Workshop report

238th ENMC International Workshop: Updating management recommendations of cardiac dystrophinopathy - 30 November–2 December 2018

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Highlights

- For families, there is no ‘pre-symptomatic’ phase once dystrophinopathy is diagnosed.
- A care-coordinator facilitated, multi-specialty adult follow-up model is advocated.
- Hearts of patients with DMD should be considered abnormal ‘from the start’.
- Ventricular dysfunction is preceded by changes, detectable by cardiac MR-imaging.
- A patient’s phenotype and not genotype should guide clinical decision-making.

Outline

Highlights

Keywords

1. Introduction
2. The heart in dystrophinopathy and genotype-phenoty...
3. Disease modifying therapies for the heart in dystrophi...
4. Cardiac-specific management for patients with DMD
5. Cardiac Specific Management for DMD / BMD
6. Other heart-related topics in DMD / BMD
7. Conclusions and recommendations
8. Participants
Acknowledgements
Appendix A. Supplementary materials
Appendix 1. Participants responded to the following ques...
Research Data
References