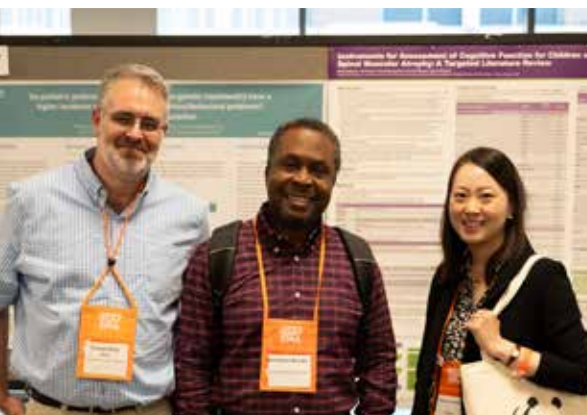


cure SMA 2025 ANNUAL SMA CONFERENCE

DISNEYLAND HOTEL IN ANAHEIM, CALIFORNIA



THURSDAY, JUNE 26 – SUNDAY, JUNE 29

WELCOME LETTER

Welcome to the 2025 Annual SMA Conference in Anaheim, California!

We are excited to celebrate all the progress our community has made and to prepare for additional breakthroughs, all while connecting with friends, family, and collaborators.

This conference is generously supported by 12 sponsors and 17 exhibitors. Our special thanks to Genentech, Biogen, and Scholar Rock as the Presenting Sponsors of the 2025 Annual SMA Conference. Through these sponsorships, we are able to provide incredible workshops and events for our community!

We have three powerful disease modifying SMA treatments, with over three quarters of all affected individuals in the U.S. getting access. The SMA landscape has changed significantly, and we are expanding and changing our research, advocacy, and support programs accordingly.

Now it is important to optimize the impact of our current therapies and to develop new combination approaches focused on restoring strength, function, and reversing symptoms. Since 2004, we have awarded over 140 basic research grants for more than \$17.5 million. These grants helped to fund the first steps leading to the approved treatments. Cure SMA is committed to growing our investments in basic research as we know it will continue to be foundational to new treatments to meet the needs of people living with SMA at all ages and stages.

To support the changing SMA community, we continue to collect data directly from the community through online surveys to understand the evolving landscape and unmet needs of the community. Our advocacy and support programs are utilizing our survey data for addressing important new needs in our community around daily living. As we get new treatment approvals, we focus on ensuring access for the whole community and we are updating resources to address insurance challenges and continuously updating the Find a Treatment Center locator tool.

Each year the Annual SMA Research & Clinical Care Meeting is held in conjunction with the Annual SMA Conference. During the scientific sessions, researchers from industry and academia will meet to create open communication, accelerating the pace of research. During the care meeting, multidisciplinary clinicians will share knowledge to optimize care and grow our SMA community of healthcare professionals. On the individual and family side, we have 61 workshops that serve all of the different groups in our community. We look forward to our joint researcher and community member events like the Meet and Greet on Thursday evening and the Family Friendly Poster Session on Friday.

Please reach out to any of us if there is anything we can do to make this conference as meaningful for you as possible.

Sincerely,



Kenneth Hobby
President



Colleen McCarthy O'Toole
Senior Vice President,
Community Support



Jackie Glascock, PhD
Chief Scientific Officer

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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.



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 may be used for Cure SMA's websites and Cure SMA's pages on social networking platforms (e.g., Facebook), for use in editorial, educational, promotional, and advertising purposes, for the solicitation of contributions, and for any other purpose in furtherance of the organization's purposes and objectives, without payment to the attendee.]

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 personal medical equipment with you.

- Difficulty breathing
- Chest pain
- Low oxygen saturations
- Persistent fever
- Worsening of symptoms despite using 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:

Children's Hospital of Orange County
1201 W La Veta Ave, Orange, CA 92868
Phone: 714-509-9095
Open 24/7

Adult Care:

UCI Medical Center Emergency Room
101 The City Dr S, Orange, CA 92868
Phone: 714-456-5705
Open 24/7

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

SPONSORS

Thank you to our generous sponsors for their support of the
2025 Annual SMA Conference.

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DIAMOND SPONSOR



TITLE SPONSOR



VISIONARY SPONSOR



SUPPORTING SPONSORS

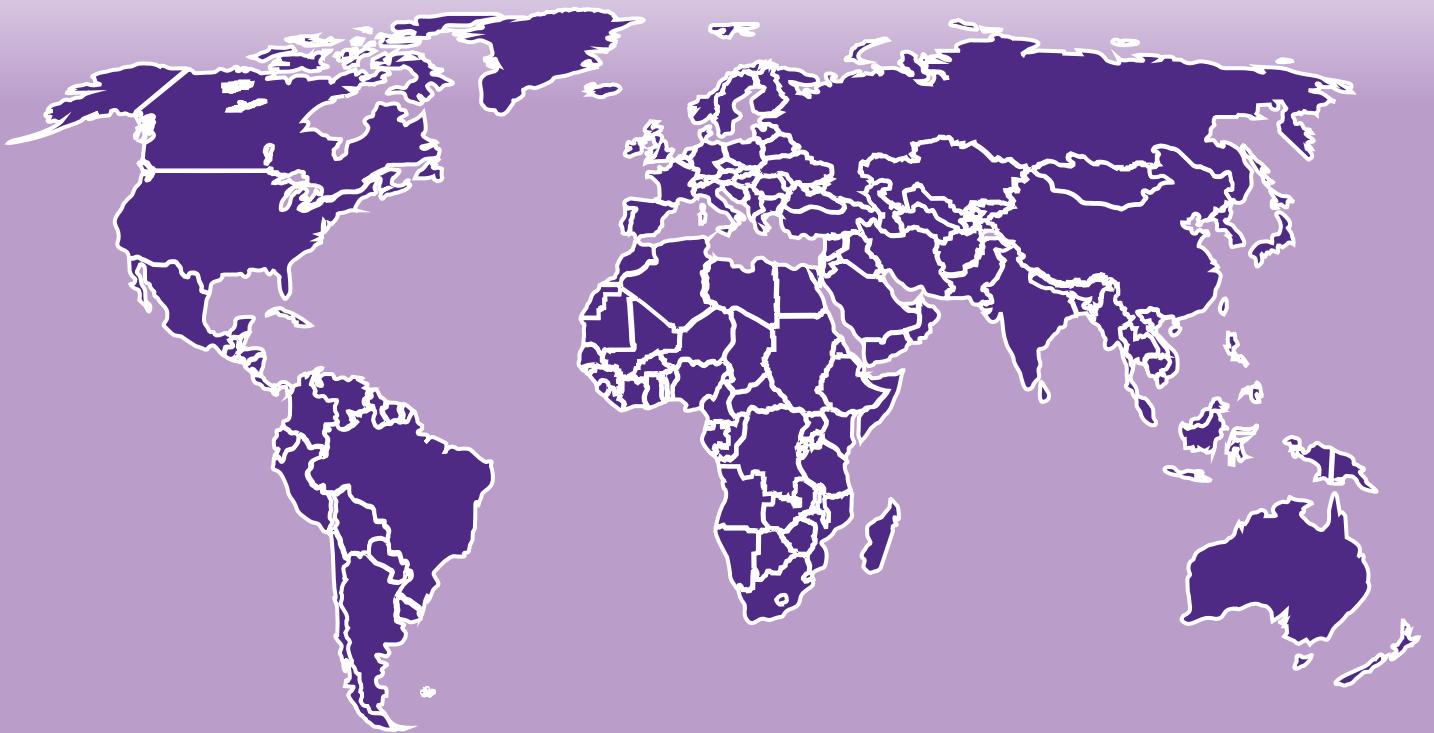


GOLD SPONSORS



WELCOME!

We are honored to have SMA families, researchers, and clinicians attend this conference from all over the world! There are individuals attending from 40 countries, including: Argentina, Australia, Bangladesh, Belgium, Brazil, Bulgaria, Canada, Chile, Colombia, Costa Rica, Czech Republic, Estonia, Finland, France, Germany, Hungary, India, Ireland, Italy, Japan, Latvia, Malaysia, Mexico, Netherlands, New Zealand, Norway, Panama, Paraguay, Philippines, Poland, Portugal, Slovakia, Slovenia, South Africa, Spain, Switzerland, Taiwan, Turkey, United Kingdom, and United States.



As of April 21, 2025

Celebrating All The Years!

2025



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

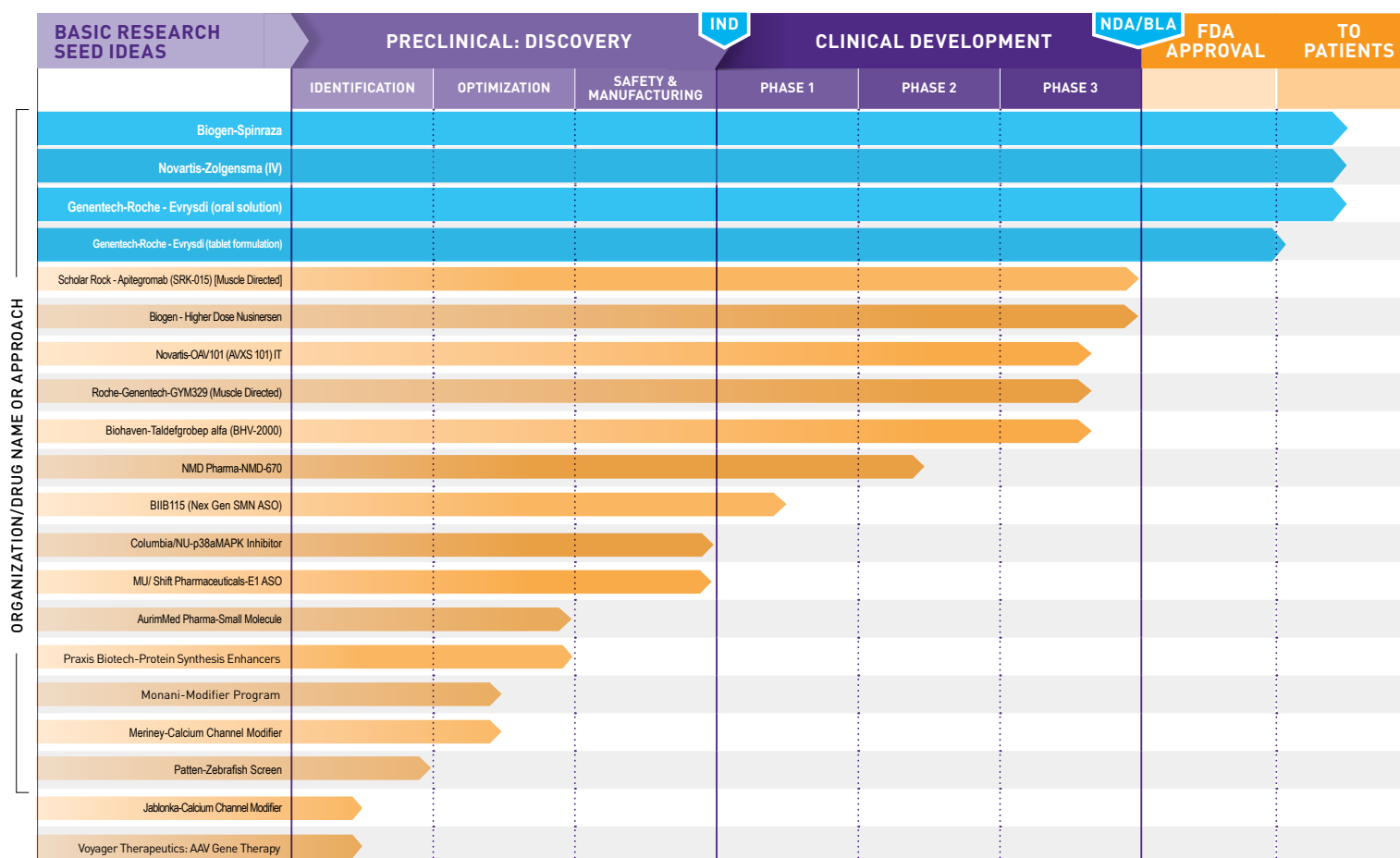
1988

SMA DRUG PIPELINE

We are funding and directing research with more breadth and depth than ever before. We know that funding of basic research studies is foundational for drug development and reaching our goal of new therapies or combinations of therapies, to address the unmet needs of all individuals with SMA.

The Cure SMA Drug Pipeline is one of the primary ways to evaluate the success of our research program. It identifies the major drug program in development and tracks their progress from basic research through U.S. Food and Drug Administration (FDA) approval and beyond. The Cure SMA Drug Pipeline identifies several possible treatment targets:

- Replacement or correction of the faulty SMN1 gene.
- Modulation of the low functioning SMN2 back-up gene.
- Muscle protection to prevent or restore the loss of muscle function in SMA.
- Neuroprotection of the motor neurons affected by loss of SMN protein.
- Newer approaches that identify additional systems and pathways affected by SMA.



BLA = Biologics License Application

IND = Investigational New Drug

NDA = New Drug Application

Last updated: May 2025



THE IMPORTANCE OF CONTINUING TO INVEST IN BASIC RESEARCH

- In the past two decades, Cure SMA has invested over \$17.5 million in funding for more than 140 basic research grants that have furthered our understanding of SMA.
- Cure SMA provided early funding for basic research projects that resulted in the development of our now approved genetically targeted drugs.
- While the currently approved therapies dramatically alter SMA, there remains significant unmet needs especially for our older and symptomatic SMA population.
- Continued basic research ensures a robust pipeline to now identify potential therapeutic avenues that will work in different ways and in combinations to address these needs and help restore strength and function.
- The role of SMN protein and when and where it is needed. We're investigating what critical functions it performs, where it is lacking in the body tissues of those with SMA, and how quickly it needs to be replaced to provide benefit for those with SMA.

HOW IS CURE SMA COMMITTED TO CONTINUED BASIC RESEARCH?

- Cure SMA awarded 6 new basic research grants at the beginning of this calendar year for a total of \$740,000. These grants were featured in our recent Compass publication.
- We are funding more basic research grants. These grants will be focused on the above key areas of research. These grants are being collected now, will be reviewed in the fall, and will be announced early next year. Be on the lookout for information about these grants in upcoming Cure SMA publications.
- By continuing our investment into basic research, we can help ensure that we find answers to the key questions that will drive the next generation of therapeutic development.

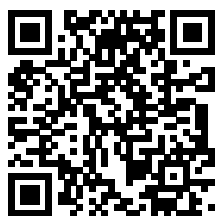
WHAT IS THE CURE SMA FUNDING MODEL?

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 funded 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 others’ work.

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

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

- Non-SMN targets. We're looking for other targets, such as nerves, muscles, and neuromuscular junctions, that can serve as the basis for an SMA treatment. We're asking how we can best measure the effectiveness of these “non-SMN” approaches.
- How to best utilize both SMN-enhancing approaches and non-SMN approaches. We're asking how these different approaches can be used in combination to provide treatments for all ages and stages of SMA.



Nunemaker Family Research Community Challenge

Special thanks to the Nunemaker Family for partnering with Cure SMA in our quest to invest in research that will focus on ways to enhance muscle strength and function as well as investigating nerve muscle connections and the regeneration of nerves. To achieve these goals, the Nunemakers have generously offered to match all gifts up to \$150,000. To join the Nunemakers in investing in the future of SMA, please visit: donate.curesma.org/Nunemaker or scan the QR code

ADVOCATE AT CONFERENCE!

Every day is an opportunity to educate about SMA and the legislative priorities of the SMA community. Here are ways you can continue your advocacy journey while at the Cure SMA Conference.



Share on social media that you are attending the 2025 Cure SMA Conference and raising awareness about SMA

- Scan the QR code to include a Cure SMA Conference graphic or take your own conference photo for your post



Learn advocacy tips by attending a conference workshop hosted by Cure SMA's Advocacy Team

- Check out page 41 for information about attending the conference workshop on Saturday, June 28 at 1:00PM in Center Ballroom



Stop by the Family Friendly Poster Session for a poster on the use of advocacy to increase engagement among adults with SMA and their families

- Friday, June 27: 6:30 – 8:30 PM

Raise awareness about SMA by asking your state's Governor to proclaim August as SMA Awareness Month

- Scan the QR code to send your request to your Governor through the Cure SMA Action Center



Cure SMA Launches State & Local Advocacy Toolkit

When you return home, be sure to check out Cure SMA's State and Local Advocacy Toolkit. This new online resource features fact sheets and opportunities to engage on state and local issues important to the SMA community. The toolkit is another opportunity for you to advocate in support of children and adults with SMA.

The State & Local Advocacy Toolkit was created with support from Biogen and Genentech

The underlying Grassroots Advocacy Tool was made possible through support from Genentech, Biogen, and Scholar Rock

The 4th Annual State of SMA is here!

– pick up your copy today!

The report showcases outcomes and the changing SMA landscape from Cure SMA's three databases:

- The Membership Database with patient-reported outcomes on over 11,000 affected individuals worldwide that also includes data from the annual community update survey
- The SMA Clinical Data Registry (CDR) containing electronic medical record (EMR) sourced data for over 1,200 patients receiving care from US-based SMA Care Center Network sites
- The SMA Newborn Screening Registry (NBSR) with parent-reported outcomes for over 90 babies with SMA identified through statewide SMA newborn screening

Topics from the report include:

- The current unmet needs of those living and caring for one with SMA
- The 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 changing average age at diagnosis of SMA
- Access and use of SMA treatments
- Access to SMA care...and much more!



If you have not already received a copy of the 4th Annual State of SMA, please visit the conference registration desk or email 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 provided by the Cure SMA Industry Collaboration (SMA-IC) and the Cure SMA Real World Evidence Collaboration (RWEC).

