

2024 Annual SMA Conference Austin, Texas

Please note the schedule is subject to change

Wednesday, June 5

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

Thursday, June 6

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

1:00pm – 3:00pm 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

6:30pm – 8:30pm Meet & Greet
Includes Researcher Relay Race and Games

8:30pm – 11:00 pm Dad's Night Out

Friday, June 7

7:00am Breakfast Opens

7:15am – 5:30pm Registration Open for all Conference Attendees

7:45am – 5:30pm Exhibitor Tables Open

7:45am – 8:45am Symposium by Genentech: Taking Center Stage: Stories from the Community

8:45am – 5:30pm SMA Community Self-Expression Exhibit Sponsored by Biogen

8:45 am – 5:30pm A Piece of Us, Sponsored by Novartis

8:45am – 5:30pm Muscle Station, Sponsored by Scholar Rock

9:00am – 12:20pm Children's Program
& 1:45pm – 4:45pm Sponsored by The Jacob Isaac Rappoport Foundation
(drop off opens at 8:30am & 1:15pm)

9:00am – 10:30am **Kids Talk it Out (Ages 12 – 17)**

- 9:00am – 11:00am General Session Opening Remarks
- 11:00am – 5:30pm Adults with SMA Lounge Sponsored by Biogen
for adults with SMA and their attendants
- 11:00am – 5:30pm Teen Lounge Sponsored by Luke 18:1 Foundation
for all teens ages 12 - 18

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

- **Finding a Job, Interviewing and How to Ask for Modifications Panel**
- **Pre-symptomatic and Early Diagnosis Experiences**
- **Spouses and significant others of adults with SMA sharing your experience**
- **Aquatic Physical Therapy - The Why and How for Individuals with SMA**
- **Ethics, Angst, Excitement and Realities of SMA Treatments and Research**
- **Navigating Power Mobility Options, While Living with SMA**
- **The Difference of Donations: How Fundraising Can Change the Future of SMA**
- **From Counting Sheep to a Good Night's Sleep: Getting a Good Night's Sleep for Patients with SMA and Their Caregivers**
- **"Talk it Out" for Kids with an SMA-affected Parent (Ages 6- 17)**

- 12:20pm – 1:45pm Lunch

1:45pm – 3:05pm **Workshop Session # 2**

- **The Role of Therapy PT and OT in your Child's Life – Being Part of the Team!**
- **Easier Living: Unleashing the Power of Tech in your home**
- **Financial and Estate Planning with Special Needs Trusts**
- **Healing the Grieving Heart – Part I**
- **Parenting With SMA**
- **Personal Care Assistants: From Recruitment and Hiring to Day-to-Day Management and Everything In-Between**
- **What it Means to be a Teen on Wheels**
- **Sharing Your Type I Experiences**

3:25pm – 4:45pm **Workshop Session # 3**

- **Mindfulness for Everyday Life**
- **Navigating The Special Education Process: Setting our Children Up for Success In Preschool and Elementary School**
- **How to Travel with SMA**
- **Physical Therapy for Eating, Speaking and Breathing: HOW and WHEN can a Speech Pathologist help?**
- **Urology in SMA**
- **Young Adults Talk it Out (Ages 18+)**
- **Orthopedic Management**
- **Do-It-Yourself (DIY) Advocacy: Have an Impact on Issues That Matter to You**

6:30pm – 8:30pm	Family Friendly Researcher Poster Session
7:30pm – 9:30pm	Teen Social Sponsored by Luke 18 :1 Foundation <i>**for all teens ages 12 – 18**</i>
7:30pm – 11:00pm	Adults with SMA Reception Sponsored by Biogen and The Dhont Family Foundation
8:30pm – 11:00pm	Mom’s Night Out

