

2024 ANNUAL SMA CONFERENCE

THURSDAY, JUNE 6 – SUNDAY, JUNE 9



**cure
SMA**

JW Marriott Austin in Austin, Texas

WELCOME LETTER

Welcome to the 2024 Annual SMA Conference

It has been six years since we last went to Texas for our Annual Conference, and we are so excited to bring our community together for this amazing event! This year, we will recognize and celebrate all the progress our community has made while also looking forward to our goals for the future.

We have three powerful SMA treatments, with three-quarters of all affected individuals in the U.S. getting access. More clinical trials are happening than ever before. Every infant born in the U.S. is now screened for SMA! And we are seeing progress in diagnosing and treating SMA around the world. While we recognize these breakthroughs, we are also aware of the work we must continue to do. The SMA landscape has changed significantly over the last eight years, as shown in the 2023 State of SMA report, and we are expanding our research, care, and support programs accordingly.

It is essential now to optimize the impact of our current therapies and to develop new combination approaches and additional therapeutic targets to focus on restoring strength and function and reversing symptoms. Since 2004 alone, we've awarded 138 basic research grants for more than \$16 million. These grants helped to fund the foundational work leading to the now-approved treatments and several more on the way! Basic research is the first step in our quest for novel therapies to meet the needs of people living with SMA at all ages and stages.

One of our important initiatives is our SMA Care Center Network. Care Centers guide our understanding of how SMA is changing and how care is being delivered at the local level to help us identify best practices. SMA best practice care recommendations and guidelines are now being updated and published. SMA diagnosis guidelines were published earlier this year, and treatment considerations will be published later this year. Publications for updated scoliosis care and nutrition care are now being developed among many important care topic areas.

Each year the Annual SMA Research & Clinical Care Meeting is held in conjunction with the Annual SMA Conference. This year, there will be more than 30 research and care presentations and two poster sessions during the meeting. We also 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.

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 70 workshops that serve all the different groups in our community.

We look forward to connecting and networking through scheduled events and informal conversations.

This conference is generously supported by 13 sponsors and 20 exhibitors. Our special thanks to Biogen and Genentech as the Presenting Sponsors of the 2024 Annual SMA Conference. Through these sponsorships, we are able to provide all of these incredible workshops and events, as well as assistance with travel and registration costs for so many attendees!

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



Mary Schroth, MD
Chief Medical Officer



Jackie Glascock, PhD
Vice President, Research

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VISION AND MISSION STATEMENT

Cure SMA leads the way to a world where everyone impacted by spinal muscular atrophy is empowered to lead independent, successful, and fulfilling lives. We strive to create a community where every individual is heard and feels welcomed. Cure SMA provides practical support programs for our community and advocates for their needs. We fund and direct comprehensive research that drives breakthroughs in treatment and we advance access to high quality care. We will not stop until we have a cure.

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:

Dell Children's Medical
Center/UT Austin
4900 Mueller Blvd
Austin TX 78723
Phone: 512-324-0150
Open 24/7

Adult Care:

Dell Seton Medical Center at
The University of Texas
– Emergency Care
1500 Red River Road
Austin TX 78705
Phone: 512-324-7010
Open 24/7

Please note that there are multiple healthcare providers in the Austin area.

Additional information is available at the Registration Desk.

Thank you to our generous sponsors for their support of the
2024 Annual SMA Conference.

