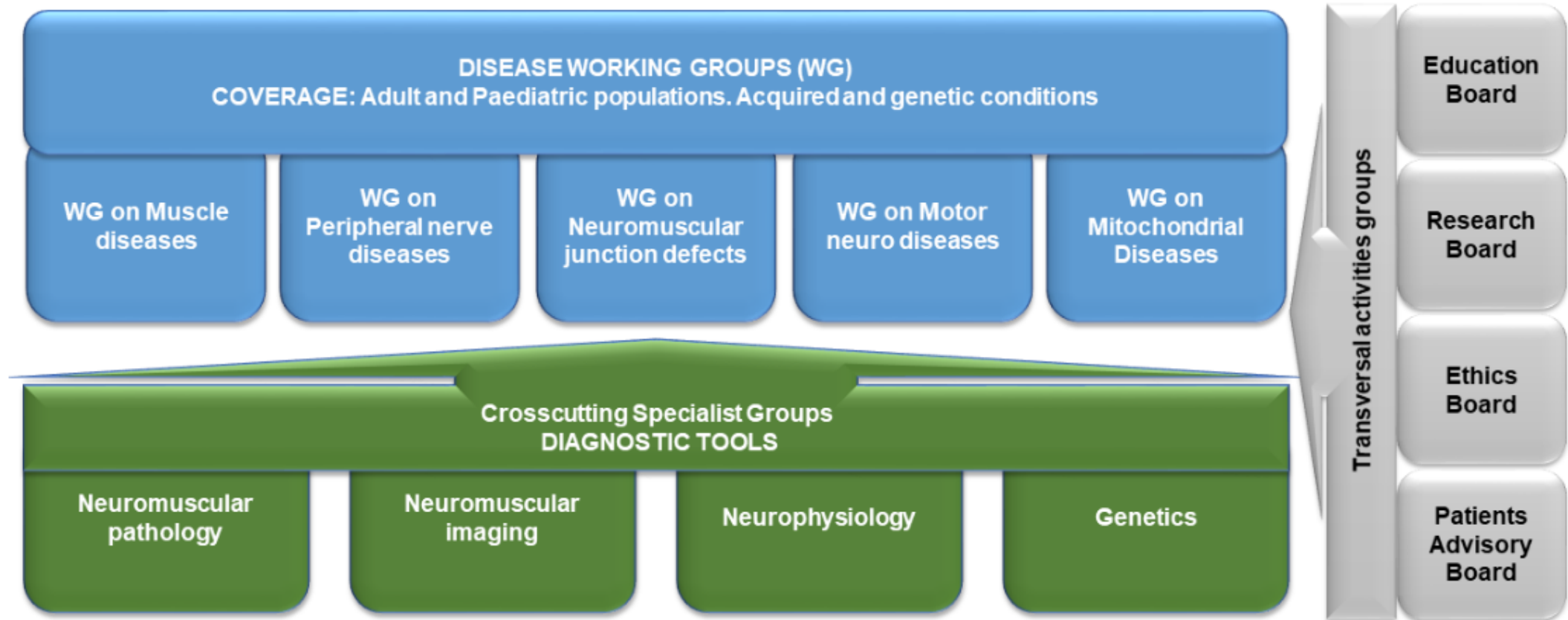


Multidisciplinary treatment and care

A Norwegian initiative for new specialty group in ERN-NMD

Current ERN-NMD groups



Treatment and care of neuromuscular disorders

- A multidisciplinary field
- Few non-medical members in the disease working groups and the specialist groups
- Same need for development and sharing of knowledge

