



2026 Annual SMA Conference Orlando, Florida

Wednesday, June 24

2:00pm – 6:00pm Registration Open for all Conference Attendees

Thursday, June 25

9:00am – 5:30pm Registration Open for all Conference Attendees

2:00pm – 4:10pm Newly Diagnosed Children’s Program
(drop off opens at 1:30pm) Sponsored by The Jacob Isaac Rappoport Foundation

2:00pm – 4:00pm Newly Diagnosed Program
For newly diagnosed families

1:00pm – 2:30pm Adults with SMA First Time Attendee Mentor Program - Welcome Meetup
Sponsored by Biogen
For adults with SMA and their attendants who are attending conference for the first time

3:00pm – 6:30pm Adults with SMA Lounge, Sponsored by Genentech
For adults with SMA and their attendants

6:30pm – 8:30pm Meet & Greet
Annual SMA Relay Race starts at 7:00pm

Friday, June 26

7:15am Breakfast Opens

7:45am – 8:45am Symposium, Sponsored by Biogen: The Journey Continues in SMA Care

8:00am – 4:35pm Registration Open for all Conference Attendees

8:45am – 5:00pm Exhibitor and Networking Area Open

9:00am – 12:30pm Children's Program
& 1:45pm – 4:45pm Sponsored by The Jacob Isaac Rappoport Foundation
**(drop off opens at 8:30am
& 1:15pm)**

9:00am – 11:00am General Session Opening Remarks

11:00am – 4:35pm Adults with SMA Lounge, Sponsored by Genentech
For adults with SMA and their attendants

11:00am – 4:35pm Teen Lounge, Sponsored by Novartis
For all teens ages 12 – 18

11:20am – 12:20pm **Workshop Session #1**

- **Grandparents Coffee and Share Your Experience**
- **Challenges in Oral Health Care in Adults With Spinal Muscular Atrophy**
- **Adaptive Sports for All**
- **Financial and Estate Planning with Special Needs Trusts**
- **Dry Land Strengthen and Stretch Your Body**
- **Lifelong Motion: Empowering Movement and Innovation in SMA**
- **Spouses and Partners of Adults with SMA: Sharing Your Experience**

12:20pm Lunch Opens

12:40pm – 1:40pm Symposium, Sponsored by Scholar Rock: Muscle: There's More to the Story in SMA

1:45pm – 3:00pm **Workshop Session #2**

- **Transition to Adult SMA Care: Defining Your Own Path**
- **Service Dogs More Than a Companion: The Service Dog Journey**
- **Understanding Your SMA Treatment Options: What You Need to Know**
- **Taking Charge of Your Health: The Transition from Pediatric to Adult Care**
- **Pre-symptomatic and Early Diagnosis Experiences**
- **Supporting Strong Bones in SMA**
- **Strengthen and Stretch Your Body in the Water - for Children Sitting/Walking Independently, Ages 6 months to 7 years and Children Requiring Head Support**
- **Empowered Parenting: Thriving as a Single or Co-Parent Raising a Child with SMA**
- **Kids Talk it Out (Ages 6 – 11)**

3:20pm – 4:35pm **Workshop Session #3**

- **Healing the Grieving Heart – Part I**
- **Genetic Therapies in SMA: Past, Present, and Future**
- **Accessible Joy: Recreation Without Limits**
- **Adult SMA Comprehensive Care and Individualized Treatment Strategies**
- **Financial Empowerment: Understanding ABLE Accounts**
- **Accessible Fashion and Body Image as a Disabled Adult**

- **Community Art Time: Getting to the Art of it**
- **Strengthen and Stretch Your Body in the Water - for Children Sitting/Walking Independently, Ages 8 - 13-year-old**
- **Asymptomatic Roundtable and Coffee**

6:30pm – 8:30pm	Family Friendly Researcher Poster Session
7:30pm – 9:30pm	Teen Social <i>**For all teens ages 12 – 18**</i>
8:30pm – 10:30pm	Adults with SMA Reception, Sponsored by Biogen and The Dhont Family Foundation <i>**For adults with SMA and their attendants**</i>
8:30pm – 10:30pm	Mom’s Night Out, Sponsored by Scholar Rock

