

# Holistic concept on disability organization of people with NMD

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EAMDA AGM, Milan 16<sup>th</sup> -18<sup>th</sup> sept. 2010



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# Does this man have a good life?



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**”It is no disaster to have muscular dystrophy ... but sometimes it is damn difficult!”**

Evald Krog



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# Our goal is to

- Get a good life with NMD
- Get a higher level in quality of life with NMD
- We will not just sit and wait for a cure
- We will act ourselves – not let other act on behalf of us
- All members of our board are people with NMD or parents to children with NMD
- Our research in disease we do mostly by supporting Treat-NMD and ENMC.
- In our rehabilitation center we do research in social fields of NMD.



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# When you ask about disability in general: is it a good life?

**Conclusion:** There is an obvious gap between the way professional people see us and the way we look at ourselves as people with disabilities. Average population does not quite position just as professionals do.



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The overall goal of our organisation:

Muskelsvindfonden aims to **improve quality of life** for people with muscular dystrophy and their families. Quality of life among other things is that you **as a human being** has the opportunity to **participate** in social life - going to school, an education, get a job, go to the movies, to concerts, the theater, sports or whatever you want.



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# From our mission statement

The Muscular Dystrophy Foundation aims to improve **living conditions** for people with muscular dystrophy and other neuromuscular diseases, including:

- to improve treatments.
- to support and stimulate research in these diseases causes **and consequences**.
- to provide information about the diseases.
- to promote **disability policy initiatives to improve social and economic conditions for the disease group**.
- to **organize activities and provide support and service** to members.

The priority of this work has a strong emphasis on **solving the tasks raised by members**



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# Our vision

Muskelsvindfonden will help to **create a society** where there is:

## Space for differences

- Regardless of **gender, ethnic origin, religion, age, disability and sexual orientation.**

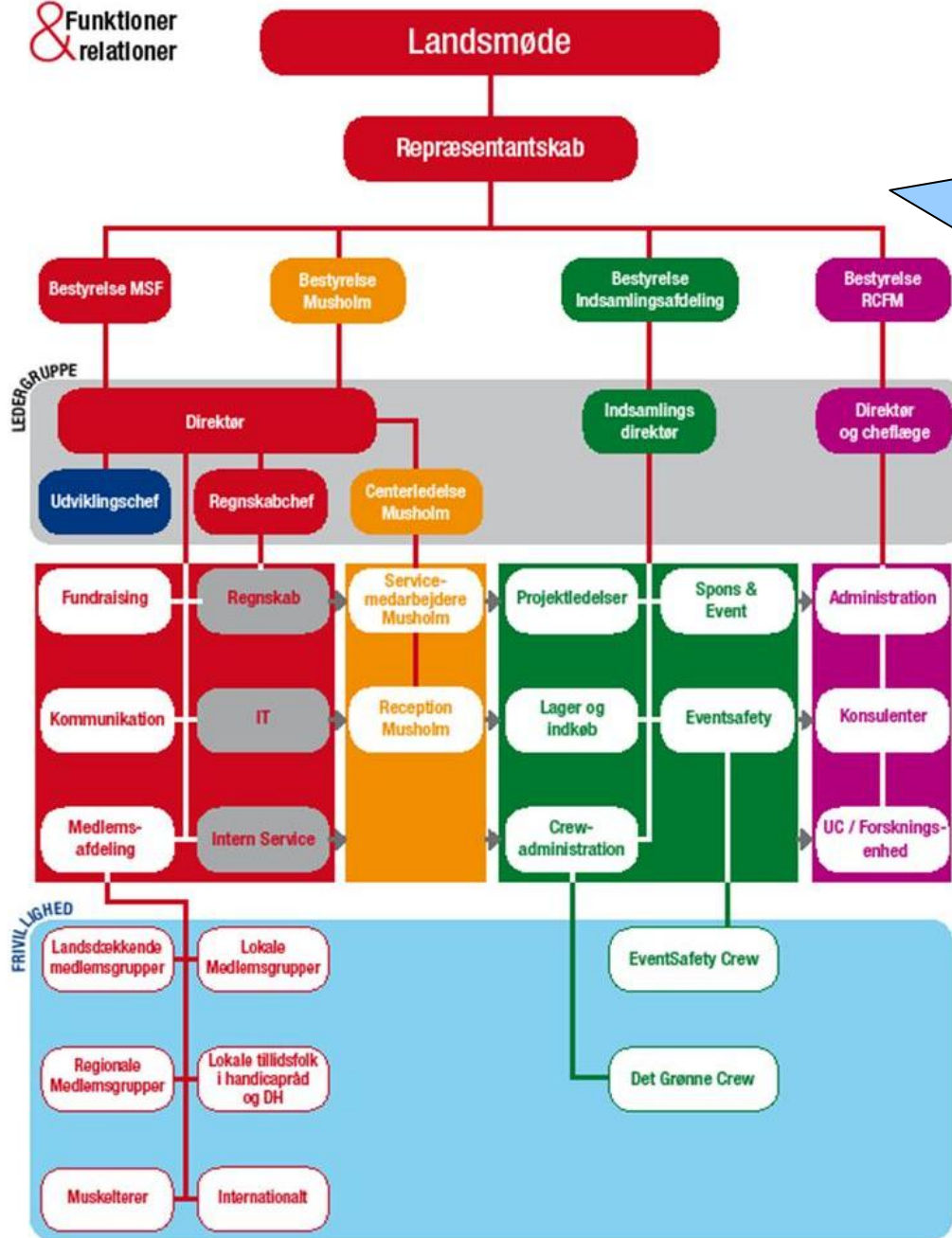
Muskelsvindfonden works for inclusion in all facets of social life by removing as many restrictions on the relationship between people as possible.

