



**ESTABLISHMENT
OF OFFICIAL
REGISTRY.
SUCCESSFUL
PROJECTS**

**I International medical on-line conference on treatment of patients with Duchenne/Becker
23/12/2020 12.00-16.10**

TOPIC: ESTABLISHMENT OF OFFICIAL REGISTRY. SUCCESSFUL PROJECTS

12.00 (online, English and Ukrainian)

Opening word by the Head of NGO Duchenne Ukraine Alina Yashchenko

12.10 (video record in English with subtitles in Ukrainian)

Establishment and maintenance of official registry of patients with neuro-muscle diseases, including Duchenne/Becker. Neurologist, expert of Czech patients' registry Dr. Lenka Jurikova.

12.40 (online, English and Ukrainian)

**Clinical trials overview in Duchenne muscular dystrophy
Mila Goomanovsky, Research director, Little Steps association for children with DBMD,
Israel**

13.20 (questions-answers online, English and Ukrainian)

13.40 (video record in English with subtitles in Ukrainian)

**Organisation of new groups of adults with neuro-muscle diseases in Czech Republic.
Member of patients' organisation 'End Duchenne', brother of Duchenne patient, David
Petrasek, Czech Republic**

14.10 (questions-answers online, English and Ukrainian)

14.30 (video record in English with subtitles in Ukrainian)

**Noninvasive Ventilation in Duchenne Muscular Dystrophy . Where are we now?
Michel Toussaint, PhD, is affiliated with the Rehabilitation Hospital Inkendaal, Belgium.**

15.00 coffee-break

15.20 (video record in English with subtitles in Ukrainian)

**Presentation of fight with Duchenne. Member of Duchenne family organisation Ilker Carsi,
Turkey.**

15.50 (questions-answers online, English and Ukrainian)

16.10 Final word by the Head of NGO Duchenne Ukraine Alina Yaschenko.

Target audience: doctors, students of medical establishments, patient organisations and parents who have children with Duchenne disease from Ukrainian side, patient organisations, parents, who have children with Duchenne from Czech Republic, Turkey and Israel.

**Videos of speakers will be uploaded on you-tube channel of NGO Duchenne Ukraine.
The transcript of the conference will be placed on the site of NGO Duchenne Ukraine
<http://dmd.org.ua/>.**