



2025 Annual SMA Conference

Disneyland Hotel
Anaheim, California
June 26 – June 29, 2025

please note that this schedule is subject to change

Wednesday, June 25

5:00pm – 7:30pm Registration Open for all Conference Attendees

Thursday, June 26

9:00am – 6:00pm Registration Open for all Conference Attendees

2:00pm – 3:00pm 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 only

2:30pm – 6:00pm Adults with SMA Lounge Sponsored by Biogen
For adults with SMA and their attendants

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

8:30pm – 10:30 pm Dad's Night Out, Sponsored by Scholar Rock

Friday, June 27

7:00am Breakfast Opens

7:15am – 4:45pm Registration Open for all Conference Attendees

7:45am – 8:45am A New Take on SMA Treatment: Hear Insights From the Community, Symposium
Sponsored by Genentech

8:45am – 5:15pm Exhibitor and Networking Area Open

8:45am – 5:15pm Living SMA YOUR Way, Sponsored by Genentech

8:45am – 5:15pm Imagination Station, Sponsored by Scholar Rock

8:45am – 5:15pm Novartis Community Booth, Sponsored by Novartis

9:00am – 12:20pm
& 1:45pm – 4:45pm
**(drop off opens at
8:30am & 1:15pm)**

Children's Program
Sponsored by The Jacob Isaac Rappoport Foundation

9:00am – 11:00am

General Session Opening Remarks

11:00am – 4:45pm

Adults with SMA Lounge, Sponsored by Biogen
For adults with SMA and their attendants

11:00am – 4:45pm

Teen Lounge, Sponsored by Novartis
For all teens ages 12 - 18

11:00am – 4:45pm

Respite/Mindfulness Space

11:20am – 12:20pm

Workshop Session #1

- **Kids Talk it Out (Ages 6 – 11)**
- **Pre-symptomatic and Early Diagnosis Experiences**
- **Dry Land Strengthen and Stretch Your Body**
- **Caring for Your Bladder and SMA**
- **Strategies and Benefits of Yoga Practice for Teens and Adults with SMA**
- **Male Reproductive Considerations in SMA**
- **Financial and Estate Planning with Special Needs Trusts**
- **Grandparents Coffee and Share Your Experience**
- **Sharing Your Type I Experiences**
- **Moving Toward Independence**

12:20pm – 1:45pm

Lunch

1:45pm – 3:05pm

Workshop Session # 2

- **Understanding SMA Treatments: From Clinical Trials to Real-Life Decisions**
- **Taking Charge of Your Health: The Transition from Pediatric to Adult Care**
- **Spouses and Partners of Adults with SMA: Sharing Your Experience**
- **The Role of Therapy PT and OT in your Child's Life – Being Part of the Team!**
- **Healing the Grieving Heart – Part I**
- **Strengthen and Stretch Your Body in the Water - for Children Sitting/Walking Independently, Ages 6 months to 7 years and Children Requiring Head Support**
- **An SMA Family Feud Experience: Fundraising for Today & Tomorrow**
- **Mindful Moments: Helping Kids Find Calm**
- **Adult Pulmonary Care**
- **Practical Home Modifications for Accessibility and Independence**

3:25pm – 4:45pm

Workshop Session # 3

- **Adaptive Sport / Recreation Testimonials and Resources**
- **I Need to Cough, I Need to Breathe, I Need to Sleep**
- **Genetics and Reproductive Options for SMA Families**
- **Finding Your Strengths: Building Resilience Against Burnout**

- **Strengthen and Stretch Your Body in the Water - for Children Sitting/Walking Independently, Ages 8 – 13 years old**
- **Dating, Intimacy, and Sex—The Disabled Perspective**
- **Navigating The Special Education/504 Process: Setting our Children Up for Success in Preschool and Elementary School**
- **Get To the Art of It: Community Art Time**

6:30pm – 8:30pm	Family Friendly Researcher Poster Session
7:30pm – 9:30pm	PJ Party & Movie Night
7:30pm – 9:30pm	Teen Social <i>**For all teens ages 12 – 18**</i>
7:30pm – 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 28