PRESENTING SPONSORS



DIAMOND SPONSOR



TITLE SPONSORS



SUPPORTING SPONSORS

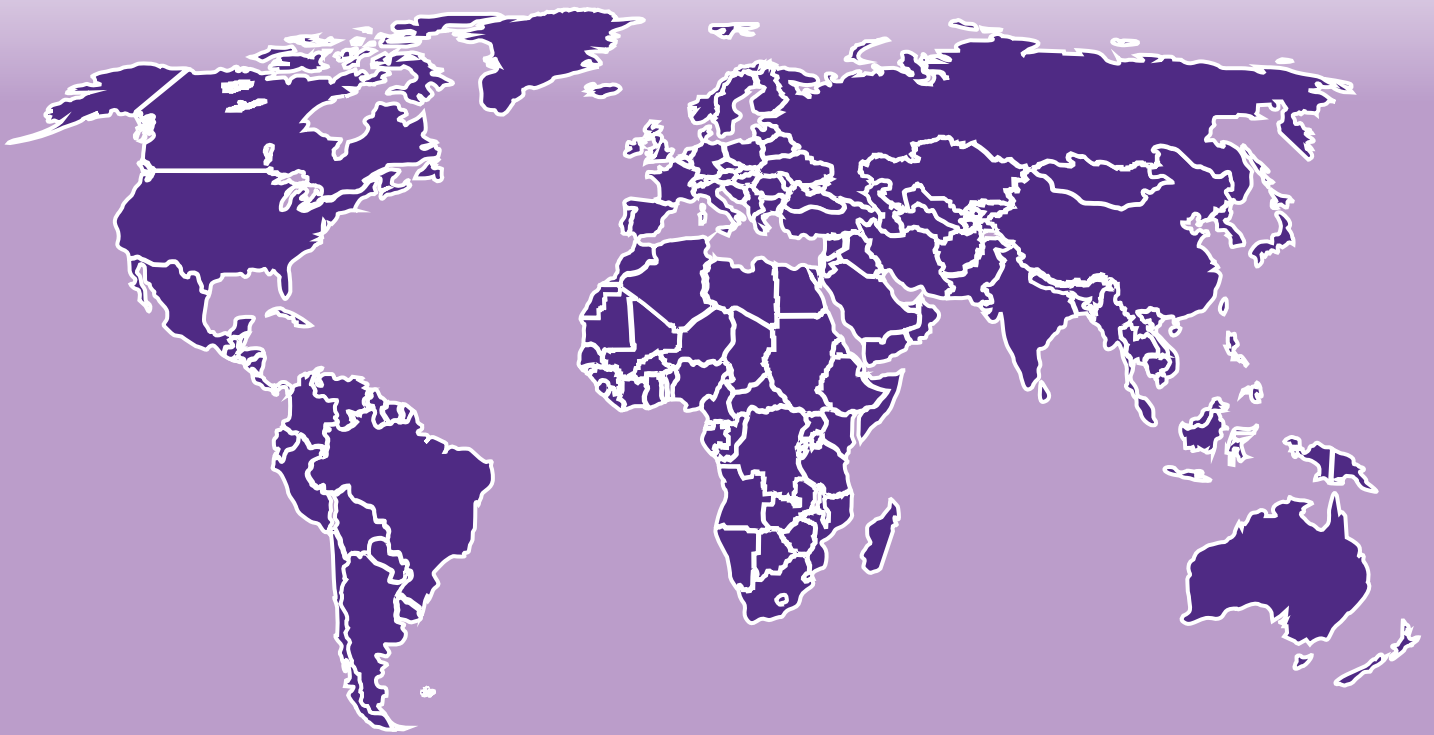


GOLD SPONSORS



WELCOME!

We are honored to have SMA families, researchers, and clinicians attend this conference from all over the world! There are individuals attending from 26 countries, including: Argentina, Australia, Bangladesh, Brazil, Bulgaria, Canada, China, Colombia, France, Germany, Hungary, India, Italy, Japan, Mexico, Netherlands, New Zealand, Norway, Panama, Philippines, Spain, Switzerland, Turkey, United Kingdom, United States and Uruguay.



As of April 24, 2024

Celebrating All The Years!