CONFERENCE SUMMARY

WEDNESDAY, JUNE 25

5:00PM – 7:30PM REGISTRATION OPEN FOR ALL CONFERENCE ATTENDEES

THURSDAY, JUNE 26

9:00AM – 6:00PM REGISTRATION OPEN FOR ALL CONFERENCE ATTENDEES

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

2:30PM – 6:00PM ADULTS WITH SMA LOUNGE *Sponsored by Biogen*
for adults with SMA and their attendants

6:00PM – 8:30PM MEET & GREET FOR ALL CONFERENCE ATTENDEES

8:30PM – 10:30PM DAD'S NIGHT OUT *Sponsored by Scholar Rock* **for dads only**

FRIDAY, JUNE 27

7:00AM BREAKFAST OPENS

7:15AM – 4:45PM REGISTRATION AND CHECK-IN

7:45AM – 8:45AM A NEW TAKE ON SMA TREATMENT: HEAR INSIGHTS FROM THE
COMMUNITY SYMPOSIUM *Sponsored by Genentech*

8:45AM – 5:15PM EXHIBITORS AND NETWORKING AREA OPEN

8:45AM – 5:15PM LIVING SMA YOUR WAY *Sponsored by Genentech*

8:45AM – 5:15PM DELTA FLIGHT PRODUCTS EXPERIENCE *brought to you by Biogen*

8:45AM – 5:15PM IMAGINATION STATION *Sponsored by Scholar Rock*

8:45AM – 5:15PM NOVARTIS COMMUNITY BOOTH *Sponsored by Novartis*

**9:00AM – 12:20PM
& 1:45PM – 4:45PM** CHILDREN'S PROGRAM & BABY ROOM (Drop off opens at 8:30am and 1:15pm)

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

11:00AM – 4:45PM ADULTS WITH SMA LOUNGE *Sponsored by Biogen*
for adults with SMA and their attendants

11:00AM – 4:45PM TEEN LOUNGE *Sponsored by Novartis*
for all teens ages 12 – 18

11:20AM – 12:20PM WORKSHOP SESSION #1

12:20PM – 1:45PM LUNCH

1:45PM – 3:05PM WORKSHOP SESSION #2

3:25PM – 4:45PM WORKSHOP SESSION #3

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

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

7:30PM – 9:30PM TEEN SOCIAL
for all teens ages 12 – 18

7:30PM – 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 28

7:00AM BREAKFAST OPENS

7:15AM – 3:40PM REGISTRATION AND CHECK-IN

7:45AM – 8:45AM FROM ONE GENERATION TO ANOTHER:
A SYMPOSIUM FOR THE AGES *Sponsored by Biogen*

8:45AM – 4:00PM EXHIBITORS AND NETWORKING AREA OPEN

8:45AM – 4:00PM DELTA FLIGHT PRODUCTS EXPERIENCE *brought to you by Biogen*

8:45AM – 4:00PM IMAGINATION STATION *Sponsored by Scholar Rock*

8:45AM – 4:00PM NOVARTIS COMMUNITY BOOTH *Sponsored by Novartis*

**9:00AM – 11:40AM
& 1:00PM – 3:40PM** CHILDREN'S PROGRAM & BABY ROOM *(Drop off opens at 8:30am and 12:30pm)*

9:00AM – 3:40PM TEEN LOUNGE *Sponsored by Novartis*
for all teens ages 12 – 18

9:00AM – 3:40PM ADULTS WITH SMA LOUNGE *Sponsored by Biogen*
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

CONFERENCE SUMMARY

1:00PM – 2:10PM WORKSHOP SESSION #6

2:30PM – 3:40PM WORKSHOP SESSION #7

4:00PM CURE SMA'S EVENING AT THE PARK

SUNDAY, JUNE 29

7:00AM BREAKFAST OPEN

7:45AM – 8:45AM MUSCLES, MYOSTATIN, AND MORE SYMPOSIUM *Sponsored by Scholar Rock*


9:00AM – 11:15AM CHILDREN'S PROGRAM & BABY ROOM
(Drop off opens at 8:30am)

9:00AM – 11:15AM CLOSING GENERAL SESSION – IT'S A WONDERFUL LIFE PANEL


WORKSHOP SESSIONS

FRIDAY, JUNE 27

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

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

WORKSHOP SESSION #2 | 1:45PM – 3:05PM

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



WORKSHOP SESSION #3 | 3:25PM – 4:45PM

- Adaptive Sport / Recreation Testimonials and Resources 
- I Need to Cough, I Need to Breathe, I Need to Sleep
- Genetics and Reproductive Options for SMA Families
- Finding Your Strengths: Building Resilience Against Burnout
- Strengthen and Stretch Your Body in the Water - for Children Sitting/Walking Independently, Ages 8-13 year old 
- Dating, Intimacy, and Sex—The Disabled Perspective
- Navigating the Special Education/504 Process: Setting Our Children Up for Success in Preschool and Elementary School 
- Get To The Art of It: Community Art Time

WORKSHOP SESSIONS

SATURDAY, JUNE 28

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

- Swallowing in SMA: Expectations for Stability and Promising Rehabilitation Methods
- The Role of the Multi-disciplinary Clinic – How it can be helpful for those identified pre-symptomatically 
- Creating Lasting Memories Through Art Making
- Power Assist, Power Wheelchairs and Alternative Drive Options for Children and Adults who are Living with SMA
- A Pediatric Yoga Approach to Movement and Wellness: A 5 Part Therapeutic Yoga Practice for Babies, Toddlers and Children with SMA
- Enhancing Clinical Care for Adults with SMA: Strategies for Achieving Optimal Outcomes 
- Empowering Futures: Unlocking the Potential of ABLE Accounts



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

- Unleashing Potential: Exploring the World of Service Dogs More Than A Companion: The Service Dog Journey
- Orthopedic Management in SMA 
- Aquatic Physical Therapy for Fun & Function, Teens and Adults 
- Technology That Makes Life Easier
- Healing the Grieving Heart - Now What? Part II
- Navigating Anesthesia, Sedations, and Pain Control for SMA Families
- Accessible Fashion and Body Image as a Disabled Adult 
- Behind the Scenes: Build the PCA Support You Need to Have More Independence
- Siblings Talk it Out (Ages 12 - 17)

WORKSHOP SESSION #6 | 1:00PM – 2:10PM

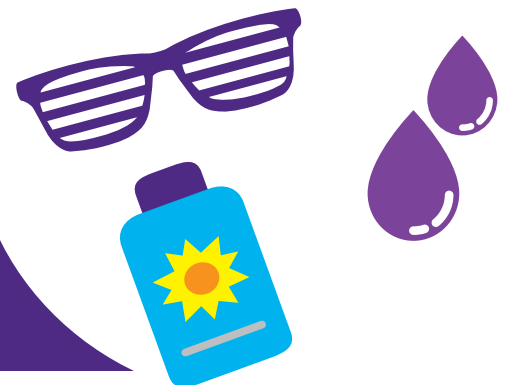
- Women's Health in SMA
- Real Food for Optimal Health
- Empowered Parenting: Thriving as a Single Parent Raising a Rare Disease Child
- Aquatic Physical Therapy for Fun & Function, Teens and Adults 
- Early Scoliosis Treatment in SMA
- Advocating for Yourself and the SMA Community: Tips for Effective Advocacy
- Navigating the Special Education/504 Process: Setting Our Children Up for Success in Middle/High School and College 
- Siblings Talk it Out (Ages 5 - 11)
- Kids Talk it Out (ages 12 - 17)

WORKSHOP SESSION #7 | 2:30PM – 3:40PM

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

PLEASE NOTE WEAR SUNSCREEN AND KEEP HYDRATED!

As many of you know, June in California 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!



SATURDAY IS CONFERENCE T-SHIRT DAY!

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



CURE SMA WOULD
LIKE TO THANK
OUR SPONSORS!

PRESENTING SPONSORS



DIAMOND SPONSOR



CONFERENCE MEALS INCLUDED WITH REGISTRATION

THURSDAY

SNACKS AT MEET & GREET:

SOFT MICKEY PRETZELS, MICKEY RICE KRISPY TREATS, WATER STATIONS, CASH BAR.

FRIDAY

BREAKFAST ITEMS AT SYMPOSIUM:

ASSORTED MUFFINS, DANISHES, CROISSANTS, ORANGE JUICE, AND COFFEE.

LUNCH:

WE WILL HAVE AN ASSORTMENT OF BOXED LUNCH OPTIONS FOR ATTENDEES, AS SUPPLIES LAST. PASTA SALAD, CHIPS, AND A COOKIE ARE INCLUDED IN BOXED LUNCH.

Each choice is limited in number.

FAMILY FRIENDLY POSTER SESSION:

LIGHT SNACKS, MINI CUPCAKES, WATER STATIONS, AND CASH BAR.

SNACKS AT THE PJ PARTY

AND MOVIE NIGHT:

POPCORN AND WATER STATIONS.

SATURDAY

BREAKFAST ITEMS AT SYMPOSIUM:

ASSORTED TEA BREADS, ORANGE JUICE, AND COFFEE.

LUNCH:

WE WILL HAVE AN ASSORTMENT OF BOXED LUNCH OPTIONS FOR ATTENDEES, AS SUPPLIES LAST. PASTA SALAD, CHIPS, AND A BROWNIE ARE INCLUDED IN BOXED LUNCH.

Each choice is limited in number.

SUNDAY

BREAKFAST ITEMS AT SYMPOSIUM:

ASSORTED MUFFINS, DANISHES, CROISSANTS, ORANGE JUICE, AND COFFEE.

There are many dining locations and options available throughout the Disneyland Hotel, Pixar Place Hotel, and Downtown Disney. Options include:

- Tangaroa Terrace Tropical Bar & Grill
- Trader Sam's Enchanted Tiki Bar
- The Coffee House
- Goofy's Kitchen
- Broken Spell Lounge
- Palm Breeze Bar at the Villas at Disneyland Hotel
- Great Maple Modern American Eatery
- The Sketch Pad Café
- Small Bytes

Check out all of the Downtown Disneyland options online!

UNFORTUNATELY, WE ARE NOT ABLE TO ACCOMMODATE FOR DIETARY RESTRICTIONS OR ALLERGIES.

ADULTS WITH SMA NETWORKING

Cure SMA is grateful for the support of both the Adults with SMA Lounge, sponsored by Biogen, and the Adults with SMA Reception, sponsored by Biogen and the Dhont Family Foundation.



The Annual SMA Conference offers numerous opportunities to connect with others in the community.

ADULTS WITH SMA LOUNGE

The Adults with SMA Lounge sponsored by Biogen 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 The Rose Court Garden at the Disneyland Hotel, the lounge is open during the following times:

- Thursday, June 26: 2:30pm – 6:00pm
- Friday, June 27: 11:00am – 4:45pm
- Saturday, June 28: 9:00am – 3:40pm

ADULTS WITH SMA RECEPTION

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. **This event will be held on Friday, June 27, from 7:30pm – 10:30pm in the South Exhibit Hall.** Meet and mingle with others while enjoying light snacks and a bar for a memorable evening together.

ADULTS WITH SMA WORKSHOP TRACK



- Enhancing Clinical Care for Adults with SMA: Strategies for Achieving Optimal Outcomes
- Adult with SMA Relationships Panel – Sharing Your Experience
- Accessible Fashion and Body Image as a Disabled Adult
- Strategies and Benefits of Yoga Practice for Teens and Adults with SMA
- Male Reproductive Considerations in SMA
- Spouses and Partners of Adults with SMA: Sharing Your Experience
- Dating, Intimacy, and Sex—The Disabled Perspective
- Empowering Futures: Unlocking the Potential of ABLE Accounts
- Women's Health in SMA
- Breathing Easy: Optimizing Pulmonary Care in Adults with Spinal Muscular Atrophy
- Moving Toward Independence
- Story Tellers with SMA
- Behind the Scenes: Build the PCA Support You Need to Have More Independence
- Technology That Makes Life Easier
- Practical Home Modifications for Accessibility and Independence
- Your Voice in the Workplace: Job Hunting, Interviewing, and Advocating for Accommodations
- Taking Charge of Your Health: Transition from Pediatric to Adult Care

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

TEEN NETWORKING



The Annual SMA Conference offers many ways to socialize throughout the weekend, however, there are a few special opportunities designed specifically for teens to meet and mingle.

All teens ages 12 – 18 can access the Teen Lounge, sponsored by Novartis. We are grateful to Novartis for their generous support in providing this space specifically for teens to connect and relax throughout the conference.

SPONSORED BY  **NOVARTIS**

The Teen Lounge is located in the Sleeping Beauty Pavillion in the Convention Center at the Disneyland Hotel. The lounge is open during the following times:

- Friday, June 27
11:00am – 4:45pm
- Saturday, June 28
9:00am – 3:40pm

Calling All Teens!

TEENS ARE INVITED
FOR AN EVENING
OF ENTERTAINMENT
AT THE TEEN SOCIAL

**ON FRIDAY, JUNE 27 FROM 7:30PM - 9:30PM
IN THE ADVENTURE ROOM OF THE ADVENTURE
TOWER AT THE DISNEYLAND HOTEL.**

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

MEET & GREET**THURSDAY 6:00PM - 8:30PM**

GRAND BALLROOM

Kick off to the Conference!

- Annual Relay Race
- Family Fun Fest/Carnival
- Meet Disney Characters: Mickey & Minnie, Donald & Daisy, Pluto, and Goofy

**FAMILY FRIENDLY RESEARCHER POSTER SESSION****FRIDAY 6:30PM - 8:30PM**

GRAND BALLROOM

- Visit over 30 posters presented by researchers
- Meet Disney Characters

**PJ PARTY & MOVIE NIGHT****SATURDAY 7:30PM - 9:30PM**

ADVENTURE LAWN

Family movie for kids and adults alike!

**CURE SMA EVENING AT THE PARK**
SATURDAY 4:00PM

Disneyland Park Entrance Ticket to begin at 4:00pm

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

NUNEMAKER FAMILY RESEARCH COMMUNITY CHALLENGE

DOUBLE YOUR IMPACT

This June, your gift goes twice as far. Thanks to the incredible generosity of the Nunemaker Family, all donations to our upcoming Nunemaker Research Campaign will be matched dollar-for-dollar—up to \$150,000.

That means every contribution you make will have double the power to fund groundbreaking spinal muscular atrophy (SMA) research, accelerate new treatment discoveries, and bring us closer to a cure.



Together, we've changed what's possible.
Together, we'll go even further.

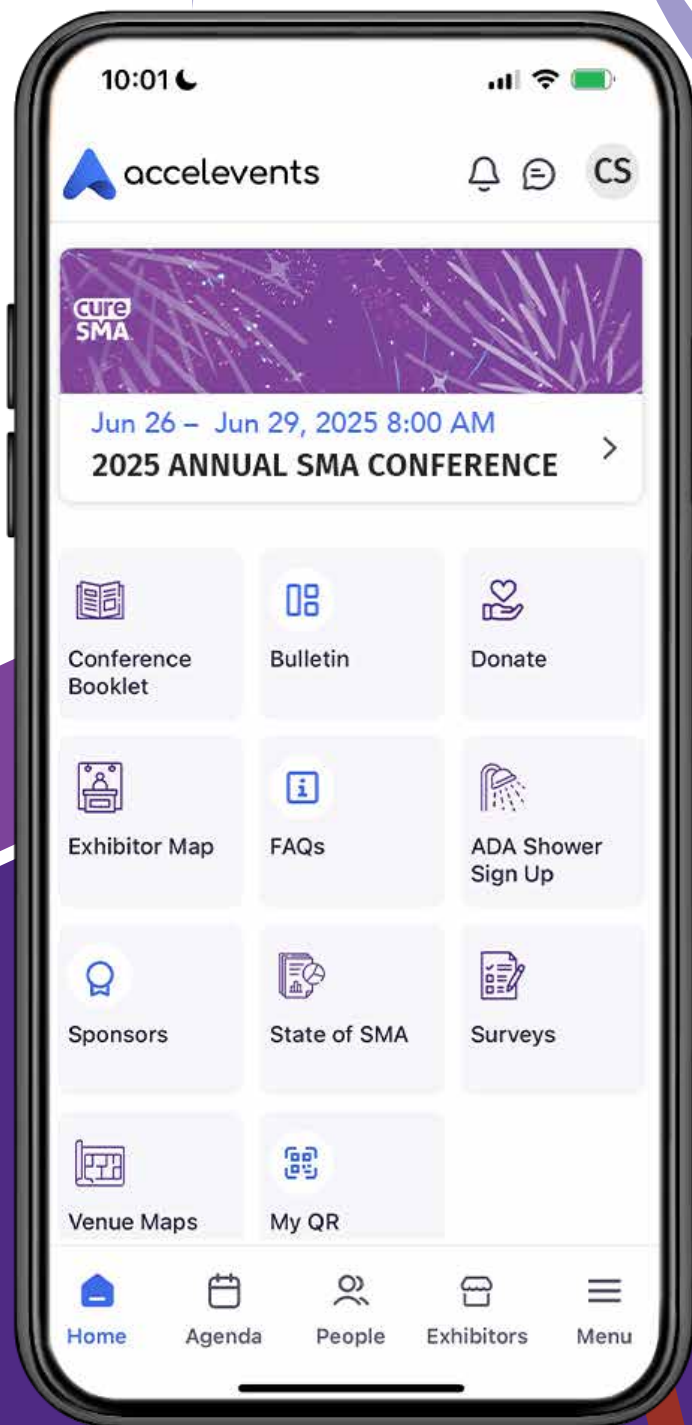
Give boldly. Your impact will be doubled
and you can be a part of changing the
future of SMA.

