

# PPMD'S 2026 ANNUAL CONFERENCE



June 24-27, 2026 | Orlando, Florida *Agenda accurate as of June 17, 2026. Subject to changes.*

## WEDNESDAY, JUNE 24

|                   |                                                                                                 |   |
|-------------------|-------------------------------------------------------------------------------------------------|---|
| 3:00 PM - 5:00 PM | <b>Newly Diagnosed Meeting</b><br>(private session)<br>Room: Yucatan                            |   |
| 5:00 PM - 6:00 PM | <b>Newly Diagnosed Reception</b><br>(private session)<br>Room: Yucatan                          |   |
| 6:30 PM - 9:30 PM | <b>Teen/Adult Social hosted by PPMD's PAAC</b><br>(open to all attendees 13+)<br>Room: Monterey | ★ |

## THURSDAY, JUNE 25

|                     |                                                                                                                                                                             |    |
|---------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----|
| 9:45 AM - 10:30 AM  | <b>Dads and Grandads Meet Up</b><br>Room: Fiesta 5                                                                                                                          | 🔗  |
|                     | <b>Meet Your Mentor</b><br>Newly Diagnosed families are encouraged to spend time with their mentor family.<br>Room: Fiesta 6                                                | 🔗  |
|                     | <b>Becker Brunch</b><br>Gather to meet others in the Becker space and learn about Becker specific initiatives, sponsored in part by Edgewise Therapeutics.<br>Room: Yucatan | 🔗  |
| 10:00 AM - 10:30 AM | <b>Gaming and Social Connection</b><br>Room: Monterey                                                                                                                       | ★  |
| 10:45 AM - 11:30 AM | <b>Breakout Sessions:</b><br><b>Moms and Grandmas Meet Up</b><br>Room: Fiesta 5                                                                                             | 🔗  |
|                     | <b>Understanding Genetics in Duchenne</b><br>A Discussion and Open Q&A Session<br>Room: Fiesta 6                                                                            | 🧑🏫 |
|                     | <b>Life with Becker: A Lived Experience Panel</b><br>Sponsored in part by Edgewise Therapeutics.<br>Room: Yucatan                                                           | 🔗  |
| 11:30 AM - 1:00 PM  | <b>From Our Experts to Our Community: PPMD Care Meeting Highlights</b><br>Room: Veracruz C                                                                                  | 🧑🏫 |
| 11:30 AM - 12:00 PM | <b>Global Duchenne Group</b><br>Room: Monterey                                                                                                                              | ★  |

## THURSDAY, JUNE 25 (CONTINUED)

|                    |                                                                                                                      |    |
|--------------------|----------------------------------------------------------------------------------------------------------------------|----|
| 11:30 AM - 1:00 PM | <b>Lunch</b><br>Room: Veracruz B                                                                                     |    |
| 12:30 PM - 1:00 PM | <b>Kids Track Registration</b><br>Room: Durango                                                                      | 👥  |
| 1:15 PM - 2:00 PM  | <b>Main Stage: Official Conference Kickoff</b><br><b>Welcome to the 2026 Annual Conference</b><br>Room: Veracruz C   |    |
| 2:00 PM - 3:00 PM  | <b>Beyond the Diagnosis: The Family Ripple Effect</b><br>Room: Veracruz C                                            | 🧑🏫 |
|                    | <b>Q&amp;A</b>                                                                                                       |    |
| 2:30 PM - 4:00 PM  | <b>Developing Meaningful Relationships</b><br>(Closed to Teen and Adult Track)<br>Room: Monterey                     | ★  |
| 3:00 PM - 3:30 PM  | <b>Break</b>                                                                                                         |    |
| 3:15 PM - 4:30 PM  | <b>Siblings Track Meet Up</b><br>Room: Yucatan                                                                       | 🔗  |
| 3:30 PM - 5:30 PM  | <b>Kids Track</b><br>Room: Durango                                                                                   | 👥  |
| 3:30 PM - 4:30 PM  | <b>Breakout Sessions:</b><br><b>Restoring the Reading Frame</b><br>Exon skipping therapies, Part A<br>Room: Fiesta 5 | 🧪  |
|                    | <b>Managing Inflammation</b><br>Room: Fiesta 6                                                                       | 🧪  |
| 4:30 PM - 5:30 PM  | <b>Breakout Sessions:</b><br><b>Restoring the Reading Frame</b><br>Exon skipping therapies, Part B<br>Room: Fiesta 5 | 🧪  |
|                    | <b>PPMD Funded Research</b><br>Room: Fiesta 6                                                                        | 🧪  |
|                    | <b>Navigating School Support Systems: Understanding and Leveraging Your Academic Team</b><br>Room: Yucatan           | 🔗  |
|                    | <b>DIY Accessibility (PAAC Hacks)</b><br>Room: Monterey                                                              | ★  |
| 5:45 PM - 7:45 PM  | <b>Meet Mickey and Minnie</b><br>Room: Veracruz Foyer                                                                |    |
| 6:00 PM - 8:00 PM  | <b>Welcome Reception and Resource Fair</b><br>Room: Veracruz B                                                       |    |

