

**cure  
SMA**

**2026**

**ANNUAL SMA  
CONFERENCE**

**Disney's Yacht and Beach Club in Orlando, Florida**



**THURSDAY, JUNE 25 – SUNDAY, JUNE 28**

# WELCOME LETTER

## Welcome to the 2026 Annual SMA Conference in Orlando, Florida!

We are excited to gather together to celebrate the remarkable progress our community continues to make, to focus on near term challenges, and to look ahead to the next breakthroughs. All while reconnecting with friends, families, clinicians, researchers, and partners from across our SMA community. This Conference is generously supported by 11 sponsors and 16 exhibitors. We extend our sincere thanks to Biogen, Genentech, Novartis, and Scholar Rock, the Presenting Sponsors of the 2026 Annual SMA Conference. Through their support, we are able to offer impactful workshops, meaningful community events, and opportunities for connections for all attendees.

We have had some remarkable success recently with three approvals from the FDA for improvements to our existing genetic treatments. All of which directly advance our top priorities of full broad approvals for all ages and types of SMA and for treatments that are easier to use and more powerful for our older community. We are now back and pending a decision from the FDA for the key next opportunity - the different approach of a muscle-directed therapy.

Our programs will ensure that we roll out access to these four newly approved treatments. These involve advocacy to payers to provide coverage, education for health care providers to ensure we have the capacity to deliver all our treatment options, and outreach to our community to ensure good understanding of the multiple pathways now available and also to reach the remaining 20% of untreated individuals in the US.

At the same time, we now need to increase our efforts at the earlier stages of research to strengthen our drug pipeline. The Cure SMA Board recently approved an increase in our basic research funding from \$750,000 last year to \$1 million now. And then to \$1.5 million for the year after. This will also include supporting new translational research programs to turn promising new ideas into practical future treatments.

To ensure our programs continue to reflect the realities of the SMA community, we actively collect data directly from individuals and families. These insights inform our advocacy and support initiatives as daily living needs, access challenges, and care considerations continue to evolve. Throughout the past year, we have created opportunities for community members to engage virtually, continued to update resources to address insurance challenges, and launched an online Advocate Training Program to empower individuals with SMA to engage on issues that matter most to them.

Each year, the Annual SMA Research & Clinical Care Meeting is held alongside the Annual SMA Conference. During the scientific sessions, researchers from academia and industry come together to foster collaboration and accelerate discovery. In the clinical care sessions, multidisciplinary healthcare professionals share expertise to advance best practices and optimize care. For individuals and families, we are proud to offer a robust lineup of workshops serving all segments of our community. We especially look forward to shared experiences such as the Thursday evening Meet and Greet and the Family Friendly Researcher Poster Session on Friday, which bring researchers, clinicians, and community members together.

Please don't hesitate to reach out to any of us if there is anything we can do to help make this conference meaningful and rewarding for you.

Sincerely,



**Kenneth Hobby**  
President



**Colleen McCarthy O'Toole**  
Senior Vice President,  
Community Support



**Jackie Glascock, PhD**  
Chief Scientific Officer

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**USE OUR HASHTAG**  
**#2026SMACONFERENCE**



Cure SMA often hires professionals to take pictures, video, and audio to capture some of the special, fun, and amazing moments that happen at our events. During registration, you are required to complete an Event Image Release and Waiver Form which applies to any individuals who you register who attend the Annual SMA Conference. Registering for and attending the Annual SMA Conference is considered consent to the terms of the Image Release and Waiver Form. Images and recordings may be used by Cure SMA across its websites and social media platforms (e.g., Facebook), as well as for editorial, educational, promotional, advertising, and fundraising purposes, and for any other use that supports the organization's mission, without compensation to attendees.

## VISION AND MISSION STATEMENT

Our mission is to drive research for treatments and a cure for SMA, and to support and empower everyone impacted by SMA today.

## OUR VALUES

### Innovation

Our commitment to a treatment and cure is not just about seeking solutions—it's also about creating them. We're working with some of today's sharpest minds to advance a diversity of approaches and champion the most promising discoveries and methods.

### Balance

As relentlessly as we pursue a treatment and cure, we are also strategic. We know the fastest way to a future without SMA is to take a comprehensive, unbiased approach to research and maintain a balance of optimism and realism.

### Collaboration

Our community is everything to us. We would not have made it this far in our fight without the invaluable contributions of our researchers, doctors, and families. Together, we are—and always will be—stronger than SMA.

### Respect

There is no "right way" to live with a disease like SMA. Every person's experience is different, and it's every family's right to decide what SMA means for them.

### Compassion

Thanks to the Cure SMA community, no person is ever alone in facing this disease. We offer unconditional support to people with SMA and their families, and communicate openly and honestly, giving them clear and accurate information.

### Determination

Our work is not done until we have a cure, and we'll remain strong in our fight no matter what challenges come our way.

# ILLNESS AND EMERGENCY INFORMATION

## IF YOU HAVE AN ILLNESS OR HEALTH EMERGENCY WHILE AT THE ANNUAL SMA CONFERENCE PLEASE SEE BELOW:

If you are experiencing a life-threatening emergency, please call 911.

If you are not feeling well, please take care of yourself. We also ask that you avoid others at the Annual SMA Conference until you are feeling well.

If you or someone you are caring for experiences any of the following, please go to an Emergency Department. Please take all home medical equipment with you.

- Difficulty breathing
- Chest pains
- Low oxygen saturations
- Persistent fever
- Worsening of symptoms despite implementation of illness protocols
- Not able to keep fluids in
- Equipment failure
- Injury and/or possible broken bones

## WHERE TO GO IF AN EMERGENCY OCCURS:

### Pediatric Care:

Nemours Children's Hospital Emergency  
Department  
6535 Nemours Parkway  
Orlando, FL 32827  
407-561-4000

Nemours Children's Health Urgent Care  
750 Centerview Boulevard  
Kissimmee, FL 34741  
407-850-3497

### Adult Care:

Advent Health Celebration Hospital  
Emergency Department  
400 Celebration Place  
Celebration, FL 34747  
407-303-4000

AdventHealth Centra Care Lake Buena  
Vista Urgent Care  
12500 South Apopka Vineland Road  
Orlando, FL 32836  
407-934-2273

*Please note that there are multiple healthcare providers in the Orlando area.  
Additional information is available at the Cure SMA Registration Desk.*

# SPONSORS

Thank you to our generous sponsors for their support of the  
2026 Annual SMA Conference.

## PRESENTING SPONSORS



## TITLE SPONSOR



## SUPPORTING SPONSORS



LUKE 18:1

## PLATINUM SPONSOR



## GOLD SPONSORS



# WELCOME!

We are honored to have SMA families, researchers, and clinicians attend this conference from all over the world! There are individuals attending from 30 countries, including: Argentina, Australia, Bangladesh, Belgium, Brazil, Bulgaria, Canada, Chile, Ecuador, Egypt, Estonia, Gabon, Georgia, Germany, Hungary, India, Israel, Italy, Japan, Luxembourg, Netherlands, Slovakia, Slovenia, Spain, Taiwan, Trinidad and Tobago, Turkey, United Kingdom, United States, and Uruguay.



As of April 22, 2026

# Celebrating All The Years!

2026



**2026** - Disney's Yacht and Beach Club Orlando, Florida

- 2025** - Disneyland Hotel Anaheim, California
- 2024** - JW Marriott Austin Austin, Texas
- 2023** - Disney's Yacht and Beach Club Resort Orlando, Florida
- 2022** - Disneyland Hotel Anaheim, California
- 2021** - Virtual SMA Conference At Home
- 2020** - Virtual SMA Conference At Home
- 2019** - Disneyland Hotel Anaheim, California
- 2018** - Hilton Anatole Hotel Dallas, Texas
- 2017** - Disney World Contemporary Resort Orlando, Florida
- 2016** - Disneyland Hotel Anaheim, California
- 2015** - Westin and Sheraton Hotels Kansas City, Missouri
- 2014** - Gaylord National Washington, D.C.
- 2013** - Disneyland Hotel Anaheim, California
- 2012** - DoubleTree-Bloomington Bloomington, Minnesota
- 2011** - Disney World Swan and Dolphin Resort Orlando, Florida
- 2010** - Marriott-Santa Clara Santa Clara, California
- 2009** - Hyatt Regency Cincinnati Cincinnati, Ohio
- 2008** - Beantown-Boston Park Plaza Boston, Massachusetts
- 2007** - Moving Forward-Hyatt Regency Woodfield Schaumburg, Illinois
- 2006** - Surfin' SMA-Mission Valley Marriott San Diego, California
- 2006** - International SMA Research Meeting Montreal, Canada
- 2005** - Together for a Cure-Marriott Downtown Philadelphia, Pennsylvania
- 2004** - Connect for a Cure-Hyatt Regency Woodfield Schaumburg, Illinois
- 2003** - SMA Takes the Hill-Hyatt Regency Capital Hill Washington, D.C.
- 2002** - Greatest Conference Ever-Hyatt Regency Woodfield Schaumburg, Illinois
- 2001** - Magnificent Milestones-Fairmont Chicago Chicago, Illinois
- 2000** - Conference of the Century-Hilton St Louis St. Louis, Missouri
- 1999** - Countdown to a Cure-Hyatt Regency Milwaukee, Wisconsin
- 1998** - SMA: Past, Present and Future-Hyatt Regency Denver, Colorado
- 1997** - New Horizons... Making Progress-Wyndham Itasca, Illinois
- 1995** - MGM Grand-Las Vegas Las Vegas, Nevada
- 1995** - International SMA Research Meeting Amsterdam, the Netherlands
- 1994** - The Clarion Plaza Hotel Orlando, Florida
- 1992** - Pheasant Run Resort St. Charles, Illinois
- 1990** - Pheasant Run Resort St. Charles, Illinois
- 1988** - The First SMA Conference-Hyatt Regency Chicago Chicago, Illinois

1988

# SMA DRUG PIPELINE

We are funding and directing research with greater breadth and depth than ever before. We recognize that investment in basic research is foundational to drug development and essential to achieving our goal of delivering new therapies that address the unmet needs of all individuals living with SMA.

The Cure SMA Drug Pipeline serves as one of the primary measures of our research program's progress and impact. It highlights the major drug programs currently in development and tracks their advancement from early-stage basic research through FDA approval and beyond. Today, the pipeline features **four FDA-approved therapies**, reflecting the significant progress made possible through sustained research investment and collaboration.

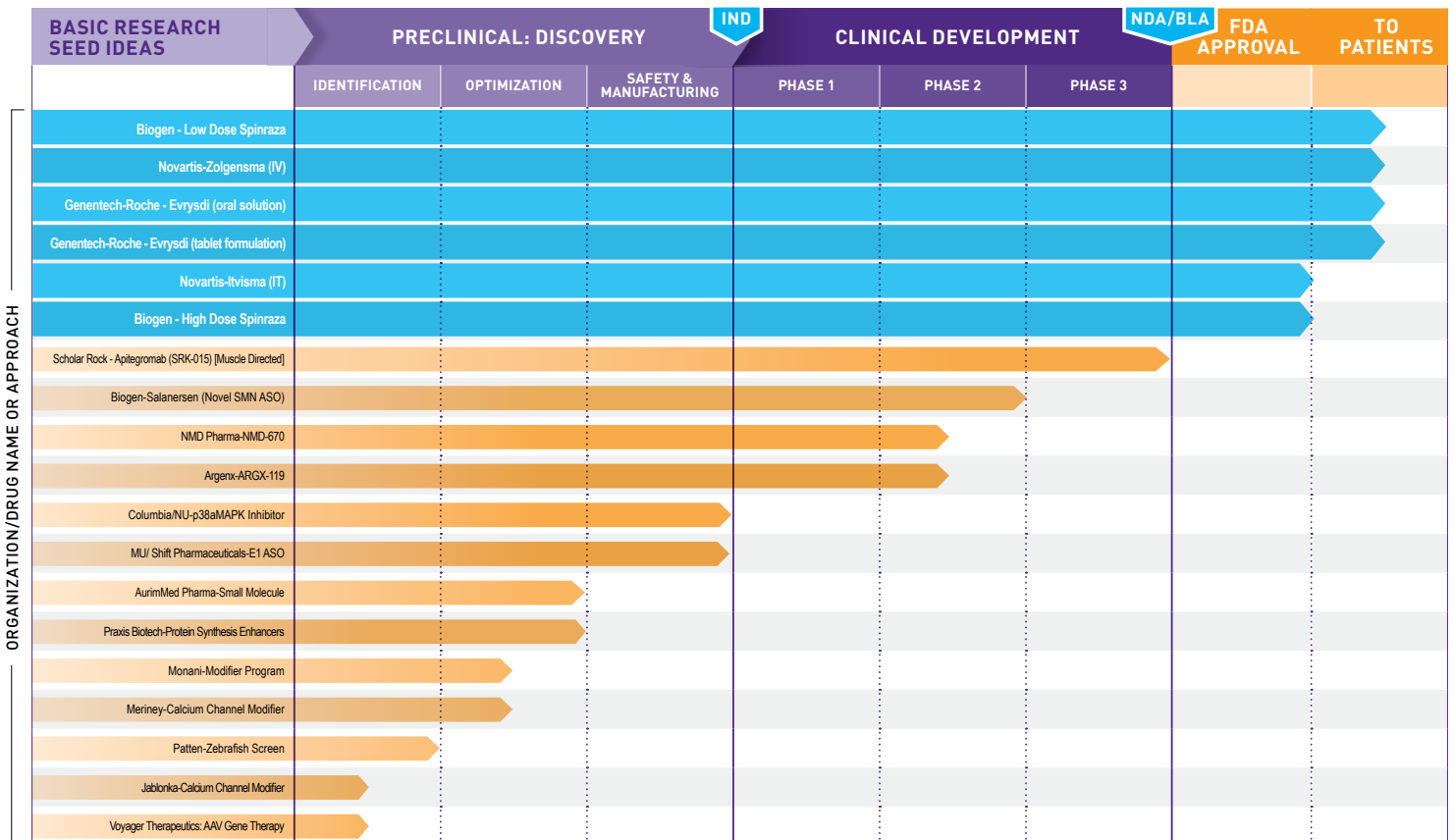
**The Cure SMA Drug Pipeline identifies several promising new treatment strategies, including:**

- Replacement or correction of the faulty *SMN1* gene
- Modulation of the low-functioning *SMN2* backup gene
- Muscle protection to prevent or restore the loss of muscle function in SMA
- Neuroprotection of motor neurons affected by loss of SMN protein
- Emerging approaches that target additional biological systems and pathways impacted by SMA



## SMA DRUG PIPELINE

We're funding and directing research with more breadth and depth than ever before. We know what we need to do to develop and deliver new therapies, which could also work in combination, to reach our goal of treatments for all ages and types. And we're on the verge of further breakthroughs that will continue to change the course of SMA, and eventually lead to a cure.



BLA = Biologics License Application

IND = Investigational New Drug

NDA = New Drug Application

Last updated: April 2026

## THE IMPORTANCE OF CONTINUING TO INVEST IN BASIC RESEARCH

Over the past two decades, Cure SMA has invested more than \$18.5 million in over 145 basic research grants, significantly advancing scientific understanding of spinal muscular atrophy (SMA). Cure SMA's early investments in foundational research directly contributed to the development of the genetically targeted therapies that are now approved and transforming the standard of care. While currently approved therapies have dramatically altered the course of disease, significant unmet needs remain — particularly for older individuals and those living with symptomatic SMA. Continued investment in basic research is essential to sustain a robust and diversified pipeline that identifies new therapeutic avenues. These next-generation strategies aim to work through complementary mechanisms and, ultimately, in combination to further restore strength and function.

### WHAT ARE THE KEY AREAS OF RESEARCH WE WANT TO UNDERSTAND?

**Cure SMA is strategically focused on answering critical scientific questions that will shape the next era of therapeutic development:**

#### • NON-SMN TARGETS

We are investigating biological targets beyond SMN, including nerves, muscles, and neuromuscular junctions, as potential pathways for treatment. This includes determining how to best measure the effectiveness of these non-SMN approaches.

#### • OPTIMIZING COMBINATION STRATEGIES

We are evaluating how SMN-enhancing therapies and non-SMN approaches can be used together to provide meaningful benefit across all ages and stages of SMA.

#### • THE ROLE OF SMN PROTEIN

We continue to study the role of SMN protein — what essential functions it performs, where deficiencies occur in different tissues, and how quickly restoration is needed to achieve therapeutic benefit.

### HOW IS CURE SMA COMMITTED TO CONTINUED BASIC RESEARCH?

**Cure SMA remains firmly committed to advancing foundational discovery:**

- At the beginning of this calendar year, Cure SMA awarded six new basic research grants totaling \$750,000.
- Additional grant applications focused on the key priority areas outlined above are currently under review. These proposals will be evaluated in the fall, with new awards announced early next year.
- Through sustained and strategic investment in basic research, Cure SMA is working to generate the scientific insights necessary to drive the next generation of therapeutic development.

### WHAT IS THE CURE SMA FUNDING MODEL?

The Cure SMA research-funding model is firmly based on the philosophy of expert and independent review and oversight of research projects. The Cure SMA strategy consists of having expert advisors review, select, and then oversee the research projects that we fund. This system has many advantages. Primarily, it ensures that Cure SMA funds the most promising research. In addition, funded projects are then run in a professional manner with the guidance of world-class experts. This type of system is the gold standard for effective scientific funding worldwide and is used extensively by both governments and nonprofit groups. It is often referred to as “peer review”, which means scientists working in similar areas judge each other's work.

*Special thanks to the Concepcion Family, Nunemaker Family, Thomas Sireta Memorial Fund, Weisman Family, Luke 18:1 Foundation, Dhont Family Foundation, and Cure for Casey Foundation for their generosity to Cure SMA in our pursuit to invest in basic research that will ultimately drive the next generation of SMA treatments.*

## ADVOCACY AT CONFERENCE

Continue your advocacy journey at the 2026 Annual SMA Conference alongside fellow SMA community advocates.

### TAKE ACTION

Support a key SMA community advocacy priority



Scan the QR code to access the Cure SMA Action Center



### ATTEND ADVOCACY WORKSHOP

Learn how your personal story can be used to effectively advocate for change by attending the conference workshop hosted by Cure SMA's Advocacy Team



Check out page 37 for information about date, time and location

### STOP BY THE FAMILY FRIENDLY RESEARCHER POSTER SESSION

Stop by the Family Friendly Poster Session to learn how SMA community advocates shared their stories and experiences to advance SMA research



Family Friendly Researcher Poster Session on Friday, June 26 from 6:30 to 8:30 PM Grand Harbor Ballroom

## NEW

### ADVOCATE TRAINING PROGRAM

NOW AVAILABLE ONLINE



At conference or when you return home, scan the QR code to access Cure SMA's Advocate Training Program.

This new online resource includes short advocacy videos and guided questions designed to help you and other SMA community advocates strengthen your advocacy skills and increase your impact.

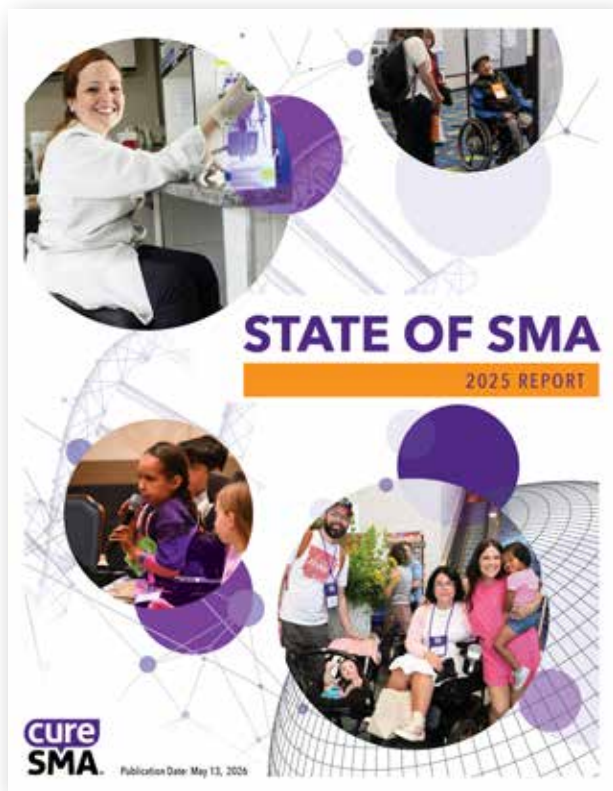


\*Thank you to Biogen, Genentech, and Scholar Rock for their support of the Grassroots Advocacy Tool, which now houses this Advocate Training Program

# THE 5TH ANNUAL STATE OF SMA IS HERE!

*pick up your copy today*

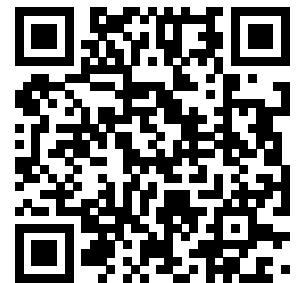
This report showcases outcomes and the changing SMA landscape from Cure SMA's data sources. Cure SMA captures data from a variety of perspectives – including individuals living with SMA, their caregivers, and the clinicians that care for them.



Topics from the report include:

- Current clinical, social, and financial unmet needs of those living with and caring for someone with SMA
- The continued increase in the individuals with SMA living into adulthood
- Demographics and their representativeness of the SMA community
- Changing prevalence of SMA type and SMN2 copy number
- Current motor function status of children and adults living with SMA
- Social determinants of health
- The increase in diagnoses via newborn and prenatal screening
- SMA treatment use, experiences, and remaining unmet needs
- Changes in activities of daily living
- Access to SMA treatments, care, and durable medical equipment
- Additional health conditions...and much more!