To learn more and make a gift today,
please visit: www.curesma.org/nunemaker
or scan the QR code below:



A Breakthrough Begins with You.

The Annual SMA Conference App



The 2025 Annual SMA Conference App is the perfect tool to keep you up to date on everything happening at conference! Download it today!

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

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.

expo
convention
contractors



Since Jacob Rappoport's diagnosis in 2001, Shaina and Adi Rappoport have been deeply dedicated to supporting Cure SMA's mission. In 2002, to create a lasting legacy for Jacob, the Rappoport Family established the Jacob Isaac Rappoport Foundation (JIRF). Since 2003, JIRF has been an invaluable partner to Cure SMA, contributing to groundbreaking research, essential support programs, and the Annual SMA Conference. One of the most impactful initiatives supported by JIRF at the conference is the Children's Program, which provides a safe and engaging space for children while their parents participate in crucial workshops and lectures. This program offers a variety of fun activities, from crafts to performances, all thanks to an extraordinary group of volunteers. In addition to their work at the Annual SMA Conference, JIRF also sponsors Newly Diagnosed Packages, which are sent to every newly diagnosed family seeking support from Cure SMA. These packages contain toys and helpful resources, offering comfort and guidance during difficult times. Furthermore, the JIRF has made significant investments in research, funding efforts that are vital to discovering new treatments.

We are profoundly grateful to the Rappoport Family and the Jacob Isaac Rappoport Foundation for their relentless support and dedication over the years. Their contributions have had a lasting impact on the SMA community, and we are deeply appreciative of their unwavering commitment.

Thank you, Rappoport Family, for your remarkable partnership and dedication to the SMA community.

THANK YOU

LUKE 18:1



Since 2017, the Luke 18:1 Foundation has been a steadfast partner in the fight to cure SMA. Founded in honor of Luke Stickane, the Foundation has contributed over \$2.5 million to Cure SMA, fueling groundbreaking research, essential care, and vital support programs.

In 2025, their impact continues to grow. This year alone, the Luke 18:1 Foundation:

- ✓ Sponsored nearly 150 first-time attendees at the Annual SMA Conference
- ✓ Awarded over \$150,000 in basic research grants
- ✓ Supported the Cure SMA Equipment Pool with new equipment

We are deeply grateful to the Stickane Family, the Giglio Family, and the Luke 18:1 Foundation for their unwavering dedication to the SMA community.



Thank you to The Dhont Family Foundation, leaders in scientific and social research investment, for their continued support for those living with SMA, their families, and caregivers.

MEET & GREET



GRAND BALLROOM THURSDAY, JUNE 26, 6:00PM – 8:30PM

Every registered attendee is invited to join.

We are looking forward to a great Annual SMA Conference! Please join everyone at the Meet & Greet kick-off event!

There will be games and prizes for all ages and types to participate in throughout the evening. After we welcome everyone to conference the ever-so-popular Annual Relay Race will begin, where researchers and clinicians compete against individuals affected by SMA in a tight race to finish line. The catch is that the researchers and clinicians race in manual wheelchairs and are always left in the dust!

Light snacks and desserts will be provided at the event. Come enjoy an evening as the community comes together!

- **Annual Relay Race 6:30pm**

Meet Disney Characters

Mickey & Minnie, Donald & Daisy, Pluto, and Goofy



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 25

Please check the Conference App for the most updated agenda.

5:00PM – 7:30PM	Registration Open for all Conference Attendees	La Strada Foyer
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AGENDA | THURSDAY, JUNE 26


9:00AM – 6:00PM	Registration Open for all Conference Attendees	La Strada Foyer
2:00PM – 4:00PM Drop off opens at 1:30pm	Newly Diagnosed Children's Program <i>Sponsored by The Jacob Isaac Rappoport Foundation</i>	Center South Ballroom A
2:00PM – 4:00PM	Newly Diagnosed Program <i>(For Newly Diagnosed Families Only)</i>	South Ballroom A
2:00PM – 2:15PM	Introduction to Cure SMA and the Community <i>**for newly diagnosed families only**</i> Kenneth Hobby, President Colleen McCarthy O'Toole, Senior Vice President, Community Support	
2:15PM – 2:25PM	Parent Welcome Al Freedman, PhD, SMA Parent Joe Wiseman, SMA Parent Nick Farrell, SMA Parent	
2:25PM – 2:30PM	Advocacy Maynard Friesz, Vice President, Advocacy	
2:30PM – 2:40PM	Understanding Current and Future Treatment Options Rob Graham, MD	
2:40PM – 3:05PM	Life After Diagnosis – Parents Share Their Journey Danyelle Sun, SMA Parent Amy Medina, SMA Parent Ashley Pantier, SMA Parent	
3:05PM – 4:00PM	Newly Diagnosed Program Meet and Mingle <i>**for newly diagnosed families only**</i>	South Lounge
2:30PM – 6:00PM	Adults with SMA Lounge <i>Sponsored by Biogen</i> <i>**for adults with SMA and their attendants**</i>	Rose Court Garden
6:00PM – 8:30PM	Meet & Greet Annual Relay Race starts at 6:30pm	Grand Ballroom
8:30PM – 10:30 PM	Dad's Night Out <i>Sponsored by Scholar Rock</i> <i>**for dads only**</i>	Magic Kingdom Ballroom 1

DAD'S NIGHT OUT AND MOM'S NIGHT OUT!

Enjoy tasty snacks and refreshing beverages and connect with old friends and new in this relaxing and friendly setting just for parents. Dad's Night Out will take place on Thursday, June 26, from 8:30pm – 10:30pm in Magic Kingdom Ballroom 1 and Mom's Night Out will be on Friday, June 27, from 8:30pm – 10:30pm in Magic Kingdom Ballroom 2. Thank you to Scholar Rock for their generous sponsorship of these events.




7:00AM	Breakfast Opens	South Exhibit Hall
7:15AM – 4:45PM	Registration Open for all Conference Attendees	La Strada Foyer
7:45AM – 8:45AM	A New Take on SMA Treatment: Hear Insights From the Community Symposium  <small>A Member of the Roche Group</small>	South Exhibit Hall
8:45AM – 5:15PM	Exhibitor and Networking Area Open	South Exhibit Hall
8:45AM – 5:15PM	Living SMA YOUR Way <small>Sponsored by Genentech</small>  <small>A Member of the Roche Group</small>	South Exhibit Hall
8:45AM – 5:15PM	Delta Flight Products Experience <small>Brought to you by Biogen</small> 	South Exhibit Hall
8:45AM – 5:15PM	Imagination Station <small>Sponsored by Scholar Rock</small> 	South Exhibit Hall
8:45AM – 5:15PM	Novartis Community Booth <small>Sponsored by Novartis</small> 	South Exhibit Hall
9:00AM – 12:20PM & 1:45PM – 4:45PM <small>(Drop off opens at 8:30am & 1:15pm)</small>	Children's Program <small>Sponsored by The Jacob Isaac Rappoport Foundation</small> 	North Exhibit Hall
9:00AM – 11:00AM 	General Session Opening Remarks 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 	 Center Ballroom
11:00AM – 4:45PM	Adults with SMA Lounge <small>Sponsored by Biogen</small> <small>**for adults with SMA and their attendants**</small> 	Rose Court Garden
11:00AM – 4:45PM	Teen Lounge <small>Sponsored by Novartis</small> <small>**for all teens ages 12 - 18**</small> 	Sleeping Beauty Pavillion
11:00AM – 4:45PM	Respite/Mindfulness Space	Adventure Gazebo
11:20AM – 12:20PM Workshop Session #1		
	Kids Talk it Out (Ages 6 – 11) Amber Bosselman, Certified Life Coach and SMA-Affected Adult Julia Feinberg, Psy.D., Clinical Psychologist & SMA-Affected Adult Al Freedman, PhD, Clinical Psychologist & SMA Dad This facilitated session will provide SMA-affected children (ages 6-11) an opportunity to talk with each other about their lives. To encourage our children to truly "Talk It Out", this session is open to children only and requires parental consent.	North Ballroom A

	<p>Pre-symptomatic and Early Diagnosis Experiences Dany Sun, MSW, SMA Mom, Social Work Senior Manager, Cure SMA Darlsha Barnes, SMA Mom Jarrett Barnes, SMA Dad Ashley Pantier, 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>Magic Kingdom Ballroom 1</p>
	<p>Dry Land Strengthen and Stretch Your Body Jennifer Martyn, PT Krista Torseth, PT, DPT Kendra Paker, PT, DPT, PCS</p>  <p>Come hang with a team of physical therapists for the dry land portion of the pool program to learn about the why and how of getting yourself or your loved one in the water. The aquatic physical therapists will introduce participants to the various pieces of equipment used in aquatic therapy including items such as: flotation devices, resistance toys and water weights. Participants will also learn about the concepts and techniques that are central to aquatic therapy, such as buoyancy and resistance. Understanding these principles will help participants maximize the benefits of their time in the water.</p>	<p>Adventure Lawn</p>
	<p>Caring for Your Bladder and SMA Douglas Storm, MD Angelena Edwards, MD</p> <p>This session will discuss common urinary issues in people with SMA and ways to manage them for better comfort and quality of life. We will explain how SMA affects the bladder and pelvic muscles and share tips for toileting, hydration, constipation, and kidney stone prevention. We will also discuss medical and surgical options that can help with bladder care such as clean intermittent cathing, suprapubic catheter placement, and creating a channel through the skin to the bladder to catheterize for urine. All ages are welcome.</p>	<p>Safari</p>
	<p>Strategies and Benefits of Yoga Practice for Teens and Adults with SMA 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>	<p>Magic Kingdom Ballroom 2</p>
	<p>Male Reproductive Considerations in SMA Natan Bar-Chama MD Reproductive Urologist Reproductive Medicine Associates of New York / The Mount Sinai Hospital</p> <p>This workshop will review the current understanding of SMA's direct impact on male reproductive health including physical and functional aspects and sperm production. It will address the known effects of disease-modifying therapies like Evrysdi on male fertility. Attendees will learn about new technologies for convenient home sperm testing, advancements in Assisted Reproductive Technologies for male infertility, and fertility preservation to help them make informed choices about their options.</p>	<p>Adventure</p>
	<p>Financial and Estate Planning with Special Needs Trusts Richard Rubenstein, Esq., RICP®</p> <p>Legal and financial planning parents must undertake to protect their family 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. Parents must go through these difficult steps to ensure a well-planned future for their special child.</p>	<p>South Ballroom</p>

	Grandparents Coffee and Share Your Experience Moderated by: Pat Wolff, grandparent to SMA type 2 grandchild Sylvia and Romero Resendez, grandparents to SMA type 1 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.	Magic Kingdom 4
	Sharing Your Type I Experiences <i>(for individuals with SMA type 1 born in 2017 or earlier, and their families)</i> Moderated by, Amy Medina This session is to provide a space for families and individuals who understand the unique experience of having managed SMA without medical intervention or facing the reality of treatment not leading to life changing milestones. This is especially relevant for those whose lives have been touched by SMA Type 1, particularly those born in 2017 or earlier. Come together in this session to foster connections and share experiences.	Amazon
	Moving Toward Independence Lyza Weisman, adult with SMA Doug McCullough, adult with SMA Tyler Dukes, adult with SMA Annie Heathcote, adult with SMA Tips and tricks for people with SMA or caregivers who want to learn more about what it's like to live with SMA and engage with the world. Many individuals with SMA struggle to move out of the family home, live independently, or go out of state for work or college—but as the panelists can attest, it is possible. The world has the resources to make anything happen. This workshop will feature a variety of lived experiences, tips, tricks, and advice on what to do (or avoid) to help you go wherever your heart desires, no matter your physical limitations.	Center Ballroom
12:20PM – 1:45PM	Lunch	South Exhibit Hall
1:45PM – 3:05PM	Workshop Session #2	
	Understanding SMA Treatments: From Clinical Trials to Real-Life Decisions Thomas Crawford, MD Crystal Proud, MD Robert Graham, MD With more treatments for SMA approved and in development, individuals and families are faced with complex choices. This interactive session brings together a panel of neurologists who lead SMA clinical trials to help unpack how to interpret trial results and apply them to real-world decision-making. Beyond the science, we'll explore the ethical, emotional, and practical realities of SMA treatment—including access, equity, and the hopes and challenges that come with emerging therapies. Ample time will be provided for open discussion.	Center Ballroom
	Taking Charge of Your Health: The Transition from Pediatric to Adult Care Sarah Heintzman, APRN-CNP, FNP-C Bakri Elsheikh, MBBS, FRCP Julianne Meiser, MSS, LCSW Amber Bosselman, adult with SMA Joshua Scurria, adult with SMA This workshop will focus on the patient and professional experience related to the transition to adult care. You will hear about the journey of two adults with SMA who have already navigated this process. You will also hear from several medical professionals about the importance of transitioning, identifying some key resources and skills needed for a successful transition, an adult provider's perspective on adult clinics, and any differences you.	Genentech <i>A Member of the Roche Group</i> Adventure Lawn
	Spouses and Partners of Adults with SMA: Sharing Your Experience Kyla Pollock, spouse of adult with SMA Are you married to or in a committed relationship with an adult who has SMA? Then this workshop is 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.	Western






	<p>The Role of Therapy PT and OT in your Child's Life – Being Part of the Team! Jennifer Hubbell, OTR/L Leslie Nelson, PT, PhD, OCS Anne Stratton, MD Tina Duong, PT, PhD</p> <p>The goal of this session is to explore the general physical and occupational therapy needs of children with SMA geared toward those families who may be newer to navigating this world. We will discuss how to create your team and different therapy options, as well as how different teams may approach therapy considerations. We will provide and share examples of treatment ideas that you can also share with your local therapists. We will discuss evidence-based interventions to help your child maximize their function and how to work with your team to develop functional goals. We will also discuss some basic body mechanics to help the caregiver. A large amount of time will be devoted to encouraging an open discussion with all participants with opportunities to share experiences and frustrations and to answer questions you might have.</p>	<p>Magic Kingdom Ballroom 4</p>
	<p>Healing the Grieving Heart – Part I David Sereni, MPT Natasha Abruzzo, RN</p> <p>The healing process, Part 1: This workshop is for those dealing with the loss of a child or family member and provides an opportunity for those attending to address their experience with bereavement and feelings of loss.</p>	<p>Amazon</p>
	<p>Strengthen and Stretch Your Body in the Water - for Children Sitting/ Walking Independently, Ages 6 months to 7 years and Children Requiring Head Support Jennifer Martyn, PT Krista Torseth, PT, DPT Kendra Paker, PT, DPT, PCS</p> <p>Are you ready to dive into a unique and invigorating experience? Bring your swimsuits and head to the pool for an active 85 minutes with a team of aquatic physical therapists. This session is designed to focus on improving functional strength and skills in a dynamic environment, promoting both physical and mental well-being through the power of water-based activities. A parent or caregiver is required to be in the water with each child. We look forward to seeing you in the water!</p>	<p>D-Ticket Pool</p>
	<p>An SMA Family Feud Experience: Fundraising for Today & Tomorrow Cure SMA Development Team</p> <p>Get ready for a high-energy, game-show-style session where fundraising meets fun! In this Family Feud-inspired experience, teams will go head-to-head, guessing the most popular responses to today's biggest fundraising challenges, trends, and best practices. From digital campaigns to storytelling tactics to event fundraising strategies, we'll dive into how fundraising is evolving, what it means for the future of Cure SMA, and how you play a vital role in it all.</p>	<p>Magic Kingdom Ballroom 2</p>
	<p>Mindful Moments: Helping Kids Find Calm Tara Davenport, Parent of a child with SMA Claire Miles, Child with SMA</p> <p>If anxiety and stress are affecting your child, join us for this interactive session to explore proven mindfulness-based techniques that can help. 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>	<p>Magic Kingdom Ballroom 1</p>
	<p>Breathing Easy: Optimizing Pulmonary Care in Adults with Spinal Muscular Atrophy Jeremy Orr, MD</p> <p>This workshop explores best practices for respiratory care in adults with SMA, including non-invasive ventilation strategies, airway clearance techniques, infection prevention, and multidisciplinary care approaches. Designed for healthcare professionals, caregivers, and individuals with SMA, this session will also address evolving challenges and practical solutions to support respiratory health, enhance quality of life, and reduce complications. Join us to deepen your understanding of pulmonary care in SMA and foster collaboration across care teams.</p>	<p>Adventure</p>

	Practical Home Modifications for Accessibility and Independence Spencer Cook, accessibility consultant, adult with SMA Whether you're adapting a home for the first time or planning a major renovation, this session offers a clear, practical guide to creating spaces that support your independence. Led by an accessibility consultant with a background in architecture and design, this presentation covers every step of the home modification process—from identifying funding sources to working effectively with contractors. We'll explore key design considerations to ensure that your project is a long-term success.	South Ballroom
3:25PM – 4:45PM	Workshop Session #3	
	Adaptive Sport / Recreation Testimonials and Resources Ed Bronsdon, Moderator Charlie Zerzan, Wheelchair Basketball Player Marley Robinson, Volt Hockey Player Kurt Beach, Adaptive Sports Program Director at University of Michigan Alyssa Briglio, Power Soccer Player  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.	Adventure Lawn
	I Need to Cough, I Need to Breathe, I Need to Sleep Oren Kupfer, MD Peter Schochet, MD Richard Kravitz, MD In this workshop, we will focus on the respiratory complications seen in SMA. We will discuss the importance of having an adequate cough and how its inherent weakness can impact on pulmonary health. We will review what makes for an effective cough and how we can optimize an individual's ability to clear their airways and keep their lungs clear. We will also discuss why the muscle weakness causes difficulty breathing during sleep, illness and after surgery, and how to know when breathing support machines such as BIPAP should be considered. Furthermore, with the availability of our 3 SMN modulators, the need for nighttime respiratory support is changing and more traditional sleep is being seen. We will outline what is considered appropriate sleep for children and adults with SMA and how, through appropriate behavioral interventions and respiratory support, a good night's sleep (both for the affected individual and their family) can be achieved. Various interventions available to optimize an individual's respiratory function and sleep quality will be reviewed.	South Ballroom
	Genetics and Reproductive Options for SMA Families Harvey J. Stern, MD, PhD, FACMG, FAAP Melissa Gibbons, MS, CGC 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.	Magic Kingdom Ballroom 1
	Finding Your Strengths: Building Resilience Against Burnout Wendy Godfrey, ST Wellness In a world where burnout feels inevitable, the rare disease community faces unique challenges. But within each of us lies a powerful resource: our personal strengths. This workshop is an opportunity for patients and caregivers to discover those strengths, connect them to practical strategies, and build a supportive community. We'll leave with a plan for daily practices that will help build resilience and navigate the journey with more ease.	Magic Kingdom Ballroom 4



PLEASE NOTE WEAR SUNSCREEN AND KEEP HYDRATED!