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## FRIDAY, JUNE 26

7:45 AM- 9:15 AM

**Breakfast**

Room: Veracruz B

8:00 AM- 8:45 AM

**Breakfast Sessions:**

**Lighthouse Meet Up**

Room: Fiesta 5



**Desayuno en Comunidad: Conexión para familias de habla hispana**

Room: Fiesta 6



**Resources for Approved Therapies Access**

Room: Yucatan



9:00 AM - 9:45 AM

**Keynote Address**

Joel Wood, President and Co-Founder of the Foundation to Eradicate Duchenne (FED)

Room: Veracruz C

9:00 AM - 11:00 AM

**Kids Track**

Room: Durango



9:45 AM - 11:00 AM

**Siblings Track Meet Up**

Room: Yucatan



9:45 AM - 10:30 AM

**The Heart of the Matter: A Cardiac Care Panel**

Room: Veracruz C



10:30 AM - 11:00 AM

**Cardiac Research Therapies**

Investigational & Repurposed Progress

Room: Veracruz C



11:00 AM - 11:15 AM

**Break**



11:00 AM - 12:30 PM

**Travel 101**

Room: Monterey

11:15 AM - 12:30 PM

**Breakout Sessions:**

**Essential Elements of Care: Insights from Specialists**

**Early Care**

Room: Fiesta 5



**Middle Childhood**

Room: Fiesta 6



**Teen/Adult**

Room: Yucatan



11:15 AM - 12:30 PM

**Kids Track**

Room: Durango



## FRIDAY, JUNE 26 (CONTINUED)

12:00 PM - 1:30 PM

**Meet the Incredibles Lunch**

A special character lunch sponsored by Elite Sponsor, Sarepta Therapeutics.

Room: Veracruz A



**Siblings Lunch**

Room: Yucatan



1:30 PM - 3:30 PM

**Kids Track**

Room: Durango



1:30 PM - 3:00 PM

**Main Stage:**

**Gene Therapy: Today & Tomorrow with Q&A**

Room: Veracruz C



1:15 PM - 2:15 PM

**Remembrance of Those We've Lost**

Room: Monterey



2:15 PM - 2:30 PM

**PAAC Member Talk**

Room: Monterey



2:30 PM - 3:30 PM

**Mental Health and Well-being**

Room: Monterey



3:30 PM - 4:15 PM

**Breakout Sessions:**

**Beyond Dystrophin Restoration: Approved and Investigational Products**

Room: Fiesta 5



**Support at Every Stage: What Palliative Care Really Means**

Room: Fiesta 6



**Understanding Services:**

**What are Medicaid, SSI and other Services Useful in our Community**

Room: Yucatan



4:30 PM - 5:30 PM

**PPMD Team Open House**

If you need some support or want to check in with a member of the PPMD team, we're here!

