

**PPMD's Duchenne Healthcare Professionals Summit
Nugget Casino Resort – Reno, NV
January 19-21, 2022**

Tuesday, January 18

8:00 am – 4:00 pm Neuromuscular Nurse and Coordinator
Preconference Meeting

6:00 pm – 8:00 pm Welcome Reception

Wednesday, January 19

7:30 am – 8:30 am Registration; Breakfast Available

8:30 am – 8:50 am Welcome and Introductions

8:50 am – 9:00 am Introduction to Polling

9:00 am – 10:35 am Session I: The Duchenne Brain

9:00 am – 9:20 am Survey Findings from PPMD's Brain Project

9:20 am – 9:40 am Early Findings from Arkansas Tool Pilot

9:40 am – 10:00 am Recap: 2021 PPMD Brain Meeting

10:00 am – 10:20 am Summary of Psychopharmacology Learnings
from PPMD Brain Meeting

10:20 am – 10:35 am *Panel Q&A*

**10:35 am – 10:50 am Trending Topic: Arkansas EHR Pilot &
Registry**

10:50 am – 11:00 am Break

11:00 am – 12:00 pm Session II: Duchenne & COVID-19

11:00 am – 11:15 am COVID-19 and Duchenne Consensus
Publication

11:15 am – 11:30 am COVID-19 Community Survey Data

11:30 am – 11:45 am Lessons Learned in the Lab: COVID-19 and
Duchenne

11:45 am – 12:00 pm *Panel Q&A*

Parent Project Muscular Dystrophy

JOIN THE FIGHT.
END DUCHENNE.

12:00 pm – 1:00 pm	Session III: Case Study Presentations
12:00 pm – 12:20 pm	Case Study #1
12:20 pm – 12:40 pm	Case Study #2
12:40 pm – 1:00 pm	Case Study #3
1:00 pm – 2:00 pm	Lunch with Subspecialty Breakouts
2:00 pm – 4:00 pm	Session IV: Practical and Ethical Considerations Around Carrier Reproduction
2:00 pm – 2:10 pm	The PPMD Experience with Prenatal Genetic Screening
2:10 pm – 2:40 pm	Currently Available Reproductive Options
2:40 pm – 3:10 pm	Ethical Considerations Around Reproduction
3:10 pm – 3:40 pm	Increasing Prevalence of DMD Mutation in Carrier Screening
3:40 pm – 4:00 pm	<i>Panel Q&A</i>
4:00 pm – 4:15 pm	Break
4:15 pm – 4:25 pm	Live Polling Session II
4:25 pm – 5:25 pm	Session V: Interim Findings from CDCC Collaboration Grant
4:25 pm – 4:45 pm	ACTION Network
4:45 pm – 5:05 pm	Endocrinology Fellowship
5:05 pm – 5:25 pm	Duchenne Journey Map
5:30 pm – 6:30 pm	Welcome Cocktail Reception
6:30 pm – 8:00 pm	Dinner <i>Keynote Presentation</i>
8:00 pm – 9:00 pm	Special Interest Group: GI, Nutrition, and Metabolism

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Thursday, January 20

- 7:00 am – 8:00 am Breakfast Available
- 7:00 am – 7:45 am Breakfast Session I**
Prenatal Genetic Testing Panel
- 7:00 am – 7:45 am Breakfast Session II**
Managing Neurodevelopmental Comorbidities
- 7:50 am – 8:00 am Live Polling Session III
- 8:00 am – 8:45 am **Keynote Presentation: Health Equity**
- 8:45 am – 10:30 am Session VI: Adult Duchenne Care**
- 8:45 am – 9:15 am Palliative Care and End of Life Decision Making
- 9:15 am – 9:45 am Legacy Building: Helping Patients Find Independence and Purpose
- 9:45 am – 10:15 am Assumed Sorrow: Clinician Coping and Maintaining Boundaries
- 10:15 am – 10:30 am *Panel Q&A*
- 10:30 am – 10:50 am Trending Topic: Updated Duchenne Guidance**
- 10:50 am – 11:35 am Session VII: Case Studies**
- 10:50 am – 11:05 am Case Presentation #4
- 11:05 am – 12:20 am Case Presentation #5
- 12:20 pm – 11:35 pm Case Presentation #6
- 11:35 pm – 12:30 pm Lunch**
- 12:30 pm – 2:00 pm Session VIII: Research**
- 12:30 pm – 1:00 pm Overview of Clinical Trial Landscape in Duchenne

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1:00 pm – 2:00 pm Impact of Approved Therapies on Clinical Trials,
Panel Discussion

2:00 pm – 2:20 pm **Trending Topic: Newborn Screening Pilot
Data and Decode Duchenne**

2:20 pm – 2:30 pm Live Polling Session IV

2:30 pm **Free for the Evening**

Friday, January 21

7:00 am – 8:00 am Breakfast Available

7:00 am – 7:45 am **Breakfast Session I**
Clinician Burnout and Boundary Setting

7:00 am – 7:45 am **Breakfast Session II**
*Health Equity, Compliance, and Medical
Tourism*

7:50 am – 8:00 am Live Polling Session V

8:00 am – 10:30 am **Session IX: Post-Gene Therapy Clinical Care**

8:00 am – 9:00 am Long-Term Clinical Care and Management,
Panel Discussion

9:00 am – 9:15 am Break

9:15 am – 10:15 am Post-Gene Therapy Cardiac Considerations,
Panel Discussion

10:15 am – 10:45 am Advocating at the Federal Level for Meaningful
Changes in a Post-Gene Therapy World

10:45 am – 11:15 am Global Access to Gene Therapy

11:15 am – 11:45 am Learnings from Zolgensma

10:45 am – 12:15 pm *Panel Discussion*

12:15 pm – 12:30 pm **Closing Remarks and Conclude**