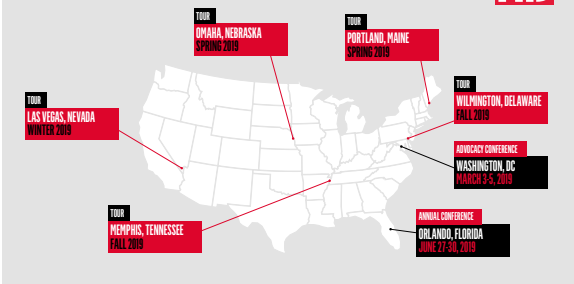


## 2019 EDUCATIONAL EVENTS



## Parent Project Muscular Dystrophy End Duchenne Tour Saturday, September 14<sup>th</sup>

**Nemours Children's Health System  
Lecture Hall  
1600 Rockland Rd.  
Wilmington, DE 19803**

8:00 – 8:15	<b>Breakfast &amp; Coffee Available</b>	
8:15 – 8:30	<b>Welcome &amp; Introductions</b>	Pat Furlong <i>Parent Project Muscular Dystrophy</i>
8:30 – 9:00	<b>Orthopedic Standards of Care</b>	William Mackenzie, MD <i>Nemours Children's Health System</i>
9:00 – 9:30	<b>Physical Therapy Standards of Care</b> *Sign up for individual appointments	Laura Dougherty, PT <i>Nemours Children's Health System</i>
9:30 – 10:00	<b>Research Overview</b>	Pat Furlong <i>Parent Project Muscular Dystrophy</i>
10:00 – 10:15	<b>Research at Nemours Children's</b>	Michael Lo Sapio <i>Parent</i> Melissa Witman, PhD <i>University of Delaware</i>
10:15 – 10:30	<b>BREAK</b>	
10:30 – 11:45	<b>Sponsor Presentations</b> Wave Solid Sarepta Santhera Roche	Ha Nguyen TBD TBD Jessa Depew TBD
11:45 – 12:15	<b>Genetics, The Duchenne Registry and Your Family</b> Understanding Your Mutation Decode Duchenne The Duchenne Registry	Jen Ely, CGC <i>Parent Project Muscular Dystrophy</i>
12:15 – 12:25	<b>Race to End Duchenne</b> *Sign up for race during lunch!	David Hofstein <i>Grandparent, Runner</i>
12:25 – 12:30	<b>Local Resources</b> Muscle Movement Foundation Lawall Prosthetics & Orthotics, Inc.	
12:30 – 1:00	<b>LUNCH</b>	
1:00 – 1:30	<b>Who is PPMD?</b>	Kathi Kinnett, APRN <i>Parent Project Muscular Dystrophy</i>
1:30 – 2:45	<b>Sponsor Presentations</b> PTC Pfizer NS Pharma Italfarmaco Catabasis	TBD Helene Schlupe, MD Ana Christensen Ana Christensen Erica Gagnon
2:45 – 3:15	<b>Psychosocial Considerations</b>	Stephanie Chopko, PhD <i>Nemours Children's Health System</i>
3:15 – 3:45	<b>Duchenne Standards of Care</b>	Mena Scavina, MD <i>Nemours Children's Health System</i>