

Communication and Empowerment of people with a NMD

Follow up from the TREAT-NMD Communication meeting

EUROPEAN
NEURO
MUSCULAR
CENTRE

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EAMDA 40th Annual General Meeting,
Milan, September 17 2010

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What is TREAT-NMD ?

Advancing diagnosis, care
and treatment for people
with neuromuscular diseases
around the world.



TREAT-NMD can't work without the active involvement and support of those people it is all about **People with a neuromuscular disease.**

We have expertise, experience, insight information and knowledge on TREAT-NMD topics as much as physicians and researchers. Combining this strengthens the TREAT-NMD impact for the benefit for all

Concrete outcomes of the “Patient” Voice Workshop

- This meeting- responsive to the need to make sure that there is a meaningful patient voice as TREAT-NMD moves forward
- We need to think both of rights and responsibilities
 - Rights of patient groups
 - Responsibilities of patient groups
 - And responsibilities of the broader network
- Diversity in national needs, set ups and situations
 - Not addressed: diversity of disease specific organisations
 - There needs to be a forum where these diverse groups and needs all have a voice
- Aims need to be achievable - no-one can do everything
 - Not duplicating what others are already fulfilling

Themes identified by patient organisations as crucial

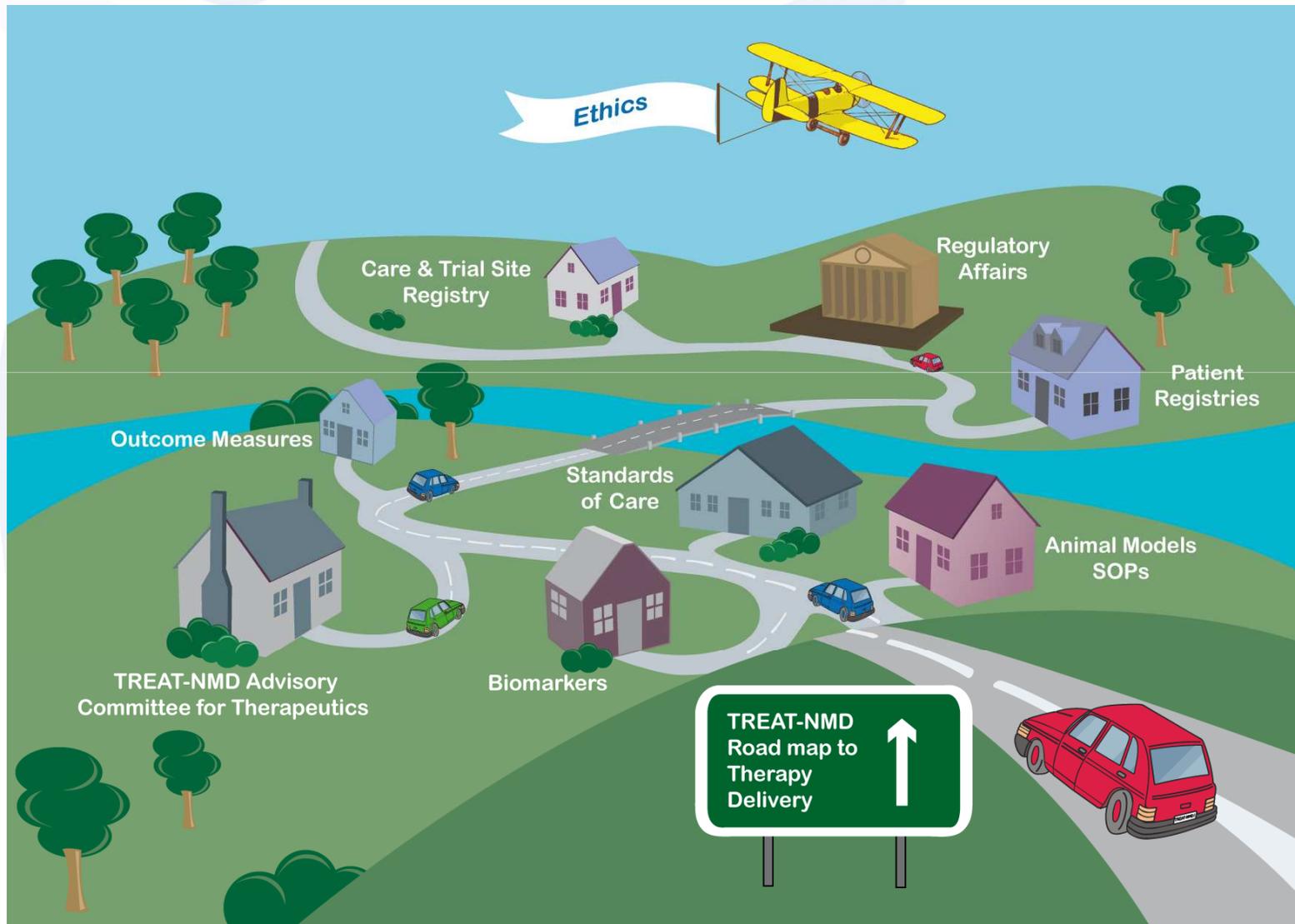
- **Respect, changing attitudes**
 - TREAT-NMD should have this as standard
- **Implementation of standards of care**
 - Rating from patient perspective on care delivery
- **More emphasis on quality of life and disability**
 - Add to current care standards
- **These are key areas where there needs to be full participation from everyone involved in TREAT-NMD:**
 - Define the programmes leading to the outcomes mentioned above
 - Feed into the activities actively depending on national situation