Room: Yucatan

4:30 PM - 6:30 PM

**DDDR Meeting (Private)**

Room: Monterey

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## SATURDAY, JUNE 27

7:45 AM - 9:15 AM

**Breakfast**  
Room: Veracruz B

8:00 AM - 8:45 AM

**Breakfast Sessions:**  
**Family Assistance with Team Joseph**  
Room: Fiesta 5



**Carrier Connections**  
Room: Yucatan



9:00 AM - 10:00 AM

**Understanding the Brain and Behavior Across Life's Stages**  
Room: Veracruz C



9:00 AM - 11:00 AM

**Kids Track**  
Room: Coronado A



10:00 AM - 11:00 AM

**Main Stage:**  
**Research: Looking Ahead at Gene Therapy (Part 2)**  
Room: Veracruz C



**Breakout Sessions:**  
**Real Life Behavior**  
Open Q&A/discussion on managing behaviors in daily life.  
Room: Fiesta 6



**Difficult Conversations about Future Plans**  
(Open to all attendees 18+)  
Room: Monterey



11:00 AM - 11:15 AM

**Break**

11:15 AM - 11:30 AM

**PAAC Member Talk**  
Room: Monterey



11:15 AM - 12:15 PM

**Breakout Sessions:**  
**Practical Tips For Thriving at School: Friendships, Behavior and The Learning Environment**  
Room: Fiesta 6



**Finding Your Path After High School**  
Room: Yucatan



## SATURDAY, JUNE 27 (CONTINUED)

12:30 PM - 1:30 PM

**Lunch**  
Room: Veracruz B

12:30 PM - 1:30 PM

**Lunch 'n Learn Sessions:**  
**Emergency Care for Cardiac, Pulmonary and Neuromuscular Emergencies**  
Room: Fiesta 5



**Grandparents Lunch**  
Room: Fiesta 6



**Balancing Caregiving and Romantic Relationships**  
When your caregiver is your spouse or significant other.  
Room: Yucatan



1:45 PM - 2:45 PM

**Breakout Sessions:**  
**What's New in Carrier Care and Research**  
Room: Fiesta 5



**Ask a PT/OT**  
An informative session to answer your physical and occupational therapy questions.  
Room: Fiesta 6



**Cardiac Advanced Therapies**  
• Advanced Medications  
• What to expect if you're admitted  
• The Heart-Lung Connection  
• Adult Cardiac Decision Making  
Room: Yucatan



2:30 PM - 3:30 PM

**Jobs and Working**  
Room: Monterey



2:45 PM - 4:30 PM

**Kids Track**  
Room: Coronado A



2:45 PM - 3:00 PM

**Break**

3:00 PM - 3:30 PM

**Winner of 50/50 Announced at 3:00 PM**  
Room: Veracruz C

**Mainstage Session:**  
**Moving Advocacy Forward: Duchenne and Becker in Today's World**  
Room: Veracruz C



**Breakout Session:**  
**Family Assistance with Team Joseph**  
\*Repeat Session for those that could not attend Breakfast Session.  
Room: Fiesta 5



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## SATURDAY, JUNE 27 (CONTINUED)

3:30 PM - 4:10 PM

### Main Stage:

#### Exercise Throughout the Lifespan

What do we know about exercise in dystrophinopathy and how do you find the right exercise program for different individuals.

Room: Veracruz C



4:10 PM - 4:30 PM

### Late Breaking News

Room: Veracruz A

4:30 PM - 5:15 PM

### The Sibling Experience

A candid panel where siblings share their perspectives on growing up in a Duchenne household, offering insight into the challenges, connections, and unique bonds that shape their journeys.

Room: Veracruz A



5:15 PM - 5:20 PM

### Closing Remarks

Room: Veracruz A

5:20 PM - 5:45 PM

### Community Group Photo

PPMD team will guide you to photo location.

6:00 PM

### Transportation to Animal Kingdom

\*You must be in PPMD t-shirt with conference badge to board bus.

7:00 PM - 10:00 PM

### The Lion King Event at Animal Kingdom

## Key



= Kids Track



= Teen/Adult Sessions



= Care Sessions



= Research Sessions



= Community Sessions  
(Carriers, Siblings, Dads, Grandparents, etc.)



= Advocacy Sessions