If you have not already received a copy of the 5th Annual State of SMA, please visit the conference registration desk or email [research@curesma.org](mailto:research@curesma.org) to request one at no charge.



Cure SMA wishes to thank all the members of the SMA community who have generously shared their data. Additionally, Cure SMA is grateful for the support and funding for this report, which was provided by the Cure SMA Industry Collaboration (SMA-IC).

## 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

**1:00PM – 2:30PM** ADULTS WITH SMA FIRST TIME ATTENDEE MENTOR PROGRAM - WELCOME MEETUP *Sponsored by Biogen*

**2:00PM – 4:00PM** NEWLY DIAGNOSED PROGRAM (FOR NEWLY DIAGNOSED FAMILIES ONLY)

**3:00PM – 6:30PM** ADULTS WITH SMA LOUNGE *Sponsored by Genentech*  
\*\*for adults with SMA and their attendants\*\*

**6:30PM – 8:30PM** MEET & GREET FOR ALL CONFERENCE ATTENDEES

## FRIDAY, JUNE 26

**7:15AM** BREAKFAST OPENS

**7:45AM – 8:45AM** SYMPOSIUM - THE JOURNEY CONTINUES IN SMA CARE  
*Sponsored by Biogen*

**8:00AM – 4:35PM** REGISTRATION AND CHECK-IN

**8:45AM – 5:00PM** EXHIBITORS AND NETWORKING AREA OPEN

**9:00AM – 12:30PM** CHILDREN'S PROGRAM & BABY ROOM (Drop off opens at 8:30am and 1:15pm)  
**& 1:45PM – 4:45PM** *Sponsored by the Jacob Isaac Rappoport Foundation*

**9:00AM – 11:00AM** GENERAL SESSION OPENING REMARKS

**11:00AM – 4:35PM** TEEN LOUNGE *Sponsored by Novartis*  
\*\*for all teens ages 12 – 18\*\*

**11:00AM – 4:35PM** ADULTS WITH SMA LOUNGE *Sponsored by Genentech*  
\*\*for adults with SMA and their attendants\*\*

**11:20AM – 12:20PM** WORKSHOP SESSION #1

**12:20PM** LUNCH OPENS

**12:40PM – 1:40PM** SYMPOSIUM – MUSCLE: THERE'S MORE TO THE STORY IN SMA  
*Sponsored by Scholar Rock*

**1:45PM – 3:00PM** WORKSHOP SESSION #2

**3:20PM – 4:35PM** WORKSHOP SESSION #3

**6:30PM – 8:30PM** FAMILY FRIENDLY RESEARCHER POSTER SESSION

**7:30PM – 9:30PM** TEEN SOCIAL  
*Sponsored by Argenx \*\*for all teens ages 12 – 18\*\**

**8:30PM – 10:30PM** ADULTS WITH SMA RECEPTION *Sponsored by Biogen and the Dhont Family Foundation*  
*\*\*for adults with SMA and their attendants\*\**

**8:30PM – 10:30PM** MOM'S NIGHT OUT *Sponsored by Scholar Rock \*\*for moms only\*\**

## SATURDAY, JUNE 27

**7:15AM** BREAKFAST OPENS

**7:45AM – 8:45AM** SYMPOSIUM – EVERYDAY IMPACT: HEAR FROM TEENAGERS AND ADULTS IN THE SMA COMMUNITY *Sponsored by Genentech*

**8:15AM – 5:00PM** REGISTRATION AND CHECK-IN

**8:45AM – 5:30PM** EXHIBITORS AND NETWORKING AREA OPEN

**9:00AM – 11:50AM** CHILDREN'S PROGRAM & BABY ROOM *(Drop off opens at 8:30am and 12:30pm)*  
*Sponsored by the Jacob Isaac Rappoport Foundation*  
& **1:00PM – 5:10PM**

**9:00AM – 5:00PM** TEEN LOUNGE *Sponsored by Novartis*  
*\*\*for all teens ages 12 – 18\*\**

**9:00AM – 5:00PM** ADULTS WITH SMA LOUNGE *Sponsored by Genentech*  
*\*\*for adults with SMA and their attendants\*\**

**9:00AM – 10:10AM** WORKSHOP SESSION #4

**10:30AM – 11:40AM** WORKSHOP SESSION #5

**11:40AM – 1:00PM** LUNCH

**1:00PM – 2:10PM** WORKSHOP SESSION #6

**2:30PM – 3:40PM** WORKSHOP SESSION #7

**4:00PM – 5:00PM** WORKSHOP SESSION #8

**7:00PM – 9:30PM** PJ PARTY & MOVIE NIGHT

**7:30PM – 9:30PM** TEEN NETWORKING EVENT

# CONFERENCE SUMMARY

**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 – 10:30PM** DAD'S NIGHT OUT *Sponsored by Scholar Rock \*\*for dads only\*\**

## SUNDAY, JUNE 28

**7:15AM** BREAKFAST OPENS

**7:45AM – 8:45AM** SYMPOSIUM – NAVIGATING GENE REPLACEMENT THERAPY IN ADULT AND PEDIATRIC PATIENTS: INFORMATION TO SUPPORT YOUR DECISION-MAKING *Sponsored by Novartis*


**9:00AM – 10:25AM** CHILDREN'S PROGRAM & BABY ROOM *(Drop off opens at 8:30am)*  
*Sponsored by the Jacob Isaac Rappoport Foundation*

**9:00AM – 10:15AM** CLOSING GENERAL SESSION – IT'S A WONDERFUL LIFE PANEL




## WORKSHOP SESSIONS

### FRIDAY, JUNE 26




#### WORKSHOP SESSION #1 | 11:20AM – 12:20PM

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

#### WORKSHOP SESSION #2 | 1:45PM – 3:00PM

- Service Dogs More Than a Companion: The Service Dog Journey
- Understanding Your SMA Treatment Options: What You Need to Know  BIOTEN
- Transition to Adult SMA Care: Defining Your Own Path  GENENTECH  
A Member of the Roche Group
- 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  NOVARTIS
- Empowered Parenting: Thriving as a Single Parent Raising a Rare Disease Child
- Kids Talk It Out (ages 6-11)



#### WORKSHOP SESSION #3 | 3:20PM – 4:35PM

- Healing the Grieving Heart - Part I
- Genetic Therapies in SMA: Past, Present and Future
- Accessible Joy: Recreation Without Limits  NOVARTIS
- Adult SMA Comprehensive Care and Individualized Treatment Strategies  GENENTECH  
A Member of the Roche Group
- Accessible Fashion and Body Image as a Disabled Adult
- Financial Empowerment: Understanding ABLE Accounts
- 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 years old  NOVARTIS
- Asymptomatic Roundtable and Coffee

# WORKSHOP SESSIONS

## SATURDAY, JUNE 27


### WORKSHOP SESSION #4 | 9:00AM - 10:10AM

- 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
- Navigating Presymptomatic SMA: How a Multidisciplinary Team Can Help 
- 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)

### WORKSHOP SESSION #6 | 1:00PM - 2:10PM

- 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
- Gyn Care & Women's Health with SMA - Practical Care, Choices, and Confidence
- Aquatic Physical Therapy for Fun & Function, Teens and Adults 
- Kids Talk it Out (ages 12 - 17)



### WORKSHOP SESSION #5 | 10:30AM - 11:40AM

- 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)

### WORKSHOP SESSION #7 | 2:30PM - 3:40PM

- 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
- Physical Therapy for SMA: Building Your Therapy Team

### WORKSHOP SESSION #8 | 4:00PM - 5:00PM

- Navigating the Special Education/504 Process: Setting Our Children Up for Success 
- 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 

# FRIDAY IS CONFERENCE T-SHIRT DAY!



CURE SMA WOULD  
LIKE TO THANK  
OUR SPONSORS!

#### PRESENTING SPONSORS



**Genentech**  
A Member of the Roche Group



Please wear your conference t-shirts, which you received at registration,  
to show support and awareness for our SMA community!

# CONFERENCE MEALS INCLUDED WITH REGISTRATION

## THURSDAY

### MEET & GREET:

ASSORTED DESSERTS AND REFRESHMENTS

## FRIDAY

### BREAKFAST ITEMS:

ASSORTED CEREALS, BANANAS, ORANGE JUICE, AND COFFEE

### LUNCH:

AN ASSORTMENT OF BOXED LUNCH OPTIONS WILL BE AVAILABLE FOR ATTENDEES WHILE SUPPLIES LAST. EACH BOX INCLUDES A SANDWICH OR SALAD, PASTA SALAD, CHIPS, FRUIT, AND A COOKIE  
*OPTIONS ARE LIMITED IN QUANTITY*

### FAMILY FRIENDLY POSTER SESSION:

DESSERTS OF MICKEY RICE KRISPY TREATS, AND REFRESHMENTS

## SATURDAY

### BREAKFAST ITEMS:

ASSORTED YOGURTS, BANANAS, ORANGE JUICE AND COFFEE

### LUNCH:

AN ASSORTMENT OF BOXED LUNCH OPTIONS WILL BE AVAILABLE FOR ATTENDEES WHILE SUPPLIES LAST. EACH BOX INCLUDES A SANDWICH OR SALAD, PASTA SALAD, CHIPS, FRUIT, AND A COOKIE  
*OPTIONS ARE LIMITED IN QUANTITY*

### SNACKS AT THE PJ PARTY AND MOVIE NIGHT:

POPCORN AND REFRESHMENTS

## SUNDAY

### BREAKFAST ITEMS:

ASSORTED CEREALS, BANANAS, ORANGE JUICE, AND COFFEE

Unfortunately, we are not able to accommodate for dietary restrictions or allergies.

There are many dining locations and options available throughout the Disney Yacht & Beach Club and Disney's Boardwalk. Options at the Yacht & Beach Club include:

- Ale & Compass Restaurant
- Beaches & Cream Soda Shop
- Cape May Café
- Yachtsman Steakhouse
- Beach Club Marketplace
- Martha's Vineyard
- Hurricane Hanna's Waterside Bar and Grill
- Crew's Cup Lounge
- Mobile Dining through the Disney World App



Please fill out the conference surveys for a chance to win an apple watch or 2027 Conference Scholarship



### MAIN CONFERENCE SURVEY

You can also fill out the survey online at <https://o2o.to/i/3ptfVy>



### WORKSHOPS SURVEY

You can also fill out the survey online at <https://o2o.to/i/qJHfhl>

USE OUR HASHTAG

#2026SMACONFERENCE

# The Annual SMA Conference App



The 2026 Annual SMA Conference App is the perfect tool to keep you up to date on everything happening at conference!

## Features you will find on the app:

- Ability to add conference sessions to your own personal calendar
- A bulletin for important conference updates
- A virtual edition of our full conference booklet
- Information about the Children's Program
- Maps of all the hotels and the convention center
- Real time notifications to let you know if any session changes
- Detailed bios for all our Conference Speakers

**APP LIVE JUNE 19TH!**

# ADULTS WITH SMA WORKSHOP TRACK

- Move with Yoga for Teens and Adults with SMA
- Challenges in Oral Health Care in Adults with Spinal Muscular Atrophy
- Spouses and Partners of Adults with SMA: Sharing Your Experience
- Dating with SMA: Confidence, Communication, and Connection
- Adult SMA Comprehensive Care and Individualized Treatment Strategies
- For Your Pleasure - Talking Intimacy with SMA Adults
- Gyn Care & Women's Health with SMA - Practical Care, Choices, and Confidence
- Change Your Brain - Change Your Life
- Apartment Hunting 101
- Empowered by Nutrition: Supporting Adults with SMA
- Navigating SMA and Pregnancy: Medical Guidance and Personal Stories
- Financial Empowerment: Understanding ABLÉ Accounts
- Accessible Fashion and Body Image as a Disabled Adult
- Storytellers with SMA
- Practical AI for Everyday Independence: Real Tools
- Evolving your wheels - Adaptive driving for independence
- Transition to Adult SMA Care: Defining Your Own Path

Be sure to check out these sessions!

Thank you to Genentech for their generosity and support of our Adults with SMA Workshop Track.

**Genentech**  
A Member of the Roche Group



## ADULTS WITH SMA LOUNGE

The Adults with SMA Lounge provides a welcoming space to recharge throughout the conference. Take a break and unwind in a dedicated area for adults with SMA and their attendants.

Located in Cape Cod Hall, at Disney's Yacht Club Hotel Convention Center, the lounge is open during the following times:

Thursday, June 25  
3:00pm - 6:30pm

Friday, June 26  
11:00am - 4:35pm

Saturday, June 27  
9:00am - 5:00pm

**Genentech**  
A Member of the Roche Group

Cure SMA is grateful for Genentech's sponsorship of the Adults with SMA Lounge.

# TEEN NETWORKING



## TEEN NETWORKING AT CONFERENCE

There are many ways to socialize throughout the conference weekend, however, there are a few special opportunities designed specifically for teens to meet and mingle.

All teens ages 12 – 17 can access the Teen Lounge, sponsored by Novartis. We are happy to once again offer this popular space specifically for teens to connect and relax throughout the conference.

**The Teen Lounge** is located in Saybrook at Disney's Yacht Club Hotel Convention Center. The lounge is open during the following times:

Friday, June 26  
from 11:20am – 4:35pm

Saturday, June 27  
from 9:00am – 5:00pm

SPONSORED BY  NOVARTIS

Teens are also invited to join in for two lively evenings of entertainment, both taking place in Hampton at Disney's Yacht Club Hotel Convention Center:

### Teen Social

Friday, June 26  
from 7:30pm – 9:30pm

Mingle, enjoy snacks, compete in a fun trivia game, and make unforgettable memories with friends new and old!

### Teens Networking Event

Saturday, June 27  
from 7:30pm – 9:30pm

We are excited to introduce a fun team scavenger hunt that will take place throughout the meeting space. Work together to follow clues and embark on an interactive adventure with other teens!

## AQUATIC THERAPY

The pool offers great benefits for individuals of all ages with SMA. The focus of aqua therapy is to help with improving functional strength and skills in a dynamic environment.

There will be 5 different aqua therapy sessions available throughout the weekend. We cannot wait to see you at one of them!

### Friday, June 26

- Dry Land Strengthen and Stretch Your Body
- Strengthen and Stretch Your Body in the Water - for Children Sitting/Walking Independently, Ages 6 months to 7 years and Children Requiring Head Support
- Strengthen and Stretch Your Body in the Water - for Children Sitting/Walking Independently, Ages 8 -13 year old

### Saturday, June 27

- Aquatic Physical Therapy for Fun & Function, Teens and Adults
- Aquatic Physical Therapy for Fun & Function, Teens and Adults

SPONSORED BY  NOVARTIS

**MEET & GREET**

**THURSDAY 6:30PM - 8:30PM**

GRAND HARBOR BALLROOM

**Kick off to the Conference!**

- Annual Relay Race
- Family Fun Fest/Carnival
- Meet Disney Characters: Woody & Bo Peep, Buzz Lightyear & Jessie, Lotso, Sarge & Toy Soldier



**FAMILY FRIENDLY RESEARCHER POSTER SESSION**

**FRIDAY 6:30PM - 8:30PM**

GRAND HARBOR BALLROOM

- Visit over 34 posters presented by researchers
- Meet Disney Characters: Mickey Mouse and Minnie Mouse



**PJ PARTY & MOVIE NIGHT**

**SATURDAY 7:00PM - 9:30PM**

GRAND HARBOR BALLROOM

Family movie for kids and adults alike!



Conference wristbands must be worn during the entire conference. You will not be admitted into any conference event or workshop without this conference wristband.

# ADULTS WITH SMA FIRST TIME ATTENDEE MENTOR PROGRAM

The Adults with SMA First Time Attendee Mentor Program is a great opportunity for adults with SMA who are attending the Annual SMA Conference for the first time to be paired up with current and former members of Cure SMA's Adults with SMA Advisory Council and receive guidance and resources on site.

Thank you to Biogen for their generous sponsorship of this program.



## ADULTS WITH SMA RECEPTION



Friday, June 26 | 8:30pm - 10:30pm

Grand Harbor Ballroom 1- 4 | Disney's Yacht Club Hotel Convention Center

Join fellow adults with SMA and their attendants for an evening of fun at the Adults with SMA Reception, sponsored by Biogen and the Dhont Family Foundation.



Enjoy a vibrant social atmosphere with a live set by DJ Brave, as you connect with others over light snacks and a cash bar.

# ADULTS WITH SMA NETWORKING EVENT



## *Who is ready for a fun night of trivia?*

Join fellow adults with SMA and their attendants for an evening of trivia games at the Adults with SMA Networking Event, sponsored by Scholar Rock and the Dhont Family Foundation.

This event will be held on Saturday, June 27, from 8:30pm – 10:30pm in the Grand Harbor Ballroom 5 - 8 Disney's Yacht Club Hotel Convention Center.

Meet and mingle with others while enjoying light snacks and a cash bar for a memorable evening together.



# movement starts with you

**Every wheel rolled. Every step taken.  
Every dollar raised. Every event hosted.**

It all fuels progress for the SMA community.

Cure SMA fundraising programs and events bring people together across the country to support groundbreaking research, vital support programs, and a stronger future for everyone impacted by SMA.

There are so many ways to get involved:

- Join a Walk-n-Roll event
- Participate in a community fundraiser
- Run in an Endurance race
- Support a Distinguished Event
- Start your own DIY fundraiser
- And so much more!

No matter how you participate, you help power the progress happening for the SMA community.



Scan the QR code to explore upcoming Cure SMA fundraising events and find your way to get involved



Together, we are creating **movement** to Cure SMA.

# Fill out the conference survey

FILL OUT THE CONFERENCE SURVEY FOR YOUR CHANCE TO WIN AN APPLE WATCH OR 2027 CONFERENCE SCHOLARSHIP

**The success of our conference can only be improved by the feedback we receive from you!**

Please take the time to provide any comments by filling out our conference survey, and the workshop surveys. You can find hard copies of your surveys in the workshop rooms, at the registration desk, or you can scan the QR codes on the signage throughout conference, access them in the conference app or use the QR codes in the workshop.

You can drop completed hard copy surveys into the many bins throughout the meeting space or at the Registration Area. Any workshops completed on-line will also be electronically pulled into the drawing.

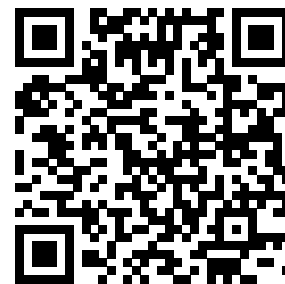


## FILL OUT THE CONFERENCE SURVEY FOR YOUR CHANCE TO WIN AN APPLE WATCH OR 2027 CONFERENCE SCHOLARSHIP

All completed surveys will also be entered into a drawing for a chance to win a trip, including airfare to the 2027 Annual SMA Conference (the locations will be announced on Sunday), or a brand-new Apple Watch! The winners will be drawn and announced on Sunday, June 28, at the Closing General Session/It's a Wonderful Life. All participants who complete the surveys by 9:30am on Sunday, June 28, will have their name entered into a raffle.

### WORKSHOPS SURVEY

You can also fill out the survey online at <https://o2o.to/i/qJHfhl>



### MAIN CONFERENCE SURVEY

You can also fill out the survey online at <https://o2o.to/i/3ptfVy>

## THANK YOU

# Jennifer Miller-Smith, Aaron Smith, and Family

We are profoundly grateful to Jennifer Miller-Smith, Aaron Smith, and the entire Smith family for their unwavering support and significant contributions to the success of our Annual SMA Conference. Over the years, their dedication has been a cornerstone of the event's success, and their generosity in providing signage has added a touch of warmth and professionalism to the atmosphere. Their ongoing involvement, whether through their thoughtful planning, tireless volunteering, or invaluable expertise, has greatly enhanced the experience for all participants. We extend our deepest thanks to the Smith family for their selflessness and commitment to improving the conference each year. Their efforts have not only helped to bring our vision to life but also ensured that every detail contributes to a truly memorable and impactful event for the entire community.



### EXPO CCI

We would like to express our heartfelt gratitude to the entire team at Expo CCI, with special recognition to Richard Curran, for their generous sponsorship and outstanding contribution to our conference. The team's donation of exceptional signage and banners transforms our meeting space, adding a professional and visually stunning element to the event. The care and attention to detail reflected in the signage are evident throughout the venue, making the entire environment feel inviting. Expo's commitment to excellence and their seamless assistance with conference setup significantly enhance the overall experience for attendees. Their partnership and support have been invaluable in making this conference a remarkable success, and we are truly thankful for their ongoing collaboration in helping to elevate the event to new heights.





Since Jacob Rappoport's diagnosis in 2001, Shaina and Adi Rappoport have been deeply committed to advancing the mission of Cure SMA.

In 2002, they established the Jacob Isaac Rappoport Foundation (JIRF) to create a legacy in Jacob's honor. JIRF has been an invaluable partner to Cure SMA, supporting groundbreaking research, essential support programs, and the Annual SMA Conference.

At the conference, JIRF proudly supports the Children's Program, which provides a safe and engaging environment for children while parents attend workshops and educational sessions. The foundation also sponsors Newly Diagnosed Care Packages, which are sent to families seeking support from Cure SMA and include helpful resources and comforting items during an incredibly difficult time. In addition, JIRF has made important investments in research, helping advance discoveries that continue to move the SMA field forward.

**We are deeply grateful to the Rappoport Family and the Jacob Isaac Rappoport Foundation for their enduring partnership and dedication to the SMA community.**

THANK YOU

# LUKE 18:1

Since 2017, the Luke 18:1 Foundation has been a powerful partner in advancing the mission of Cure SMA.



Established in honor of Luke Stickane, the Foundation has contributed more than \$3 million to accelerate research, expand care, and strengthen the programs that support the SMA community.

