

TREAT-NMD in Ukraine

- The aim of TREAT-NMD is to improve treatments and find cures for neuromuscular diseases by linking leading clinicians and researchers in a “network of excellence”.
- TREAT-NMD already integrates 21 partner organisations in 11 countries in Europe.
- A number of other countries in Europe (Greece, Czech Republic and Bulgaria) and worldwide (Japan, the USA, Chile, Argentina) are very interested in becoming involved.
- The work of the network includes:
 - Developing “gold standards” for the diagnosis and care of patients with neuromuscular diseases;
 - Creating training and education programs and exchanges to ensure the dissemination of the latest knowledge;
 - Setting up international databases and biobanks of patients with neuromuscular diseases so that researchers working on the latest therapies can have access to patient groups for clinical trials;
 - Developing standardised preclinical and clinical research protocols and safety and toxicology procedures and standardised outcome measures for trials.
- The network aims to include all neuromuscular diseases in the longer term, but its immediate focus is on spinal muscular atrophy and Duchenne muscular dystrophy.
- In SMA, our Italian partners are leading the network’s efforts to accelerate clinical trials for the most innovative therapies by developing consensus on outcome measures and taking promising drug candidates and gene therapy approaches forward from preclinical studies into the trial stage.
- Patient organisations are integrally involved in the network: ENMC (the European Neuromuscular Centre) and EURORDIS are partners within the network, and we are working closely with representatives of EAMDA (the European Alliance of Neuromuscular Disorders Associations) and disease-specific organisations such as SMA Europe.
- The network is very interested in establishing links with Ukraine.
- Networking on a national level first is very important – it is immensely valuable for a network of links to exist *within* a particular country so that the work of the TREAT-NMD network can spread throughout the country.
- We invite interested parties from Ukraine to consider how best to create the in-country networks that would be necessary to implement TREAT-NMD in Ukraine, using patient organisations, professional societies and other links already in existence, and to set up a dialogue with us to establish ways of moving forward together. Any thoughts on opportunities to fund Ukrainian integration into TREAT-NMD would also be welcomed, as we need to seek additional funding to incorporate new members.
- Comments and questions are welcomed by email to info@treat-nmd.eu (the email address of the TREAT-NMD coordination centre in Newcastle upon Tyne, United Kingdom, led by professors Volker Straub and Kate Bushby).
- Patients and patient representatives can be put in touch with our European-wide patient organisation partners EURORDIS and ENMC by writing to info@treat-nmd.eu.
- Please visit our website at www.treat-nmd.eu for further information, where you can also sign up to receive our weekly newsletter.