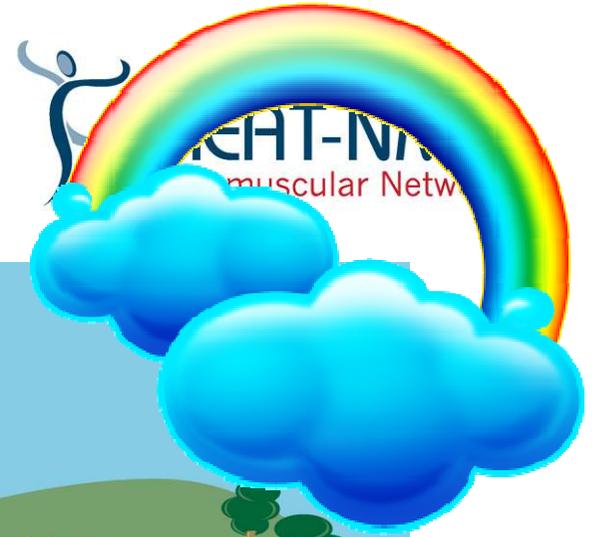
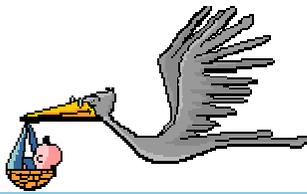
TREAT-NMD is a network addressing issues related to clinical and translational research

- How does this relate to the clinical and translational agenda?
 - Respect: eg trial design, directed and clear communication
 - Implementation of standards of care: integral to trial design and interpretation.
 - QOL: ultimate test of a drug is the impact on quality of life

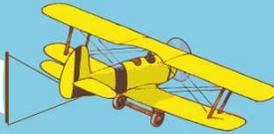
TREAT-NMD guidelines for patient involvement should be developed

- Content can be further developed
- Structure for patient involvement - we will ask you (patient organisations) how this should look
- We all need to take responsibility for making sure we are at the top of the participation ladder
 - Can be a model for other rare disease groups





Ethics



Care & Trial Site Registry

Regulatory Affairs

Patient Registries

Outcome Measures

Standards of Care

Animal Models SOPs

TREAT-NMD Advisory Committee for Therapeutics

Biomarkers

TREAT-NMD Road map to Therapy Delivery



If you as patient organisation or interested 'patient' are interested to participate in the Patient Voice Workinggroup, please contact me at: schoneveldvanderlinde@enmc.org