As many of you know, June in California 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>Strengthen and Stretch Your Body in the Water - for Children Sitting/ Walking Independently, Ages 8-13 year old</p> <p>Jennifer Martyn, PT Krista Torseth, PT, DPT Kendra Paker, PT, DPT, PCS</p> <p> NMD PHARMA[®] NEUROMUSCULAR DISORDERS</p> <p>Are you ready to dive into a unique and invigorating experience? Bring your swimsuits and head to the pool for an active 85 minutes with a team of aquatic physical therapists. This session is designed to focus on improving functional strength and skills in a dynamic environment, promoting both physical and mental well-being through the power of water-based activities. A parent or caregiver is required to be in the water with each child. We look forward to seeing you in the water.</p>	D-Ticket Pool
	<p>Dating, Intimacy, and Sex—The Disabled Perspective</p> <p>Delphine Andrews, MA, Adult with SMA, Founder of The Delta Oracle</p> <p>Content Warning: This session includes explicit discussions of sex, intimacy, and relationships. Some topics may be sensitive or triggering. Recommended for attendees 18+.</p> <p>Have you ever caught yourself believing that love, sex, and desire weren't meant for you? Have you ever questioned your value as a partner or potential partner? How would you show up in dating, relationships, and intimacy if you never felt the need to apologize for your body?</p> <p>Disabled people are often treated as non-sexual, but intimacy, pleasure, and connection are for us, too. This workshop is a candid, judgment-free space to explore sex, relationships, and dating as disabled individuals—including navigating desire, self-advocacy, and accessibility in intimate settings. Whether solo or partnered, everyone deserves fulfilling experiences, and we'll discuss how to claim that without apology or shame.</p>	Safari
	<p>Navigating The Special Education/504 Process: Setting our Children Up for Success In Preschool and Elementary School</p> <p>Kimberly Cook, Parent of a Child with SMA, Inclusion Specialist Tina Lewis, Parent of a Child with SMA, and Education Specialist</p> <p> ScholarRock.</p> <p>As you embark on the journey to send your child to preschool or elementary school, this session will focus on what you can do to set your child up for success in their very first educational experiences. Through our own personal and professional experiences, we will discuss the essentials for ensuring equitable opportunities for your child. We will discuss the specifics of developing an Individualized Education Program (IEP), a Section 504 Plan, as well as considerations for services and accommodations that will ensure success for your child!</p>	Adventure
	<p>Get To The Art of It: Community Art Time</p> <p>Rachel Johnson, M.Ed., CCLS</p> <p>It's time for some creative fun time! All are welcome! Participants will be encouraged to create mixed media art and will be provided with choices for the artmaking time. Take a break from the day for some art time and make some memories as a family or with new friends that will last a lifetime.</p>	South Exhibit Hall
6:30PM – 8:30PM	Family Friendly Researcher Poster Session	Grand Ballroom
7:30PM – 9:30PM	PJ Party & Movie Night	Adventure Lawn
7:30PM – 9:30PM	<p>Teen Social</p> <p><i>**for all teens ages 12 – 18**</i></p>	Adventure
7:30PM – 10:30PM	<p>Adults with SMA Reception</p> <p><i>Sponsored by Biogen and The Dhont Family Foundation</i></p> <p> Biogen  THE DHONT FAMILY FOUNDATION</p>	South Exhibit Hall
8:30PM – 10:30 PM	<p>Mom's Night Out <i>Sponsored by Scholar Rock</i></p> <p> ScholarRock.</p> <p><i>**for moms only**</i></p>	Magic Kingdom Ballroom 2

FAMILY FRIENDLY RESEARCHER POSTER SESSION

FRIDAY, JUNE 27 FROM 6:30 TO 8:30 PM

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:

HOW DO MOTOR NEURONS RECOVER FOLLOWING TREATMENT IN MOUSE MODELS OF SMA?

Lyndsay Murray, PhD, University of Edinburgh

REAL-WORLD EXPERIENCES WITH RISDIPLAM TREATMENT

Sheila Shapouri, PharmD, MS, Genentech, Inc., South San Francisco, CA, USA

AN INTRODUCTION TO THE CURE SMA CARE, OUTCOMES, AND REPORTED EXPERIENCES (CORE) SURVEY

Sarah M Whitmire, MS, Cure SMA

ACTIN FUNNY: HOW REDUCED SMN IMPAIRS ASTROCYTE STRUCTURE AND FUNCTION

Allison Ebert, PhD, Medical College of Wisconsin

APITEGROMAB FOR THE TREATMENT OF SPINAL MUSCULAR ATROPHY: THE PHASE 3 SAPPHIRE STUDY

Tom Brown, PhD, Scholar Rock, Inc.

INCREASING ENGAGEMENT WITH ADULTS WITH SMA THROUGH CURE SMA ADVOCACY

Maynard Friesz, Cure SMA

TOWARDS A RESEARCH AGENDA FOR SMA

Nicole Gusset, PhD, SMA Europe

HOPE AT THE JUNCTION: NEW PATHS TO TREATING SMA

Karolien Van Huynegem and Shelley Gerson, Argenx

FIVE YEARS POST-RISDIPLAM APPROVAL: ROCHE/GENENTECH'S CONTINUED COMMITMENT TO MEET PRESSING COMMUNITY RESEARCH NEEDS

Selina Tam, PharmD, Genentech, Inc., South San Francisco, CA, USA

UNMET NEEDS AMONG ADULTS LIVING WITH SPINAL MUSCULAR ATROPHY IN THE UNITED STATES

Erin F Welsh, MPH, Cure SMA

SINGLE NUCLEUS RNA SEQUENCING: UNDERSTANDING GENE EXPRESSION CHANGES IN MOTOR NEURONS

Elana Molotsky, PhD, Johns Hopkins University

EVALUATING FERTILITY AND PREGNANCY AMONG ADULTS LIVING WITH SMA UTILIZING THE 2025 CURE SMA COMMUNITY UPDATE SURVEY

Lisa Belter, MPH, Cure SMA

PREGNANCY OUTCOMES IN INDIVIDUALS WITH SMA: NEW NATURAL HISTORY OF PREGNANCIES IN THE TREATED SMA POPULATION

Shelby Vogt-Domke, B.S., Stanford University Department of Neurology

THE SMA EFFORT: A NOVEL TOOL TO CAPTURE EXPERIENCED FATIGABILITY IN SMA

Rafael Rodriguez-Torres, PT, DPT, PCS, Columbia University Irving Medical Center

MAKING SENSE OF THE CHAOS: MIS-SPICING IN SMA

Anton Blatnik, PhD, Case Western Reserve University

ENHANCING BULBAR ASSESSMENT IN SPINAL MUSCULAR ATROPHY: A RASCH ANALYSIS OF THE INTERNATIONAL BULBAR ASSESSMENT TOOL (IBAT) PILOT STUDY

Sally Dunaway Young, PT, DPT, Department of Neurology and Clinical Neurosciences, Stanford University, Palo Alto, CA

THE SMARTCARE STUDY: LATEST REAL-WORLD EVIDENCE FOR ADULTS LIVING WITH SMA

Kevin Conway, Biogen

INVESTIGATING NMJ DEFECTS IN SMA FOLLOWING CENTRAL AND PERIPHERAL SMN RESTORATION

Georgia Cinkay, BS, Ohio State University

SPINAL CORD STIMULATION IN SPINAL MUSCULAR ATROPHY

Genis Prat-Ortega, PhD, University of Pittsburgh

YOUR FUNDRAISING, YOUR IMPACT: FUELING THE FUTURE OF SMA BREAKTHROUGHS

Kyle Houlihan and Erin DiNicola, Cure SMA

PIERRE AND PIERRE-PK CLINICAL TRIAL STUDY DESIGN FOR THE EVALUATION OF FEASIBILITY, SAFETY AND PHARMACOKINETICS OF THECAFLEX DRX™, AN IMPLANTABLE INTRATHECAL CATHETER AND SUBCUTANEOUS PORT SYSTEM FOR REPEATED INTRATHECAL DELIVERY OF NUSINERSEN

Leeann Burton, MD and Melissa Breedlove, Biogen and Alcyone

READING RNA TO UNDERSTAND SMA: WHAT'S HAPPENING IN MOTOR NEURONS?

Stephen Brown, Johns Hopkins Neurology

INTRATHECAL ONASEMNOGENE ABEPRARVOVEC FOR STUDY PATIENTS WITH SPINAL MUSCULAR ATROPHY

Crystal Proud, MD and Jennifer Kwon, MD, Novartis

HOW DOES LOSS OF MUSCLE IN SMA AFFECT WHOLE BODY METABOLISM?

Melissa Bowerman, PhD, Keele University, UK

AN UPDATE ON NMD PHARMA'S CLINICAL STUDY AND SKELETAL MUSCLE-TARGETED DRUG THERAPY (TABLET) FOR ADULTS WITH SMA

Vera Kiyasova, PhD and Daniel Brennan, MBA, NMD Pharma

CAPTURING THE CONTINUED BURDEN OF SPINAL MUSCULAR ATROPHY (SMA) FOR PATIENTS RECEIVING CURRENT STANDARDS OF CARE AND THEIR CAREGIVERS

Christabella Cherubino, DC, ScD, Scholar Rock, Inc.

FROM BIRTH TO TREATMENT: UNDERSTANDING THE NEWBORN SCREENING PROCESS

Kristin J Krosschell, PT, DPT, PCS and Lenika De Simone, MS, CGC, Northwestern University Feinberg School of Medicine, Ann and Robert H Lurie Children's Hospital

DENIED TREATMENT, DELAYED CARE: HOW INSURANCE DENIALS IMPACT THE SMA COMMUNITY

Lauren Eisenman, MS, Cure SMA








ADVANCES IN THE DIAGNOSIS AND TREATMENT OF INFERTILITY FOR THE MALE WITH SMA

Benjamin Friedman and Natan Bar-Chama MD, Reproductive Medicine Associates of New York / The Mount Sinai Hospital

TALDEFGROBEP ALFA IN SPINAL MUSCULAR ATROPHY

Lindsey Lee Lair, MD, MBA, FAAN
Biohaven Pharmaceuticals, Inc



**MEET
DISNEY
CHARACTERS**

7:00AM	Breakfast Opens	South Exhibit Hall
7:15AM – 3:40PM	Registration Open for all Conference Attendees	La Strada Foyer
7:45AM – 8:45AM	From One Generation to Another: A Symposium for the Ages 	South Exhibit Hall
8:45AM – 4:00PM	Exhibitor and Networking Area Open	South Exhibit Hall
8:45AM – 4:00PM	Delta Flight Products Experience <i>Brought to you by Biogen</i> 	South Exhibit Hall
8:45AM – 4:00PM	Imagination Station <i>Sponsored by Scholar Rock</i> 	South Exhibit Hall
8:45AM – 4:00PM	Novartis Community Booth <i>Sponsored by Novartis</i> 	South Exhibit Hall
9:00AM – 11:40AM & 1:00PM – 3:40PM (Drop off opens at 8:30am & 12:30pm)	Children's Program <i>Sponsored by The Jacob Isaac Rappoport Foundation</i> 	North Exhibit Hall
9:00AM – 3:40PM	Adults with SMA Lounge <i>Sponsored by Biogen</i> <i>**for adults with SMA and their attendants**</i> 	Rose Court Garden
9:00AM – 3:40PM	Teen Lounge <i>Sponsored by Novartis</i> <i>**for all teens ages 12 - 18**</i> 	Sleeping Beauty Pavillion
9:00AM – 3:40PM	Respite/Mindfulness Space	Adventure Gazebo
9:00AM – 10:10AM Workshop Session #4		
	Swallowing in SMA: Expectations for Stability and Promising Rehabilitation Methods Katlyn McGrattan, PhD Swallowing difficulties have impacted the quality of life for individuals living with SMA. While the introduction of SMA treatments like Spinraza, Zolgensma, and Risdiplam have greatly improved these outcomes among those who receive treatment early, many still experience serious swallowing challenges. In this session, Dr. McGrattan will present the latest information on how SMA treatments may help people with varying severities of SMA maintain or improve swallowing. She will also share promising therapy techniques for managing saliva, improving mouth opening, and safely returning to eating by mouth when possible.	North Ballroom B

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, so please take advantage.




	<p>The Role of the Multi-disciplinary Clinic - How it can be helpful for those identified pre-symptomatically</p> <p>Leslie Nelson, PT, PhD, OCS Anne Stratton, MD Jennifer Hubble, OT</p>  <p>The goal of this session is to identify the general components of a multidisciplinary clinic and how the various clinicians and members of the team may be beneficial to you as you navigate the process of guiding the care for your child that was identified with SMA pre symptomatically. We will discuss the potential for guidance regarding rehabilitation, including orthopedic considerations as well as physical and occupational therapy needs of children with SMA. We will also discuss how you might take the recommendations provided from your multidisciplinary team and incorporate them into your larger care team (treating therapists and even team members within the school and community settings). A large amount of time will be devoted to encouraging an open discussion with all participants with opportunities to share experiences and frustrations and to answer questions you might have.</p>	<p>Magic Kingdom Ballroom 2</p>
	<p>Creating Lasting Memories Through Art Making</p> <p>Rachel Johnson, M.Ed., CCLS</p> <p>During this workshop participants will be provided with choices to create a keepsake in memory of a loved one. Everyone is encouraged to share memories of their loved one while artmaking and will have an opportunity to learn about projects they can complete outside of the group setting. Participants are encouraged to bring photos of their loved ones for use in the workshop. There will also be a printer available to print a few photos. All ages are welcome to come and create art.</p>	<p>Magic Kingdom Ballroom 1</p>
	<p>Power Assist, Power Wheelchairs and Alternative Drive Options for Children and Adults who are Living with SMA</p> <p>Amy Pasternak PT, DPT, PCS</p> <p>In this workshop, a physical therapist who specializes in SMA and prescription of powered 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 & A.</p>	<p>North Ballroom A</p>
	<p>A Pediatric Yoga Approach to Movement and Wellness: A 5 Part Therapeutic Yoga Practice for Babies, Toddlers and Children with SMA</p> <p>Anne Buckley-Reen, OTR/RYT, FORKIDS OT Assisted by: Eve Raymond, OTR</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>	<p>South Ballroom</p>
	<p>Enhancing Clinical Care for Adults with SMA: Strategies for Achieving Optimal Outcomes</p> <p>Tina Duong, PT, PhD Bakri Elsheikh, MBBS, FRCP</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>	<p>Adventure Lawn</p>
	<p>Empowering Futures: Unlocking the Potential of ABLE Accounts</p> <p>Mark Fry, J.D., CPA (Inactive); Louisiana Board Certified Legal Specialist in Estate Planning and Administration</p> <p>The scope of this presentation will include the fundamental and advanced concepts which underly the use of ABLE (Achieve a Better Life Experience) accounts to expand the financial empowerment for individuals with exceptionalities. The discussion will explore the various limitations, income tax benefits, and asset protective aspects associated with the ABLE accounts, and will compare the use of these accounts with the use of special needs or supplemental care trusts and reveal the benefits of combining both strategies.</p>	<p>Center Ballroom</p>




