

# NORDIC ALS- CONFERENCE

Denmark, August 23 – 25

MUSKELSVINDFONDEN 



It is with great joy that Muskelsvindfonden is inviting to the 9th Nordic ALS-Conference and we are hoping for a big turnout from all Nordic countries. The conference is aimed at ALS-patients, their families, healthcare professionals and health care organization employees.

The conference will be held in English.

We wish to create an atmosphere where new insights, new knowledge, new friendships and networking can flourish. We hope that by coming together we can create a good dialog and a productive debate.

Friday afternoon there will be a timeslot between 16.40 and 17.30 where participants are asked to speak on a topic of their own choice. We advise that participants from each country already at this point start to consider which subjects they find important to discuss.

In addition we ask each country's delegates to prepare a short piece for Friday evening's entertainment. This could e.g. be a small sketch, a song, or something third.

**Date:** August, Friday 23th – Sunday 25th

**Location:** Musholm Bay Holiday Resort,  
Musholmvej 100, 4220 Korsør,  
tlf. +45 -70137700,  
[www.musholm.dk](http://www.musholm.dk) ,  
[musholm@musholm.dk](mailto:musholm@musholm.dk)

**Price:** Participant fee of 250 Euro. The fee covers meals and accommodation from lunch Friday till lunch Sunday. Participants diagnosed with ALS will receive a subsidy of 1500 Swedish Kroner.

For enquiries of accommodation between Thursday and Friday, please contact Musholm directly.

**Registration:**

Before June 1st to Jens Dalsgaard-Jensen,  
email: [jdjals@fiberpost.dk](mailto:jdjals@fiberpost.dk),  
participant fee to be paid no later than June 15th  
to: SPAR NORD 85 10 - 4560248976

Questions and enquiries can be directed to Jutta and Birger at [birgerbj@webspeed.dk](mailto:birgerbj@webspeed.dk)

Muskelsvindfonden, [www.muskelsvindfonden.dk](http://www.muskelsvindfonden.dk)

# PROGRAM

Nordic ALS/MND Alliance meeting  
23rd - 25rd August 2013.

## Friday 23rd of august 2013:

- 12.00 -14.00 Registration and lunch  
14.00 -14.15 Welcome (by Jens Spanfelt, chairman of the conference and Gudjon Sigurdsson, chairman of The Nordic ALS-alliance)  
14.20 -15.00 Presentation of Muskelsvindfonden and Musholm Holiday Center (by Evald Krog, chairman of Muskelsvindfonden)  
15.05 -15.35 The importance of networking (by Jens Spanfelt, teamleader, Muskelsvindfonden)  
15.35 -16.05 Coffee break  
16.05 -16.35 Communication controlled by brain movements. (by Birger Bergman Jeppesen, who has had ALS/MND for 17 years)  
16.40 -17.30 This 50 minutes are open for topics, which any of the participants might find interesting to share with the assembly. The speakers must contact the chairman of the conference during the coffee break. We recommend, that each country appoints a spokesman to prepare a 5-10 minute speech.  
18.30 Get together. A glas of champagne.  
19.00 Dinner.

# PROGRAM

## Saturday the 24th of august 2013:

- Until 10.00 Breakfast in the apartments.
- 10.00 -10.15 The decision whether to prolong ones life with a ventilator or to accept death after being diagnosed with ALS/MND. (by Jens Hansen who has had ALS/MND for 17 years and ventilator for 14 years)
- 10.20 -10.35 topic x by x
- 10.40 -10.55 The challenges living with a ventilator. (by Bo Møller Hansen who has had ALS/MND for 14 years and ventilator for 9 years)
- 11.00 -11.30 The decision to turn of the ventilator once you have got it. When is the right moment and what is the procedure in Denmark. (by Ole Nørregaard, managing doctor of the respiratory dept., Aarhus University Hospital)
- 11.30 -12.00 Coffee break.
- 12.00 - 13.00 Panel discussion on above topics. Moderator will be Jes Rahbek, director of The Danish Rehabilitation Centre for Neuromuscular Diseases. The panel members will represent the different participating countries.
- 13.00 -14.30 Lunch
- 14.30 -15.00 If you live with ALS, so does your family (by Charlotte Bundgaard who lost her husband, Preben, to ALS. Charlotte and Preben raised two young boys during Prebens 10 years with ALS.)
- 15.05 -15.35 The Danish Rehabilitation Centre for Neuromuscular Diseases has a group of consultants, who helps ALS-patients and their families. They will share their experiences with us from several hundreds of meetings with ALS patients. (by Merete Vægter, consultant of The Danish Rehabilitation Centre for Neuromuscular Diseases.)
- 15.35 -16.05 Coffee break.
- 16.05 -16.35 Facing the unthinkable –living the unexpected. Some thoughts on adjusting to a different life (by Gunnar Rúnar Matthíasson, Hospital Chaplain, Reykjavík University Hospital, Iceland)
- 18.30 Dinner and entertainment.

# PROGRAM

## Sunday 25th of august 2013

- Until 10.00 Breakfast in the apartments.
- 10.00 -11.00 Workshops. There will be a number of workshops, where you can discuss any topic related to ALS. The chairman of the conference will call for topics Saturday afternoon.
- 11.00 -11.30 Coffee break
- 11.30 -12.15 Living a happy life with ALS, totally paralysed and with a ventilator. (by Arne Lykke Larsen who has had ALS/MND for 13 years and ventilator for 8 years.)
- 12.20 -12.35 Closing remarks (by Jens Spanfelt, chairman of the conference and by Gudjon Sigurdsson, chairman of The Nordic ALS-alliance)
- 12.35 Lunch and goodbye.