Their generosity continues to drive meaningful impact in 2026. This year alone, the Luke 18:1 Foundation:

- Created the Fold & Go Wheelchair Grant Program, helping provide more than 60 power chairs to individuals living with SMA
- Funded over \$220,000 in basic research grants, fueling innovation and discovery to advance the next generation of treatment breakthroughs
- Sponsored nearly 150 first-time attendees at the Annual SMA Conference, helping more families and adults connect with resources and community

Their commitment reflects the power of partnership and the incredible progress that is possible when we work together.

Thank you to the Stickane Family, the Giglio Family, and the Luke 18:1 Foundation for your continued leadership and generosity in support of the SMA community.

THE  
**DHONT**  
FAMILY FOUNDATION

**Cure SMA gratefully recognizes the Dhont Family Foundation for their continued investment in scientific and social research.**

**Through their support, individuals living with SMA, their families, and caregivers benefit from stronger programs, deeper knowledge, and a more hopeful future.**

**We are deeply thankful for The Dhont Family Foundation's commitment to the SMA community.**

# MEET and GREET

GRAND HARBOR BALLROOM

THURSDAY, JUNE 25, 6:30PM – 8:30PM

To infinity and beyond! Join us for the Meet & Greet, the official kickoff to the 2026 Annual SMA Conference. All registered attendees are invited to join the fun as our community comes together to celebrate the start of conference week.

Throughout the evening, enjoy games, activities, and prizes for all ages. Whether you're a space ranger, a sheriff, or somewhere in between, there's something for everyone!

After a warm welcome to kick off the conference, get ready for one of the most exciting traditions of the night: the Annual Relay Race. Watch as researchers and clinicians compete against children with SMA in a race to the finish line, with a twist! The researchers and clinicians must race in manual wheelchairs. Year after year, the kids prove they've got the fastest moves, leaving the researchers in the dust.

Assorted Toy Story desserts will be provided so come to connect, have fun, and celebrate the start of an incredible conference with the SMA Community. Just like in Toy Story, you've got a friend here!

**ANNUAL RELAY RACE 7:00PM**

Meet Disney Characters Woody & Bo Peep, Buzz Lightyear & Jessie, Lotso, Sarge & Toy Soldier

CONFERENCE WRISTBANDS MUST BE WORN DURING THE ENTIRE CONFERENCE. YOU WILL NOT BE ADMITTED INTO ANY CONFERENCE EVENT OR WORKSHOP WITHOUT THIS CONFERENCE WRISTBAND.












# AGENDA | WEDNESDAY, JUNE 24




Please check the Conference App for the most updated agenda.

2:00PM – 6:00PM	<b>Registration Open for all Conference Attendees</b>	Asbury Rotunda
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# AGENDA | THURSDAY, JUNE 25

9:00AM – 5:30PM	<b>Registration Open for all Conference Attendees</b>	Asbury Rotunda
1:00PM - 2:30PM	<b>Adults with SMA First Time Attendee Mentor Program - Welcome Meetup</b> <i>Sponsored by Biogen</i> 	Grand Harbor Salon 5
2:00PM – 4:10PM <i>Drop off opens at 1:30pm</i>	<b>Newly Diagnosed Children’s Program</b> <i>Sponsored by The Jacob Isaac Rappoport Foundation</i> 	Newport Ballroom
2:00PM – 4:00PM  2:00PM – 2:15PM  2:15PM – 2:25PM  2:25PM – 2:30PM  2:30PM – 2:40PM  2:40PM – 3:05PM	<b>Newly Diagnosed Program</b> <i>(For Newly Diagnosed Families Only)</i>  <b>Introduction to Cure SMA and the Community</b> <i>**for newly diagnosed families only**</i>  Kenneth Hobby, President Colleen McCarthy O’Toole, Senior Vice President, Community Support Jessica Clark, Senior Director, Community Support  <b>Parent Welcome</b> Al Freedman, PhD, SMA Parent Kevin O’Brien, SMA Parent Nick Farrell, SMA Parent  <b>Understanding Current and Future Treatment Options</b> Rob Graham, MD  <b>Advocacy</b> Maynard Friesz, Vice President, Advocacy  <b>Life After Diagnosis – Parents Share Their Journey</b> Danyelle Sun, SMA Parent Amy Medina, SMA Parent Marnie Harris, SMA Parent	Saybrook
3:05PM – 4:00PM	<b>Newly Diagnosed Program Meet and Mingle</b> <i>**for newly diagnosed families only**</i>	Hampton
3:00PM – 6:30PM	<b>Adults with SMA Lounge</b> <i>Sponsored by Genentech</i> <i>**for adults with SMA and their attendants**</i> 	Cape Cod Hall
6:30PM – 8:30PM	<b>Meet &amp; Greet</b> Annual Relay Race starts at 7:00pm	Grand Harbor Ballroom




7:15AM	<b>Breakfast Opens</b>	Grand Harbor Lobby
7:45AM – 8:45AM	<b>Symposium – The Journey Continues in SMA Care</b> <i>by Biogen</i>	 Grand Harbor Ballroom North & South
8:00AM – 4:35PM	<b>Registration Open for all Conference Attendees</b>	Asbury Rotunda
8:45AM – 5:00PM	<b>Exhibitor and Networking Area Open</b>	Asbury Hall
8:45AM – 5:00PM	<b>Evryday Your Way</b> <i>Sponsored by Genentech</i>	 Asbury Hall
8:45AM – 5:00PM	<b>SMASHing My Limits</b> <i>Sponsored by Novartis</i>	 Asbury Hall
9:00AM – 12:30PM & 1:45PM – 4:45PM <i>(Drop off opens at 8:30am &amp; 1:15pm)</i>	<b>Children’s Program</b> <i>Sponsored by The Jacob Isaac Rappoport Foundation</i>	 Newport Ballroom
9:00AM – 11:00AM	<b>General Session Opening Remarks</b> Do not miss this opening session where members of Cure SMA’s leadership review our progress, changes in our community, and our goals for meeting the needs of everyone impacted by SMA today and into the future: Hear about our next treatment breakthroughs that are happening this year, an update on our future research investments, and learn about new support programs and advocacy initiatives underway to break down barriers and improve access to healthcare, treatments, and everyday living needs	Grand Harbor Ballroom North & South
11:00AM – 4:35PM	<b>Adults with SMA Lounge</b> <i>Sponsored by Genentech</i> <b>**for adults with SMA and their attendants**</b>	 Cape Cod Hall
11:00AM – 4:35PM	<b>Teen Lounge</b> <i>Sponsored by Novartis</i> <b>**for all teens ages 12 - 18**</b>	 Saybrook
<b>11:20AM – 12:20PM Workshop Session #1</b>		
	<b>Grandparents Coffee and Share Your Experience</b> Moderated by: Sylvia and Romero Resendez, grandparents to SMA grandchild  Grab some coffee while you join other grandparents who have a grandchild affected by SMA. Share stories, photos and make new connections. This session is intended for grandparents of those who have SMA.	Hampton
	<b>Challenges in Oral Health Care in Adults With Spinal Muscular Atrophy</b> Aaron Zelikovich, MD  Individuals with SMA can have a limited range of motion in the jaw muscles, which can make it challenging to have optimal oral care hygiene. Dentist appointments can also be challenging in non-ambulatory patients, and many offices are unable to accommodate patients in wheelchairs. The goal of this session is to discuss limitations and potential strategies to improve access to high-quality oral health care both in the clinical office setting and at home. Join this session to share your experience and learn from others as we discuss preliminary survey data related to this topic from the Northwell Health SMA Oral Health Care survey.	Grand Harbor Ballroom 5 & 6

	<p><b>Adaptive Sports for All</b>                  Ed Bronsdon, Moderator, President Bronsdon for Good, LLC                  Charlie Zerzan, Wheelchair Basketball Player                  Marley Robinson, Volt Hockey Player                  Kurt Beach, Head Athletic Trainer for the Adaptive Sports Program, University of Michigan                  Alyssa Briglio, Power Soccer Player</p> <p>Listen and learn from the personal testimonials of individuals with SMA who are active in various adaptive sport and recreation programs. What activities have proven particularly rewarding / challenging / fun for others? What are some examples of accommodations that can be made to adapt an activity to your abilities? What resources are available to get started? How costly are various activities? Are they safe? What benefits may come from being active in sport and recreation? How can you get involved? After learning more from the panelists, attendees will be able to individually ask questions to gain more insight into adaptive sport and recreation options for themselves and their families.</p>	<p> <b>NOVARTIS</b></p> <p>Grand Harbor Ballroom 7 &amp; 8</p>
	<p><b>Financial and Estate Planning with Special Needs Trust</b>                  Richard Rubenstein, Esq., RICP®</p> <p>Legal and financial planning for people who have disabilities and their families can be difficult and confusing. It is vital for all parents to have an estate plan in place, more so for parents of children with disabilities. Find out how to assure that the money you set aside for your child with special needs does not jeopardize government benefits your child is entitled to receive. Richard will give a general overview of the basics of estate planning and the differences between the various types of Special Needs Trusts. He will also discuss various techniques to advocate on behalf of your child in order maximize resources from insurance companies and government agencies.</p>	<p>Grand Harbor Ballroom 1</p>
	<p><b>Dry Land Strengthen and Stretch Your Body</b>                  Jennifer Martyn, PT                  Krista Torseth, PT, DPT                  Kendra Paker, PT, DPT, PCS</p> <p>Join a group of physical therapists on dry land (no water involved this time!) to discover why and how you or your loved one can safely get in the water. Aquatic physical therapists will showcase different types of equipment used in aquatic therapy, such as flotation devices, resistance toys, and water weights. Participants will gain insight into key concepts and techniques that enhance safety and function in the water, including buoyancy and resistance. By learning how to use these tools effectively, you'll be able to make the most of your time during aquatic activities.</p>	<p> <b>NOVARTIS</b></p> <p>Grand Harbor Ballroom 2</p>
	<p><b>Lifelong Motion: Empowering Movement and Innovation in SMA</b>                  Tanja Taivassalo, PhD                  Tina Duong, PT, PhD</p> <p>Staying active with SMA is about more than physical exercise, it's about moving through life with confidence, purpose, and a mindset that supports long-term success. This session moves beyond one-size-fits-all advice to help you build a sustainable relationship with activity at every stage of life. We will bridge the gap between the latest clinical research and your lifestyle, exploring how new tools, from wearable insights to home modifications that can be tailored to your unique physical journey.</p> <p>This is a collaborative space where your experience matters. You'll have the opportunity to learn from others in the SMA community, sharing the real-world resources and strategies that fits into a busy life. To ensure you leave with confidence to have a discussion with your care team on how to include exercise as part of your treatment plan, we will dedicate time to addressing your specific safety questions, flagging key medical considerations, and discussing the mental health habits that turn movement into a lasting, rewarding habit. Whether you are navigating new treatments or refining a lifelong routine, let's design a movement plan that prioritizes your goals, your safety, and your well-being.</p>	<p>Grand Harbor Ballroom 3 &amp; 4</p>
	<p><b>Spouses and Partners of Adults with SMA: Sharing Your Experience</b>                  Kyla Pollock, spouse of Adult with SMA</p> <p>Are you married to or in a committed relationship with an adult who has SMA? Then this workshop is for just for you! Our time together will allow attendees to connect with others in this similar walk of life as we share our unique perspectives, ideas and experiences. This session is intended only for spouses and partners of those with SMA.</p>	<p> <b>Genentech</b>  <small>A Member of the Roche Group</small></p> <p>Ariel's</p>






12:20PM

Lunch Opens


Asbury Lobby

<p>12:40PM – 1:40PM</p>	<p><b>Symposium – Muscle: There’s More to the Story in SMA</b> by <i>Scholar Rock</i></p> 	<p>Grand Harbor Ballroom North &amp; South</p>
<p>1:45PM – 3:00PM <b>Workshop Session #2</b></p>		
	<p><b>Kids Talk it Out (Ages 6 – 11)</b> Amber Bosselman, Certified Life Coach, Adult with SMA Al Freedman, PhD, Clinical Psychologist, SMA Dad</p> <p>This interactive session is designed especially for children ages 6–11 living with SMA. In a supportive, kids-only environment, participants will have the opportunity to share their experiences, make connections, and talk it out with others who understand their world. This session is facilitated by a trained moderator and requires parental consent.</p>	<p>Hampton</p>
	<p><b>Service Dogs More Than a Companion: The Service Dog Journey</b> KateLynne Steinke &amp; Jones on the Job</p> <p>Anybody that has typed “service dog” into a search engine knows that it can become overwhelming and confusing easily; distinguishing fact from fiction is difficult unless you already know what you’re looking for. This workshop will cover all things service dog related, from what a service dog is and does to acquisition options, handler rights, and the needs of having a working dog. Join KateLynne and her service dog, Jones, for a presentation full of accurate information and plenty of time to have all your questions answered. KateLynne has firsthand knowledge and experience with multiple schools, different breeds, and has a vast amount of overall working dog knowledge she’s ready to share with you. You’ll leave with the information you need to continue with your service dog journey, whichever path you choose, and end up with the dog you deserve to have by your side as your safe and helpful partner. Just starting to think about a service dog, already applied and waiting, retiring your dog, or on a successor; please join us, no matter where you are in the service dog process, and see what assistance and tasks are possible that could help you in your daily life. You’ll even see the possibilities of task work a service dog can perform, bring your questions!</p>	<p>Grand Harbor Ballroom 1</p>
	<p><b>Understanding Your SMA Treatment Options: What You Need to Know</b></p>  <p>Crystal Proud, MD Susan Matesanz, MD</p> <p>The SMA treatment landscape has changed dramatically in recent years — and understanding your options has never been more important. This workshop offers a clear, accessible overview of the four FDA-approved treatments currently available for SMA. We’ll walk through how each therapy works, how it’s administered, who it may be right for, and what questions to bring to your care team. Whether you’re newly diagnosed, exploring a change in treatment, or simply want to better understand the science behind your current therapy, this session will give you the foundation to have more informed, confident conversations with your doctors. Come ready to ask questions.</p>	<p>Grand Harbor Ballroom 7 &amp; 8</p>
	<p><b>Transition to Adult SMA Care: Defining Your Own Path</b></p>  <p>Bakri Elsheikh, MBBS, FRCP Julianne Meiser, MSS, LCSW Mckenna Ellixson, young Adult with SMA Joshua Scurria, MHA, Adult with SMA</p> <p>This session is intended for teens or young adults with SMA and their caregivers. We will discuss the importance of transitioning to adult care, resources and information needed to prepare for adult care, as well as an adult providers perspective on adult clinics and differences you can anticipate. We will hear directly from two young adults with SMA, one who has completed their adult care transition and one just beginning their journey. The goal of this session is to be informative as well as an outlet for any anxieties regarding this process. Everyone should leave feeling more confident about their transition of care plan.</p>	<p>Grand Harbor Ballroom 5 &amp; 6</p>
	<p><b>Pre-symptomatic and Early Diagnosis Experiences</b> Dany Sun, MSW, SMA Mom, Social Work Senior Manager, Cure SMA Alexis Bailey, SMA Mom Jeremy Bailey, SMA Dad Mamie Harris, SMA Mom</p> <p>If you’re a family who has received an SMA diagnosis either in-utero, through newborn screening, or some other early diagnosis avenue, please join us in this session. You will have an opportunity to hear stories from others who can relate to your experience and to make connections with other parents, too. Professionals in the SMA community who support newly diagnosed families will also provide support, answer questions, and speak to the unique place you may find yourself in with an early or pre-symptomatic diagnosis.</p>	<p>Grand Harbor Ballroom 2</p>



	<p><b>Adult SMA Comprehensive Care and Individualized Treatment Strategies</b>                  Bakri Elsheikh, MBBS, FRCP                  Jacqueline Montes, PT, EdD</p> <p style="text-align: right;"><b>Genentech</b>  <small>A Member of the Roche Group</small></p> <p>This workshop will focus on three key areas: 1) Standards of Care related to the adult medical and rehabilitation management of SMA in the current natural history landscape. 2) We will discuss challenges related to obtaining treatments, present experience, and expectations. 3) We will also discuss the latest research associated with other combination therapies that may be effective in adults with SMA. Specific attention will be aimed toward the importance of integrating, coordinating, and directing one's own care. The session is ideal for families and participants who are transitioning to adult clinics or adults with SMA.</p>	Grand Harbor Ballroom 1
	<p><b>Financial Empowerment: Understanding ABLÉ Accounts</b>                  Jeanine Geraci, Partner, National Special Needs Coordinator, Protected Tomorrows                  Kimberly Woodsum, Financial Advisor, Protected Tomorrows</p> <p>During Protected Tomorrows presentation, we will discuss how these accounts can be used for tax-free expenses for your loved one with a disability, without losing government benefits. Protected Tomorrows will review eligibility, impact, the rules with ABLÉ accounts and what they can be used for. Learn about the advantages of the ABLÉ Act and if it's right for you!</p>	Grand Harbor Ballroom 2
	<p><b>Accessible Fashion and Body Image as a Disabled Adult</b>                  Jessica Hetzel, Adult with SMA                  Noelle Hazel, Adult with SMA</p> <p>In this workshop, Jess and Noelle will be diving into the experiences of being young disabled women in a world where appearances are more important than ever, yet fashion is lacking disabled representation more than ever. Jess and Noelle will discuss the pathways they've taken on their journeys to loving and accepting the beauty of their disabled bodies. Their goal for their workshop is to make everyone feel confident and comfortable, the vibe of a late-night chat with your besties!</p>	Grand Harbor Ballroom 3 & 4
	<p><b>Community Art Time: Getting to the Art of it</b>                  Jennifer Lemisch, MA, ATR-BC, LPC</p> <p>Attendees of the community artmaking time will have opportunities to explore various art media that can support creative expressions of feelings. Whether you join alone or come with friends or family, attendees will have choices of media to try and support in a creative art expression.</p>	Porte Cochere
	<p><b>Strengthen and Stretch Your Body in the Water - for Children Sitting/                  Walking Independently, Ages 8 - 13-year-old</b></p> <p style="text-align: right;"> <b>NOVARTIS</b></p> <p>Jennifer Martyn, PT                  Krista Torseth, PT, DPT                  Kendra Paker, PT, DPT, PCS</p> <p>Join us for a 75-minute pool session led by aquatic physical therapists, aimed at boosting functional strength and skills. Water activities support physical and mental health. Each child must be accompanied in the pool by a parent or caregiver. We look forward to seeing you in the water!</p>	Admiral Pool
	<p><b>Asymptomatic Round Table and Coffee</b>                  Moderated by Marnie Harris and Travis Harris, Parents of SMA Child</p> <p>Come join others in the community to meet, mingle, and grab coffee. This is a relaxed setting.</p>	Ariel's
6:30PM – 8:30PM	<p><b>Family Friendly Researcher Poster Session</b></p>	Grand Harbor Ballroom
7:30PM – 9:30PM	<p><b>Teen Social</b>                  Sponsored by Argenx <b>**for all teens ages 12 – 18**</b></p> <p style="text-align: right;"></p>	Hampton
8:30PM – 10:30PM	<p><b>Adults with SMA Reception</b>                  Sponsored by Biogen and The Dhont Family Foundation</p> <p style="text-align: right;"> <b>Biogen</b> </p>	Grand Harbor Ballroom 1 – 4
8:30PM – 10:30PM	<p><b>Mom's Night Out</b>                  **for moms only** Sponsored by Scholar Rock</p> <p style="text-align: right;"></p>	Lakeview at the Swan Hotel

7:15AM	<b>Breakfast Opens</b>	Grand Harbor Lobby
7:45AM – 8:45AM	<b>Symposium – Everyday Impact: Hear From Teenagers and Adults in the SMA Community</b> <i>by Genentech</i>	Grand Harbor Ballroom South
8:15AM – 5:00PM	<b>Registration Open for all Conference Attendees</b>	Asbury Rotunda
8:45AM – 5:30PM	<b>Exhibitor and Networking Area Open</b>	Asbury Hall
8:45AM – 5:30PM	<b>Evryday Your Way</b> <i>Sponsored by Genentech</i>	Asbury Hall
8:45AM – 5:30PM	<b>SMAsing My Limits</b> <i>Sponsored by Novartis</i>	Asbury Hall
9:00AM – 11:50AM & 1:00PM – 5:10PM <i>(Drop off opens at 8:30am &amp; 12:30pm)</i>	<b>Children’s Program</b> <i>Sponsored by The Jacob Isaac Rappoport Foundation</i>	Newport Ballroom
9:00AM – 5:00PM	<b>Adults with SMA Lounge</b> <i>Sponsored by Genentech</i> <b>**for adults with SMA and their attendants**</b>	Cape Cod Hall
9:00AM – 5:00PM	<b>Teen Lounge</b> <i>Sponsored by Novartis</i> <b>**for all teens ages 12 - 18**</b>	Saybrook
9:00AM – 5:00PM	<b>Personalized ABE &amp; Future Planning Session</b> These 30-minute private meetings provide a dedicated space for families and individuals living with Spinal Muscular Atrophy (SMA) to sit down with our dedicated staff. While the group presentation covers the “what” and “how” of ABE accounts, these check-ins focus on your “why” and “when.” Whether you are ready to open an account or are still navigating the complexities of eligibility, these sessions are designed to move you from information to action. <b>Sign-up here to reserve your time slot:</b>	Asbury Rotunda
<b>9:00AM – 10:10AM Workshop Session #4</b>		
	<b>SMA Clinical Trials Today: Understanding Your Options</b> Rob Graham, MD Thomas Crawford, MD Crystal Proud, MD	Grand Harbor Ballroom North
	<b>Turning Your Experiences into Change: Storytelling as a Tool for Legislative Advocacy</b> Sarah Bellish, Senior Manager, Policy & Advocacy, Cure SMA Maynard Friesz, Vice President, Policy & Advocacy, Cure SMA	Grand Harbor Ballroom South