10:30AM – 11:40AM

Workshop Session #5

	Navigating Anesthesia, Sedation, and Pain Control for SMA Families Alan Bielsky, MD <p>This workshop will provide an overview of anesthesia, sedation, and pain management for patients and families with SMA. We will discuss the risks of different kind of anesthesia and pain control, as well as common ways to minimize bad outcomes. We will also discuss common myths and misconceptions regarding anesthesia, sedation, and pain control.</p>	North Ballroom B
	Orthopedic Management in SMA Brian Snyder, MD, PhD Samuel Rosenfeld, MD Anne Stratton, MD  <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>	North Ballroom A
	Unleashing Potential: Exploring the World or Service Dogs More Than A Companion: The Service Dog Journey KateLynne Steinke & Jones on the Job <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>	Adventure
	Aquatic Physical Therapy for Fun & Function, Teens and Adults Jennifer Martyn, PT Krista Torseth, PT, DPT Kendra Parker, PT, DPT, PCS  <p>Are you ready to dive into a unique and invigorating experience in the water? Put your swimsuit on and head to the pool for 70 minutes with a team of aquatic physical therapists. This session is designed to focus on improving functional strength and active movement in a dynamic environment, promoting both physical and mental well-being through the power of water-based activities. This is an excellent chance to explore how different tools can enhance your success and independence in the water. From floatation devices to resistance tools, each piece of equipment serves a purpose in aiding your movement and stability.</p> <p>**If you are unable to attend this session, please join us in the pool for the afternoon session**</p>	D-Ticket Pool
	Technology That Makes Life Easier Tyler Dukes, DevOps Manager, adult with SMA Jenna Coburn, Creative Director, adult with SMA Jose Flores, Corporate Keynote Speaker, #1 Best-Selling Author & Workshop Facilitator, adult with SMA Amber Bosselman, Certified Life Coach, adult with SMA <p>In this panel discussion, four adults with SMA will discuss all things relating to technology and assistive devices that help make life easier for individuals with SMA. The panelists will dive into how they use assistive technology in their personal and work lives. They will share information on the different devices on the market and how to navigate funding those devices. The presentation will be followed by an audience Q and A.</p>	Center Ballroom
	Healing the Grieving Heart – Now What? Part II David Sereni, MPT Natasha Abruzzo, RN <p>This workshop is a continuation of Part 1. For those dealing with the loss of a child or family member and provides an opportunity for those attending to address their experiences.</p>	Amazon

	<p>Behind the Scenes: Build the PCA Support You Need to Have More Independence</p> <p>Carolyn Barrett, adult with SMA Annie Heathcote, adult with SMA Spencer Cook, adult with SMA</p> <p>Join three adults with SMA as they share candid, real-life experiences of hiring and managing their own Personal Care Assistants (PCAs). This panel is designed for teens and adults with disabilities, as well as family members and caregivers looking for practical insight on how to find, train, and sustain quality in-home care. With honesty and humor, panelists will cover everything from red flags in interviews to building respectful working relationships—and what to do when things go wrong. Whether you're just starting to think about independent living or already managing your own care, this session offers tips, hard-earned wisdom, and encouragement that independence is not only possible, but worth the challenges that sometimes arise.</p>	South Ballroom
	<p>Accessible Fashion and Body Image as a Disabled Adult</p> <p>Jessica Hetzel, adult with SMA Noelle Hazel, adult with SMA</p> <p>Genentech <i>A Member of the Roche Group</i></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>	Adventure Lawn
	<p>Siblings Talk it Out (Ages 12 to 17)</p> <p>Katlyn O'Brien, Sister of an Adult with SMA Traci O'Brien, Sister of an Adult with SMA</p> <p>This workshop is for the siblings of brothers and sisters with SMA. With the unique relationship siblings have, we have much to offer one another. This workshop will create a fun and comfortable setting in which siblings can express themselves and their feelings, both positive and negative, of having a sibling with SMA through activities and discussions. This workshop will be facilitated by SMA family siblings and other family members. It is geared for siblings between the ages of 12-17 years old. They will learn ways to cope and manage common situations that are experienced by brothers and sisters. Dress comfortably and be prepared to make friends and have fun!</p>	Magic Kingdom Ballroom 4
11:40AM – 1:00PM	Lunch	South Exhibit Hall
1:00PM – 2:10PM	Workshop Session #6	
	<p>Women's Health in SMA</p> <p>Loralei Thornburg, MD Annie Heathcote, adult with SMA Christine Getman, adult with SMA Cory Jacobson, adult with SMA</p> <p>This workshop will explore key aspects of comprehensive women's health care for individuals with SMA, emphasizing the importance of proactive and routine care. Topics will include reproductive planning, hormonal health, gynecologic considerations, and wellness strategies tailored to the unique needs of people with SMA. While pregnancy-related care and planning will be addressed, the workshop will also highlight broader health concerns such as menstrual management, contraception, and preventive screenings.</p> <p>Attendees will benefit from the insights of a practicing OB/GYN with experience in neuromuscular disorders, as well as hear firsthand perspectives from adults with SMA on navigating their own health journeys.</p>	Adventure Lawn
	<p>Real Food for Optimal Health</p> <p>Rebecca Hurst Davis, MS, RD, CSP, CD, CNSC Stacey Tarrant, BS, RD, LDN</p> <p>In this workshop, we will discuss nutrition for people with SMA of all ages, focusing on real food intake for optimal health. We will address the unique nutritional needs of infants, toddlers, school-aged children, teenagers, and adults, whether food is eaten by mouth, provided by tube-feeding, or a mixture of both.</p>	South Ballroom



	<p>Empowered Parenting: Thriving as a Single or Co-Parent Raising a Child with SMA</p> <p>Moderated by: Kristen Resendez Sapna Pringle Mark Courteau Erin Walsh</p> <p>Navigating the journey of raising a child with SMA as a single or co-parent comes with unique challenges—but you are not alone. In this session, you'll hear from single and co-parents of SMA who have discovered valuable tools, resources, and strategies to support their children and themselves. Gain insights into practical approaches that foster resilience, confidence, and well-being for both you and your child. Plus, connect with other parents who truly understand your path, leaving with a renewed sense of empowerment and a community to lean on.</p>	<p>Magic Kingdom Ballroom 1</p>
	<p>Advocating for Yourself and the SMA Community: Tips for Effective Advocacy</p> <p>Maynard Friesz, Vice President of Policy and Advocacy, Cure SMA Sarah Bellish, Manager of Policy and Advocacy, Cure SMA, and Adult with SMA SMA Community Advocates</p> <p>The voices and advocacy actions of individuals with SMA and their families are key to raising awareness and driving change. In this session, Cure SMA's Advocacy Team and fellow SMA community advocates will share practical tips and strategies for connecting with and educating elected leaders and other stakeholders about SMA and SMA community needs and priorities. Leave feeling empowered to make a difference for yourself and others in the SMA community.</p>	<p>Center Ballroom</p>
	<p>Navigating The Special Education/504 Process: Transitioning to Middle School, High School, and College</p> <p>Kimberly Cook, Parent of a Child with SMA, Inclusion Specialist Tina Lewis, Parent of a Child with SMA, and Education Specialist</p>  <p>As your child strives for greater independence in middle, high school and college, this session will focus on what you can do to set your child up for success as they transition into these settings. Through our own personal and professional experiences, we will discuss the essentials for ensuring equitable opportunities for your child. We will discuss the specifics of transition planning, tools for independence, and disability services typically available for students who plan to attend college.</p>	<p>Magic Kingdom Ballroom 2</p>
	<p>Siblings Talk it Out (Ages 5 to 11)</p> <p>Katlyn O'Brien, Sister of an Adult with SMA Traci O'Brien, Sister of an Adult with SMA</p> <p>This workshop is for the siblings of brothers and sisters with SMA. With the unique relationship siblings have, we have much to offer one another. There will be activities and discussions in a fun and comfortable setting where everyone is given the opportunity to express themselves and their feelings, both positive and negative, regarding having a sibling with SMA. This workshop will be facilitated by SMA family siblings and other relatives. It is geared for siblings between the ages of 5-11 years old. They will learn ways to cope and manage common situations that are experienced by brothers and sisters. Dress comfortably and be prepared to connect with others like you!</p>	<p>Magic Kingdom Ballroom 4</p>
	<p>Kids Talk it Out (Ages 12 – 17)</p> <p>Amber Bosselman, Certified Life Coach and SMA-Affected Adult Julia Feinberg, Psy.D., Clinical Psychologist & SMA-Affected Adult Al Freedman, PhD, Clinical Psychologist & SMA Dad</p> <p>This facilitated session will provide SMA-affected children (ages 12-17) an opportunity to talk with each other about their lives. To encourage our children to truly "Talk It Out", this session is open to children only and requires parental consent.</p>	<p>North Ballroom B</p>
	<p>Early Scoliosis Treatment in SMA</p> <p>Samuel Rosenfeld, 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>	<p>North Ballroom A</p>

	<p>Aquatic Physical Therapy for Fun & Function, Teens and Adults Jennifer Martyn, PT Krista Torseth, PT, DPT Kendra Parker, PT, DPT, PCS</p> <p> NMD PHARMA NEUROMUSCULAR DISORDERS</p> <p>Are you ready to dive into a unique and invigorating experience in the water? Put your swimsuit on and head to the pool for 70 minutes with a team of aquatic physical therapists. This session is designed to focus on improving functional strength and active movement in a dynamic environment, promoting both physical and mental well-being through the power of water-based activities. This is an excellent chance to explore how different tools can enhance your success and independence in the water. From floatation devices to resistance tools, each piece of equipment serves a purpose in aiding your movement and stability.</p> <p>**If you were unable to attend the earlier session, please come by the pool to partake in this session**</p>	D-Ticket Pool
2:30PM – 3:40PM	Workshop Session #7	
	<p>Adults with SMA Relationships Panel – Share Your Experience Jose Flores and Andraea Flores Jenna Vega and Tanya Vega Spencer Cook and Michaela Arzola Collin Pollock and Kyla Pollock</p> <p> Genentech A Member of the Roche Group</p> <p>A spin off of the spouses and partners of those with SMA. This session is intended for the adult with SMA and their spouses, partners, and significant others to join and share their experiences and engage in discussion. Time will be allotted for all attendees to ask questions and contribute to the group discussion.</p>	North Ballroom A
	<p>An Approach to Exercise in Individuals with SMA Leslie Nelson, PT, PhD, OCS Anne Stratton, MD Tina Duong, PT, PhD Tanja Taivassalo, PhD</p> <p>The goal of this session is to provide a broad overview of exercise guidelines and options to support an active lifestyle in participants of all ages and types of SMA. Information will be based on current exercise literature in SMA and expert clinical opinion and experiences. This session will help you better understand the possibility of different forms of exercise and ways to partner with your healthcare team when formal therapy sessions may not be the best option. To ensure the session encompasses a wide range of physical abilities, we will also provide alternatives and modifications for all levels of fitness as well as discuss relevant medical considerations and precautions prior to initiating an exercise program. We will help provide options and resources for various forms of group and individual exercise. The focus of this session will center around personalized exercise to meet your personal activity goals. This session is ideal for families and participants interested in learning more about initiating and progressing exercise activity throughout the lifespan.</p>	Magic Kingdom Ballroom 2
	<p>Storytellers with SMA Kevin Schaefer, moderator James Ian Brianna Albers Jenni Gold Candis Welsch</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&A will follow the main conversation.</p>	South Ballroom
	<p>Traveling with SMA Kevan Chandler, travel blogger, adult with SMA Christine Getman, travel blogger, adult with SMA Christa Saul, travel blogger, adult with SMA</p> <p> Biogen</p> <p>Do you have dreams of seeing the world, and you're trying to figure out how to make traveling with SMA more of a reality? Christine, Christa, and Kevan will share with you their experiences, their challenges and joys of travel. Navigating airplanes, transit, and hotels with a wheelchair; traveling with medicine; and working with travel companions to make the trip a success for all involved. Join the discussion and explore with us ways to explore the world!</p>	Center Ballroom
	<p>Your Voice in the Workplace: Job Hunting, Interviewing, and Advocating for Accommodations Brian Ronningen Doug McCollough Julia Feinberg Sarah Boggess</p> <p>Join us for an open and engaging session focused on the job search journey—covering the highs, the challenges, and everything in between. We'll explore real experiences with job hunting and interviewing, and offer guidance on how to confidently advocate for accommodations in the workplace. This interactive discussion is a chance to share, listen, and learn together.</p>	North Ballroom B

SATURDAY, JUNE 28 | AGENDA

	Mindfulness for Stress & Resilience: Practical Tools for Everyday Life Tara Davenport, Parent of a child with SMA <p>Join us for a relaxed, hands-on session where we'll break down mindfulness in a simple, approachable, accessible way and explore how it can bring more calm, focus, and resilience into your daily life. Through simple guided exercises and practical strategies, you'll discover easy ways to manage stress and navigate challenges with a greater sense of ease. Whether you're new to mindfulness or looking to deepen your practice, you'll leave with helpful tools to support your well-being—no pressure, just an open space for all to learn and explore.</p>	Magic Kingdom Ballroom 1
	Staying Prepared: Daily Care Strategies and Emergency Response in the Community Rob Graham, MD Michael Manchester, Emergency Manager <p>Targeting all types of SMA, this workshop means to prepare families, young adults, and other providers for emergency situations encountered by those with SMA. Through shared experiences from parents and hospital providers, we hope to anticipate challenges, establish contingency plans, and identify resources to optimize community and hospital-based emergency care. Open discussions about system barriers, professional perceptions and biases, misunderstandings of SMA, and practical issues are important to avert problems and advocate effectively when emergencies occur.</p>	Adventure Lawn
4:00PM	Cure SMA's Evening at the Park	Disneyland Theme Park

AGENDA | SUNDAY, JUNE 29

7:00AM	Breakfast Opens	South Exhibit Hall
7:45AM – 8:45AM	Muscles, Myostatin, and More Symposium 	South Exhibit Hall
9:00AM – 11:15AM (Drop off opens at 8:30am)	Children's Program Sponsored by The Jacob Isaac Rappoport Foundation 	North Exhibit Hall
9:00AM – 11:15AM	It's a Wonderful Life/Closing General Session	Center Ballroom

Thank you to our 2025 Annual SMA Conference Speakers and Panelists

We extend a heartfelt thank you to the speakers and panelists of the 2025 Annual SMA Conference!

We are deeply grateful to each of you for your invaluable contributions in bringing our community together in person this year. Your dedication to sharing your time, knowledge, and expertise to educate on the latest advancements in SMA is truly commendable. The impact of your work resonates throughout our community, offering fresh perspectives and fostering a stronger sense of unity.

The success of this year's conference would not have been possible without your selfless commitment. By sharing your insights and experiences, you've not only enriched the event but also played a key role in supporting individuals and families affected by SMA.

Your passion for advancing education and awareness has undoubtedly left a lasting mark and has helped to further strengthen our community. Thank you once again for being such a crucial part of the 2025 Annual SMA Conference!

CURE SMA'S SATURDAY EVENING AT THE DISNEYLAND THEME PARK



You are invited to join us on Saturday for
an evening of fun at the Disneyland Park.
Evening at the park bags sponsored by:

PRESENTING SPONSORS



DIAMOND SPONSOR





Fill out the conference survey

FILL OUT THE CONFERENCE SURVEY FOR YOUR CHANCE TO WIN AN APPLE WATCH OR 2026 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.



All participants who complete the surveys by 10:30am on Sunday, June 29, will have their name entered into a raffle.

The winners of the raffle will receive a brand new Apple Watch!

All completed surveys will also be entered into a drawing for a chance to win a trip, including airfare to the 2026 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 29, at the Closing General Session/It's a Wonderful Life. All participants who complete the surveys by 10:30am on Sunday, June 29, will have their name entered into a raffle.

You can also fill out the survey online at

<https://survey.alchemer.com/s3/8193570/2025-Annual-SMA-Conference-Disneyland>

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 27, 2025

CHILDREN'S PROGRAM MORNING SESSION 9:00AM – 12:20PM

11:15AM – 12:15PM

Fire and Ice Show

Children will be dazzled and entertained as they interact with our Mad Scientists! Foggy dry ice storms, Eggbert the Egg, and even a special Mad Science "burp" potion will amaze children as they learn about chemical reactions, air pressure and the 3 states of matter.

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

2:30PM – 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!

3:00PM – 4:00PM

Sounds Like Science Show

Make waves and make some noise in this fun and funky science show! The Mad Scientist will create crazy cacophony with a garbage can, a swinging sound tube and a metal pipe! Children will cheer as potatoes pop! What are all the kids talking about? Sounds Like Science!

SATURDAY, JUNE 28, 2025

CHILDREN'S PROGRAM MORNING SESSION 9:00AM – 11:40AM

10:30AM – 11:30AM

Up, Up and Away!

This exciting show deals with the incredible pressure we all live under – Air Pressure! Selected participants will try their best to pull apart a Magdeburg sphere, try to tame flying toilet paper and blow out a Birthday candle that has a surprise of its own. They'll discover that sometimes the air around us is more than meets the eye and why you should be careful where you strike a match. Volunteers will launch indoor hot air balloons and be amazed as a giant vortex generator blows puffs of fog rings over them.

CHILDREN'S PROGRAM AFTERNOON SESSION 1:00PM – 3:40PM

1:15PM – 2:00PM

Tea Party

Any children interested in joining the Tea Party are also welcomed to bring their dolls.

2:00PM – 3:00PM

Energize it!

This show dives into science to create a high-energy hour of engaging and interactive experiments. Students will participate in energetic activities including lightning-fast siphon chains, crackling static relay races, a hot hands dance and popping hot chemical reactions.

Sponsored by



CHILDREN'S PROGRAM FAQ



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!



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.



THANK YOU TO OUR VOLUNTEERS



Thank You to The Conference Children's Program Volunteers

Without this incredible group of individuals, our conference would not be possible. Every volunteer has a major impact on the success and atmosphere of our conference and each year their impact radiates throughout the weekend! Their long days of hard work provide families with the reassurance that their children are well cared for and are having fun, all while they attend important workshops to learn about the latest information on SMA. The level of enthusiasm each volunteer provides throughout the day in the children's program and during the evening events is endless! Our volunteers take great pride in helping to ensure families leave with the feeling that this was the best conference yet. Thank you to every single volunteer who helps make this conference possible and for everything you do!