Saturday, June 27

7:15am	Breakfast Opens
7:45am – 8:45am	Symposium, Sponsored by Genentech: Everyday Impact: Hear From Teenagers and Adults in the SMA Community
8:15am – 5:00pm	Registration Open for all Conference Attendees
8:45am – 5:30pm	Exhibitor and Networking Area Open
9:00am – 11:50am & 1:00pm – 5:10pm (drop off opens at 8:30am & 12:30pm)	Children’s Program Sponsored by The Jacob Isaac Rappoport Foundation
9:00am – 5:00pm	Adults with SMA Lounge, Sponsored by Genentech <i>**For adults with SMA and their attendants**</i>
9:00am – 5:00pm	Teen Lounge, Sponsored by Novartis <i>**For all teens ages 12 – 18**</i>

9:00am – 10:10am

Workshop Session #4

- **SMA Clinical Trials Today: Understanding Your Options**
- **Turning Your Experiences into Change: Storytelling as a Tool for Legislative Advocacy**
- **Guidance on selection of wheelchairs in SMA, including manual wheelchairs, power assist, power wheelchairs and alternative drive options**
- **Pediatric Yoga for SMA**

- **Adolescence, Puberty, and Reproductive Health**
- **The Role of the Multi-disciplinary Clinic - How it might be helpful for those identified pre-symptomatically**
- **Ask What You Came to Ask: Get it Off Your Chest**
- **Healing the Grieving Heart - Part II - Connections Continued**
- **Teen Siblings in the SMA Community (Ages 13–18)**

10:30am – 11:40am **Workshop Session # 5**

- **Orthopedic Management in SMA**
- **Practical AI for Every Day Independence: Real Tools**
- **Experiencing the Power of Hippotherapy**
- **Dating with SMA: Confidence, Communication, and Connection**
- **Change Your Brain - Change Your Life**
- **Sharing Your Type 1 Journey**
- **Navigating SMA and Pregnancy: Medical Guidance and Personal Stories**
- **Aquatic Physical Therapy for Fun & Function, Teens and Adults**
- **Connecting as Siblings in the SMA Journey (Ages 5–12)**

11:40am – 1:00pm Lunch Opens

1:00pm – 2:10pm **Workshop Session # 6**

- **I CAN Go to College: Resources and Stories from Young Adults with SMA**
- **Enforcing Your Rights through the Americans With Disabilities Act**
- **Genetics and Reproductive Options for SMA Families**
- **Move With Yoga for SMA for Teens and Adults**
- **Finding Your Strengths: Sustainable Resilience for SMA Caregivers**
- **Creating Lasting Memories; Using Creative Outlets to Support Grief**
- **Women's Health in SMA**
- **Aquatic Physical Therapy for Fun & Function, Teens and Adults**
- **Kids Talk it Out (ages 12 - 17)**

2:30pm – 3:40pm **Workshop Session # 7**

- **Apartment Hunting 101**
- **Storytellers with SMA**
- **Calm Minds for Little Bodies: Playful Mindfulness for Kids and Parents**
- **Empowered by Nutrition: Supporting Adults with SMA**
- **Preservation of Oral Function and Airway Integrity in Spinal Muscular Atrophy across the Lifespan**
- **Early Scoliosis Treatment in SMA**
- **Sweet Dreams and Restful Nights: Optimizing Sleep Health for SMA Patients and Families**
- **The role of Physical Therapy Your Child's Life**

4:00pm – 5:00pm

Workshop Session # 8

- **Navigating the Special Education/504 Process: Setting Our Children Up for Success An Approach to Exercise in Individuals with SMA**
- **The Best Nap Ever: Staying Safe With Anesthesia and Pain Care for Individuals with SMA**
- **The Calm Within: Practices for Self-Regulation**
- **SMA Nutrition – Keeping It Real!**
- **Evolving your wheels - Adaptive driving for independence**
- **Engaging in the SMA Community in the era of Early Diagnosis and Treatment**
- **For Your Pleasure – Talking Intimacy with SMA Adults**

7:00pm – 9:30pm

PJ Party & Movie Night

7:30pm – 9:30pm

Teen Networking Event

For all teens ages 12 – 18

8:30pm – 10:30pm

Adults with SMA Networking Event, Sponsored by Scholar Rock and The Dhont Family Foundation

For adults with SMA and their attendants

8:30pm – 10:30 pm

Dad's Night Out, Sponsored by Scholar Rock

Sunday, June 28

7:15am

Breakfast Opens

7:45am – 8:45am

Symposium, Sponsored by Novartis: Navigating Gene Replacement Therapy in Adult and Pediatric Patients: Information to Support Your Decision-Making

9:00am – 10:15am

It's a Wonderful Life/Closing General Session

9:00am – 10:25am

Children's Program

(drop off opens at 8:30am) Sponsored by The Jacob Isaac Rappoport Foundation