

EU DMD Patient Organization Meeting
9-Sep-13
Amsterdam, NL

Patient organisations in Czech Republic:

- **Parent Project**
 - 62 members, all volunteers, no professional employee
 - Goals:
 - Social support of families with children with DMD/BMD
 - Collecting and giving out information about DMD-related research, treatment and care
 - promoting public awareness of DMD and BMD in CR
 - promoting care improvement through cooperation with experts
 - Member of Treat-NMD, UPPMD
- **End Duchenne**
 - Newly established organisation
 - Main goals: fundraising, drug research and development funding

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DMD/BMD in Czech Republic:

- Registry from 2005, now 258 DMD/BMD boys from Czech Rep. and Slovakia
- Good diagnosis and genetic testing
- 2 good neurological centers: Brno, Prague
 - Members of Treat-NMD
 - Participation at Drisapersen CT
 - Increasing quality of care
- Weak points:
 - Lack of experts, not able to cover the whole DMD population
 - No center of complex care
 - Rare use of corticosteroids
 - Respiratory care, cardiac care
 - Improving thanks to documents published by Treat-NMD