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 35 YEARS

George Ghorbanian
Chicago Police Officer



VOLUNTEER FOR 25 YEARS

Lance Northcutt
Lawyer



VOLUNTEER FOR 33 YEARS

Patti Slojkowski
Dental Hygienist



VOLUNTEER FOR 25 YEARS

Kelly Basso
Electrologist



VOLUNTEER FOR 30 YEARS

Steve Smith
Physical Therapist



VOLUNTEER FOR 24 YEARS

Katlyn O'Brien
Teacher



VOLUNTEER FOR 26 YEARS

Kelly Milito
Hair Stylist



VOLUNTEER FOR 23 YEARS

Noreen Reilly
IT Project Manager

THANK YOU TO OUR VOLUNTEERS



VOLUNTEER FOR 23 YEARS

Traci O'Brien
Organic Skincare Entrepreneur
+ Creative Marketer



VOLUNTEER FOR 13 YEARS

Jennifer Walsh
Business Systems Analyst



VOLUNTEER FOR 13 YEARS

Hayley Miller
Software Product Manager



VOLUNTEER FOR 13 YEARS

Kelly Gibbons
Client Success Manager



VOLUNTEER FOR 13 YEARS

Lexi Basso
Registered Nurse



VOLUNTEER FOR 12 YEARS

Georgia Slojkowski
Elementary Orchestra Teacher



VOLUNTEER FOR 11 YEARS

Patrick Slojkowski
Associate Scientist at PepsiCo



VOLUNTEER FOR 11 YEARS

Megan Besler
Senior Financial Analyst



VOLUNTEER FOR 10 YEARS

Bridget Yagihashi
Teacher, Writer & Artist



VOLUNTEER FOR 16 YEARS

Jackie Bohl
Event Planner



VOLUNTEER FOR 15 YEARS

Patrick Hogan
High School Social Studies Teacher and Coach



VOLUNTEER FOR 14 YEARS

Patti Northcutt



VOLUNTEER FOR 14 YEARS

Megan Milito
Dance Instructor



VOLUNTEER FOR 14 YEARS

Joy Martin
Physical Therapist



VOLUNTEER FOR 14 YEARS

Donna Budil
Preschool Director



VOLUNTEER FOR 13 YEARS

Emily Yagihashi
Anesthesiologist

THANK YOU TO OUR VOLUNTEERS



VOLUNTEER FOR 10 YEARS

Raphi Milito
Sales Specialist



VOLUNTEER FOR 10 YEARS

Ralph Milito
Real Estate Agent



VOLUNTEER FOR 10 YEARS

Daniela Milito
Banquet Chef



VOLUNTEER FOR 10 YEARS

Michael Milito
Project Manager



VOLUNTEER FOR 10 YEARS

Kamryn McKenzie
Navy Medical Corps Ensign



VOLUNTEER FOR 10 YEARS

Sally McCarthy
Retired Nurse



VOLUNTEER FOR 9 YEARS

Alanna Woods
Financial Banking Representative



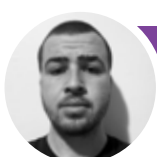
VOLUNTEER FOR 9 YEARS

Emma Rubenstein
College Graduate



VOLUNTEER FOR 9 YEARS

Rebeka Nekolova
Videographer/Video Editor



VOLUNTEER FOR 9 YEARS

Jack Jomarron
Policy Analyst



VOLUNTEER FOR 8 YEARS

Cara Freedman
Sr. Research Assistant



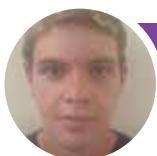
VOLUNTEER FOR 8 YEARS

Katie Dieckhoff
Behavioral Treatment Therapist



VOLUNTEER FOR 7 YEARS

Anne Wallo
DVC Sales Counselor



VOLUNTEER FOR 7 YEARS

Will Reilly
Automation Programmer



VOLUNTEER FOR 7 YEARS

Morgan Ramirez
Student



VOLUNTEER FOR 7 YEARS

Clara Dylewsk
Graduate Student; Nurse Practitioner



VOLUNTEER FOR 6 YEARS

Sarah Grimson
Retail Manager



VOLUNTEER FOR 4 YEARS

Alison Williams
Finance Analyst

THANK YOU TO OUR VOLUNTEERS



VOLUNTEER FOR 4 YEARS

Hannah Smith
Student



VOLUNTEER FOR 4 YEARS

Kamil Jerominski
Architect



VOLUNTEER FOR 4 YEARS

Dave Richmond
Property Manager



VOLUNTEER FOR 4 YEARS

Lola Hernandez
Student



VOLUNTEER FOR 4 YEARS

Molly Ramirez
Student at Nebraska Wesleyan University



VOLUNTEER FOR 4 YEARS

Stacy Hernandez



VOLUNTEER FOR 4 YEARS

Sally O'Toole
Student



VOLUNTEER FOR 4 YEARS

Paul Enwia
Retired Teacher



VOLUNTEER FOR 4 YEARS

Jack Olech
Student



VOLUNTEER FOR 4 YEARS

Logan Dimitriou
College Student



VOLUNTEER FOR 4 YEARS

Terry McGovern
Vice President of Sales, Atlas Forms and Graphics



VOLUNTEER FOR 4 YEARS

Dolores Courtney O'Toole
Social Worker



VOLUNTEER FOR 4 YEARS

Kay McGovern
Private Investigator



VOLUNTEER FOR 4 YEARS

Lily Carlson
Student



VOLUNTEER FOR 4 YEARS

Stacey McDonogh
Social Worker



VOLUNTEER FOR 4 YEARS

Eric Berghoff
Sports Medicine



VOLUNTEER FOR 4 YEARS

Kristi Lazic
Registered Nurse



VOLUNTEER FOR 4 YEARS

Lena Ahrens
Student at University of Iowa

THANK YOU TO OUR VOLUNTEERS



VOLUNTEER FOR 3 YEARS

Sam Rossi
Software Engineer



VOLUNTEER FOR 3 YEARS

Emily Pehoski
Board Certified Behavior Analyst



VOLUNTEER FOR 3 YEARS

Sam Olech
Student



VOLUNTEER FOR 3 YEARS

Kathleen O'Hare
Associate Director DePaul University



VOLUNTEER FOR 3 YEARS

Jayne O'Brien
Retired RN



VOLUNTEER FOR 3 YEARS

Liz Molbeck
Food Service Director



VOLUNTEER FOR 3 YEARS

Caitlin McGrath
Paramedic



VOLUNTEER FOR 3 YEARS

Mark McDonogh
Paramedic



VOLUNTEER FOR 3 YEARS

Dawn McCarthy
Retired Chicago Public School Teacher



VOLUNTEER FOR 3 YEARS

Frank Magnelli
Durable Medical Equipment Sales



VOLUNTEER FOR 3 YEARS

Jack Koteles
Student



VOLUNTEER FOR 3 YEARS

Teresa Hayes
Communications Professor at DeVry University



VOLUNTEER FOR 3 YEARS

Ben Goldberg
Chef



VOLUNTEER FOR 3 YEARS

Braden Gebavi
Chief Product Officer at Bet Caddy



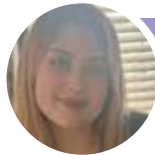
VOLUNTEER FOR 3 YEARS

Rick Fernandez
Chicago Police Officer



VOLUNTEER FOR 3 YEARS

Ronna Fernandez
Business Manager



VOLUNTEER FOR 3 YEARS

Sophia Fager
Student



VOLUNTEER FOR 3 YEARS

Eric Fager
Chicago Police Officer

THANK YOU TO OUR VOLUNTEERS



VOLUNTEER FOR 3 YEARS

Amy Fager
Insurance Broker



VOLUNTEER FOR 3 YEARS

Vince Coughlin
Teacher



VOLUNTEER FOR 3 YEARS

Neena Campos
Student



VOLUNTEER FOR 3 YEARS

Matt Breslin
Student



VOLUNTEER FOR 3 YEARS

Regina Ballesteros
Student



VOLUNTEER FOR 2 YEARS

Roland Rencz
Investigator



VOLUNTEER FOR 2 YEARS

Aubree Munno
Cosmetology Student & Waitress



VOLUNTEER FOR 2 YEARS

Emma Francis
Student



VOLUNTEER FOR 2 YEARS

Alyssa Francis
Caregiver + Patient Care



VOLUNTEER FOR 2 YEARS

Svetlana Fager
Student



VOLUNTEER FOR 2 YEARS

Tyler Ellixson
Senior Associate

THANK YOU TO OUR VOLUNTEERS



GEORGE GHORBANIAN VOLUNTEER FOR 35 YEARS

The 2025 Annual SMA Conference marks a huge milestone for our longest returning volunteer George Ghorbanian! George has volunteered at every single conference since the Children's Program started back in 1988 making this his 35th consecutive year attending a conference! Every year he takes time away from his job as a Chicago Police Officer, as well as his family and busy life, to travel and support the Children's Program. He also has enhanced the security in the children's program by recruiting some of his police officer friends the past few years to help ensure the kids are safe! George is the definition of a truly dedicated volunteer; never missing a year even when he was injured with a broken leg many years ago. Everyone at Cure SMA would like to thank George for all of his hard work and dedication over the last 35 years! George is not only one of Chicago's finest but clearly one of SMA's finest!



STEVE SMITH VOLUNTEER FOR 30 YEARS

The 2025 Annual SMA Conference also marks a big milestone for another one of our long-standing volunteers Steve Smith! Steve got involved many years ago and this year marks his 30th year as a conference volunteer! Each year Steve takes time away from his family and off of work as a physical therapist to come out and volunteer in the Children's Program. Throughout the years he has also recruited some of his wonderful family as volunteers including his wife and his now adult children! Although he is a big kid at heart, he blends right in with the other kids and is a great representation of a dedicated volunteer we are lucky to have! Everyone at Cure SMA would like to thank Steve for his dedication and service over the last 30 years!





LANCE NORTHCUTT VOLUNTEER FOR 25 YEARS

The 2025 Annual SMA Conference also marks a big milestone for another one of our long-standing volunteers Lance Northcutt! Lance got involved many years ago and this year marks his 25th year since making his debut as a conference volunteer! Lance takes time away from his family and off of work as a busy lawyer to come out and volunteer in the Children's Program. Throughout the years he has recruited his wife to become a volunteer as well and as soon as his kids are old enough they are planning to volunteer as well! Everyone at Cure SMA would like to thank Lance for his hard work and dedication over the last 25 years!



KELLY BASSO VOLUNTEER FOR 25 YEARS

The 2025 Annual SMA Conference marks a big milestone for one of our longest returning volunteers, Kelly Basso! Kelly volunteered at her first conference 25 years ago and has been involved ever since! Every year she takes time away from her own family and grandkids to travel and support the Children's Program. You may even recognize her as a familiar face at the check-in desk as she has become a regular there ensuring everyone gets checked in and checked out! Kelly is the true definition of a dedicated volunteer. Everyone at Cure SMA would like to thank Kelly for all her hard work and dedication over the last 25 years!



CURE SMA FIND A TREATMENT CENTER TOOL

Our online location tool is designed to help you find centers that provide SMA treatment and care.



www.curesma.org/find-a-treatment-center



For questions, contact Cure SMA at info@curesma.org or (800) 886-1762.



BOARDING PASS to see the potential future of travel with SMA



SMA → ANA

You're invited to see how Biogen is facilitating discussions to make the travel experience more accessible for people with SMA.

Passenger: You

Date: June 26-29, 2025

Destination:
2025 Annual Cure SMA
Conference
Anaheim, CA



We heard the SMA community loud and clear. That's why we're raising awareness about the importance of improving air travel for people with SMA. **Come see us at Cure SMA and hear more about our vision for a better travel experience.**

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225 Binney Street, Cambridge, MA 02142



Disclaimer: The acceptance of Exhibitors and Sponsors does not constitute or imply endorsement by Cure SMA of any company, product or service. Cure SMA accepts no responsibility for any claims made by any outside party.

PUT YOUR OWN SPIN *on* SMA



COME SAY HELLO
at our booth!

WHAT IS SPINRAZA?

SPINRAZA® (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 include lower respiratory infection, fever, constipation, headache, vomiting, back pain, and post-lumbar puncture syndrome.

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 on SPINRAZA.com.

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



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225 Binney Street, Cambridge, MA 02142



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Learn how others have put their **SPIN** on **SMA**. See inspiring **personal stories** from patients and caregivers across various stages of the SMA journey.



Watch
SPINRAZA Stories

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).

Patients and caregivers are paid spokespersons for Biogen

IMPORTANT FACTS ABOUT SPINRAZA® (NUSINERSEN)

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 include** lower respiratory infection, fever, constipation, headache, vomiting, back pain, and post-lumbar puncture syndrome (headache related to the intrathecal procedure).
- 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 or 1-844-4SPINRAZA (1-844-477-4672).

MANUFACTURED FOR

Biogen, Cambridge, MA 02142

Some things get everywhere

In spinal muscular atrophy (SMA) treatment, that's what you want

Janelle,
living with Type 2 SMA

Evrysdi is an oral, non-invasive treatment designed to produce SMN protein throughout the body.*

*This was observed when Evrysdi was studied in animals.

SMN=survival motor neuron.

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.evrysdi-pregnancyregistry.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

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For illustrative purposes only.

**Now available in
liquid and tablet forms***
providing more choices and flexibility

*Evrysdi 5-mg tablets are approved for people aged 2 years and older who weigh at least 44 lb (20 kg). The tablets cannot be taken with feeding tubes.

Meet us for a community symposium

Here, There, Everywhere: Discover What's New With Evrysdi

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

When: Friday, June 27 at 7:45 AM

Stop by our booth:

Friday, June 27 from 8:45 AM - 5:00 PM & Saturday, June 28 from 8:45 AM - 4:00 PM

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. You may also report side effects to Genentech at 1-888-835-2555.

Please see accompanying brief summary for additional Important Safety Information.



EVERYWHERE

Patient Information	
EVRYSDI® [ev-RIZ-dee] (risdiplam) for oral solution	EVRYSDI® [ev-RIZ-dee] (risdiplam) tablets
<p>What is EVRYSDI?</p> <ul style="list-style-type: none"> EVRYSDI is a prescription medicine used to treat spinal muscular atrophy (SMA) in children and adults. <p>Before taking EVRYSDI, tell your healthcare provider about all of your medical conditions, including if you:</p> <ul style="list-style-type: none"> 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. are a woman who can become pregnant: <ul style="list-style-type: none"> 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. 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.evrysidipregnancyregistry.com. 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. 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. <p>Tell your healthcare provider about all the medicines you take, 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>How should I take EVRYSDI?</p> <ul style="list-style-type: none"> 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. Your healthcare provider will either prescribe: EVRYSDI for oral solution Or EVRYSDI tablet 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"> Take EVRYSDI exactly as your healthcare provider tells you to take it. Do not change the dose without talking to your healthcare provider. 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. <p>If you are taking EVRYSDI for oral solution:</p> <ul style="list-style-type: none"> see the detailed Instructions for Use that comes with it for information on how to take or give EVRYSDI for oral solution 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, do not use it. Contact your pharmacist for a replacement. 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. In infants who are breastfed, EVRYSDI can be given before or after breastfeeding. Do not mix EVRYSDI with formula or milk. 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. <p>Reusable Oral Syringes for EVRYSDI for Oral Solution</p> <ul style="list-style-type: none"> 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. From the bottle, draw up (measure) the dose of EVRYSDI with these syringes, as they are made to protect the medicine from light. Take EVRYSDI right away after it has been drawn into the syringe. Do not 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. Do not throw the syringes away because they are reusable. Wash the syringes per instructions after use. Contact your healthcare provider or pharmacist if your oral syringes are lost or damaged. <p>If you are taking EVRYSDI Tablets:</p> <ul style="list-style-type: none"> Take EVRYSDI one time daily with or without a meal at about the same time each day. Do not chew, cut, or crush the tablet. Swallow the EVRYSDI tablet whole with some water. <p>Or</p> <ul style="list-style-type: none"> You can take an EVRYSDI tablet by mouth after it is mixed with a teaspoon (5 mL) of room temperature non-chlorinated drinking water (e.g., filtered water). See the instructions below for taking EVRYSDI this way. <p>EVRYSDI Tablets Mixed with Non-chlorinated Drinking Water (e.g., Filtered Water)</p> <ul style="list-style-type: none"> Wash your hands before and after preparing or taking EVRYSDI tablets. Put EVRYSDI tablets in a small cup with a teaspoon (5 mL) of room temperature non-chlorinated drinking water (e.g., filtered water). Do not mix EVRYSDI tablets with any liquids other than non-chlorinated drinking water. 	<ul style="list-style-type: none"> Do not expose the EVRYSDI tablet mixture to sunlight. Swirl the cup gently until the tablet and non-chlorinated drinking water are fully mixed (though some particles may remain). This may take up to 3 minutes. Take EVRYSDI tablet mixture right away after mixing with non-chlorinated drinking water. If you do not take it within 10 minutes of adding non-chlorinated drinking water, throw the mixture away and make a new dose. After taking EVRYSDI tablet mixture, to make sure there is no medicine left, refill the small cup with at least a tablespoon (15 mL) of non-chlorinated drinking water, swirl, and take right away. If the EVRYSDI tablet mixture is spilled, use a dry paper towel to dry the area and then clean with soap and water. Throw the paper towel away in the trash and wash your hands with soap and water. Do not give the EVRYSDI tablet mixture via a nasogastric (NG-tube) or gastrostomy tube (G-tube). <p>If you miss a dose of EVRYSDI:</p> <ul style="list-style-type: none"> 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. 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. If you do not fully swallow the dose, or you vomit after taking a dose, do not take another dose of EVRYSDI to make up for that dose. Wait until the next day to take the next dose at your usual time. <p>What are the possible side effects of EVRYSDI? The most common side effects of EVRYSDI include:</p> <ul style="list-style-type: none"> For later-onset SMA: <ul style="list-style-type: none"> fever diarrhea rash For infantile-onset SMA: <ul style="list-style-type: none"> fever runny nose, sneezing, and sore throat constipation (upper respiratory infection) diarrhea lung infection (lower respiratory infection) vomiting rash cough <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>How should I store EVRYSDI? EVRYSDI for Oral Solution:</p> <ul style="list-style-type: none"> 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"> 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. Keep EVRYSDI in an upright position in the original amber bottle to protect from light. 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 Instructions for Use that comes with EVRYSDI for oral solution). <p>EVRYSDI Tablets:</p> <ul style="list-style-type: none"> Store at room temperature between 68°F to 77°F (20°C to 25°C). Keep the bottle tightly closed in order to protect from moisture. <p>Keep EVRYSDI, all medicines and syringes out of the reach of children.</p> <p>General information about the safe and effective use of EVRYSDI. 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>What are the ingredients in EVRYSDI? Active ingredient: risdiplam Inactive ingredients: EVRYSDI for Oral Solution: ascorbic acid, disodium edetate dihydrate, isomalt, mannitol, polyethylene glycol 6000, sodium benzoate, strawberry flavor, sucralose, and tartaric acid. EVRYSDI Tablets: 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>Genentech <i>A Member of the Roche Group</i> EVRYSDI® (risdiplam) Distributed by: Genentech, Inc. 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(v7.0) ©2025 Genentech, Inc. All rights reserved.</p> <p>For more information, go to www.EVRYSDI.com or call 1-833-387-9734.</p>

This Patient Information has been approved by the U.S. Food and Drug Administration.