	<p><b>Guidance on selection of wheelchairs in SMA, including manual wheelchairs, power assist, power wheelchairs and alternative drive options</b>                  Amy Pasternak PT, DPT, PCS</p> <p>In this workshop, a physical therapist who specializes in SMA and prescription of manual and power seating and mobility devices will discuss decision-making regarding best options for individuals with SMA of different ages and ability-levels. The workshop will include information on different devices available in the U.S, and guidance on decision-making for different clients. The presentation will be followed by an audience Q &amp; A.</p>	Grand Harbor Ballroom 5 & 6
	<p><b>Pediatric Yoga for SMA</b>                  Anne Buckley-Reen, OTR/RYT, FORKIDS OT</p> <p>Yoga is a wonderful foundation for wellness. Anne will discuss the physical, emotional, respiratory, cognitive and immunological benefits of yoga. The workshop will begin with a seated/chair yoga routine followed by an overview of the benefits and modifications for individual practice.</p> <p>The workshop will introduce you to the benefits of the 5 parts of yoga practice for SMA which includes postures to improve mobility, endurance, and enhanced metabolic function; breath work with sounds, songs, and postures to support respiration and immune function: and relaxation and meditation practice to enhance emotional well being. Please join us for this stress busting, health enhancing experience.</p>	Grand Harbor Ballroom 7 & 8
	<p><b>Adolescence, Puberty, and Reproductive Health</b>                  Nora Renthal, MD, PhD                  Amanda Appel, MD, MPH</p>  <p>Sexual health, relationships, and fertility are important parts of quality of life, yet many young people with SMA report that these topics are rarely discussed in clinical care. This session will explore how conversations about puberty, sexuality, and relationships can begin early and evolve throughout adolescence and adulthood. We will review research from interviews with young adults with neuromuscular conditions, discuss common questions about puberty and fertility, and provide practical strategies for individuals living with SMA and their families/caregivers to support healthy development, autonomy, and reproductive health goals.</p>	Grand Harbor Ballroom 1
	<p><b>Navigating Presymptomatic SMA: How a Multidisciplinary Team Can Help</b>                  Leslie Nelson, PT, PhD, OCS</p> <p>If your child was recently identified with SMA before showing any symptoms, you may be wondering what comes next — and who can help. This session breaks down what a multidisciplinary clinic is, who's on the team, and how each specialist can support your child and your family along the way. We'll talk through rehabilitation considerations, orthopedic care, and physical and occupational therapy, and how to take what you learn at the clinic back to your local providers, therapists, and even your child's school. Most importantly, this is a space for you to ask questions, share what you're going through, and hear from other families navigating the same path.</p>	Grand Harbor Ballroom 2
	<p><b>Ask What You Came to Ask: Get it Off Your Chest</b>                  Oren Kupfer, MD                  Peter Schochet, MD                  Nick Fitzpatrick, MD</p> <p>Don't hold your breath, or your questions. This audience-led session is a choose-your-own-adventure about breathing in SMA, where you pick the path the conversation takes. Bring the questions you've been meaning to ask about airway clearance, cough assist, ventilation, sleep, respiratory infections, or anything else on your mind — and our panel of pulmonary specialists will follow your lead. Whether you're newly diagnosed, a longtime care partner, or an adult living with SMA, come ready to steer the conversation toward what matters most to you.</p>	Grand Harbor Ballroom 3 & 4
	<p><b>Healing the Grieving Heart Part II – Connections Continued</b>                  David Sereni, MPT                  Natasha Abruzzo, NP</p> <p>This gathering is a safe social space to continue conversations from Part 1 and connect with others. This time is intended for those dealing with the loss of a child or family member and provides an opportunity for you to address your experiences with bereavement and feelings of loss. Light refreshments will be provided during this session. You do not have to participate in Part 1 to attend Part 2.</p>	Ariel's




## PLEASE NOTE WEAR SUNSCREEN AND KEEP HYDRATED!


As many of you know, June in Florida can be very hot during the day. We strongly encourage everyone to take proper precautions when outside for any amount of time, by applying sunscreen and covering your body as much as possible to avoid excessive sun exposure. Also, with the high temperatures and humidity, drink plenty of water to remain hydrated in the heat!





	<p><b>Teen Siblings in the SMA Community (Ages 13–18)</b>                  Katlyn O'Brien, Sister of an Adult with SMA                  Traci O'Brien, Sister of an Adult with SMA</p> <p>This teen-focused session offers a safe space for open discussion and peer connection. Through facilitated conversation and reflection, participants will explore the realities, responsibilities, and rewards of being an SMA sibling. Teens will share their perspectives, strengthen connections, and leave feeling supported within the SMA community.</p>	Hampton
<p>10:30AM – 11:40AM <b>Workshop Session #5</b></p>		
	<p><b>Orthopedic Management in SMA</b>                  Brian Snyder, MD, PhD                  Rob Graham, MD</p> <p>This workshop will focus on life with SMA as it pertains to maintaining the best possible orthopedic management. It will also address the orthopedic complications of SMA. Children with SMA often have musculoskeletal impairments that interfere with mobility, function, and efficiency, and can contribute to restrictive pulmonary disease. Orthopedic intervention can improve or stabilize these impairments and help prevent deterioration in function. Orthopedic surgical procedures can correct hip instability and scoliosis, facilitate orthotic management, and accommodate the demands of continued growth. Musculoskeletal integrative medicine is important in normal development, especially in the child with SMA.</p>	Grand Harbor Ballroom North
	<p><b>Practical AI for Everyday Independence: Real Tools That Empower People With SMA</b>                  Tyler Dukes, DevOps Manager with Concentra Health, Board of Directors with Cure SMA, Adult with SMA</p> <p>This session focuses on real, practical AI tools people can use right now to make everyday tasks easier. The goal is to show how tools like ChatGPT, Claude, ElevenLabs, and built-in device features can help reduce physical effort, support communication, and make technology easier to work with, especially for those who deal with mobility limits, fatigue, or speech challenges. The talk stays away from technical deep dives. Instead, it uses straightforward examples—how to generate written content without typing, how to create a natural-sounding voice if speaking isn't possible, how to get detailed descriptions of images or documents, and how to use voice input or conversational tools to handle tasks completely hands-free. Security is a key part of the session. Attendees will learn how to use these tools safely, what information they should avoid sharing, and simple ways to keep their data protected while still getting real value out of AI. The session wraps up with a few live demos, followed by time for questions.</p>	Grand Harbor Ballroom South
	<p><b>Experiencing the Power of Hippotherapy</b>                  Katherine Cammack, MA, CCC-SLP, Director of Development, HorsePlay Therapy Center</p> <p>Hippotherapy is an innovative treatment that involves physical therapy, occupational therapy, and speech therapy on horseback. Experiencing the Power of Hippotherapy will explain how hippotherapy is an effective treatment tool that improves motor function, postural control, social and emotional development and helps improve muscle weakness and fatigue associated with inactivity in SMA individuals.</p>	Grand Harbor Ballroom 5 & 6
	<p><b>Dating with SMA: Confidence, Communication, and Connection</b>                  Delphine Andrews, ACC candidate, Founder of Disability Reclaimed, Adult with SMA                  Ryan Manriquez, MPP, Adult with SMA                  Maylan Chavez, Patient Advocate, Adult with SMA</p> <p>This session is for teens and adults with SMA who want to explore dating and relationships in a supportive space. Topics discussed will include building confidence, navigating vulnerability, communicating needs, setting boundaries, and addressing common misconceptions around disability and dating. Whether you're new to dating or looking to deepen connections, this workshop offers practical insights, real-life perspectives, and resources to help you date authentically and confidently.</p>	Grand Harbor Ballroom 7 & 8
	<p><b>Change Your Brain - Change Your Life</b>                  Amber Bosselman, Certified Life Coach</p> <p>Are you an Adult with SMA? Do you feel like you lack power or control in your life? Do your interactions with caregivers, healthcare systems, or an inaccessible world feel overwhelming and stressful? If so, this workshop is for you! Disability life coach Amber Bosselman will train you to use your greatest asset for overcoming life's challenges: your ability to separate external events from your internal perspectives. Don't stay stuck – come and learn a life-changing skill that you can start implementing today!</p>	Grand Harbor Ballroom 1
	<p><b>Sharing Your Type 1 Journey</b>                  (for individuals with SMA type 1 born in 2017 or earlier, and their families)                  Moderated by, Amy Medina,</p> <p>A safe environment to share experiences and ideas of those living with type 1 that were either born before any treatments existed or in a country where treatments are not available.</p>	Grand Harbor Ballroom 2




	<p><b>Genetics and Reproductive Options for SMA Families</b>          Harvey Stern, MD, PhD, Director, Reproductive Genetics, Genetics &amp; IVF Institute          Melissa Gibbons, MS, CGC</p> <p>This workshop will provide an introduction to the genetics and inheritance of SMA. Our objective is to provide a better understanding of the role SMN1 and SMN2 play in SMA and to discuss the different genetic testing and treatment options available for SMA. These tests allow us to diagnose 5q-SMA in infants and adults, identify SMA carriers, and determine if your unborn child has SMA. The wide range of reproductive options for couples who are at-risk for having children with 5q-SMA will be discussed including Preimplantation Genetic Testing (PGT-M) with in vitro fertilization (IVF), Sperm/Egg Donation, Chorionic Villus Sampling, Amniocentesis, Newborn Screening and at birth diagnostic testing.</p>	Hampton
	<p><b>Move with Yoga for Teens and Adults with SMA</b>          Anne Buckley Reen, OTR, RYT          Peyton Tansey- Adult with SMA, Yoga Practitioner</p> <p>This program will provide attendees with clinical guidance and an opportunity to experience the many therapeutic aspects of Seated/Chair and Bed Yoga for SMA. A complete yoga class with suggested adaptations will be provided including postures, breath work, guided relaxation, breathing meditation and an energizing breath/ song circle to complete our practice. Peyton and Anne will demonstrate assisted postures and share reflections on the impact of his long-standing regular yoga practice. Modifications for a bed practice will be shared in a recorded session prepared by Anne and Peyton. Please join us for this exciting opportunity to practice, learn, experience, share and enjoy these wellness tools.</p>	Grand Harbor Ballroom 5 & 6
	<p><b>Finding Your Strengths: Sustainable Resilience for SMA Caregivers</b>          Wendy Godfrey, ST Wellness</p> <p>Over time, even the most capable caregivers can experience chronic stress and burnout. This workshop is designed specifically for caregivers — a space to pause, reflect, and reconnect with the strengths that already help you navigate complex challenges. This is not about adding more to your plate. It's about using what's already strong within you to make the journey more sustainable.</p>	Grand Harbor Ballroom 7 & 8
	<p><b>Creating Lasting Memories: Using Creative Outlets to Support Grief</b>          Jennifer Lemisch, MA, ATR-BC, LPC</p> <p>Mourning the loss and navigating grief can be an overwhelming process. Expression through creative art activities can support feelings of restoration and healing for those experiencing loss. Attendees of this workshop are invited to bring photos or other small objects to incorporate into artmaking. This workshop will provide attendees an opportunity to make a keepsake object that can support coping their loss and also learn about other creative legacy ideas to explore for supporting grief.</p>	Grand Harbor Ballroom 1
	<p><b>Gyn Care &amp; Women's Health with SMA — Practical Care, Choices, and Confidence</b>          Lorelei Thomburg, MD          Cory Jacobson, Single Parent with SMA          Lyza Weisman, Adult with SMA</p> <p>This interactive workshop is created for people living with SMA who want clear, practical guidance on gynecologic and women's health care in a supportive, judgment-free setting. We'll take our lead from you, and your questions and topics that are important to you related to women's health, but plan that we will cover what to expect before, during, and after routine and specialty GYN care, including pelvic exams, contraception, menstrual management, cervical and breast screening, sexual health, urinary and pelvic floor concerns, bone health, and medication considerations. We will use to this session to combine concise medical information with lived experiences and short patient stories. Participants will be encouraged to ask questions throughout—no topic is off limits—as well as share their own experiences and strategies for care in this space. The goal is to help you feel informed, empowered, and confident making reproductive health decisions that fit your needs.</p>	Grand Harbor Ballroom 3 & 4
	<p><b>Aquatic Physical Therapy for Fun &amp; Function, Teens and Adults</b>          Jennifer Martyn, PT          Krista Torseth, PT, DPT          Kendra Parker, PT, DPT, PCS</p> <p style="text-align: right;"> <b>NOVARTIS</b></p> <p>Ready for a refreshing and distinctive aquatic adventure? Slip into your swimsuit and spend 70 minutes at the pool with a team of aquatic physical therapists. The session includes two groups: a fast-paced class (which requires independent balance in the water, reminiscent of Zomba, Cure SMA style) packed with take-home ideas for your own pool workouts. There's also a slower-paced group where participants can pursue personal goals, focusing on building functional strength and active movement in a dynamic setting. These activities nurture both physical and mental well-being through the benefits of water therapy. You'll have a chance to try various tools—like flotation devices and resistance gear—each designed to support your movement goals and stability needs. If you can't join this session, come visit us before lunch for another opportunity to discover what restorative powers the water can offer you!</p>	Admiral Pool

	<p><b>Kids Talk it Out (Ages 12 – 17)</b>                  Amber Bosselman, Certified Life Coach and Adult with SMA                  Al Freedman, PhD, Clinical Psychologist &amp; SMA Dad</p> <p>Teens with SMA (ages 12–17) are invited to join this open, teen-only conversation space. Facilitated with respect and authenticity, this session offers a chance to talk about real-life challenges, wins, and everything in between with peers who truly understand. The focus is connection, confidence, and shared experience. Parental consent is required.</p>	Grand Harbor Ballroom 2
2:30PM – 3:40PM <b>Workshop Session #7</b>		
	<p><b>Apartment Hunting 101</b>                  Ashley Fox, M.S., Adult with SMA                  Tyler Dukes, DevOps Manager with Concentra Health, Board of Directors with Cure SMA, DevOps Manager with Concentra Health                  Carlee Weber, Adult with SMA</p> <p>This workshop aims to help young adults with SMA find what they want, what they need, and manage everything in between to transition to independent living. We will share our experiences with finding an apartment and adapting it to SMA needs. We will also discuss tenants' rights and how to approach a landlord to address situations in which your needs were not adequately met.</p>	Grand Harbor Ballroom North
	<p><b>Storytellers with SMA</b>                  Kevin Schaefer, moderator                  Quinn Bucher                  Maylan Chavez                  Ty Dykema                  Sory Rivera                  Ira Walker</p> <p>Are you an aspiring writer, artist, actor, musician, filmmaker, or digital creator with SMA? Are you eager to share your stories and art? This session will feature a panel of storytellers with SMA as they share their experiences in various creative enterprises. Panelists will also discuss the representation of disabled creators, and making various industries more inclusive. An audience Q&amp;A will follow the main conversation.</p>	Grand Harbor Ballroom South
	<p><b>Calm Minds for Little Bodies: Playful Mindfulness for Kids and Parents</b>                  Tara Davenport, Parent of a child with SMA</p> <p>Bring your child to this interactive session to explore proven mindfulness-based techniques that can help with stress and anxiety. Through hands-on practice, you'll learn simple exercises and strategies designed to help kids find calm and navigate stressful moments with greater ease. Children are welcome to participate with caregivers to try out a variety of approaches tailored for all abilities. Together we'll discover practical ways to create more moments of peace, even in challenging times.</p>	Hampton
	<p><b>Empowered by Nutrition: Supporting Adults with SMA</b>                  Stephani Joseph, MS, RD</p> <p>Adults living with SMA have unique nutritional needs that differ from childhood. This session explores practical strategies to support energy, strength, general GI issues, and nutrition myths. We'll address common challenges such as weight fluctuations, protecting muscle mass, and supplement use. Attendees will leave with realistic, everyday guidance to help optimize their nutrition and how to make informed nutrition choices that support long-term health and quality of life.</p>	Grand Harbor Ballroom 5 & 6
	<p><b>Preservation of Oral Function and Airway Integrity in Spinal Muscular Atrophy across the Lifespan</b>                  Renee Hill MS, CCC/SLP, CLC Certified: Orofacial Myofunctional Disorders (2019, #329-C-19, IAOM)</p> <p>Advances in disease-modifying therapies have significantly changed the landscape of Spinal Muscular Atrophy (SMA), resulting in improved survival and functional outcomes. As longevity increases, preservation of oral function and airway integrity across the lifespan becomes increasingly critical.</p> <p>Neuromuscular weakness associated with SMA can influence oral rest posture, craniofacial development, swallowing efficiency, respiratory coordination, and speech production. Structural adaptations may evolve over time. Particularly when muscle activation patterns are altered during key developmental windows.</p> <p>This presentation will examine the structural-functional interactions of the oral mechanism in SMA from infancy through adulthood. Emphasis will be placed on early identification of these differences, restorative versus compensatory intervention approaches, considerations of fatigue and integration within multidisciplinary care models. Clinical frameworks will be provided to support a proactive, lifespan-oriented management of care.</p>	Grand Harbor Ballroom 7 & 8

	<p><b>Early Scoliosis Treatment in SMA</b>                  Rob Graham, MD                  Brian Snyder, MD                  Amy Pasternak PT, DPT, PCS</p> <p>This workshop will focus on care of early scoliosis with SMA including monitoring and management considerations and strategies.</p>	Grand Harbor Ballroom 1
	<p><b>Sweet Dreams and Restful Nights: Optimizing Sleep Health for SMA Patients and Families</b>                  Richard Kravitz, MD</p> <p>People living with SMA face increased susceptibility to sleep disturbances. These challenges may stem from muscle weakness associated with the condition or typical developmental phases in children. It's essential for SMA families to recognize these potential sleep issues and communicate them with their healthcare providers and specialized SMA medical teams. Healthcare professionals have access to multiple assessment methods to identify the root causes of sleep difficulties. A range of treatment approaches—including both medical therapies and lifestyle modifications—can effectively address sleep disorders. As SMN-targeting therapies continue to advance treatment standards, individuals with SMA and their families should stay informed about emerging opportunities to achieve quality rest. This educational session will explore the relationship between SMA and sleep health, while highlighting available strategies to enhance sleep quality for both patients and their loved ones, ensuring everyone can enjoy restorative rest.</p>	Grand Harbor Ballroom 2
	<p><b>Physical Therapy for SMA: Building Your Therapy Team</b>                  Leslie Nelson, PT, PhD, OCS</p> <p>Whether you're just getting started or looking to get more out of the therapy your child is already receiving, this session is for you. We'll explore the physical and occupational therapy needs of children with SMA and talk through how to build a team that works for your family — including what to look for, what questions to ask, and how different therapists may approach care. We'll share real treatment examples you can bring to your providers, discuss how to work toward goals that make a genuine difference in your child's daily life, and offer some tips for protecting your own body as a caregiver. This session is designed to be a conversation, and we want to hear from you.</p>	Grand Harbor Ballroom 3 & 4
<p>4:00PM – 5:00PM <b>Workshop Session #8</b></p>		
	<p><b>Navigating the Special Education Process: Setting Our Children Up for Success</b></p> <p> ScholarRock.</p> <p>Kimberly Cook, SMA Parent, Inclusion Specialist                  Tina Lewis, SMA Parent, Assistant Principal, Howard County Public School System (MD)</p> <p>Raising a child with SMA comes with unique challenges—especially when it comes to ensuring they receive the support and services they need in school. This workshop is designed to empower families with the knowledge, tools, and confidence to successfully navigate the special education process. Participants will gain a practical understanding of key components such as Individualized Education Programs (IEPs), 504 Plans, evaluations, eligibility, and related services. We'll break down complex terminology, explain your rights as a parent or caregiver, and share strategies for effective communication and collaboration with school teams. Through real-life examples and guided discussion, families will learn how to advocate for appropriate accommodations, accessibility, and inclusive learning environments that support both the medical and educational needs of students with SMA. Whether you are new to the process or looking to strengthen your advocacy skills, this session will provide actionable insights and a supportive space to ask questions and connect with others on a similar journey.</p>	Grand Harbor Ballroom North
	<p><b>The Best Nap Ever: Staying Safe With Anesthesia and Pain Care for Individuals with SMA</b>                  Alan Bielsky, MD</p> <p>The chance to talk with a practicing pediatric anesthesiologist about anesthesia, sedation, and pain care. Alan Bielsky is an anesthesiologist at Children's Hospital Colorado and takes care of patients with SMA both in the operating room and on the pain service.</p>	Grand Harbor Ballroom South
	<p><b>The Calm Within: Practices for Self-Regulation</b>                  Tara Davenport, Parent of a child with SMA</p> <p>Join us as we learn mindfulness-based practices to help us stay steady and regulated as we navigate this ever-changing world. Through simple guided exercises and practical strategies, you'll discover ways to manage stress and navigate challenges with a greater sense of ease. This session is open to anyone who wants to try out helpful tools to support your well-being—no pressure, just an open space for all to learn and explore.</p>	Hampton