Saturday, June 8

7:00am	Breakfast Opens
7:15am – 5:00pm	Registration Open for all Conference Attendees
7:45am – 5:30pm	Exhibitor Tables Open
7:45am – 8:45am	Symposium by Biogen: Our Vision: Improving Air Travel for People with SMA
8:45am – 5:30pm	SMA Community Self-Expression Exhibit Sponsored by Biogen
8:45am – 5:30pm	A Piece of Us, Sponsored by Novartis
8:45am – 5:30pm	Muscle Station, Sponsored by Scholar Rock
9:00am – 11:40am & 1:00pm – 5:00pm	Children’s Program Sponsored by The Jacob Isaac Rappoport Foundation (drop off opens at 8:30am & 12:30pm)
9:00am – 5:00pm	Adults with SMA Lounge Sponsored by Biogen <i>**for adults with SMA and their attendants**</i>
9:00am – 5:00pm	Teen Lounge Sponsored by Luke 18:1 Foundation <i>**for all teens ages 12 - 18**</i>

9:00am – 10:10am

Workshop Session #4

- **Unpacking Clinical Trials**
- **Pediatric Therapeutic Yoga for SMA**
- **Empowering Independence: The Benefits of Service Dogs**
- **The Role of the Multi-disciplinary Clinic - How can it be helpful for those identified pre-symptomatically**
- **Beyond high school – from interest to employment**
- **I Need to Cough, I Need to Breathe**

- **Taking Charge of Your Health: The Transition from Pediatric to Adult Care**
- **University of Utah TRAILS Program: Advancing Adaptive Sports and Innovative Equipment Solutions**
- **Memory Boxes: Create a Treasure (for children & teens only)**

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

- **The Being in Doing: Making Your To-Do List Work for YOU!**
- **How to Build Your Presence and Advocate Through Writing & Social Media**
- **Incorporating Exercise into Your Life**
- **Keepsake Creation: Grieving Through Art**
- **Achieving a Better Life Experience with ABLE Accounts**
- **Preventing Emergencies – Daily Care, Contingencies and Response in the Community**
- **Time is Neurons: Exploring Legacy Giving for SMA**
- **Transition to Adulthood Panel**
- **Kids Talk it Out (Ages 6 – 11)**

11:40am – 1:00pm Lunch

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

- **Adults with SMA Relationships Panel – Share your experience**
- **Spinal Muscular Atrophy Nutrition – Food for Thought**
- **Get To The Art of It: Community Art Time**
- **Your Mental Health Toolbox**
- **Navigating The Special Education Process: Transitioning to Middle School, High School, and College**
- **Adaptive Sport / Recreation Testimonials and Resources**
- **Healing the Grieving Heart – Now What? Part II**
- **Shifting Perspectives: Media Representation and the Disabled Community - Roundtable Dialogue for Inclusive Narratives**
- **Siblings Talk it Out (Ages 12 to 17)**

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

- **Evolving Your Wheels: Driving with SMA**
- **Personal Care Assistant Panel**
- **Grandparents Coffee and Share Your Experience**
- **Medical Management of Adults with SMA**
- **Therapeutic Yoga for Adults and Teens with SMA**
- **Genetics and Reproductive Options for SMA**
- **Supporting Emotional Health in SMA Families**
- **Siblings Talk it Out (Ages 5 to 11)**

4:00pm – 5:00pm **Workshop Session # 8**

- **Empowering Women: Sharing Health Tips and Journeys in the SMA Community**
- **Tech for Seamless Living: Wheelchairs, driving and more**

- **Dating Disabled: Navigating the Dating World as a Disabled Person**
- **Impacting the Creative Landscape**
- **Mindfulness for Kids**
- **Q and A Session with The Pulmonary Team**
- **Early Scoliosis Management in SMA**
- **Must-Love Fundraising: Find Your Perfect Event Match**

6:00pm – 7:30pm Most Likely Not to...An SMA My Way Musical Experience, Sponsored by Genentech

7:00pm – 9:00pm PJ Party and Movie Night

7:30pm – 9:30pm Teen Social *Sponsored by Luke 18:1 Foundation*
 for all teens ages 12 – 18

Sunday, June 9

7:45am Breakfast Opens

9:00am – 11:15am Children’s Program
(drop off opens at 8:30am) Sponsored by The Jacob Isaac Rappoport Foundation

9:00am – 11:15am It’s a Wonderful Life/Closing General Session