Issued: 2/2025

GET STARTED ON YOUR CLINICAL TRIAL



JOURNEY WITH CURE SMA

Cure SMA has developed resources for navigating the exciting world of clinical trials. These tools are designed to empower you at every step of your decision-making process.

WHAT'S NEW?

- **SMA Registry and Clinical Trial Finder:** Explore SMA clinical trials with our easy-to-use search widget. Filter by SMA type, location, trial phase, treatment status, and more to find trials that fit your needs and preferences.
- **Screening Visit Checklist:** Prepare for your screening visit with a thorough checklist that organizes your medical history and suggests questions to ask the research team.
- **Decoding Informed Consent:** Understanding informed consent is crucial! Our handout will guide you through the key sections of the informed consent form, ensuring you're confident in your decision to participate in a clinical trial.
- **Travel Planners (Air and Ground):** Manage your travel details with ease! Our itineraries will help you plan your trip, and are tailored to the unique needs of our community.



Dedicated to new possibilities. Dedicated to the SMA community.

Since Scholar Rock's founding over a decade ago, we've been committed to making a difference for those living with SMA. We've listened to and learned from you, and as our journey together continues, we'll keep striving to create new possibilities for the SMA community.

scholarrock.com



US-SMA-0035 02/25

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LIFE TAKES MUSCLE

STOP **SMA** FROM DOING THE SAME

Muscles work together to power almost everything we do, from breathing, to sitting upright, and even blowing bubbles. By definition, spinal muscular atrophy (SMA) is a neuromuscular disease that results in the loss of both nerve cells and muscle. Survival motor neuron (SMN)-targeted treatments have made great strides in treating people living with SMA; however, progressive muscle weakness persists. The community is looking for more, starting with a focus on preserving motor function and improving muscle strength.

Visit us at the Life Takes Muscle booth and our symposium to learn how muscle matters to people living with SMA.

Explore the latest in SMA at
LifeTakesMuscle.com



Bear, 10

Living with SMA

On an approved SMN-targeted treatment for 9 years



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US-SMA-0032 06/2025

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Committed to **reimagining** medicine in SMA

Stop by and say hello at the Novartis booths
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Novartis is supporting the
SMA community at the
Novartis Community booth.



Visit the Novartis team
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and participate in an
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on another
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We are a proud sponsor of the 2025 Cure SMA Annual Meeting

**NMD Pharma is currently enrolling
adults with SMA Type 3 into an
investigational clinical trial aiming to
improve muscle strength and endurance.**

For more information on this study,
visit us at the Family Friendly
Researcher Poster Session and here:



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Check Out Cure SMA's YouTube Channel!

Our channel shares over 100 educational webinars that are presented by experts in the SMA community, along with insightful career and college panels led by adults with SMA, and much more!



These educational webinars cover topics such as:

- Physical therapy
- Sleep
- Mindfulness
- Nutrition
- Driving
- Pain management
- Laughter yoga
- Mental health
- Pulmonary care
- Creating a life care plan
- Role of social workers
- Yoga therapy
- Women's health
- Assistive technology
- Scoliosis management

In every playlist you will find a robust lineup of knowledgeable speakers who share valuable information and advice for people of all ages and types of SMA, as well as their caregivers. This channel is where you will find Cure SMA's most up-to-date webinars, packed with incredible information.

Take advantage of these fantastic webinars today!
www.youtube.com/c/CureSMA/playlists

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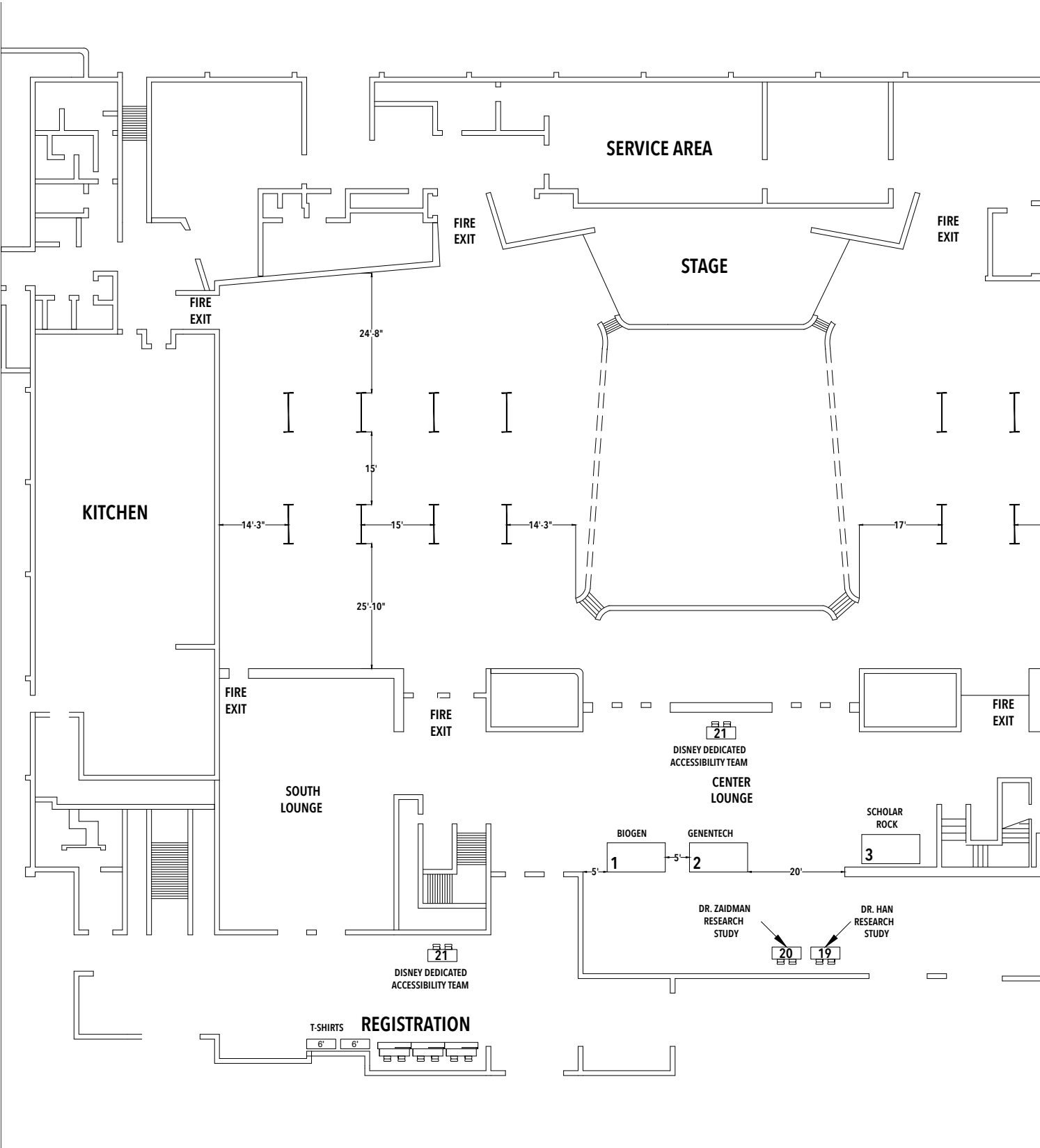
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ORANGE EXHIBITORS



EXHIBITOR BOOTHS





National Paralysis Resource Center

We provide free information, programs, and support for individuals living with paralysis, their caregivers and their families.

SMA Fact
Sheet



Free
Resources



Children's
Books



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The Permobil Foundation is proud to support SMA families around the world by enhancing the quality of life through the gift of mobility.

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Learn more about programs we offer at
www.PermobilFoundation.org





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What Matters to You...

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

To learn more about the exciting new products that support those living with spinal muscular atrophy (SMA), please visit our website or contact us for more information.

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ASL 102 UNO Single Switch Scanner



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and more!



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

The Cure SMA Board and Committee Members

These individuals demonstrate exceptional dedication, advocating for every family affected by SMA. They play a pivotal role in guiding the organization's direction, continuously seeking innovative solutions to support individuals with SMA, assist families, and fund research initiatives. We are deeply grateful to these devoted volunteers for their outstanding contributions and relentless efforts, which go above and beyond to benefit the entire community.

Nick Farrell

As Chair of the Board for Cure SMA, Nick exemplifies outstanding dedication and passion, putting his full effort into every endeavor. He is constantly working to improve, advocate for, and support the SMA community, always seeking new ways to enhance its well-being. We are grateful to have such a remarkable leader on our team and sincerely appreciate his ongoing commitment and support.

Cure SMA Chapter Leaders

We are deeply grateful for the commitment and support these individuals provide in representing our organization across the U.S. Their dedication to community spirit shines through as they generously give their time, listen attentively, and wholeheartedly contribute to the pursuit of an SMA cure. The success of our organization would not be possible without each of them. Thank you for all that you do!

The Cure SMA Medical Advisory Council Members

We are incredibly fortunate to have a distinguished group of SMA medical and clinical experts in the U.S. as vital members of our community. The Medical Advisory Council plays a key role in driving initiatives to raise awareness of SMA within the medical field, improve care for SMA patients and their families, and support various other efforts. These dedicated professionals generously volunteer their time outside of their clinical practices and family responsibilities to organize conference workshops and educate families on the medical aspects of SMA. We are deeply grateful for the invaluable expertise and support each of you provides to Cure SMA.

The Cure SMA Scientific Advisory Board Members

Every year, the Scientific Advisory Board carefully reviews all research grant applications and plays a vital role in shaping the agenda for the Annual Researcher Meeting. We are grateful for the expertise of the SAB members. Their unwavering commitment and diligent efforts are deeply appreciated, ensuring that Cure SMA supports the most impactful and promising SMA research.

The Cure SMA Adults with SMA Advisory Council

Made up entirely of adults with SMA, the Adults with SMA Advisory Council provides high level guidance, advice, and feedback to Cure SMA regarding many topics such as support programs, patient care, engagement, independence, advocacy, accessibility, education, and transitioning into adulthood. In addition, council members actively participate in and promote Cure SMA activities, such as events, programs, surveys, and advocacy actions. Thank you for your leadership, collaboration, and participation!

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

We are honored to offer sponsorship to any adult with SMA, allowing them and an aide to attend this year's conference, thanks to the generous support and funding from the Dhont Foundation. We deeply appreciate your dedication to providing this opportunity to many in the community, as well as sponsoring the highly anticipated Adults with SMA Social throughout the conference. Your support is invaluable in ensuring the Annual SMA Conference remains an inclusive space for everyone in the community.

Jacob Isaac Rappoport Foundation

We extend our heartfelt gratitude to this incredible foundation for its steadfast support over the years, especially for newly diagnosed families, the conference, and beyond. Your generous contribution is what makes the Children's Program at the conference possible. We truly appreciate your kindness and generosity.

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

We are deeply grateful to this family for their continued contributions to the conference, year after year. Cure SMA truly values and appreciates their unwavering support and willingness to assist in any capacity. Your exceptional signage, generous support, and thoughtful kindness have helped transform this conference into a truly special and memorable event. Thank you for consistently going above and beyond to make a lasting impact on our community.

Luke 18:1 Foundation

We are deeply grateful to the Luke 18:1 Foundation for sponsoring the First Time Attendee Scholarship at this year's Annual SMA Conference. Your generous support has provided an incredible opportunity for new attendees to join our community, connect with others, and experience the conference for the first time. Thank you for helping make this meaningful experience possible and for your continued commitment to supporting those impacted by SMA.

OFFICIAL CURE SMA MERCHANDISE

Black Quarter Zip
Pullover



Purple Drawstring
Sportpack

Purple Stemless
Wine Glass



cure
SMA



Heathered Purple
Unisex V-Neck Tee

Brand New Items

Debuting at Conference!

Items will be on sale at the merchandise table next to registration on the Lobby Level of the Disneyland hotel Convention Center. Make sure to stop by and check it out while supplies last!

Share a photo on your social media of you sporting your Cure SMA gear during this week's Conference using hashtag #2025SMACONFERENCE

Additional Merch Items will be available and on sale such as:

- Men, Women and Youth Apparel
- Blankets
- Stickers
- Promo items
- Bags
- Hats
- Drinkware
- Accessories

WALK-N-ROLL

JOIN THE MOVEMENT: WALK-N-ROLL WITH US!

The 2025 Walk-n-Roll season is **OPEN NOW**
— and we want **YOU** to be part of it!

Step Up. Roll Forward. Make Your Mark.

Cure SMA's Walk-n-Roll events unite communities together to fund groundbreaking research and provide vital support for those living with spinal muscular atrophy (SMA). Walk-n-Roll is like a Cure SMA block party where the SMA community's collective fundraising impact is celebrated and highlighted for those living with SMA!

It's as easy as 1, 2, 3:

1. Find your local Walk-n-Roll or participate with Cure SMA virtually and register!
2. Start your fundraising to earn your commemorative t-shirt!
3. Celebrate at Walk-n-Roll and make an impact!

Whether you walk, roll, or cheer from the sidelines, every action brings us closer to a cure. Gather your friends, family, and co-workers to join us at one of our events nationwide.

Find an event near you and register today!



A BRIGHTER FUTURE IS
ON THE HORIZON FOR SMA



2025 EVENT MILESTONES

25 YEARS - NEW ENGLAND WALK-N-ROLL



The New England Walk-n-Roll marks its 25th anniversary, a powerful legacy born from the determination of Silvia and Brian Murphy. Following the loss of their children, Cianan and Cecilia, to SMA, Silvia sought a way to make a difference. What began in 2001 as a simple walk – a path, t-shirts, and water – under the umbrella of Families of SMA, has grown into a cornerstone of the SMA community.

Through 25 years of unwavering commitment, the New England Walk-n-Roll has become more than just a fundraiser; it's a vibrant gathering, an annual SMA family reunion that has collectively raised over \$2 million. Silvia remembers a time when the diagnosis of SMA offered no hope, no treatments, not even a research model. The advancements witnessed since then – from walking pre-symptomatically treated children to newborn screening in every state – are a testament to the collective impact of this community. Today, as we celebrate this milestone, we honor Silvia Murphy's spirit and the incredible New England community.

20 YEARS - PHILADELPHIA WALK-N-ROLL



For two decades, the Philadelphia Walk-n-Roll has stood as a champion of Cure SMA, all thanks to the vision of Karen McRory-Negrin, who started this vital event 20 years ago. The event quickly became championed in partnership with the Henkel Family and has blossomed from a small community affair into one of the organization's largest and most welcoming events.

Today, the legacy continues, in large part by Allyson Henkel and her family in tribute to her son Peter. Held on the campus of Villanova University, the event offers a wide array of engaging community activities, led through a strong partnership between Allyson and dedicated members of the local community – individuals deeply connected to SMA through personal loss or as parents. The Philadelphia Walk-n-Roll has also fostered tremendous corporate engagement from within the community, further amplifying its impact and the message of Cure SMA. Here's to 20 years of unity, progress, and the unwavering commitment of the Philadelphia Walk-n-Roll!

10 YEARS - VIRGINIA WALK-N-ROLL



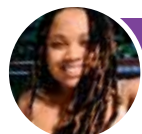
For the past ten years, the Virginia Walk-n-Roll has stood as a testament to the unwavering commitment of this community to Cure SMA. As the event enters its tenth year, it does so with significant momentum, fueled by record-breaking attendance and fundraising at last year's event. This milestone is not just a celebration of the past, but an opportunity to continue driving meaningful impact and strengthening the vital connections within our Virginia chapter. Thank you, Virginia, for a decade of heartfelt commitment and for the exciting future ahead!

