



# The Role of Patient Organizations

Jes Rahbek

Danish National Center of NMD

Budapest, April 2013



# Role of Patient Organizations

## SLOGANS

Leading the fight to end Duchenne

Erase/cure DMD

Embrace diversity





# Values and political causes

- Improving life conditions for people with NMD
- Acceptance of equal rights – political front
- Influence the outside world's perspective people with a physical disability
- Improving rehabilitation and treatment efforts = longer and better life





# Historical overview

- 1971-1985 secure life/survival  
acceptance – ventilator – wheelchair
- 1985-2000 independant living  
help – access – own home – car – money
- 2000→  
to be like everybody else  
education – job – girlfriend – children -  
holiday – a citizen







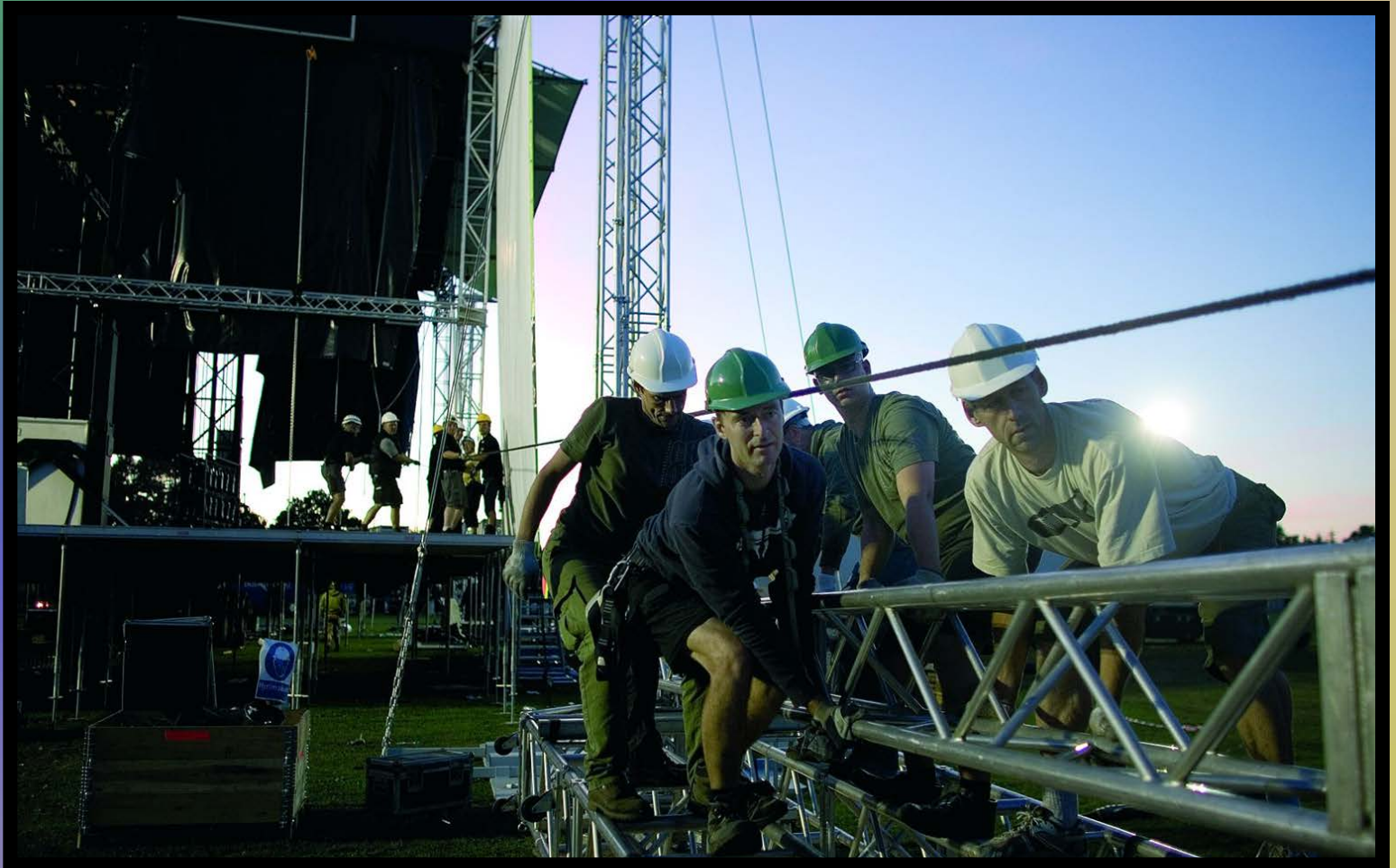
# Music to 190,000 people Fundraising through concerts and circus







# Crew working day and night





# Spreading the word to the audience







# Security and First Aid







# Political Influence

## National: MSF

- Annual General Meeting in May
- The representatives and the board
- Umbrella organisation is Danish Handicap Organizations
- Lobbyism at the parliament
- Active member of national disability organizations

## International: RCfM

- EAMDA / WAMDA
- EURORDIS
- ENMC
- TREAT-NMD
- ALS Alliance





# EMPOWERMENT

- **Aims to strengthen a person's ability to control his/her own life**
- **Cooperation based on respect and acceptance of differences**
- **Influence on how the person experiences his/her own life situation**
- **A member of Muskelsvindfonden is a unique person and an expert on his/her own life**
- **A member takes responsibility for her/himself and her/his family and takes part in all decisions**
- **Member activities are developed by the members and MSF consultants**
- **Decisions are made on the basis of information to the individual member from membership consultants or other competent members.**







# Member groups and workshops



- 2500 members (people with NMD and relatives)
- 15 parent groups, interest groups, diagnoses groups
- Groups based on: age, gender, geographical area
- Workshops, theme days, evening meetings.

RCfM weekend workshops on:

- Diagnoses
- School
- Loss of ambulation
- Focus on family
- NIV/IV ventilation
- Teenage/adult life
- Etc.





# Member activity

**Encouraging members to be active through:**

- **Providing a platform to talk**
- **Networking**
- **Focusing on every-day life, family, children, boy or girlfriend, friends, husband/wife, personal assistants, spare time, job, volunteer work, travel, house, education and much more**







# CONTACT POINTS



- Finding role models
- Annual General M.
- Summer camps
- One-day meetings
- Workshops
- Information
- Projects
- Diagnoses groups
- Concert crew, Muscleteers
- Meetings
- Visiting org. in other countries.



# MUSKELSVINDFONDEN

## The patients' organization

- Muskelsvindfonden
  - 2400 members
  - 2400 volunteers
  - 31 employees
  - RCfM: 36 employees
- Income plus 6 mill. US \$
- Expenses
  - Member activities: 580,000 US \$
  - Dissemination of information: 110,000 US \$
  - Conference center: 150,000 US \$
  - Political work: 135,000 US \$
  - RCfM : 4 mio US \$







# Summercamps

- 90% of all boys with DMD participate in summer camps
- One week







# Summer camps and Club days







# Children's annual meeting







# DMD in Denmark

- 1990 – 90 people with DMD
- 2013 – 160 people with DMD
- 2013 demographics: 50 per cent above the age of 20
- 1990 – oldest person with DMD, 20 years old
- Today several men in their 40s, oldest person 47 years old





# TAKE HOME MESSAGE

- All present, known treatments of DMD result in a larger and older DMD population.
- No cure but delay of symptoms = still a need for rehabilitation (physical, mental and social).
- This is the future challenge for patient organizations.

