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# Appendices

## Appendix 1. List of Co-Authors and Affiliations

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## **Appendix 2. Curriculum Vitae**

Holly Landrum Peay was born on 15 February in Washington, DC, USA. She grew up in Virginia and attended college at the University of Virginia. In 1995 she graduated with distinction with a Bachelor of Arts in Interdisciplinary Studies in Biomedical Ethics. Holly then attended the University of South Carolina School of Medicine, where she received a Masters of Genetic Counseling degree in 1997.

Holly has a range of professional experience, including developing healthcare provider education programs for the National Coalition for Health Professional Education in Genetics; providing clinical genetic counseling for neuropsychiatric disorders at the Greater Baltimore Medical Center and the National Institutes of Health; and acting as Associate Director of the Master's Program in Genetic Counseling at the National Human Genome Research Institute and Staff Scientist at the Social and Behavioral Research Branch. She has received numerous grants for educational and research projects. Holly was elected to the American Board of Genetic Counseling and the Accreditation Council for Genetic Counseling. She holds an adjunct faculty appointment at the Johns Hopkins Bloomberg School of Public Health in Baltimore, MD, USA.

In 2010 she started studies for her PhD (Prof. Aad Tibben). At present she is Senior Vice President for Community Research at Parent Project Muscular Dystrophy and Director of the DuchenneConnect registry, where she is Principal Investigator of a PCORnet award from the Patient Centered Outcomes Research Institute. In addition, she is a Guest Researcher at the Social and Behavioral Research Branch, National Institutes of Health and a consultant with the United States Military HIV Research Program.

### Appendix 3. List of Publications

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## **Appendix 4. Acknowledgements**

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