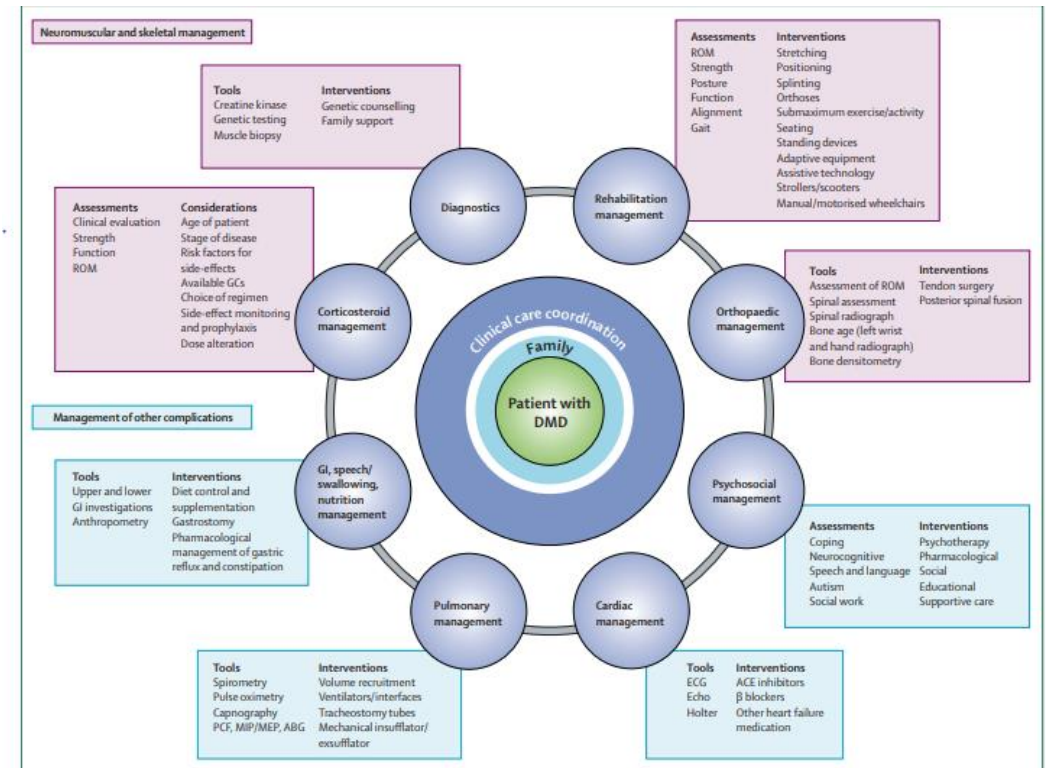


Figure: Interdisciplinary management of Duchenne Muscular Dystrophy. From Bushby et al., 2009, Lancet.

Multidisciplinary treatment and care

Open to all relevant professions involved in management and care of NMD

Cover the areas:

- Physical and occupational therapy
- Speech therapy and oral/dental care
- Dietetics
- Nursing
- Psychosocial aspects
- Social work
- Cognitive assessments and management

Proposed leadership of the group



Chair: Marianne Nordstrøm (PhD)
Clinical Dietitian and Researcher
Frambu Resource Centre for Rare
Disorders, Oslo University Hospital
and University of Oslo



Co-chair: Andreas D. Rosenberger (MSc)
Clinical Specialist in Neurological
Physiotherapy and Head of National
Neuromuscular Centre, University
Hospital of North Norway



Co-chair: Hanne Ludt Fossmo (MSc)
Physiotherapist and PhD-candidate
Oslo University Hospital and
Vikersund Rehabilitation Centre



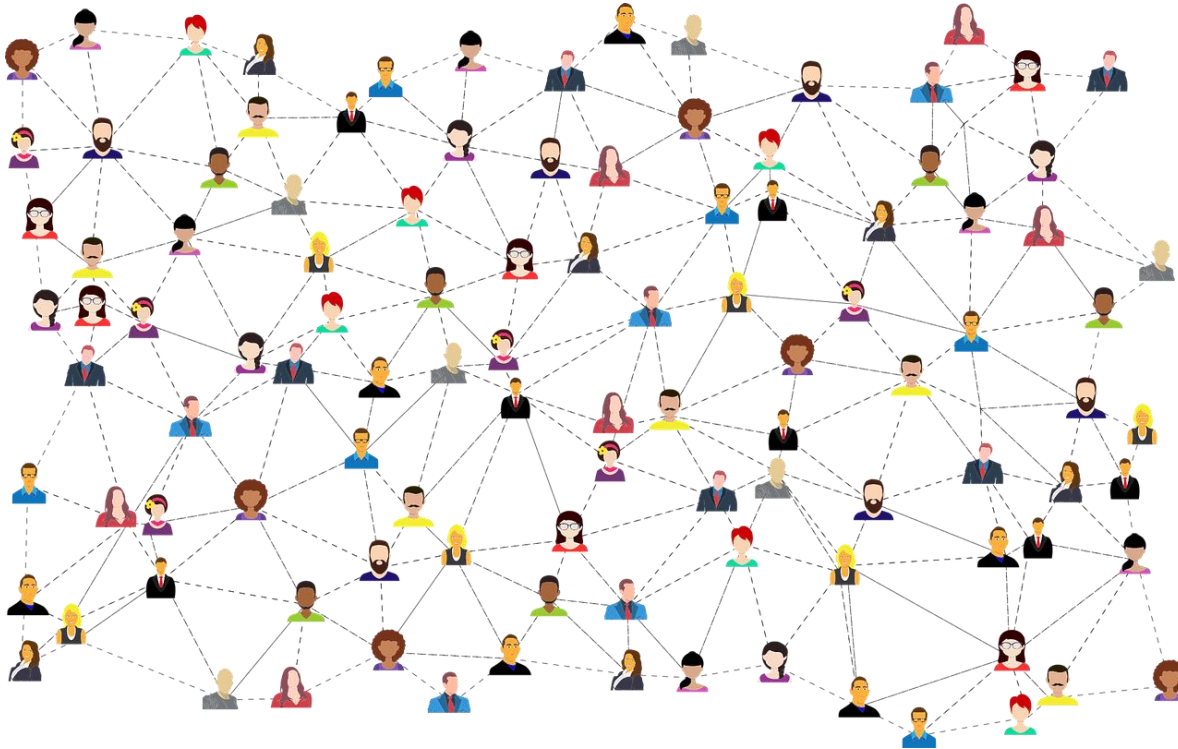
Co-chair: Kristin Ørstavik (MD, PhD)
Senior Consultant in Neurology and
Clinical Neurophysiology. Head of Section
for Rare Neuromuscular disorders and
EMAN, Oslo University Hospital.

Aims

Standardization and validation of multidisciplinary treatment of care by means of:

- Facilitate international multidisciplinary research
- Standardization of clinical outcome measures including patient reported outcome measures
- Family/patient centered care and empowerment
- Develop and endorse the use of evidence based multidisciplinary care guidelines
- Data mining registry projects
- Cross cutting with other working and specialty groups

Activites



- Workshops to facilitate development and collaboration in research projects
- Arrange webinars on relevant topics to the specialty group