	<p><b>SMA Nutrition – Keeping It Real!</b>                  Rebecca Hurst Davis, MS, RD, CSP, CD, CNSC                  Stacey Tarrant, BS, RD, LDN</p> <p>Emerging nutrition research is showing the importance of eating real, whole foods for optimal health while minimizing intake of ultra-processed foods. In this workshop, we will discuss how to choose real foods starting in infancy, through childhood, and into adulthood, while addressing the unique nutritional challenges of people with SMA, including food-based tube feeding options.</p>	Grand Harbor Ballroom 5 & 6
	<p><b>Evolving your wheels - Adaptive driving for independence</b>                  Jill Sclease, CTRS, CDRS                  Amber Bosselman, Certified Life Coach, Adult with SMA                  Lyza Weisman, Adult with SMA</p> <p>Do you want the independence of driving but aren't sure how to get there, or even if it's possible? This workshop will feature a Certified Driving Rehabilitation Specialist and two adults with SMA sharing their experiences and perspectives. It will cover the safety and feasibility of driving, as well as options for adaptive tech. From initial assessment to funding and licensing, this workshop will help guide you on your path to greater independence.</p>	Grand Harbor Ballroom 7 & 8
	<p><b>Engaging in the SMA Community in the era of Early Diagnosis and Treatment</b>                  Mamie Harris, SMA Parent                  Al Freedman, PhD, Clinical Psychologist, SMA Parent</p> <p>Newborn screening and early treatment have transformed SMA, creating a new and evolving experience for children who received early diagnosis and treatment. The opportunities many families experience today exist because of generations of advocacy, research participation, and resilience from individuals and families who came before — a shared legacy that connects all members of the SMA community.</p> <p>As a result, parents may find themselves navigating both feelings of gratitude and feelings of uncertainty as they consider where they belong within a community shaped by very different experiences.</p> <p>This facilitated session offers a space for connection and reflection among families of children who experienced early diagnosis and early treatment and are now living in the new world of SMA. Participants will explore how their stories fit within the larger SMA narrative and discuss how their voice and continued advocacy is critical for the next phase of SMA research and progress.</p>	Grand Harbor Ballroom 1
	<p><b>For Your Pleasure – Talking Intimacy with SMA Adults</b>                   Delphine Andrews, ACC candidate, Founder of Disability Reclaimed, Adult with SMA                  Ryan Manriquez, MPP, Adult with SMA</p> <p>Warning: This session includes explicit discussions of sex, intimacy, and relationships. Some topics may be sensitive or triggering. Recommended for attendees 18+.</p> <p>Sex and intimacy with SMA comes with its own terrain — and its own rewards. Grounded in personal stories and expertise, we'll explore what it actually looks like to build confidence, communicate needs, and embrace your sexuality with SMA — in whatever form that takes for you. Come as you are, bring your questions, and expect a judgment-free space that is honest, practical, and unapologetically real. This session is intended for adults 18 and older and will include candid discussion of sexual topics.</p>	Grand Harbor Ballroom 3 & 4
7:00PM – 9:30PM	<b>PJ Party &amp; Movie Night</b>	Grand Harbor Ballroom
7:30PM – 9:30PM	<b>Teen Networking Event</b> **for all teens ages 12 – 18**	Hampton
8:30PM – 10:30PM	<p><b>Adults with SMA Networking Event</b>                  Sponsored by  ScholarRock and  THE DHONT FAMILY FOUNDATION</p>	Grand Harbor Ballroom 5 - 8
8:30PM – 10:30 PM	<p><b>Dad's Night Out</b> **for Dads only**                  Sponsored by  ScholarRock</p>	Ariel's

7:15AM	<b>Breakfast Opens</b>	Grand Harbor Lobby
7:45AM – 8:45AM	<b>Symposium – Navigating Gene Replacement Therapy in Adult and Pediatric Patients: Information to Support Your Decision-Making</b> <i>by Novartis</i>	 Grand Harbor Ballroom North & South
9:00AM – 10:25AM <i>(Drop off opens at 8:30am)</i>	<b>Children’s Program</b> <i>Sponsored by The Jacob Isaac Rappoport Foundation</i>	Newport Ballroom
9:00AM – 10:15AM	<b>It’s a Wonderful Life/Closing General Session</b>	Grand Harbor Ballroom North & South

## We extend our sincere thanks to the speakers and panelists who contributed to the 2026 Annual SMA Conference.

We are truly grateful for your time, insight, and dedication in helping bring our community together once again. Your willingness to share your expertise and perspectives on the latest developments in SMA continues to inspire and educate everyone who participates in this event.

Your contributions play an essential role in advancing knowledge, fostering meaningful dialogue, and strengthening connections across the SMA community. Through your presentations and discussions, you help ensure that individuals and families affected by SMA have access to the most current information and a supportive network of experts and advocates.

The success of this year’s conference would not have been possible without your commitment and generosity in sharing your experience and knowledge. Your efforts make a lasting difference and help move the entire community forward.

## Thank you for being such an important part of the 2026 Annual SMA Conference.

### PLEASE NOTE

During this conference we would like to strongly encourage our conference attendees to take proper sanitary actions. Please remember to wash your hands frequently so we can keep the spread of germs to a minimum. If you or a family member are feeling under the weather, we advise that you not attend workshops or the children’s program. There are hand sanitizers throughout the conference.



# FAMILY FRIENDLY RESEARCHER POSTER SESSION

## FRIDAY, JUNE 26 FROM 6:30PM TO 8:30PM

The Family Friendly Researcher Poster Session allows for one-on-one interactions between individuals, families, and researchers. Cure SMA has invited researchers and healthcare providers, who are attending the Annual SMA Research & Clinical Care Meeting, to present their research to attendees of the Annual SMA Conference. During the event, individuals and families are encouraged to rotate to the different posters to ask questions and learn directly from the researchers and healthcare providers involved in each of the projects being presented.

### POSTERS INCLUDE:

**COMBINATION THERAPIES TO ENHANCE SYNAPTIC FUNCTION**  
Allison Ebert, PhD, Medical College of Wisconsin

**LIFE'S A DANCE: TOO LITTLE SMN TO PASS AROUND**  
Anton Blatnik, PhD, Case Western Reserve University

**A POST-APPROVAL CLINICAL STUDY OF INTRATHECAL ONASEMNOGENE ABEPARVOVEC IN STUDY PARTICIPANTS WITH SPINAL MUSCULAR ATROPHY**  
Bakri Elsheikh, MBBS, The Ohio State University, Wexner Medical Center

**LONG-TERM FOLLOW-UP DATA IN ZOLGENSMA-TREATED STUDY PARTICIPANTS WITH SPINAL MUSCULAR ATROPHY**  
Carol Welch, RN, BSN, MSCN and Lesley Milliner, BSN, MBA, Novartis

**STELLAR-1, STELLAR-2, AND SOLAR: PHASE 3 STUDY DESIGNS EVALUATING SALANERSEN IN SPINAL MUSCULAR ATROPHY**  
Christabella Cherubino, DC, ScD, MS, Biogen

**SMA BEYOND THE MOTOR NEURON: A STUDY OF WHOLE-BODY TREATMENT EFFECTS**  
Cortnie Hartwig, PhD, MCB Clinical Research Centers

**OUR MISSION IN MOTION: BUILDING BREAKTHROUGHS TOGETHER**  
Cure SMA Development Team, Cure SMA

**THE ROLE OF TREATED MUSCLE IN SMA**  
Elana Molotsky, PhD, Johns Hopkins University

**DUAL THERAPY FOR SYMPTOMATIC SMA NEWBORNS WITH 2 COPIES OF SMN2**  
Elicia Estrella, MS, LCGC, Boston Children's Hospital

**TREATING SMA BEFORE BIRTH: HOW PRENATAL TREATMENT CHANGES OUTCOMES**  
Emma Sutton, PhD, The Ottawa Hospital Research Institute

**INDIVIDUALIZING TREATMENT FOR BABIES WITH SMA DETECTED THROUGH NEWBORN SCREENING: ONE CENTER'S EXPERIENCE**  
Eric Cahue-Gasca, BS, Ann & Robert H Lurie Children's Hospital of Chicago

**THE STORY OF APITEGROMAB: SCIENCE, PROGRESS, AND PATIENTS**  
Erik DeBoer, PhD, Scholar Rock, Inc.

**KEY FINDINGS FROM THE CURE SMA UNMET NEEDS AMONG ADULTS ACROSS THE HEALTHCARE SPECTRUM SURVEY**  
Erin Welsh, MPH, Cure SMA

**MEDICAL EMERGENCIES IN SMA: DEVELOPMENT OF A EUROPEAN EMERGENCY CARD TEMPLATE**  
Federica Fontana, PhD, SMA Europe

**THE ADULT SMA TREATMENT AND RESEARCH PROGRAM AT THE OHIO STATE UNIVERSITY**  
Gia Cinkay, CCRP, The Ohio State University Wexner Medical Center

**MANATEE PART 1: ROCHE/GENENTECH'S CLINICAL STUDY OF EMUGROBART (GYM329) IN COMBINATION WITH RISDIPLAM**  
Helen Lin, MD, Genentech, Inc., South San Francisco, CA, USA

**TIME TO SPARKLE: THE PHASE 2 STUDY IN SMA**  
Karolien Van Huynegem, PhD, argenx

**ADULT-ONSET (TYPE 4) SMA: INSIGHTS INTO EARLY SYMPTOMS, DIAGNOSIS, AND UNMET NEEDS**  
Lauren Eisenman, MS, Cure SMA

**BEHIND THE DIAGNOSIS - HOW SMA IMPACTS THE LIVES OF CAREGIVERS**  
Laurey Brown, PT, DPT, Ann & Robert H Lurie Children's Hospital of Chicago

**UNDERSTANDING SMN'S ROLE IN NEURONAL RNA DYNAMICS**  
Licia Corona and Lorina Bilalli, Luxembourg Centre for Systems Biomedicine - University of Luxembourg

**EVALUATING THE EVOLVING SMA PHENOTYPE IN CHILDREN. RESULTS FROM THE CURE SMA COMMUNITY UPDATE SURVEY**  
Lisa Belter, MPH, Cure SMA

**NEUROMUSCULAR JUNCTION RECOVERY FOLLOWING SMN UP-REGULATION IN MOUSE MODELS OF SMA**  
Lyndsay Murray, PhD, University of Edinburgh

**HOW SMA COMMUNITY STORIES HELPED SECURE FEDERAL RESEARCH FUNDS**  
Maynard Friesz and Sarah Bellish, Cure SMA

**HOW DOES LOSS OF MUSCLE IN SMA AFFECT WHOLE BODY METABOLISM?**  
Melissa Bowerman, PhD, Keele University, UK

**VOICES OF SMA CAREGIVERS: EXPERIENCES FROM ACROSS THE UNITED STATES**  
Ndeye Yague, MS, Cure SMA

**OPTIMIZING THE PEDIATRIC TO ADULT TRANSITION PROCESS IN A PATIENT AND FAMILY FOCUSED WAY - THE CHOP-PENN MODEL**  
Oscar Mayer, MD, The Children's Hospital of Philadelphia

**LEARN ABOUT THE DEVOTE TRIAL AND THE HIGH DOSE REGIMEN OF SPINRAZA® (NUSINERSEN)**  
Puanoa Higginson, MBA, Biogen

**THE SMA EFFORT MEASURES PERCEIVED PHYSICAL FATIGABILITY IN SMA**  
Rafael Rodriguez-Torres, PT, DPT, Cara H. Kanner, PT, DPT, EdD, Thomas Corbeil, MPH, Melanie Wall, PhD, and Jacqueline Montes, PT, EdD, Department of Rehabilitation and Regenerative Medicine, Columbia University Irving Medical Center

**BONE HEALTH IN INDIVIDUALS WITH SPINAL MUSCULAR ATROPHY WHO HAVE RECEIVED DISEASE-MODIFYING THERAPY**  
Regina Laine, PNP, MSN, Boston Children's Hospital

**EMERGING TREATMENTS IN DEVELOPMENT FOR PATIENTS LIVING WITH SMA: INSIGHTS FROM CLINICAL SPECIALISTS**  
Richard S. Finkel, MD, Center for Experimental Neurotherapeutics, St. Jude Children's Research Hospital, Memphis, TN, USA

**REAL WORLD EXPERIENCES OF RISDIPLAM TREATMENT: FEEDING AND SWALLOWING OUTCOMES IN THE CURE SMA COMMUNITY UPDATE SURVEY**  
Sheila Shapouri, PharmD, MS, Genentech, Inc., South San Francisco, CA, USA

**PREGNANCY OUTCOMES IN INDIVIDUALS WITH SMA: NEW NATURAL HISTORY OF PREGNANCIES IN THE TREATED SMA POPULATION**  
Shelby Vogt-Domke, B.S., Stanford University

**READING RNA TO UNDERSTAND SMA: HOW MOTOR NEURONS CHANGE THEIR MESSAGES**  
Stephen Brown, PhD, Johns Hopkins University

**AN UPDATE ON IGNASECLANT (NMD670): AN INVESTIGATIONAL ORAL THERAPY ENHANCING MUSCLE ACTIVATION TO IMPROVE STRENGTH, ENDURANCE, AND DAILY FUNCTION IN ADULTS WITH SMA**  
Vera Kiyasova MD, PhD and Dan Brennan, NMD Pharma A/S

**TARGETING MITOCHONDRIA, THE POWERHOUSE IN MOTOR NEURONS, FOR TREATING SMA**  
Zhaofa Xu, Ph.D., Northwestern University and Lurie Children's Hospital of Chicago





# Breakthroughs

Built Together



We're \$250,000 short of our next research breakthrough.  
**We can change that together.**



Cure SMA has committed to investing \$1 million in basic research by June 30 and we have \$250,000 left to go.

Our next treatment breakthrough isn't built by one person or one gift. It's built by you and everyone in our SMA community who refuses to stop moving forward.

**Will you be part of what comes next?**



**Donate today at [CureSMA.org/BuiltTogether](https://CureSMA.org/BuiltTogether)**



# CHILDREN'S PROGRAM ENTERTAINMENT SCHEDULE



## No Food Allowed in Children's Program

Please do not bring any food into the children's program since some of the children attending have severe food allergies.

## FRIDAY, JUNE 26, 2026

### CHILDREN'S PROGRAM MORNING SESSION 8:30AM – 12:30PM

#### 11:30AM – 12:00PM

##### Bubble Show

Mr. Keith your Bubbleologist will perform a 30-minute, interactive show featuring rainbow bubbles, giant bubbles, small bubbles, bubbles inside of bubbles, smoke (vapor) bubbles and Mr. Keith's "friend" Snapper. All this happens while sharing some of the fascinating Science behind bubbles!

### CHILDREN'S PROGRAM AFTERNOON SESSION 1:15PM – 4:45PM

#### 3:00PM – 4:30PM

##### Build-A-Stuffed Animal

Stop by this fun station and pick out your own animal to stuff and take home as a fun conference memento!

## SATURDAY, JUNE 27, 2026

### CHILDREN'S PROGRAM MORNING SESSION 8:30AM – 11:50AM

#### 10:40AM – 11:25AM

##### Spin Pop Boom! Show

Be amazed when our Mad Scientist is able to defy gravity in this energetic and spectacular event! Foaming cups and steaming chemical reactions will introduce you to a world of exciting chemistry as our Mad Scientist creates awesome rainbow reactions, foams amazing elephants' toothpaste, and even makes liquid defy gravity!

### CHILDREN'S PROGRAM AFTERNOON SESSION 12:30PM – 5:10PM

#### 2:00PM – 2:30PM

##### Magic Show

Mr. Keith presents this magic show which features big laughs and a fun guarantee!

#### 4:00PM – 4:45PM

##### Big Top Science Show

This spectacular special event features incredible demonstrations that help children to understand important physics and chemistry concepts. From a Bed of Nails to a Pin in a Ballon, this is one circus you won't want to miss!

Sponsored by





## HOW DO BATHROOM BREAKS WORK?

Every time any child has to use the restroom a parent will be contacted via text message or phone call to come take their child to the restroom. Volunteers are not allowed to escort any children to the bathroom. Parents please have your phones handy so you can be reached for toileting breaks.

## CAN I LEAVE MY CHILD WITH SMA WHO REQUIRES BREATHING ASSISTANCE IN THE CHILDREN'S PROGRAM?

No, since the children's program is run by volunteers they are not responsible for any medical care for children with SMA. A child who requires any breathing support, cough assist or suction cannot be left in the Children's Program without a nurse or caretaker.



## CAN MY CHILD CHECK THEMSELVES IN AND OUT OF THE CHILDREN'S PROGRAM?

If your child is 12 years of age or older and you give permission at registration through KidCheck they are allowed to check themselves in and out of the children's program through the app.

## WHAT DO VOLUNTEERS ASSIST WITH THROUGHOUT THE DAY?

Volunteers supervise and assist children by playing games, watching movies, doing arts and crafts, etc. Volunteers are not responsible for any medical care, medicine disbursement, bathroom breaks/diaper changes, feeding responsibilities or wheelchair/stander transfers. Parents or their caretakers will be notified via cell phone or text message to assume those responsibilities no matter the type of SMA the child has.



## IF I AM NOT LEAVING MY CHILD ALONE IN THE CHILDREN'S PROGRAM, DO I STILL HAVE TO ADD THEM TO KIDCHECK?

Yes- we require every child who enters the room (with or without a parent or caretaker) to be checked in via KidCheck so we have contact information in case of emergency.

## CAN I BRING FOOD OR DRINKS INTO THE CHILDREN'S PROGRAM?

No, food and drinks are NOT allowed into the children's program since some of the children attending have severe food allergies.



## WHEN IS THE CHILDREN'S PROGRAM OPEN?

The children's program is open during workshops only so please make sure to pick up your children as soon as your workshops end during the morning and afternoon sessions!

# THANK YOU TO OUR VOLUNTEERS



## Thank You to The Conference Children's Program Volunteers

Our conference simply wouldn't be possible without this incredible group of individuals. Each volunteer plays a vital role in shaping the success and spirit of the event, and every year their dedication shines throughout the entire weekend.

Their long hours of hard work give families the peace of mind that their children are safe, cared for, and having fun—allowing parents to focus on learning the latest information about SMA in our workshops. The enthusiasm our volunteers bring to the children's program and evening events is truly unmatched.

They take great pride in creating an experience that leaves families feeling this was the best conference yet. To every volunteer who makes this possible, thank you for your time, energy, and heart.

**We would like to especially thank the following volunteers who return year after year, leaving their jobs and families at home to help SMA families:**