7:00am	Breakfast Opens
7:15am – 3:40pm	Registration Open for all Conference Attendees
7:45am – 8:45am	From One Generation to Another: A Symposium for the Ages, Sponsored by Biogen
8:45am – 4:00pm	Exhibitor and Networking Area Open
8:45am – 4:00pm	Imagination Station, Sponsored by Scholar Rock
8:45am – 4:00pm	Novartis Community Booth, Sponsored by Novartis
9:00am – 11:40am & 1:00pm – 3:40pm (drop off opens at 8:30am & 12:30pm)	Children’s Program Sponsored by The Jacob Isaac Rappoport Foundation
9:00am – 3:40pm	Adults with SMA Lounge, Sponsored by Biogen <i>**For adults with SMA and their attendants**</i>
9:00am – 3:40pm	Teen Lounge Sponsored by Novartis <i>**For all teens ages 12 - 18**</i>
9:00am – 3:40pm	Respite/Mindfulness Space
9:00am – 10:10am	Workshop Session #4

- **Swallowing in SMA: Expectations for Stability and Promising Rehabilitation Methods**
- **The Role of the Multi-disciplinary Clinic - How it can be helpful for those identified pre-symptomatically**
- **Creating Lasting Memories Through Art Making**

- **Power Assist, Power Wheelchairs and Alternative Drive Options for Children and Adults who are Living with SMA**
- **A Pediatric Yoga Approach to Movement and Wellness: A 5 Part Therapeutic Yoga Practice for Babies, Toddlers and Children with SMA**
- **Enhancing Clinical Care for Adults with SMA: Strategies for Achieving Optimal Outcomes**
- **Empowering Futures: Unlocking the Potential of ABLE Accounts**

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

- **Navigating Anesthesia, Sedation, and Pain Control for SMA Families**
- **Orthopedic Management in SMA**
- **Unleashing Potential: Exploring the World or Service Dogs More Than a Companion: The Service Dog Journey**
- **Aquatic Physical Therapy for Fun & Function, Teens and Adults**
- **Technology That Makes Life Easier**
- **Healing the Grieving Heart – Now What? Part**
- **Personal Care Assistants Discussion Panel**
- **Accessible Fashion and Body Image as a Disabled**
- **Siblings Talk it Out (Ages 12 to 17)**

11:40am – 1:00pm Lunch

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

- **Women’s Health in SMA**
- **Impacting the Creative Landscape**
- **Real Food for Optimal Health**
- **Empowered Parenting: Thriving as a Single or Co-Parent Raising a Child with SMA**
- **Early Scoliosis Treatment in SMA**
- **Advocating for Yourself and the SMA Community: Tips for Effective Advocacy**
- **Navigating The Special Education/504 Process: Transitioning to Middle School, High School, and College**
- **Aquatic Physical Therapy for Fun & Function, Teens and Adults**
- **Siblings Talk it Out (Ages 5 to 11)**
- **Kids Talk it Out (Ages 12 – 17)**

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

- **Adults with SMA Relationships Panel – Share Your Experience**
- **An Approach to Exercise in Individuals with SMA**
- **Storytellers with SMA**
- **Traveling with SMA**
- **Your Voice in the Workplace: Job Hunting, Interviewing, and Advocating for Accommodations**
- **Mindfulness for Stress & Resilience: Practical Tools for Everyday Life**
- **Staying Prepared: Daily Care Strategies and Emergency Response in the Community**

4:00pm **Cure SMA’s Evening at the Park**

Sunday, June 29

7:00am	Breakfast Opens
7:45am – 8:45am	Muscles, Myostatin, and More, Symposium Sponsored by Scholar Rock
9:00am – 11:15am (drop off opens at 8:30am)	Children's Program Sponsored by The Jacob Isaac Rappoport Foundation
9:00am – 11:15am	It's a Wonderful Life/Closing General Session

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