CHAPTER LEADERS

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

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

Shaakira Thomas



FL- SOUTH FLORIDA CHAPTER

Jennifer Miller Smith



AZ- ARIZONA CHAPTER

Angel Wolff



GA- GEORGIA CHAPTER

Valerie White



AZ- ARIZONA CHAPTER

Ashley Pantier



IA- IOWA CHAPTER

Megan Ramirez



AZ- ARIZONA CHAPTER

Melanie Kevin



IL- ILLINOIS CHAPTER

Kathleen Heinrich



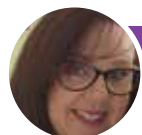
CA- NORTHERN CALIFORNIA CHAPTER

David Sereni



IN- OKI CHAPTER

Holly Sontag



CA- SOUTHERN CALIFORNIA CHAPTER

Autumn Montoya



KY- OKI CHAPTER

Alex Haas



CA- SOUTHERN CALIFORNIA CHAPTER

Rick Montoya



MA- NEW ENGLAND CHAPTER

Kristen Farrell



CO- ROCKY MOUNTAIN CHAPTER

Lyza Weisman



MD- CHESAPEAKE CHAPTER

Kelly Eakin



FL- GREATER FLORIDA CHAPTER

Amber Lavoie



MD- CHESAPEAKE CHAPTER

Derek Lewis



FL- SOUTH FLORIDA CHAPTER

Maylan Chavez



MD- CHESAPEAKE CHAPTER

Tina Lewis

CHAPTER LEADERS



MI- MICHIGAN CHAPTER

Gretchen Dorer



MI- MICHIGAN CHAPTER

Aryn Manni



MN- MINNESOTA CHAPTER

Matthew Czech



MN- MINNESOTA CHAPTER

Melanie Dennison



NJ- NORTH JERSEY CHAPTER

Laura Watson



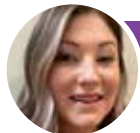
NM- NEW MEXICO CHAPTER

Natasha Abruzzo



NM- NEW MEXICO CHAPTER

Annie Wiseman



NY- NEW YORK CAPITAL REGION CHAPTER

Allie Wolfe



OH- OKI CHAPTER

Stephanie Hall



OH- OKI CHAPTER

Kevin Lockwood



OH- OKI CHAPTER

Natalie Bracone



PA- PENNSYLVANIA CHAPTER

Emily Farkas



PR- PUERTO RICO CHAPTER

Keishla Rolon



TN- TENNESSEE CHAPTER

Sarah Boggess



TX- TEXAS CHAPTER

Beth Moore



TX- TEXAS CHAPTER

Sapna Pringle



TX- TEXAS CHAPTER

Kristen Resendez



UT- UTAH CHAPTER

Trasie Mead



VA- VIRGINIA CHAPTER

Jackie Lackey



VA- VIRGINIA CHAPTER

Sam Lackey



WA- PACIFIC NORTHWEST CHAPTER

Mark Courteau



WI- WISCONSIN CHAPTER

Kim Banach



WI- WISCONSIN CHAPTER

Ashley Baumeister

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



Bradley A. Nunemaker – Vice Chair and Treasurer



Shannon Zerzan - Secretary

EXECUTIVE COMMITTEE



Robert Graham, MD



Rob Lockwood



Allyson Henkel



Spencer Perlman



Kelly Jankowski



Joe Wiseman

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Amy Medina



Peter Statile



Rachael Brown



Karen McRory-Negrin



John Weber



Diana Castro, MD



Mark Moore



Tyler Dukes



Collin Pollock



Marc Ginsky



Kaleen Robinson



Jaclyn Greenwood



Brian Snyder, MD



Brianna Gross, MS, LCGS

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Sarah Shira Emmons



Heather Vital

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In memoriam, we honor Sandy Spoonemore for her service to the Adult Advisory Council.

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Breakthroughs

BEGIN WITH YOU

SMA AWARENESS MONTH

Join Cure SMA to celebrate SMA Awareness Month!

Here are some ways to interact
with the SMA community:

- The annual candle lighting takes place on Saturday, August 9th.
- Need a candle? We have some ready for purchase at curesma.org.myshopify.com!
- Share your story! Tag us on Instagram (@curesmaorg) or email us at stories@curesma.org
- Are you a social media superstar or have a podcast you want to share? Tag us on social media and we will repost!
- Become a Cure SMA advocate and act on important advocacy issues!
Sign up at: www.votervoice.net/curesma/register



Be sure to check out www.curesma.org/sma-awareness-month
for all the latest #SMAAwarenessMonth updates!



Summits of Strength are half-day educational events hosted by Cure SMA. Summits are crafted to provide information for people of all ages and types of SMA, and their loved ones and caregivers. Join us to network and learn from national and local experts about the latest advancements in treatment, care, advocacy, and support.

Brooklyn, NY | **February 15**

Charlotte, NC | **March 1**

Philadelphia, PA | **March 15**

Madison, WI | **April 26**

Boston, MA | **July 12**

Norfolk, VA | **July 19**

Chicago, IL | **July 26**

Seattle, WA | **August 23**

Pittsburgh, PA | **September 13**

Orlando, FL | **September 27**

Phoenix, AZ | **October 4**

Anaheim, CA | **October 11**

Grapevine, TX | **November 8**

New Orleans, LA | **December 6**

San Ramon, CA | **December 13**

*This is a free program which
includes breakfast, lunch,
and parking for all attendees.*

*Thank you to the sponsors for the
2025 Summit of Strength Program*

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REGISTER TODAY!



MAKE YOUR MILES MATTER & RACE FOR CURE SMA

Ready to take on an unforgettable challenge while supporting the spinal muscular atrophy (SMA) community? Cure SMA's Endurance events are back for the 2025-2026 season with some exciting new races available to you!

Whether you're an experienced racer or looking for a new goal, we have the perfect event for you:



Disney Wine & Dine Half Marathon Weekend - October 23-26, 2025

Take part in an exciting 5K, 10K, or 2-Course Challenge with fundraising minimums starting at \$550.



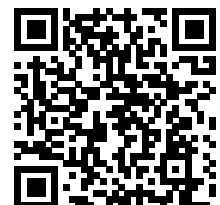
Walt Disney World Marathon Weekend - January 7-11, 2026

Pick your race from a 5K, 10K, Half Marathon, Full Marathon, Goofy Challenge, or Dopey Challenge with fundraising minimums starting at \$750



DON'T MISS OUT—GET YOUR BIB TODAY!

Together, we'll move closer to a world with more treatments, more independence, and more hope for the SMA community. Make your miles count and register for a race today! For more information please visit endurance.curesma.org or scan the QR code below:





YOU' RE CORDIALLY INVITED

TO THE

Shades OF STRENGTH GALA

Experience an unforgettable evening of elegance and purpose
at the Shades of Strength Gala on November 10, 2025

at the luxurious Ritz-Carlton, Tysons Corner in Washington, DC.

This exclusive event brings together passionate change makers for a night of fine dining, live art, curated experiences, and powerful storytelling - all in support of individuals and families impacted by spinal muscular atrophy.



LEARN MORE ABOUT THIS INAUGURAL EVENT HERE!

Follow us on social media to stay up-to-date with news and stories!



facebook.com/cureSMA



www.linkedin.com/company/curesma



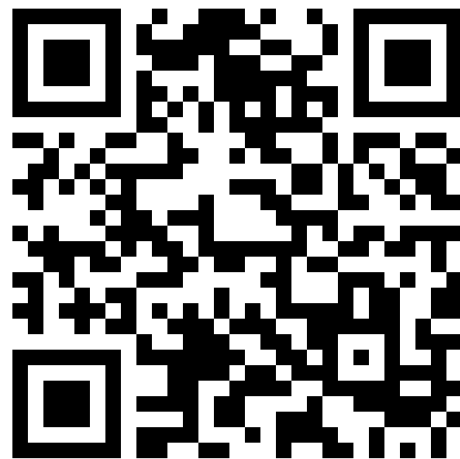
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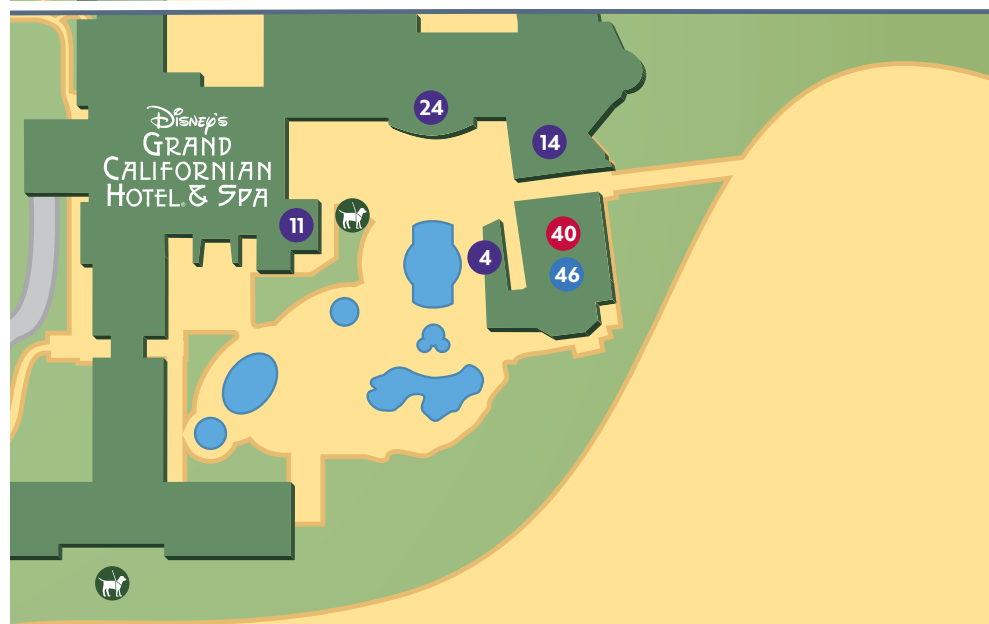
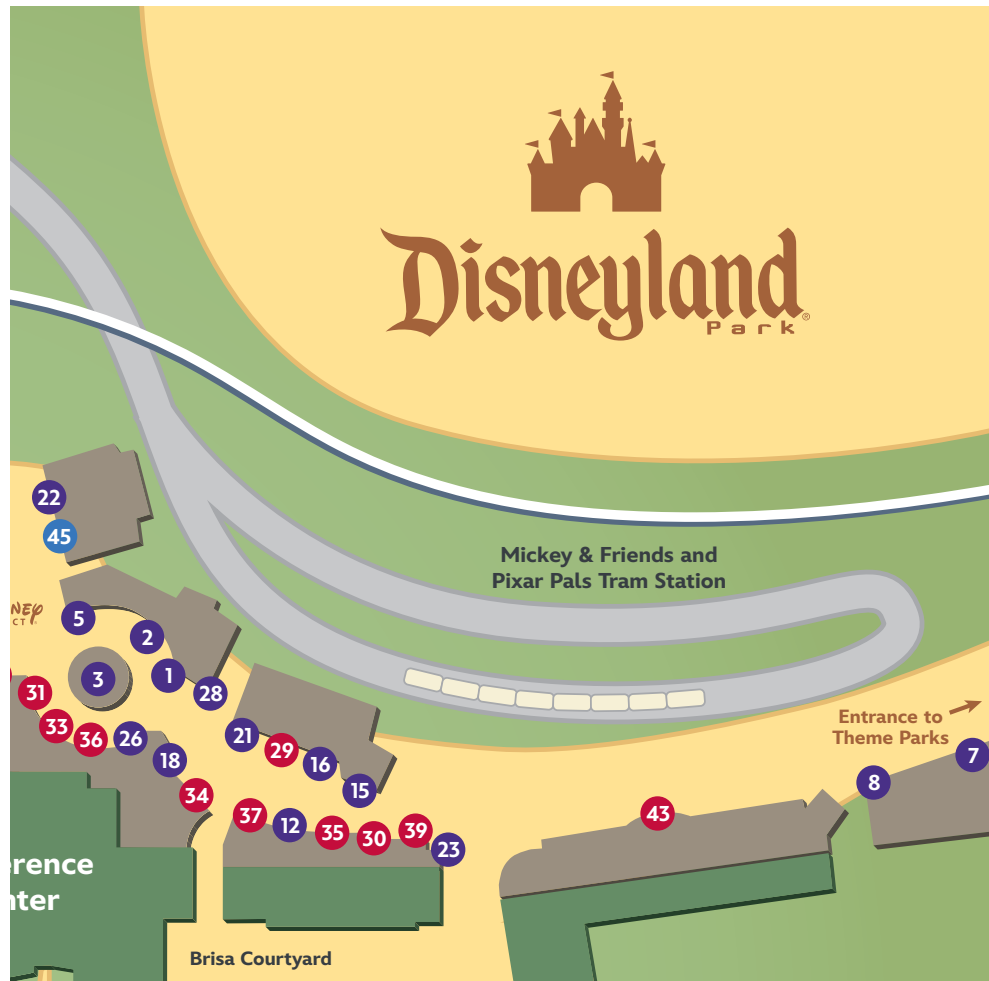
www.tiktok.com/@curesmaorg



**cure
SMA**

#2025SMAConference #CureSMA and #SMACommunity





Disney MEETINGS & Events

DINING

- 1 Ballast Point® Brewing Co.
- 2 Black Tap Craft Burgers & Shakes
- 3 Céntrico
- 4 GCH Craftsman Bar & Grill
- 5 CrazyShake™ by Black Tap
- 6 Din Tai Fung
- 7 EARL OF SANDWICH®
- 8 EARL OF SANDWICH® Tavern
- 9 Goofy's Kitchen
- 10 Great Maple
- 11 Hearthstone Lounge
- 12 Jamba™
- 13 Lobby Bar
- 14 Napa Rose
- 15 Naples Ristorante e Bar
- 16 Napolini Pizzeria
- 17 Palm Breeze Bar
- 18 Paseo
- 19 Jazz Kitchen Coastal Grill & Patio
- 20 Beignets Expressed
- 21 Salt & Straw
- 22 Splitsville Luxury Lanes™
- 23 STARBUCKS®
- 24 Storytellers Café
- 25 Tangaroa Terrace Tropical Bar & Grill
- 26 Tiendita
- 27 Trader Sam's Enchanted Tiki Bar
- 28 Wetzel's Pretzels®

RETAIL

- 29 WonderGround Gallery
- 30 Curl Surf
- 31 Disney Home
- 32 Disney's Pin Traders
- 33 Lovepop®
- 34 Marceline's Confectionery
- 35 Pandora® Jewelry
- 36 Pelé Soccer
- 37 Sephora®
- 38 Star Wars™ Trading Post
- 39 Sunglass Icon® by Sunglass Hut
- 40 Tenaya Stone Spa
- 41 The Disney Dress Shop
- 42 The LEGO® Store
- 43 World of Disney® store

ENTERTAINMENT

- 44 Downtown Disney® LIVE! Stage
- 45 Splitsville Luxury Lanes™
- 46 Tenaya Stone Spa

-  Service Animal Relief Areas

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MAPS



THE DISNEYLAND® HOTEL

Frontier Tower:

Western
Wilderness
Pioneer
Columbia
Mississippi
Mark Twain
Frontier Board Room

Outdoor Event Areas:

Rose Court Garden
Adventure Lawn
Frontier Lawn

Hotel Features & Services

- 1 Front Desk
- 2 Guest Services
- 3 Bell & Valet Services
- 4 Rose Court Garden
- 5 Adventure Lawn
- 6 Frontier Lawn
- 7 Fitness Center
- 8 Guest Laundry

Restaurants & Lounges

- 18 Goofy's Kitchen
- 19 Tangaroa Terrace Tropical Bar & Grill
- 20 Trader Sam's Enchanted Tiki Bar
- 21 The Coffee House
- 22 Palm Breeze Bar
- 23 Lobby Lounge

Shopping & Recreation

- 9 Disney's Fantasia Shop
- 10 small world Gifts and Sundries
- 11 Monorail Pool & Slides
- 12 D Ticket Pool
- 13 E Ticket Pool
- 14 Outdoor Fireplace
- 15 Palette Pool
- 16 Steamboat Willie Splash
- 17 Grill Area

Convention & Banquet Facilities

Convention Center:

- Lower Level: Castle A-C Room
Monorail A-C Room
- Main Level: Disneyland, Grand Ballroom
North, Center, & South Ballroom
North, Center, & South Lounge
Disneyland, Exhibit Hall
- Upper Level: Magic Kingdom, Ballroom 1-4
Sleeping Beauty Pavilion
A Ticket Room
B Ticket Room

Adventure Tower:

- Nile
Congo
Zambezi
Amazon
Oasis
Tiki
Safari
Adventure
Outpost
Explorer

LEGEND



ELEVATORS



ATM



RESTROOMS



AUTOMATED
EXTERNAL
DEFIBRILLATOR



MONORAIL STATION

Guest Rooms

Fantasy Tower: __ 00 - __ 35

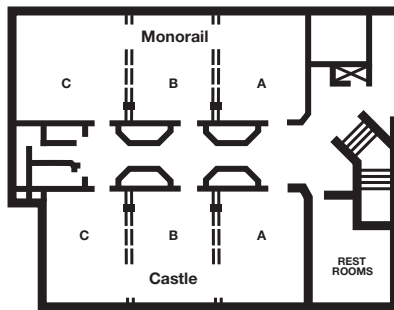
Adventure Tower: __ 36 - __ 67

Frontier Tower: __ 68 - __ 99

(Add first two numbers for floor number)

Discovery Tower: First two numbers for floor

CONVENTION CENTER



The floor plan of the second floor is divided into two main sections by a central corridor. The left section includes the Adventure, Explorer, Outpost, Safari, Tiki, and Oasis rooms. The right section includes the Nile, Congo, Amazon, and Zambezi rooms. Two elevator lobbies are located in the center: the South Lobby on the left and the North Lobby on the right. The plan also shows various stairwells and service areas.

The floor plan of the second floor of the Mark Twain Casino is shown. It includes rooms such as Wilderness, Pioneer, Western, Frontier Board Room, Columbia, Mississippi, REST ROOMS, Mark Twain, and Mark Twain Terrace. There are also restrooms and a bar area.