Muskelsvindfonden is working to realize our vision among ourselves, among our close relationships and partners and in relation to the surrounding community.



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Political (members) leadership:  
 Annual congress choosing president, vicepresident  
 And a council of 21 choose members for boards  
 4 boards: Muskelsvindfonden, Holiday center,  
 Fundraising, Rehabilitation center of MD  
 Council of Ethics

Managing leadership:  
 Managing director, Fundraising director,  
 Director/chief doctor of rehabilitation Center

Teams of employees:  
 Administration, communication,  
 members department,  
 Research in rehabilitation center

Groups of volunteers:  
 Nation wide members groups,  
 local members groups  
 Crew-members – 3.000 volunteers helping  
 with fundraising at our Green Concerts, Circus  
 Summer



In 2010 190.000 people visitet  
our Green Concerts

In 2010 80.000 persons visited  
our new concept: Circus Summarum



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The idea that all people should freely, openly and without pity accommodate any person with a disability without restrictions or limitations of any kind.

The political and social policy of encouraging tolerance for people of different backgrounds

# Diversity Inclusion

# Space for differences

The 'slogan' of  
Muskelsvindfonden



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# Our memberactivities

- Muskelsvindfonden is a **member organisation** that covers all neuromuscular diseases. There are no other organisations like Muskelsvindfonden in Denmark. **ALS** is a part of Muskelsvindfonden, too.
- Memberactivities covers parentsgroups, groups of grown up people with NMD cooperating with children and groups of young people, groups of certain diagnosis.



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# Our projects

M-power: In this project young adults with muscular dystrophy will be "coaches" for a group of teenagers with muscular dystrophy. The teenagers must be closely monitored in precisely the three-year period of their lives, which must be taken a number of difficult choices in relation to the future: education and labor, and where they are going to be responsible for relations with the public system.

M-power is based on a study one of our social employees in Muskelsvindfonden made a year ago. According to this, a lot of young people in Denmark never got an education or a job, but was on pension – early retirement pension.



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# Quote from study on work with NMD

*"If I had been given the right guidance, I could today have worked as a lecturer in IT or with images"*

Quote Tina Anderson 30 years and early retirement.



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# Quote from study on work with NMD

*"I was afraid that early retirement meant, that I would not get a work. Therefore I asked the my socialworker directly: Does early retirement mean, that I receive less funding for education and towards labor. The answer was a clear "no no we are equally active regardless of retirement" - but it was not true. They have done nothing since."*

*Quote Lasse Myrup, 29 years and early retirement.*



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# Our rehabilitation center

A study in adult life with SMA-II

A section of journalistic stories on the web-site.

Under "profile in English" and "Adult life with SMA-II" you will find these stories in English.



www.rcfm.dk



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# More than 50 years of continuous improvement – will it continue?

In Denmark we have a tradition of development of the social welfare. Sometimes faster.

Sometimes slower. But never before with the loss of rights. This is not the situation any more.

Yesterday our president of EAMDA asked: how will the financial crises affect our situation?

All over Europe this will continue to be the reality.



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# We need more cooperation

In research in diseases!

In research in rehabilitation and the right to live with a disability in the best possible way!

In the political field to avoid more social steps backward!

We need EAMDA to be a strong, professional umbrella organisation uniting all NMD-organisations in Europe.



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# PEOPLE WITH NMD IN EUROPE - UNITE!



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