2024



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



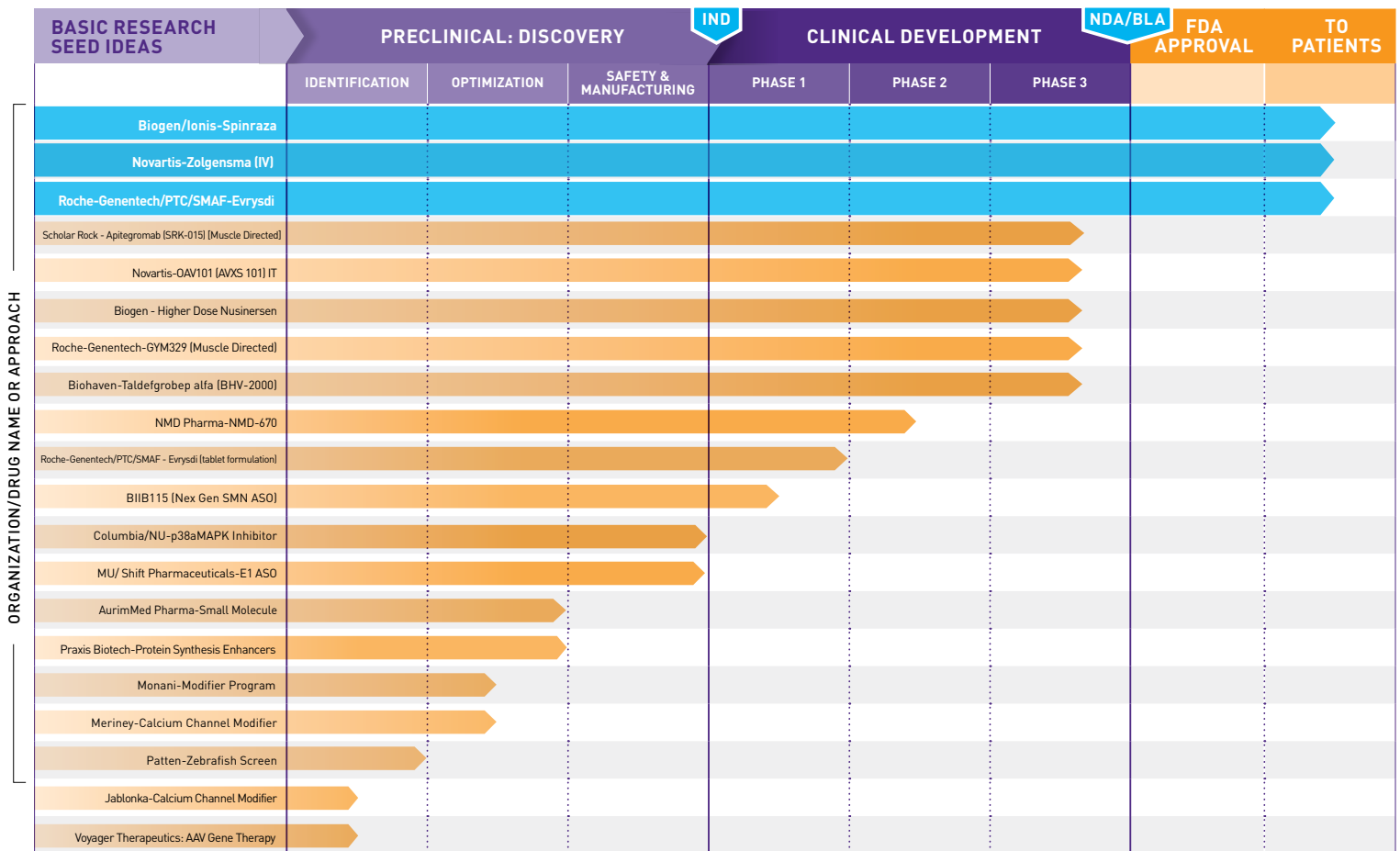
SMA DRUG PIPELINE

SMA DRUG PIPELINE

We are funding and directing research with more breadth and depth than ever before. We know what we need to do to develop and deliver new therapies, or even combinations of therapies, to reach our goal of treatments for all individuals with SMA. And we are on the verge of further breakthroughs that will continue to change the course of SMA.

The Cure SMA Drug Pipeline is one of the primary ways we evaluate the success of our research program. It identifies the major drug programs 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.