**VOLUNTEER FOR 36 YEARS**

George Ghorbanian  
Chicago Police Officer



**VOLUNTEER FOR 26 YEARS**

Lance Northcutt  
Lawyer



**VOLUNTEER FOR 34 YEARS**

Patti McCarthy Freedman  
Dental Hygienist



**VOLUNTEER FOR 26 YEARS**

Kelly Basso  
Electrologist



**VOLUNTEER FOR 31 YEARS**

Steve Smith  
Physical Therapist



**VOLUNTEER FOR 25 YEARS**

Katlyn O'Brien  
Teacher



**VOLUNTEER FOR 27 YEARS**

Kelly Milito  
Hair Stylist



**VOLUNTEER FOR 25 YEARS**

Mary Blume  
Caregiver for Grandkids



**VOLUNTEER FOR 26 YEARS**

Kevin O'Brien  
Retired



**VOLUNTEER FOR 24 YEARS**

Noreen Reilly  
IT Project Manager

# THANK YOU TO OUR VOLUNTEERS



**VOLUNTEER FOR 24 YEARS**

Traci O'Brien  
Dog Whisperer



**VOLUNTEER FOR 19 YEARS**

Julie Smith  
IT Director



**VOLUNTEER FOR 17 YEARS**

Jackie Bohl  
Meeting & Events Coordinator



**VOLUNTEER FOR 16 YEARS**

Patrick Hogan  
High School Social Studies Teacher and Coach



**VOLUNTEER FOR 15 YEARS**

Patti Northcutt



**VOLUNTEER FOR 15 YEARS**

Joy Martin  
Physical Therapist



**VOLUNTEER FOR 15 YEARS**

Donna Budil  
Preschool Director & Teacher



**VOLUNTEER FOR 14 YEARS**

Jennifer Walsh  
Software Analyst



**VOLUNTEER FOR 14 YEARS**

Kelly Gibbons  
Health Services



**VOLUNTEER FOR 14 YEARS**

Kayla Forsythe  
Registered Nurse



**VOLUNTEER FOR 14 YEARS**

Lexi Basso  
Registered Nurse



**VOLUNTEER FOR 13 YEARS**

Georgia Slojkowski  
Elementary Orchestra Teacher



**VOLUNTEER FOR 13 YEARS**

Laura Joyce  
Teacher



**VOLUNTEER FOR 12 YEARS**

Patrick Slojkowski  
Scientist at PepsiCo



**VOLUNTEER FOR 12 YEARS**

Megan Besler  
Senior Financial Analyst



**VOLUNTEER FOR 11 YEARS**

Raphi Milito  
Sales Executive at SAP



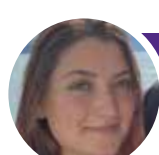
**VOLUNTEER FOR 11 YEARS**

Ralph Milito  
Realtor



**VOLUNTEER FOR 11 YEARS**

Michael Milito  
Project Manager



**VOLUNTEER FOR 11 YEARS**

Daniela Milito  
Food Pantry Coordinator



**VOLUNTEER FOR 11 YEARS**

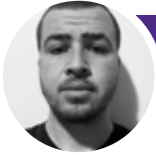
Sally McCarthy  
Retired Nurse

# THANK YOU TO OUR VOLUNTEERS



**VOLUNTEER FOR 10 YEARS**

Emma Rubenstein  
Walt Disney World Cast Member



**VOLUNTEER FOR 10 YEARS**

Jack Jomarron  
Director of Policy



**VOLUNTEER FOR 9 YEARS**

Samantha Smith  
Occupational Therapist



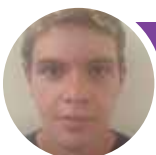
**VOLUNTEER FOR 9 YEARS**

Cara Freedman  
Sr. Research Assistant



**VOLUNTEER FOR 9 YEARS**

Katie Dieckhoff  
Behavioral Treatment Therapist



**VOLUNTEER FOR 8 YEARS**

Will Reilly  
Automation Programmer



**VOLUNTEER FOR 8 YEARS**

Clara Dylewsk  
Graduate Student; Nurse Practitioner



**VOLUNTEER FOR 7 YEARS**

Sarah Grimson  
Admin Assistant



**VOLUNTEER FOR 5 YEARS**

Alison Williams  
Finance Analyst



**VOLUNTEER FOR 5 YEARS**

Cathy Staples  
Orthodontal Assistant



**VOLUNTEER FOR 5 YEARS**

Hannah Smith  
Student



**VOLUNTEER FOR 5 YEARS**

Dave Richmond  
Property Manager



**VOLUNTEER FOR 5 YEARS**

Sally O'Toole  
Student



**VOLUNTEER FOR 5 YEARS**

Jack Olech  
Student



**VOLUNTEER FOR 5 YEARS**

Terry McGovern  
Vice President of Sales, Atlas Forms and Graphics



**VOLUNTEER FOR 5 YEARS**

Kay McGovern  
Private Investigator



**VOLUNTEER FOR 5 YEARS**

Stacey McDonogh  
Social Worker



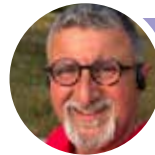
**VOLUNTEER FOR 5 YEARS**

Kristi Lazic  
Registered Nurse



**VOLUNTEER FOR 5 YEARS**

Kamil Jerominski  
Architect



**VOLUNTEER FOR 5 YEARS**

Paul Enwia  
Retired Chicago Public School Teacher

# THANK YOU TO OUR VOLUNTEERS



VOLUNTEER FOR 5 YEARS

Logan Dimitriou  
College Student



VOLUNTEER FOR 5 YEARS

Dolores Courtney O'Toole  
Community Support Worker



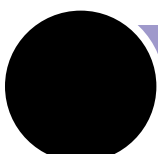
VOLUNTEER FOR 5 YEARS

Lily Carlson  
Student



VOLUNTEER FOR 5 YEARS

Eric Berghoff  
Veterinary Pharmaceutical Sales Rep



VOLUNTEER FOR 4 YEARS

Peter Saro  
Retired Cook County Sheriff Deputy



VOLUNTEER FOR 4 YEARS

Sam Rossi  
Web Developer



VOLUNTEER FOR 4 YEARS

Sam Olech  
Student



VOLUNTEER FOR 4 YEARS

Kathleen O'Hare  
Associate Director DePaul University



VOLUNTEER FOR 4 YEARS

Jayne O'Brien  
Retired RN



VOLUNTEER FOR 4 YEARS

Dawn McCarthy  
Retired Chicago Public School Teacher



VOLUNTEER FOR 4 YEARS

Frank Magnelli  
Medical Device Sales



VOLUNTEER FOR 4 YEARS

Jack Koteles  
College Student



VOLUNTEER FOR 4 YEARS

Teresa Hayes  
Communications Professor at DeVry University



VOLUNTEER FOR 4 YEARS

Ben Goldberg  
Sous Chef for City Works



VOLUNTEER FOR 4 YEARS

Braden Gebavi  
Software Engineer at Development Studio



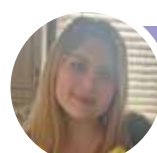
VOLUNTEER FOR 4 YEARS

Ronna Fernandez  
Business Manager



VOLUNTEER FOR 4 YEARS

Rick Fernandez  
Retired Chicago Police Officer



VOLUNTEER FOR 4 YEARS

Sophia Fager  
Student



VOLUNTEER FOR 4 YEARS

Eric Fager  
Chicago Police Officer



VOLUNTEER FOR 4 YEARS

Amy Fager  
Insurance Broker

# THANK YOU TO OUR VOLUNTEERS



VOLUNTEER FOR 4 YEARS

Vince Coughlin  
Teacher



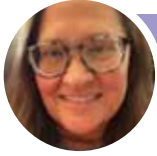
VOLUNTEER FOR 4 YEARS

Neena Campos  
Student



VOLUNTEER FOR 4 YEARS

Matt Breslin  
College Student



VOLUNTEER FOR 4 YEARS

Cheryl Breslin  
Territory Account Manager



VOLUNTEER FOR 4 YEARS

Regina Ballesteros  
Student



VOLUNTEER FOR 4 YEARS

Bryn Bahnks  
Research Technician



VOLUNTEER FOR 3 YEARS

Roland Rencz  
Investigator



VOLUNTEER FOR 3 YEARS

Aubree Munno  
Hair Stylist



VOLUNTEER FOR 3 YEARS

Shea Joyce  
Investment Strategist



VOLUNTEER FOR 3 YEARS

Svetlana Fager  
Student



VOLUNTEER FOR 2 YEARS

Molly O'Toole  
Student



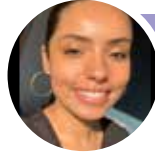
VOLUNTEER FOR 2 YEARS

Gina Lewis  
Human Services Research Analyst



VOLUNTEER FOR 2 YEARS

Bridget Harmon  
Student



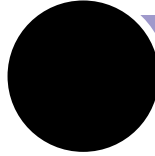
VOLUNTEER FOR 2 YEARS

Jessica Feliciano  
Pet Care Professional



VOLUNTEER FOR 2 YEARS

Jessica Faure  
Product Developer at PepsiCo



VOLUNTEER FOR 2 YEARS

Luka Fager  
Student



VOLUNTEER FOR 2 YEARS

Meghan Ellixson  
Student



VOLUNTEER FOR 2 YEARS

Mckenna Ellixson  
Student



VOLUNTEER FOR 2 YEARS

Violet Barton  
Program Assistant



## MARY BLUME VOLUNTEER FOR 25 YEARS

The 2026 Annual SMA Conference marks an incredible milestone as we celebrate 25 years of service from one of our dedicated volunteers, Mary Blume! Mary first volunteered at the conference 25 years ago and has been a committed presence ever since. She generously takes time away from her family—and from spending time with her own grandchildren, Mason, Ava and Parker—to volunteer in the Children’s Program. Families with young children may especially recognize Mary as a familiar and comforting face in the Baby Room, where she has become a beloved regular year after year. Mary truly embodies the spirit of volunteerism, and we are so fortunate to have her as part of our Cure SMA community. Everyone at Cure SMA extends our heartfelt thanks to Mary for her unwavering dedication and 25 years of remarkable service.



## KATLYN O'BRIEN VOLUNTEER FOR 25 YEARS

We are proud to recognize an extraordinary milestone—25 years of dedicated service from another longtime volunteer, Katlyn O’Brien. For a quarter of a century, Katlyn has generously given her time, energy, and heart in support of the SMA Community, making a lasting impact on countless individuals and families along the way. Her commitment, reliability, and willingness to step in wherever help is needed truly exemplify her spirit of volunteerism. Katlyn’s 25 years of service are a testament to her compassion and dedication, and we are deeply grateful for all she has contributed both as a volunteer and a conference speaker leading the Siblings Talk it Out workshops each year. Thank you, Katlyn, for 25 remarkable years of making a difference.



# Dedicated to the **SMA** community

Stop by the Novartis booth to learn more about approved treatments and explore all the booth has to offer.



**Novartis Pharmaceuticals Corporation**  
East Hanover, New Jersey 07936-1080

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fighting spinal muscular atrophy in memory of our shooting star  
[www.ourshootingstar.com](http://www.ourshootingstar.com)

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**we proudly support  
cure sma**

**congratulations  
on another  
successful conference**

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## Evrysdi is now serving:

- Everyone with SMA
- Every day with each dose
- Everywhere throughout the body\*

\*This was observed when Evrysdi was studied in animals.

With 2 non-invasive treatment options: **liquid and tablet\***

\*Evrysdi 5-mg tablets are approved for people aged 2 years and older who weigh at least 44 lb (20 kg). The tablets can be mixed with non-chlorinated drinking water (eg, filtered water, bottled water) and taken with feeding tubes.

Stop by the Evryday Cafe to see the full menu  
Open all weekend at the Evrysdi booth

### What is Evrysdi?

Evrysdi is a prescription medicine used to treat spinal muscular atrophy (SMA) in children and adults.

### Important Safety Information

- **Before taking Evrysdi, tell your healthcare provider about all of your medical conditions, including if you:**
  - are pregnant or plan to become pregnant, as Evrysdi may harm your unborn baby. Ask your healthcare provider for advice before taking this medicine
  - are a woman who can become pregnant:
    - Before you start your treatment with Evrysdi, your healthcare provider may test you for pregnancy
    - Talk to your healthcare provider about birth control methods that may be right for you. Use birth control while on treatment and for at least 1 month after stopping Evrysdi
    - **Pregnancy Registry.** There is a pregnancy registry for women who take Evrysdi during pregnancy. The purpose of this registry is to collect information about the health of the pregnant woman and her baby. If you are pregnant or become pregnant while receiving Evrysdi, tell your healthcare provider right away. Talk to your healthcare provider about registering with the Evrysdi Pregnancy Registry. Your healthcare provider can enroll you in this registry or you can enroll by calling 1-833-760-1098 or visiting <https://www.evrysdipregnancyregistry.com>.
  - are an adult male. Evrysdi may affect a man's ability to have children (fertility). Ask a healthcare provider for advice before taking this medicine
  - are breastfeeding or plan to breastfeed. It is not known if Evrysdi passes into breast milk and may harm your baby

**Genentech**

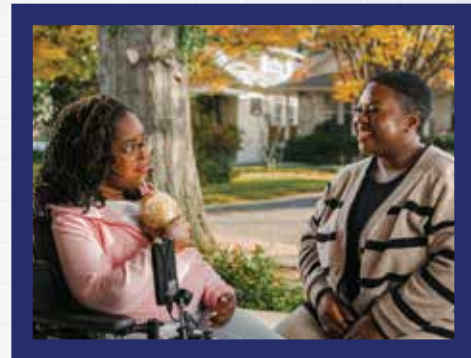
A Member of the Roche Group

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## What one of our regulars has to say:

*// To have this little bottle and be able to take it with us is awesome. It's one of those things where you find something that works and you just want to stick with it. //*

— **Keanna, mom to Brooklyn,**  
who is living with Type 2 SMA



## Most chosen SMA treatment in the United States



More people treated for SMA take Evrysdi than any other SMA treatment, according to the 2024 Cure SMA State of SMA report

### Meet us for a community event

Saturday, June 27 from 7:45 AM-8:45 AM

### Community Symposium

Featuring: An open conversation with a neurologist and people taking Evrysdi.

#### Important Safety Information (continued)

- **Tell your healthcare provider about all the medicines you take**
- If you were prescribed Evrysdi for Oral Solution, you should receive Evrysdi from the pharmacy as a liquid. If the medicine in the bottle is a powder, **do not use it**. Contact your pharmacist for a replacement
- Avoid getting Evrysdi on your skin or in your eyes. If Evrysdi gets on your skin, wash the area with soap and water. If Evrysdi gets in your eyes, rinse your eyes with water
- **The most common side effects of Evrysdi include:**
  - For later-onset SMA:
    - fever
    - diarrhea
    - rash
  - For infantile-onset SMA:
    - fever
    - diarrhea
    - rash
    - runny nose, sneezing and sore throat (upper respiratory infection)
    - lung infection (lower respiratory infection)
    - constipation
    - vomiting
    - cough

These are not all of the possible side effects of Evrysdi. For more information on the risk and benefits profile of Evrysdi, ask your healthcare provider or pharmacist.

You may report side effects to the FDA at 1-800-FDA-1088 or [www.fda.gov/medwatch](http://www.fda.gov/medwatch). You may also report side effects to Genentech at 1-888-835-2555.

**Please see accompanying brief summary for additional Important Safety Information.**



<p style="text-align: center;"><b>EVRYSDI® [ev-RIZ-dee] (risdiplam) for oral solution</b></p>	<p><b>Patient Information</b></p> <p style="text-align: right;"><b>EVRYSDI® [ev-RIZ-dee] (risdiplam) tablets, for oral use</b></p>
<p><b>What is EVRYSDI?</b></p> <ul style="list-style-type: none"> <li>EVRYSDI is a prescription medicine used to treat spinal muscular atrophy (SMA) in children and adults.</li> </ul>	<ul style="list-style-type: none"> <li>Take EVRYSDI one time daily with or without a meal at about the same time each day.</li> <li><b>Do not</b> chew, cut, or crush the tablet.</li> <li>Swallow the EVRYSDI tablet whole with some water.</li> <li>If you cannot swallow tablets whole or if you have a nasogastric (NG-tube) or gastrostomy (G-tube), see the detailed Instructions for Use that comes with it for information on how to take or give EVRYSDI tablets.</li> </ul>
<p><b>Before taking EVRYSDI, tell your healthcare provider about all of your medical conditions, including if you:</b></p> <ul style="list-style-type: none"> <li>are pregnant or plan to become pregnant. If you are pregnant, or are planning to become pregnant, ask your healthcare provider for advice before taking this medicine. EVRYSDI may harm your unborn baby.</li> <li>are a woman who can become pregnant: <ul style="list-style-type: none"> <li>Before you start your treatment with EVRYSDI, your healthcare provider may test you for pregnancy. Because EVRYSDI may harm your unborn baby, you and your healthcare provider will decide if taking EVRYSDI is right for you during this time.</li> <li>Talk to your healthcare provider about birth control methods that may be right for you. Use birth control while on treatment and for at least 1 month after stopping EVRYSDI.</li> <li><b>Pregnancy Registry.</b> There is a pregnancy registry for women who take EVRYSDI during pregnancy. The purpose of this registry is to collect information about the health of the pregnant woman and her baby. If you are pregnant or become pregnant while receiving EVRYSDI, tell your healthcare provider right away. Talk to your healthcare provider about registering with the EVRYSDI Pregnancy Registry. Your healthcare provider can enroll you in this registry or you can enroll by calling 1-833-760-1098 or visiting <a href="https://www.evrysidipregnancyregistry.com">https://www.evrysidipregnancyregistry.com</a>.</li> </ul> </li> <li>are an adult male planning to have children: EVRYSDI may affect a man's ability to have children (fertility). If this is of concern to you, make sure to ask a healthcare provider for advice.</li> <li>are breastfeeding or plan to breastfeed. It is not known if EVRYSDI passes into breast milk and may harm your baby. If you plan to breastfeed, discuss with your healthcare provider about the best way to feed your baby while on treatment with EVRYSDI.</li> </ul> <p><b>Tell your healthcare provider about all the medicines you take,</b> including prescription and over-the-counter medicines, vitamins, and herbal supplements. Keep a list of them to show your healthcare provider, including your pharmacist, when you get a new medicine.</p>	<p><b>If you miss a dose of EVRYSDI:</b></p> <ul style="list-style-type: none"> <li>If you remember the missed dose within 6 hours of when you normally take EVRYSDI, then take the dose. Continue taking EVRYSDI at your usual time the next day.</li> <li>If you remember the missed dose more than 6 hours after you normally take EVRYSDI, skip the missed dose. Take your next dose at your usual time the next day.</li> <li>If you do not fully swallow the dose, or you vomit after taking a dose, <b>do not take</b> another dose of EVRYSDI to make up for that dose. Wait until the next day to take the next dose at your usual time.</li> </ul>
<p><b>How should I take EVRYSDI?</b></p> <ul style="list-style-type: none"> <li>For infants and children, your healthcare provider will determine the daily dose of EVRYSDI needed based on your child's age and weight. For adults, take 5 mg of EVRYSDI daily.</li> <li>Your healthcare provider will either prescribe: <ul style="list-style-type: none"> <li>EVRYSDI for oral solution</li> <li><b>Or</b></li> <li>EVRYSDI tablet</li> </ul> </li> <li>Your healthcare provider will tell you how long you or your child needs to take EVRYSDI. Do not stop treatment with EVRYSDI unless your healthcare provider tells you to. <ul style="list-style-type: none"> <li>Take EVRYSDI exactly as your healthcare provider tells you to take it. Do not change the dose without talking to your healthcare provider.</li> </ul> </li> <li>Avoid getting EVRYSDI on your skin or in your eyes. If it gets on your skin, wash the area with soap and water. If it gets in your eyes, rinse your eyes with water.</li> </ul>	<p><b>What are the possible side effects of EVRYSDI?</b> <b>The most common side effects of EVRYSDI include:</b></p> <ul style="list-style-type: none"> <li><b>For later-onset SMA:</b> <ul style="list-style-type: none"> <li>fever</li> <li>diarrhea</li> <li>rash</li> </ul> </li> <li><b>For infantile-onset SMA:</b> <ul style="list-style-type: none"> <li>fever</li> <li>runny nose, sneezing, and sore throat (upper respiratory infection)</li> <li>constipation</li> <li>diarrhea</li> <li>lung infection (lower respiratory infection)</li> <li>vomiting</li> <li>rash</li> <li>cough</li> </ul> </li> </ul> <p>These are not all of the possible side effects of EVRYSDI. For more information, ask your healthcare provider or pharmacist. Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.</p>
<p><b>If you are taking EVRYSDI for oral solution:</b></p> <ul style="list-style-type: none"> <li><b>See the detailed Instructions for Use that comes with it for information on how to take or give EVRYSDI for oral solution.</b></li> <li>You should receive EVRYSDI from the pharmacy as a liquid that can be given by mouth or through a feeding tube. The liquid solution is prepared by your pharmacist or other healthcare provider. If the medicine in the bottle is a powder, <b>do not use it.</b> Contact your pharmacist for a replacement.</li> <li>Take EVRYSDI one time daily with or without a meal at about the same time each day. Drink water afterwards to make sure EVRYSDI has been completely swallowed.</li> <li>In infants who are breastfed, EVRYSDI can be given before or after breastfeeding.</li> <li><b>Do not</b> mix EVRYSDI with formula or milk.</li> <li>If you are unable to swallow and have a nasogastric (NG-tube) or gastrostomy tube (G-tube), EVRYSDI for oral solution can be given through the tube.</li> </ul> <p><b>Reusable Oral Syringes for EVRYSDI for Oral Solution</b></p> <ul style="list-style-type: none"> <li>Your pharmacist will provide you with the reusable oral syringes that are needed for taking your medicine and explain how to use them. You should receive 1 or 2 identical oral syringes depending on your prescribed daily dose.</li> <li>From the bottle, draw up (measure) the dose of EVRYSDI with these syringes, as they are made to protect the medicine from light.</li> <li>Take EVRYSDI right away after it has been drawn into the syringe. <b>Do not</b> store the EVRYSDI solution in the syringe. If EVRYSDI is not taken within 5 minutes of when it is drawn up, throw away the solution by pressing the plunger and prepare a new dose with the same syringe.</li> <li><b>Do not</b> throw the syringes away because they are reusable.</li> <li>Wash the syringes per instructions after use.</li> <li>Contact your healthcare provider or pharmacist if your oral syringes are lost or damaged.</li> </ul> <p><b>If you are taking EVRYSDI Tablets:</b></p> <ul style="list-style-type: none"> <li><b>See the detailed Instructions for Use that comes with it for information on how to take or give EVRYSDI tablets.</b></li> <li><b>Wash your hands before and after preparing or taking EVRYSDI tablets.</b></li> </ul>	<p><b>How should I store EVRYSDI?</b> <b>EVRYSDI for Oral Solution:</b></p> <ul style="list-style-type: none"> <li>Store EVRYSDI in the refrigerator between 36°F to 46°F (2°C to 8°C). Do not freeze. <ul style="list-style-type: none"> <li>If necessary, EVRYSDI can be kept at room temperature up to 104°F (up to 40°C) for a combined total of 5 days. EVRYSDI can be removed from, and returned to, a refrigerator. The total combined time out of refrigeration should not be more than 5 days.</li> </ul> </li> <li>Keep EVRYSDI in an upright position in the original amber bottle to protect from light.</li> <li>Throw away (discard) any unused portion of EVRYSDI 64 days after it is mixed by the pharmacist (constitution) or if EVRYSDI has been kept at room temperature (below 104°F [40°C]) for more than a total combined time of 5 days. Discard EVRYSDI if it has been kept above 104°F (40°C). Please see the Discard After date written on the bottle label. (See the <b>Instructions for Use</b> that comes with EVRYSDI for oral solution).</li> </ul> <p><b>EVRYSDI Tablets:</b></p> <ul style="list-style-type: none"> <li>Store at room temperature between 68°F to 77°F (20°C to 25°C).</li> <li>Keep the tablets in their original bottle with the cap tightly closed to protect from moisture.</li> </ul> <p><b>Keep EVRYSDI, all medicines and syringes out of the reach of children.</b></p> <p><b>General information about the safe and effective use of EVRYSDI.</b> Medicines are sometimes prescribed for purposes other than those listed in a Patient Information leaflet. Do not use EVRYSDI for a condition for which it was not prescribed. Do not give EVRYSDI to other people, even if they have the same symptoms you have. It may harm them. You can ask your pharmacist or healthcare provider for information about EVRYSDI that is written for health professionals.</p>
<p><b>What are the ingredients in EVRYSDI?</b> <b>Active ingredient:</b> risdiplam <b>Inactive ingredients:</b> EVRYSDI for Oral Solution: ascorbic acid, disodium edetate dihydrate, isomalt, mannitol, polyethylene glycol 6000, sodium benzoate, strawberry flavor, sucralose, and tartaric acid. <b>EVRYSDI Tablets:</b> colloidal silicon dioxide, crospovidone, mannitol, microcrystalline cellulose, polyethylene glycol 3350, polyvinyl alcohol, sodium stearyl fumarate, strawberry flavor, talc, tartaric acid, titanium dioxide, and yellow iron oxide.</p> <p><b>Genentech</b> <i>A Member of the Roche Group</i> EVRYSDI® (risdiplam) Distributed by: <b>Genentech USA, Inc.</b> A Member of the Roche Group 1 DNA Way South San Francisco, CA 94080-4990</p> <p>EVRYSDI is a registered trademark of Genentech, Inc. M-US-00007143(v8.0) ©2026 Genentech, Inc. All rights reserved.</p> <p>For more information, go to <a href="http://www.EVRYSDI.com">www.EVRYSDI.com</a> or call 1-833-387-9734.</p>	<p>This Patient Information has been approved by the U.S. Food and Drug Administration.</p> <p style="text-align: right;">Issued: 2/2026</p>

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Life Takes Muscle is for everyone who wants to change what's possible in spinal muscular atrophy (SMA). Today's treatments have transformed the outlook for children and adults living with SMA, but we believe progress doesn't have to end there. **Let's expect more—and demand more—from SMA care.**

**Bear, 11**  
Living with SMA  
and advocating  
for progress

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SEE WHY MUSCLE MATTERS



Join our movement at [LifeTakesMuscle.com](https://LifeTakesMuscle.com)  
Lend your voice and help shape the future of SMA.

