

VI Nordic ALS Alliance meeting: "Baltic Bridge"
20.–22.08.2010 in Haapsalu Neurological Rehabilitation Centre

Dear participants of the seminar,

You have come together to talk about ways how to help people who are diagnosed with very serious disease, which yet cannot be cured. Accepting and living with this disease is a challenge first for the patient, but also for their families. Support and knowledge how to provide accurate help for families and also for the health care workers is very important. Best quality of life of the patients should be the goal, and every effort to provide that is very welcome.

Best greetings,

Hanno Pevkur

Minister of Social Affairs

20.08.10 Friday, Social Policy		
Arrival/accommodation/registration	12:00:00-13.00	
Lunch	13.00-14.00	
Opening speech: <i>Küllli Reinup, EAMD; Jens Harhoff, Nordic ALS Alliance</i>	14.00-14.40	
Welcome from the Parliament of Estonia: <i>Urmas Reinsalu</i>	14.40-15.00	
Services provided by Haapsalu N. R. Centre, <i>Riina Mõim</i>	15.00-15.30	
Support for PALS in Island, <i>Gunnar Matthiasson</i>	15.30-16.00	
Refreshing coffee	16.00-16.30	
System of ALS-councillors in Denmark: <i>Jette Möller</i>	16.30-17.00	
Medical and social situation of ALS patients in Russia, <i>Gleb Levitsky</i>	17.00-17.20	
How Denmark treats handicapped people: <i>Jens Dalsgaard</i>	17.20-17.40	
Support for PALS in Finland, <i>Kristiina Jokinen</i>	17.40-18.00	
Dinner	18.00-19.00	
<i>Welcome and icebreaking</i>	19.00-...	
21.08.10 Saturday, Therapies		
Breakfast	8.30-10.00	
Resume of first day - comparing situations	10.00-10.20	
Introduction of the day	10.20-10.30	
Communication assistive technology - from letterboard to My Tobii, <i>A.L. Larsen</i>	10.30-11.15	
<i>Film 15 min Speaking with eyes, Danmark, subtitled</i>	11.15-11.30	
New strategies for the treatment of neurodegenerative diseases: <i>Mart Saarma</i>	11.30-12.15	
Diagnosis of motor neuron disease: <i>Pille Taba</i>	12.15-13.00	
Lunch break	13.00-14.00	
Sleep-disordered breathing and neuromuscular patient: <i>Mae Pindmaa</i>	14.00-14.40	

Symptoms of Sleep-Disordered Breathing, practical tests: <i>Mae Pindmaa, Peeter Pirn</i>	14.40-16.00	Group I, group II
Refreshing coffee	16.00-16.40	
Using bag-ventilation for breathing support, <i>Kristiina Jokinen</i>	16.40-18.00	Group I, group II
Dinner	18.00-19.00	
<i>Stroll together in Haapsalu or discussions together/ Film 1 h: Peeter, Estonian TV, subtitled</i>		
22.08.10 Sunday, Supporting networks		
Breakfast	8.30-10.00	
Join with International ALS-network and few points of independent living: <i>Gudjon Sigurdsson</i>	10.00-10.30	
Ergotherapeut's role with ALS-patients: <i>Jette Möller</i>	10.30-11.00	
10 years of Estonian Genome Center – where we are and what can be done in coming years? <i>Andres Metspalu</i>	11.00-11.40	
Refreshing coffee	11.40-12.00	
Heal yourself with food, <i>Annely Soots</i>	12.00-12.20	
About Latvian PALS situation, <i>Maruta Naudina</i>	12.20-12.40	
Building support system/peer supporting groups and making policy for caretaking of PALS in Estonia	12.40-13.30	
Good-bye speeches/show	13.30-14.00	
Lunch	14.00-15.00	
Departure	15.00-15.30	