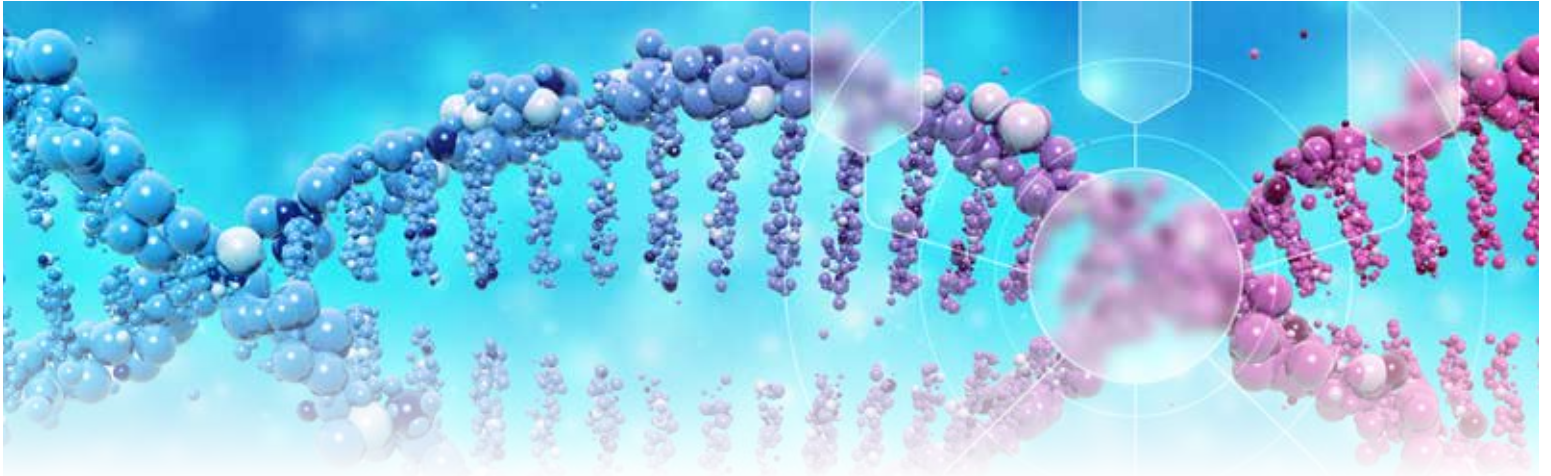


BLA = Biologics License Application

IND = Investigational New Drug

NDA = New Drug Application

Last updated: April 2024



THE IMPORTANCE OF CONTINUING TO INVEST IN BASIC RESEARCH

- In the past two decades, Cure SMA has invested over \$16 million in funding for 138 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 disease, there remains significant unmet needs especially for our older and the 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.

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

- Non-SMN targets. We're looking for other systems, pathways, and processes 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.
- 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 six new basic research grants at the beginning of this year. These grants are focused on the above key areas of research. To learn more about these grants, please see our recent Compass publication. We will also be launching a request for proposals for new basic research grants later this summer. 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. Be on the lookout for information about these new grants in upcoming Cure SMA publications.

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 other's work.

MEET CURE SMA'S 2024 BASIC RESEARCH GRANT RECIPIENTS



Melissa Bowerman, PhD, at Keele University was awarded \$150,000 for her research project, "Defining the role of skeletal muscle in metabolic defects in SMA."

Dr. Bowerman is a Senior Lecturer in Neuromuscular and Skeletal Disorders at the Keele University School of Medicine in the United Kingdom. She first became involved in SMA research approximately 20 years ago as a postgraduate fellow.

Currently, researchers in Dr. Bowerman's lab work on many projects aimed at better understanding the symptoms experienced by individuals living with SMA.

Infants and children with SMA lose muscle very quickly. Muscle loss can have negative effects on different organs and tissues in the body. In her project, Dr. Bowerman and her lab will study how muscle loss affects the rest of the body. To do so, they will use mouse models of SMA in which the SMN protein is only missing in muscle. This will allow them to study how the muscle loss that occurs in SMA impacts the health and function of other organs and tissues.

Learning more about the role of muscle in SMA will help increase our understanding of how low levels of the SMN protein cause the symptoms of SMA. It will also inform the development of future SMA treatments.