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**Maddy Gunawan,**  
living with SMA

US-SMA-0296

PICTURE YOUR

# ONE DOSE LIFE

Lab tests and administration of oral corticosteroids are required before and after injection.

Andrew hasn't received ITVISMA. Individuals shown were compensated for their time.

 **itvisma**<sup>®</sup>  
(onasemnogene abeparvovec-brve)  
suspension for intrathecal injection

**Andrew C., 22 years old**  
Sports journalist and student  
Living with spinal muscular atrophy (SMA)

**ITVISMA—the only one-time gene replacement therapy for kids 2 years of age and older, teens, and adults with SMA.**

Visit the booth or scan the QR code to learn more about ITVISMA.



## Indication and Important Safety Information

### What is ITVISMA?

ITVISMA is a prescription gene therapy used to treat adults and children 2 years of age and older with spinal muscular atrophy (SMA). ITVISMA is given as a one-time intrathecal injection.

### What is the most important safety information I should know about ITVISMA?

- ITVISMA can increase liver enzyme levels and cause hepatotoxicity.
- Patients will receive an oral corticosteroid medication before and after ITVISMA injection and will undergo regular blood tests to monitor liver function.
- Patients and caregivers should contact the patient's doctor immediately if the patient's skin and/or whites of the eyes become yellowish, if the patient misses a dose of corticosteroid or vomits it up, or if the patient experiences a decrease in alertness.

### What should I watch for before and after injection with ITVISMA?

- Infections before or after ITVISMA injection can lead to more serious complications. Patients, caregivers, and close contacts of the patient should follow infection prevention procedures. Patients and caregivers should contact the patient's doctor immediately if the patient experiences any signs of a possible infection such as coughing, wheezing, sneezing, runny nose, sore throat, or fever.
- Decreased platelet counts could occur following injection with ITVISMA. Seek immediate medical attention if the patient experiences unexpected bleeding or bruising.
- Peripheral sensory neuropathy has occurred with ITVISMA administration. Patients and caregivers should contact the patient's doctor right away if the patient experiences numbness, tingling, prickling, or pain in the arms, hands, legs, and/or feet.
- Decreased blood platelet and red blood cell counts, sudden kidney change, and increased bruising or bleeding, which could be signs of thrombotic microangiopathy (TMA), can occur. Patients and caregivers should seek immediate medical attention if the patient experiences unexpected bruising or bleeding, seizures, or decreased urine output.

- There is a theoretical risk of tumor development with gene therapies such as ITVISMA. Patients and caregivers should contact the patient's doctor and Novartis Gene Therapies, Inc. at 1-833-828-3947 if a tumor develops.

### What do I need to know about vaccinations and ITVISMA?

- Patients and caregivers should consult the patient's doctor about vaccinations and ITVISMA.
- Patients and caregivers should talk with the patient's doctor to determine if adjustments to the patient's vaccination schedule are necessary during corticosteroid use.
- Protection against influenza and respiratory syncytial virus (RSV) is recommended, and vaccination status should be up-to-date prior to ITVISMA administration.

### What do I need to know about contraception and egg or sperm donation and ITVISMA?

- Women of childbearing potential should use an effective method of contraception and refrain from egg donation for 6 months following ITVISMA injection.
- Men capable of fathering a child should use a barrier method of contraception and refrain from sperm donation for 3 months following ITVISMA injection.

### What are the possible or likely side effects of ITVISMA?

- The most common adverse reactions that occurred in patients treated with ITVISMA were upper respiratory tract infection, fever, upper gastrointestinal symptoms, increased liver enzymes, headache, dizziness, pain in extremity, low platelet counts, and sensory disturbance.

**The safety information provided here is not comprehensive. Talk to the patient's doctor about any side effects that bother the patient or that don't go away.**

**You are encouraged to report suspected side effects by contacting the FDA at 1-800-FDA-1088 or [www.fda.gov/medwatch](http://www.fda.gov/medwatch), or Novartis Gene Therapies, Inc. at 1-833-828-3947.**

**Please see Brief Summary of Prescribing Information on the next page.**



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## IMPORTANT FACTS ABOUT ITVISMA® (onasemnogene abeparvovec-brve)

### USE

ITVISMA is a prescription gene therapy used to treat adults and children 2 years of age and older with spinal muscular atrophy (SMA). ITVISMA is given as a one-time intrathecal injection (an injection into the spine).

### WARNINGS

#### Serious Liver Injury

- ITVISMA can increase liver enzyme levels.
- Patients will receive an oral corticosteroid before and after ITVISMA injection and will undergo regular blood tests to monitor liver function.
- Contact the patient's doctor immediately if the patient's skin and/or whites of the eyes appear yellowish, if the patient misses a dose of corticosteroid or vomits it up, or if the patient experiences a decrease in alertness.

**Decreased platelet counts** could occur following injection with ITVISMA. Seek immediate medical attention if the patient experiences unexpected bleeding or bruising.

**Peripheral sensory neuropathy** has occurred with ITVISMA. Contact the patient's doctor right away if the patient experiences numbness, tingling, prickling, or pain in the arms, hands, legs, and/or feet.

**Thrombotic microangiopathy (TMA)** could occur with ITVISMA. Seek immediate medical attention if the patient experiences any signs or symptoms of TMA, such as unexpected bruising or bleeding, seizures, or decreased urine output.

**A theoretical risk of tumor development** exists with gene therapies such as ITVISMA. Contact the patient's doctor and Novartis Gene Therapies, Inc. at 1-833-828-3947 if a tumor develops.

### OTHER IMPORTANT INFORMATION

**The patient's doctor may need to adjust the vaccination schedule** to accommodate corticosteroid treatment. Protection against influenza and respiratory syncytial virus (RSV) is recommended. Consult the patient's doctor.

**Infections** before or after ITVISMA injection can lead to more serious complications. Contact the patient's doctor immediately if the patient experiences any signs of a possible infection such as coughing, wheezing, sneezing, runny nose, sore throat, or fever.

**Contraception and refraining from egg or sperm donation** is recommended following ITVISMA injection for 6 months for women of childbearing potential and for 3 months for men capable of fathering a child. Patients should discuss with their doctor.

### WHO SHOULD NOT TAKE ITVISMA

Patients previously treated with ZOLGENSMA® (onasemnogene abeparvovec-xioi) should not be treated with ITVISMA.

### COMMON SIDE EFFECTS

**The most common side effects** include upper respiratory tract infection, upper gastrointestinal symptoms, fever, and headache.

**These are not all the possible side effects. Talk to the patient's doctor about any side effects that bother the patient or that don't go away.**

### QUESTIONS?

The information provided here is not comprehensive. To learn more, talk to the patient's doctor, and you can visit [www.itvisma.com](http://www.itvisma.com) for Full Product Information, or call 1-833-828-3947.



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# Discover the *High Dose* *Regimen of* **SPINRAZA<sup>®</sup>** (nusinersen)



Patients are paid spokespersons for Biogen.  
Patients shown may not be on the High Dose Regimen of SPINRAZA.

Come say hello  
at our booth!

## WHAT IS SPINRAZA?

SPINRAZA<sup>®</sup> (nusinersen) is a prescription medicine used to treat spinal muscular atrophy (SMA) in pediatric and adult patients.

## IMPORTANT SAFETY INFORMATION

**Increased risk of bleeding complications** has been observed after administration of similar medicines. Your healthcare provider should perform blood tests before you start treatment with SPINRAZA and before each dose to monitor for signs of these risks. Seek medical attention if unexpected bleeding occurs.

**Increased risk of kidney damage, including potentially fatal acute inflammation of the kidney**, has been observed after administration of similar medicines. Your healthcare provider should perform urine testing before you start treatment with SPINRAZA and before each dose to monitor for signs of this risk.

**The most common side effects of SPINRAZA in the Low Dose Regimen** in infantile- and later- onset SMA include lower respiratory infection, constipation, fever, headache, vomiting, back pain, and post-lumbar puncture syndrome.

**The most common side effects of SPINRAZA in the High Dose Regimen** in infantile-onset SMA include pneumonia, COVID-19, pneumonia aspiration, and malnutrition. COVID-19 was not discovered at the time of the studies for the Low Dose Regimen.

These are not all of the possible side effects of SPINRAZA. Call your healthcare provider for medical advice about side effects. You may report side effects to **FDA at 1-800-FDA-1088**.

**Before taking SPINRAZA**, tell your healthcare provider if you are pregnant or plan to become pregnant.

**Please see full Prescribing Information at [spinraza.com](http://spinraza.com).**

This information is not intended to replace discussions with your healthcare provider.



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The High Dose Regimen was approved in March, and we're revealing our campaign. Come to our booth to learn how to start or transition to the new regimen, and stay at the booth for connection and fun.



Learn more at  
**SPINRAZA.COM**

Individual results may vary based on several factors, including severity of disease, initiation of treatment, and duration of therapy. Pivotal trials did not include adult patients with spinal muscular atrophy (SMA).

### IMPORTANT FACTS ABOUT SPINRAZA

#### USES

SPINRAZA is a prescription medicine used to treat spinal muscular atrophy (SMA) in pediatric and adult patients.

#### WARNINGS

**Increased risk of bleeding complications** has been observed after administration of similar medications. Your healthcare provider should perform blood tests before you start treatment with SPINRAZA and before each dose to monitor for signs of these risks. Seek medical attention if unexpected bleeding occurs.

**Increased risk of kidney damage, including potentially fatal acute inflammation of the kidney**, has been observed after administration of similar medicines. Your healthcare provider should perform urine testing before you start treatment with SPINRAZA and before each dose to monitor for signs of this risk.

#### COMMON SIDE EFFECTS

- **The most common side effects of SPINRAZA in the Low Dose Regimen** in infantile- and later-onset SMA include lower respiratory infection, constipation, fever, headache, vomiting, back pain, and post-lumbar puncture syndrome.
- **The most common side effects of SPINRAZA in the High Dose Regimen** in infantile-onset SMA include pneumonia, COVID-19, pneumonia aspiration, and malnutrition. COVID-19 was not discovered at the time of the studies for the Low Dose Regimen.
- Serious side effects of complete or partial collapse of a lung or lobe of a lung have been reported.

**Talk to your healthcare provider about any side effect that bothers you or that does not go away.**

#### OTHER INFORMATION

SPINRAZA is a medication that should be administered as an injection into the lower back (a procedure called intrathecal injection) by, or under the direction of, an experienced healthcare professional.

**Before taking SPINRAZA**, tell your healthcare provider if you are pregnant or plan to become pregnant.

#### QUESTIONS?

The risk information provided here is not comprehensive. To learn more, talk about SPINRAZA with your healthcare provider or pharmacist. The FDA-approved product labeling can be found at [www.SPINRAZA.com](http://www.SPINRAZA.com) or 1-844-4SPINRAZA (1-844-477-4672).

#### MANUFACTURED FOR

Biogen, Cambridge, MA 02142

## Is your child living with spinal muscular atrophy?

Find out if your child is eligible to participate in the Sparkle Study, a clinical research study for children and teenagers living with spinal muscular atrophy (SMA).

Your child may be eligible to participate if they are:

- between 5 and less than 18 years of age
- diagnosed with **5q-SMA**
- able to walk at least 50 meters (about 165 feet) without walking aids
- currently receiving a stable SMA treatment regimen (nusinersen or risdiplam) and/or have a history of onasemnogene abeparvovec treatment

Additional criteria to participate apply, which the study doctor will discuss with you.

If your child qualifies, they will receive:

- study-related examinations and procedures at no cost
- investigational study drug at no cost

You may be compensated for study-related expenses such as meals or travel. Travel arrangements may be provided.



Or visit  
[www.clinicaltrials.gov](http://www.clinicaltrials.gov)  
for more information

The investigational study drug is not approved by any regulatory agency for use in spinal muscular atrophy, as efficacy and safety have not been established.

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Sparkle Study Ad, 27 Mar 2026 [V01 Global(en)]

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Our Phase 2a SYNAPSE-SMA trial in adults has completed enrollment, and results will be shared soon. We are deeply grateful to the patients and families who contributed.

If you participated in the SYNAPSE-SMA study and would like recognition at a special event, please contact Dan Brennan at [djb@nmdpharma.com](mailto:djb@nmdpharma.com)

We also look forward to seeing you at the Family-Friendly Researcher Poster Session at our SYNAPSE-SMA poster.

PRESENTING EXHIBITORS



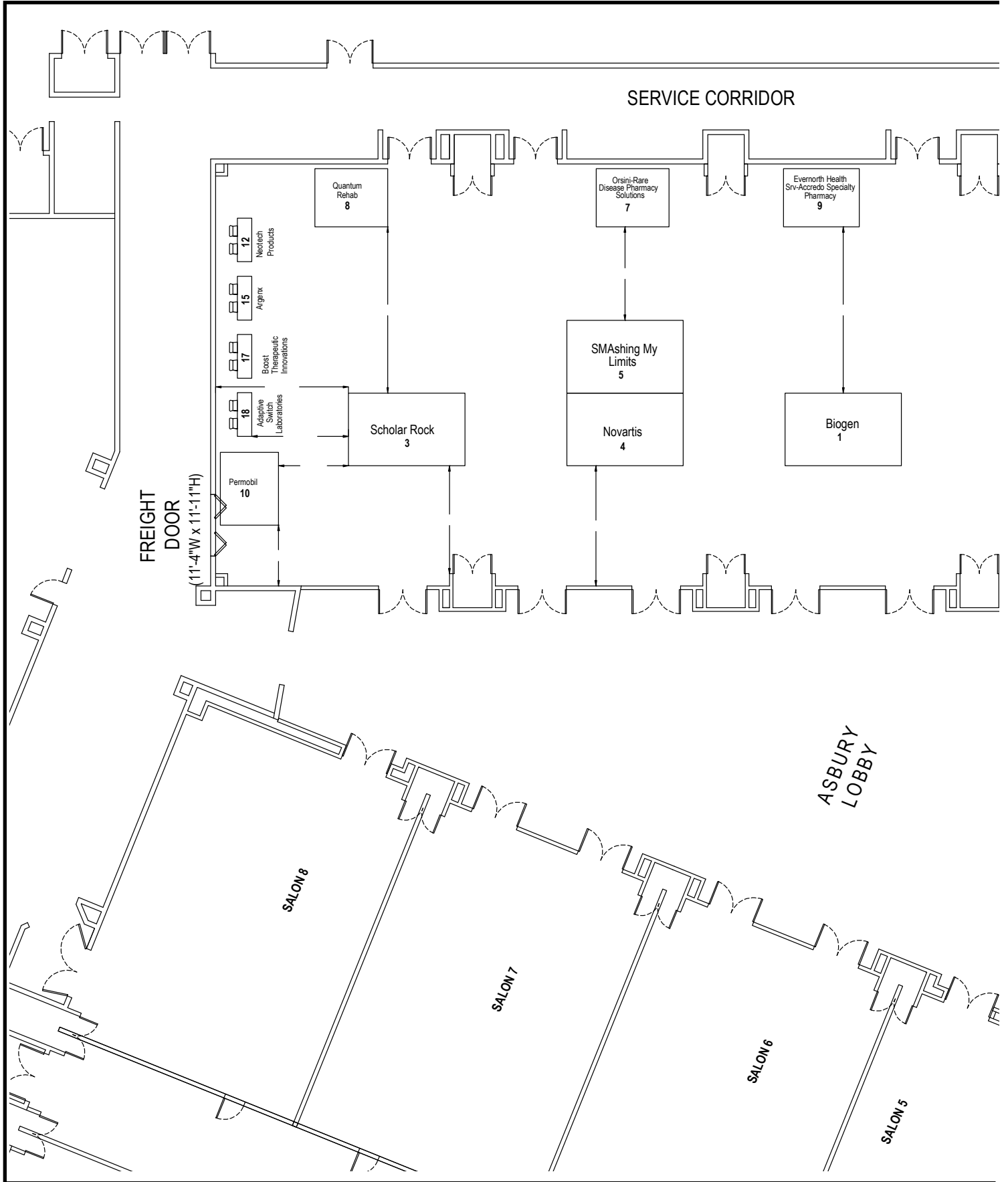
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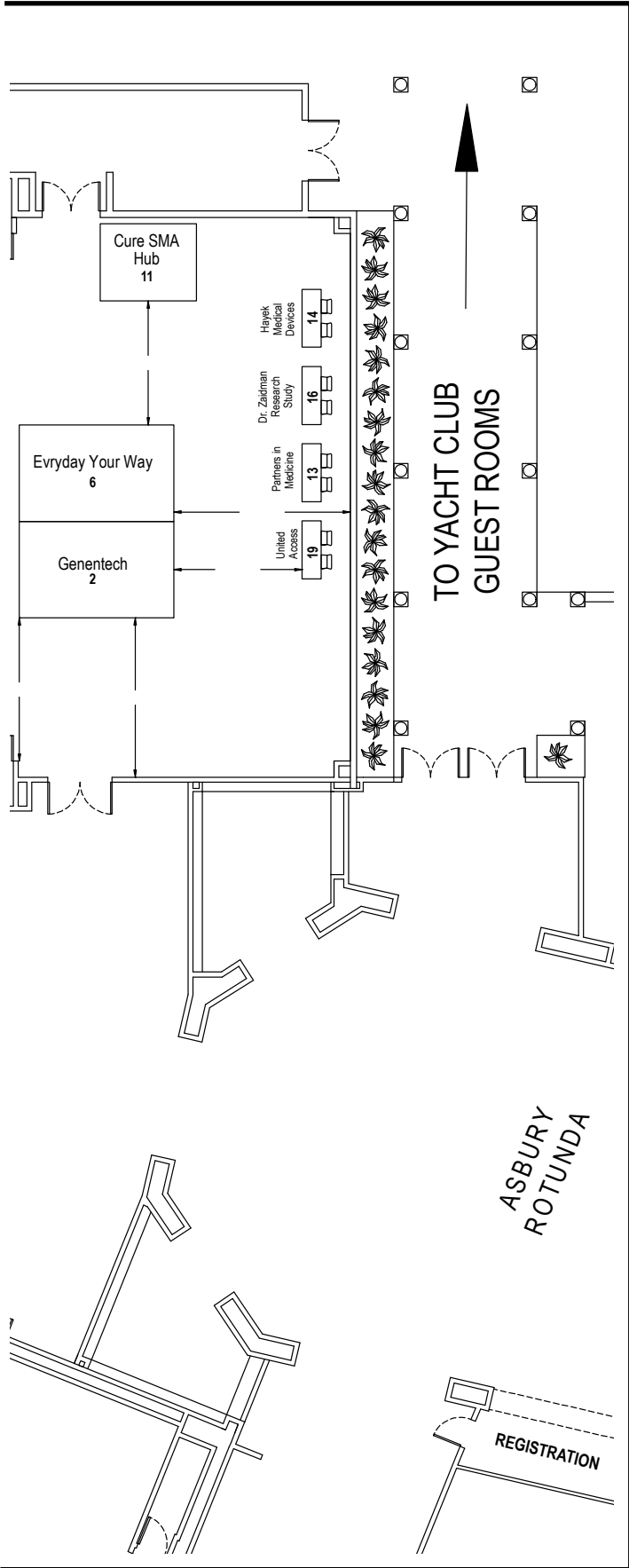
ORANGE EXHIBITORS



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10	Permobil
11	Cure SMA Hub
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14	Hayek Medical Devices
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# Accredo Specialty Pharmacy is proud to be a partner to the SMA community.

[accredo.com/raretherapies](https://accredo.com/raretherapies)

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## Adaptive Switch Laboratories



*Through thoughtful design and user centric development, Adaptive Switch Laboratories strives to create products that provide the tools for empowerment and independence.*

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GiggleFIT™ is a research-based exercise system designed for children—from birth through adolescence—who experience movement poverty and community rehabilitation access barriers.

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\*Lammers & Smith, 2024.  
Therapeutic Play Gym: Feasibility of a Caregiver-Mediated Exercise System for NICU Graduates with Neuromuscular Weakness—A Case Series.  
Pediatric Physical Therapy, 36(2), 177-185.

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PONCHO**

**CURE SMA  
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**ADDITIONAL MERCH ITEMS WILL BE AVAILABLE AND ON SALE SUCH AS:**

- MEN, WOMEN AND YOUTH APPAREL
- BLANKETS
- STICKERS
- PROMO ITEMS
- BAGS
- HATS
- DRINKWARE
- ACCESSORIES



**CURE SMA  
FULL ZIP HOODIE**

Items will be on sale at the merchandise table next to registration in the Asbury Rotunda.

**Make sure to stop by and check it out while supplies last!**



**HYDRATION  
CROSSBODY BAG**

Share a photo on your social media of you sporting your Cure SMA gear during this week's Conference using hashtag **#2026SMACONFERENCE**

## Everyone at Cure SMA would especially like to thank the following people:

### **The Cure SMA Board and Committee Members**

Our Board and Committee Members bring unwavering commitment to every family we serve. Their leadership helps shape the organization's path forward, fueling progress in support services, care, and research. We are sincerely thankful for the time, insight, and energy they invest to strengthen and uplift the entire SMA community.

### **Nick Farrell**

In his role as Chair, Nick leads with purpose, integrity, and a deep sense of responsibility to the SMA community. His thoughtful leadership and forward-thinking approach continue to move the organization ahead in meaningful ways. We are grateful for his dedication and the positive impact he makes every day.

