SHARING PHYSIOTHERAPY KNOWLEDGE ABOUT RARE DISEASES

- THE STRATEGY OF NATIONAL NEUROMUSCULAR CENTRE (NMK), NORWAY

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NATIONAL NEUROMUSCULAR CENTER, NORWAY

Patients with rare diseases have traditionally met a low level of knowledge about their diagnosis in contact with the health care system, locally and regionally. In order to get more equality and high quality health services to patients with rare diseases, the health care system has been restructured on a national level in Norway. The Norwegian National Advisory Unit for Rare Disorders (NKSD) was organized by uniting 9 centres in 2014. The National Neuromuscular Centre Norway (NMK) in Tromsø is one of these centres. It is an advisory and information centre, as well as a clinical centre with multidisciplinary staff. Three physiotherapists (PTs) specialized in neurological physiotherapy work at the centre.

The PTs are providing assessment and treatment to patients with rare hereditary neuromuscular diseases. Outreach activity from NMK's PTs contributes to increased knowledge, and provide support and areas of interaction for patients, relatives and local health professionals.



Demonstration to participants at the neuromuscular physiotherapy course

SHARING PHYSIOTHERAPY KNOWLEDGE

NMK posts information concerning physiotherapy on their own **web**

page and Facebook page

The specialized centres in NKSD have a

joint web platform nationally

(www.nksd.no), which has simplified obtaining updated diagnose specific knowledge about rare disorders

Presentations

at conferences and a physiotherapy educational institution

SHARING KNOWLEDGE

about principals for high quality physiotherapy service to patients with neuromuscular disorders nationwide:

Organizing network

conferences and clinical courses

regarding pathology, assessment, treatment and training, for PTs nationwide and for rehabilitation institutions

E-learning

program about living
with long-term
mechanical ventilation
has been developed,
and other topics are
planned

All patients get Video

clips of individual physiotherapy treatment recommended for use by the local of PT

Video conferences

with the patient's local health providers if requested