### **The Cure SMA Chapter Officers and Committee Members**

Across the country, our Chapter Officers and Committee Members serve as passionate ambassadors for Cure SMA's mission. Through their generosity, compassion, and willingness to listen, they help foster connection and hope within the community. Their efforts are essential, and we truly appreciate all they contribute.

### **The Cure SMA Medical Advisory Council Members**

We are fortunate to be supported by an exceptional group of medical and clinical professionals who share their expertise with our SMA community. The Medical Advisory Council plays a critical role in advancing SMA awareness, strengthening care, and guiding educational efforts. We are deeply appreciative of the time and knowledge they generously offer.

### **The Cure SMA Scientific Advisory Board Members**

The Scientific Advisory Board provides invaluable guidance in evaluating SMA research opportunities and shaping the direction of our scientific initiatives. Their careful review and thoughtful recommendations ensure that we continue to invest in meaningful and impactful work. We are grateful for their dedication and expertise.

### **The Cure SMA Adults with SMA Advisory Council**

The Adults with SMA Advisory Council is made up of adults with SMA from across the country who are dedicated to building community, providing feedback, and advising Cure SMA on the need of adults with SMA. Council members bring valuable insight and lived experience to inform key areas such as support programs, patient care, advocacy, greater independence, and the transition to adulthood. Thank you for your leadership, collaboration, and participation at conference and throughout the year.

### **The Trainor Family**

We are deeply grateful to the Trainor Family for their continued support over the years. Your generosity has been instrumental in helping Cure SMA and the Annual Conference reach their current levels of success. Thank you for creating a lasting impact.

### **The Dhont Family Foundation**

Thanks to the generosity of the Dhont Family Foundation, more individuals are able to attend this year's Annual SMA Conference with the support they need. Their commitment helps create a welcoming and inclusive environment, including the sponsorship of Adult with SMA social events that bring the community together. We are sincerely thankful for their meaningful support.

### **Jacob Isaac Rappoport Foundation**

We are deeply appreciative of the Jacob Isaac Rappoport Foundation's continued generosity and partnership. Their support plays a vital role in enhancing the conference experience, particularly through the Children's Program. Their commitment to families makes a lasting difference.

### **Jennifer Miller-Smith, Aaron Smith, Richard Curran and Expo**

Year after year, Jennifer, Aaron, Richard and the entire family's generosity and involvement help elevate the conference experience for everyone. From thoughtful contributions to beautiful event details, their support adds a special touch that makes the gathering truly memorable. We are incredibly grateful for their ongoing kindness and dedication.

### **Luke 18:1 Foundation**

We extend our sincere thanks to the Luke 18:1 Foundation for making the First-Time Attendee Scholarship possible. Their support opens the door for new participants to connect, learn, and feel welcomed into the SMA community. We are grateful for their commitment to creating meaningful opportunities for those we serve.

Tip: Chapter Leaders can also be identified by the orange insert in their name badge!

# CHAPTER LEADERS

Cure SMA has 37 volunteer-led chapters across the U.S. to provide support and opportunities for individuals and families impacted by SMA to connect at the local level.

Below we would like to help you put a face to a name to all our Chapter Leaders who are in attendance at this year's conference. Please make sure to say hello to those in attendance and introduce yourself if you haven't met them already.



AL - ALABAMA CHAPTER

Linda Russo



CA - SOUTHERN CALIFORNIA CHAPTER

Autumn Montoya



AL - ALABAMA CHAPTER

Shaakira Thomas



CA - SOUTHERN CALIFORNIA CHAPTER

Rickk Montoya



AR - ARKANSAS CHAPTER

DeAnna Dillon



CO - ROCKY MOUNTAIN CHAPTER

Lyza Weisman



AR - ARKANSAS CHAPTER

Sylvia Wheeler



FL - GREATER FLORIDA CHAPTER

Katie Kerns



AZ - ARIZONA CHAPTER

Melanie Kevin



FL - GREATER FLORIDA CHAPTER

Amber Lavoie



AZ - ARIZONA CHAPTER

Cassandra Thompson



FL - SOUTH FLORIDA CHAPTER

Fiorenna Stark



AZ - ARIZONA CHAPTER

Angel Wolff



FL - SOUTH FLORIDA CHAPTER

Maylan Chavez



CA - NORTHERN CALIFORNIA CHAPTER

David Sereni



FL - SOUTH FLORIDA CHAPTER

Jennifer Miller Smith

# CHAPTER LEADERS

Tip: Chapter Leaders can also be identified by the orange insert in their name badge!



GA - GEORGIA CHAPTER

Tara Ragan



MI - MICHIGAN CHAPTER

Gretchen Dorer



GA - GEORGIA CHAPTER

Valerie White



NC - CAROLINAS CHAPTER

Mimi Chan



IN - OKI CHAPTER

Holly Sontag



NJ - NORTH JERSEY CHAPTER

Laura Watson



KY - OKI CHAPTER

Kristen DeLuca



NM - NEW MEXICO CHAPTER

Natasha Abruzzo



KY - OKI CHAPTER

Courtney Ogletree



OH - OKI CHAPTER

Natalie Bracone



MD - CHESAPEAKE CHAPTER

Kelly Eakin



OH - OKI CHAPTER

Beth Lockwood



MD - CHESAPEAKE CHAPTER

Kim Heinrich



OH - OKI CHAPTER

Elizabeth Lockwood



MD - CHESAPEAKE CHAPTER

Derek Lewis



OK - OKLAHOMA CHAPTER

Amanda Chaffin



MD - CHESAPEAKE CHAPTER

Tina Lewis



PA - PENNSYLVANIA CHAPTER

Emily Farkas

# CHAPTER LEADERS



PA - PENNSYLVANIA CHAPTER

Gina Perri



PR - PUERTO RICO CHAPTER

Keishla Rolon



PR - PUERTO RICO CHAPTER

Natasha Santiago



SC - CAROLINAS CHAPTER

Idalmis Vivar



TN - TENNESSEE CHAPTER

Sarah Boggess



TX - TEXAS CHAPTER

Beth Moore



TX - TEXAS CHAPTER

Kristen Resendez



UT - UTAH CHAPTER

Trasie Mead



VA - VIRGINIA CHAPTER

Kyle Derkowski



VA - VIRGINIA CHAPTER

Laura Derkowski



WA - PACIFIC NORTHWEST CHAPTER

Mark Courteau



WI - WISCONSIN CHAPTER

Kim Banach



WI - WISCONSIN CHAPTER

Kristin Jennings



## PLEASE NOTE WEAR SUNSCREEN AND KEEP HYDRATED!

As many of you know, June in Florida can be very hot during the day. We strongly encourage everyone to take proper precautions when outside for any amount of time, by applying sunscreen and covering your body as much as possible to avoid excessive sun exposure. Also, with the high temperatures and humidity, drink plenty of water to remain hydrated in the heat!

# CURE SMA BOARD OF DIRECTORS

Cure SMA holds itself accountable to people with Spinal Muscular Atrophy, their families, donors, volunteers, and the public. Our Board of Directors is a diverse group of volunteers, who bring a variety of experiences and expertise to the governance of Cure SMA. The Board's responsibility is to direct and carry out the vision, mission, and goals of Cure SMA.

## OFFICERS



**Nick Farrell – Chairman of the Board**



**Mark Moore – Treasurer**



**Bradley A. Nunemaker – Vice Chair**



**Shannon Zerzan - Secretary**

## EXECUTIVE COMMITTEE



**Rachael Brown**



**Kelly Jankowski**



**Rob Graham, MD**



**John Weber**



**Allyson Henkel**



**Joe Wiseman**

# CURE SMA BOARD OF DIRECTORS

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**Jaclyn Greenwood**



**Collin Pollock**



**Tyler Dukes**



**Brianna Gross, MS, LCGC**



**Kaleen Robinson**



**Sarah Shira Emmons**



**Amy Medina**



**Brian Snyder, MD**



**Marc Ginsky**



**Karen McRory-Negrin**



**Heather Vital**

## COMMITTEE MEMBERS



**Doreen Ho, MD**



**Kevin Lockwood**



**Steve Kolb, MD**



**Chids Mahadevan**



**Martin Livingston**



**Brian Ronningen**

# MEDICAL ADVISORY COUNCIL (MAC)

*Advises on the strategic direction of Cure SMA Care programs target to improve healthcare quality and access to care.*



## **Chair, Bakri Elsheikh, MBBS,**

Professor of Neurology and Director, Neuromuscular Division, Department of Neurology, The Ohio State University Wexner Medical Center; Spinal Muscular Atrophy Outcome Measures, Biomarkers, and Clinical Trials



## **Jason Edinger, DO**

Program Director, Pediatric Rehabilitation Medicine Fellowship, Assistant Professor, Department of PM&R and Pediatrics University of Pittsburgh School of Medicine UPMC Children's Hospital of Pittsburgh



## **Jennifer Deans, MHA, MS, CCLS**

Manager, Cure SMA



## **Albert Freedman, PhD**

Psychology  
Independent Practice



## **Kapil Arya, MD**

Pediatric Neurologist, Arkansas Children's Hospital



## **Melissa Gibbons, MS, CGC**

Associate Professor University of Colorado SOM  
Genetic Counselor Children's Hospital Colorado



## **John Brandsema, MD**

Attending Physician, Neuromuscular/General Neurology & Electromyography Children's Hospital of Philadelphia



## **Natalie Goedeker, DNP, CPNP**

Co-director, pediatric neuromuscular clinical research  
Washington University in St. Louis/St. Louis Children's Hospital



## **Tom Crawford, MD**

Pediatric Neurology, Johns Hopkins Hospital



## **Becky Hurst-Davis, MS, RD, CSP, CD, CNSC**

Clinical Nutrition Director-Pediatrics, Intermountain Children's Health in Salt Lake City, UT



## **Stacy Dixon, MD, PhD**

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## **Oren Kupfer, MD**

Pulmonologist, Children's Hospital Colorado



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Director, Clinical Outcomes Research & Development  
Division of Neuromuscular Medicine, Stanford University  
Co-Director, Stanford Innovative Genetic Neurologic  
Investigation and Treatment Evaluation Center  
Assistant Professor, Department of Physical Medicine and  
Rehabilitation University of California, Davis



## **Luca Labianca, MD, PhD**

Pediatric's Orthopedics Surgeon,  
La Sapienza-Sant'Andrea University Hospital,  
Rome, Italy

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Division of Neuromuscular Neurology  
Department of Neurology  
Georgetown University Hospital  
Washington DC



## **Anne Stratton, MD**

Pediatric Physiatrist, Children's Hospital Colorado



## **Susan Matesanz, MD**

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Children's Hospital of Philadelphia



## **Britton Zuccarelli, MD, FCNS**

Clinical Associate Professor of Pediatrics, University of  
Kansas School of Medicine



## **Leslie Nelson, PT, PhD, OCS**

Pediatric Neuromuscular Physical Therapist, Children's Health,  
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## **Maggie B. Martinez**

Neuromuscular Program Coordinator  
Children's National Hospital



## **Crystal Proud, MD**

Pediatric Neurologist, Children's Hospital of the King's Daughters



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Hospital

# SCIENTIFIC ADVISORY BOARD (SAB)



**Jackie Glascock, PhD**  
Chief Scientific Officer, Cure SMA  
Dr. Glascock oversees the Cure SMA Scientific Advisory board.

## CURRENT MEMBERS OF THE CURE SMA SCIENTIFIC ADVISORY BOARD



**Elliot J. Androphy, MD**  
Kampen-Norins Professor and Chair of the Department of Dermatology of Indiana University School of Medicine



**Adrian Krainer, PhD**  
Professor of Molecular Genetics at Cold Spring Harbor Laboratory



**Arthur H. Burghes, PhD**  
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Professor of Pathology and Cell Biology at Columbia University



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**Allison Ebert, PhD**  
Associate Professor, Department of Cell Biology, Neurobiology and Anatomy and Director, Neuroscience Doctoral Program, Medical College of Wisconsin



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**Stephen J. Kolb, MD, PhD**  
Professor of Neurology and Molecular and Cellular Biochemistry and Director of the ALS/MND Multidisciplinary Clinic and Translational Research Program at The Ohio State University



**Rashmi Kothary, PhD**  
Professor in the Department of Cellular and Molecular Medicine at the University of Ottawa and the Deputy Scientific Director of the Ottawa Hospital Research Institute

# ADULTS WITH SMA ADVISORY COUNCIL



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Jaclyn Greenwood



Laura Watson



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LaMondré Pough

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Chief Scientific Officer, Research**



**Jessica Tingey  
Manager, Scientific Writer**



**Angie Wise  
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Specialist, Data Analyst**



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**Jaki Herrmann**  
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**Alicia Metzger**  
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Policy and Advocacy



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Chief Development Officer



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**Zach Galati**  
Manager, Donor Engagement



**Andie Meadows**  
Specialist, Development & Events



**Kitty Murphy**  
Manager, Development & Logistics



**Kaylyn Williams**  
Specialist, Development & Events



**Ciera Waga**  
Specialist, Development & Events

# CURE SMA STAFF

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Senior Director, Marketing & Communications



**Tiffany Sugar**  
Director, Graphic Design



**Sam Demogenes**  
Specialist, Marketing & Communications



**Kendall Getzinger**  
Manager, Graphic Design

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Chief Operating Officer



**Debora Pellicano**  
Chief Financial Officer



**Alissa deRamus**  
Executive Assistant



**Melissa Gonzalez**  
Director, Finance



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**Vanessa Jackson**  
Specialist, Gift Processing



**Latesa Reynolds**  
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**Jeanette Figueroa,**  
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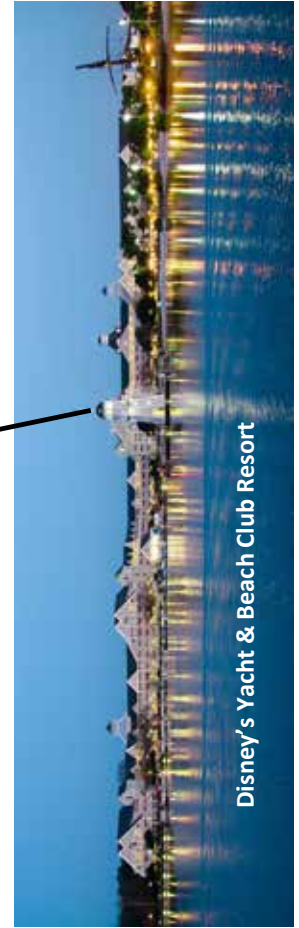
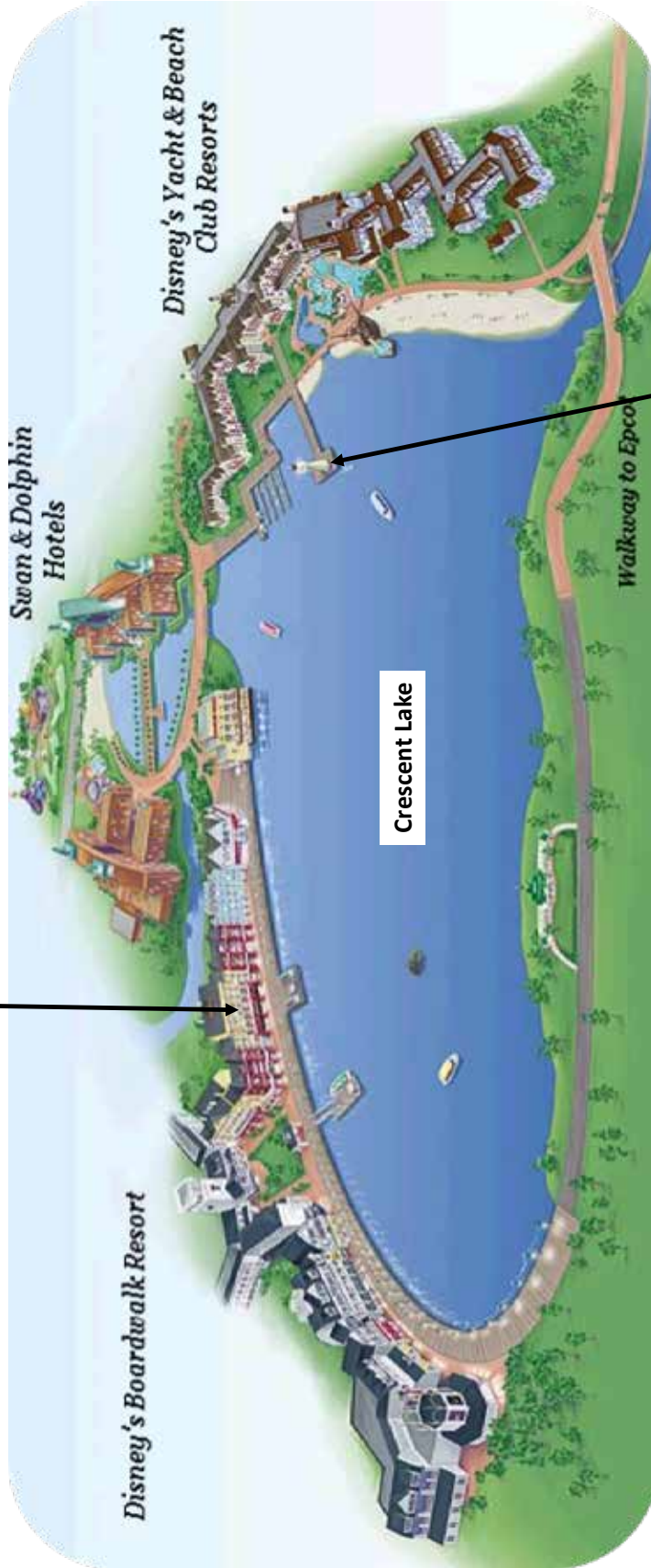
**Desiree Dalton**  
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**Larry Einhorn**  
Director, Information Technology



Disney's Boardwalk Resort



Disney's Yacht & Beach Club Resort





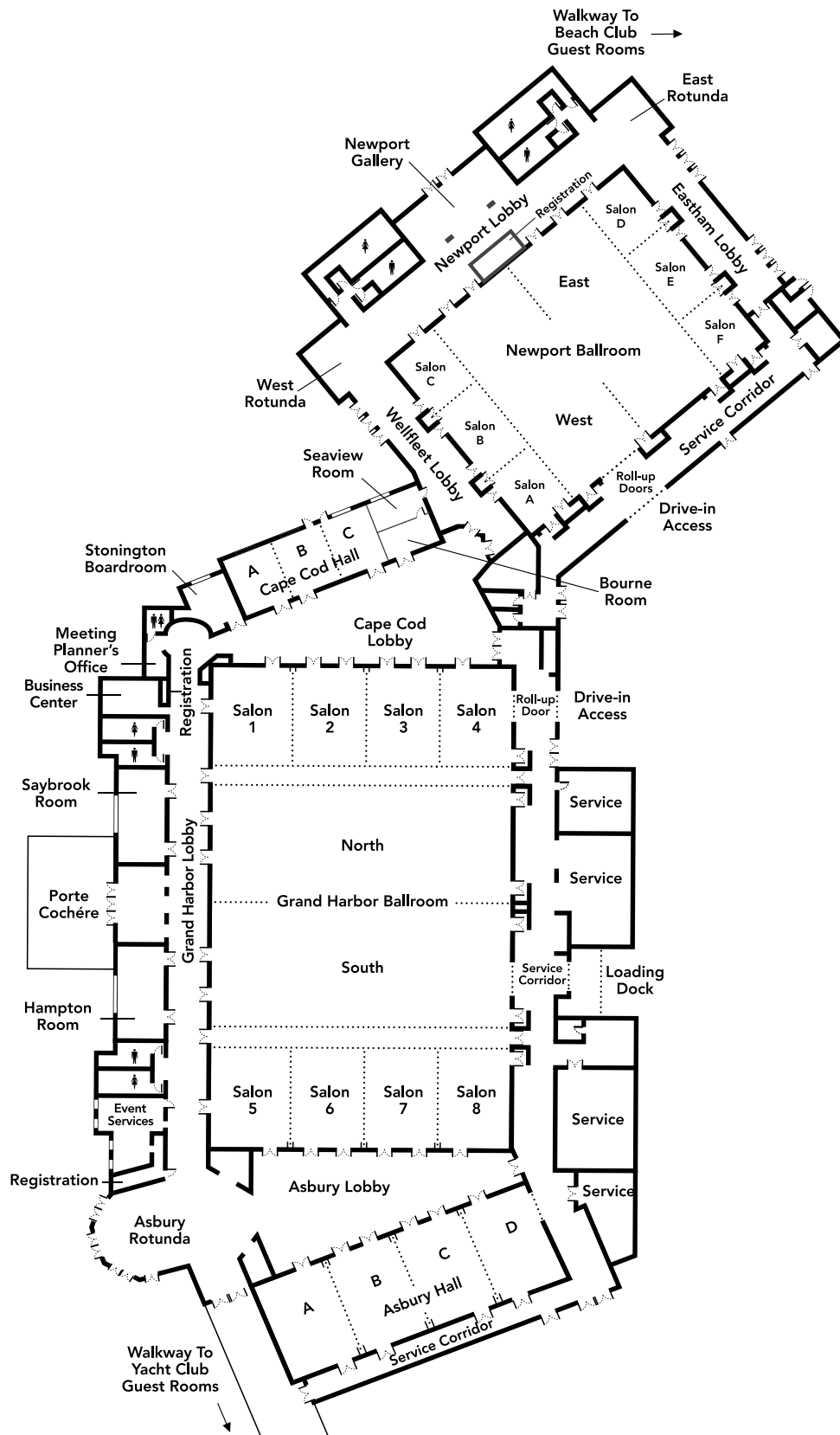
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