Allison Ebert, PhD, at The Medical College of Wisconsin was awarded \$150,000 for her research project, "The role of teneurin 4 and actin dynamics in SMA astrocyte perisynaptic processes."

Dr. Ebert is an associate professor of cell biology, neurobiology, and anatomy at the Medical College of Wisconsin. She originally became involved in SMA research about 15 years ago when she was a postdoctoral fellow. As part of her postdoctoral research, she worked with an SMA research expert, Chris Lorson, to develop a new human stem cell model for SMA. Today, Dr. Ebert leads a basic research lab where her research group studies how non-neuronal cells contribute to motor neuron loss in neurological diseases.

The brain and spinal cord are made up of neuronal and non-neuronal cells. Neuronal cells, like motor neurons, perform advanced functions like carrying messages from the brain to muscles. Non-neuronal cells, like astrocytes, support the structure and function of the more complex neuronal cells.

Dr. Ebert's previous research has shown that in SMA, astrocytes undergo changes that prevent them from being able to adequately support motor neurons.

In this project, Dr. Ebert's research group will use a human stem cell model to determine how the loss of a specific protein, teneurin (TENM4), affects the ability of astrocytes to support motor neurons. Utilizing a range of laboratory techniques, including microscopy and protein biochemistry, they will investigate how astrocytes develop and function in the absence of the TENM4 protein. Dr. Ebert and her colleagues will also determine whether supportive function can be restored to astrocytes by adding back the missing protein.

Learning more about the effects of SMA on non-neuronal cells will contribute to researchers' overall understanding of the disease process. Dr. Ebert also hopes the results of this project will uncover new targets for SMA therapeutics that, combined with existing therapies, can achieve the best possible outcomes for people with SMA.



Lyndsay Murray, PhD, at the University of Edinburgh in Scotland was awarded \$150,000 for her research project, "Investigating the viability of vulnerable motor axons following SMN restoration in mouse models of SMA."

Dr. Murray leads a research laboratory at the University of Edinburgh in Scotland. She became involved in SMA research during graduate school, when she was one of the first scientists to describe how the connections between motor neurons and muscle break down in SMA mice. After graduate school, Dr. Murray continued to research SMA, and in 2014, she established her own lab in Edinburgh.

Today, Dr. Murray's research group uses SMA mouse models to better understand how motor neurons and muscles recover when treatment is given. They want to find new ways to speed and improve the recovery of motor neurons affected by SMA.

Motor neurons carry messages from the brain to muscles. In people with SMA, SMN protein deficiency can cause motor neurons to become unhealthy, causing muscle wasting (shrinkage). Dr. Murray's group believes that in infants with SMA, a specific sub-group of **motor neurons** are developmentally immature and vulnerable to disease. They believe that these immature **motor neurons** do not respond well to currently approved treatments for SMA.

In their current project, Dr. Murray's group wants to learn more about these immature **motor neurons** and how to support them. The researchers will use high power microscopes to study immature **motor neurons** in an inducible SMA mouse model. The inducible SMA mouse is normally deficient in the **SMN protein**. However, Dr. Murray and her colleagues can use a chemical switch to turn on the expression of the **SMN protein** in the inducible mouse.

This technique will enable Dr. Murray's research lab to study how immature **motor neurons** function with and without the **SMN protein**. They will also investigate whether a combination of approved SMA treatments can help protect these **motor neurons**. Insights from this research could improve the effectiveness of current treatments and result in better outcomes for people with SMA.



Stephen Kolb, PhD, at The Ohio State University was awarded \$85,000 for his research project, “Spliceosome and splicing alterations leading up to motor neuron degeneration in the SMA piglet.”

Dr. Kolb is a researcher and adult neurologist specializing in neuromuscular diseases with a focus on diseases that affect motor neurons. He first became involved in SMA research as a postdoctoral fellow when he worked in the laboratory of Dr. Gideon Dreyfuss, the scientist who discovered the central biological function of the *SMN* protein. Currently, Dr. Kolb leads a research lab at The Ohio State University that focuses on how disease affects the development, health, and function of motor neurons.

In people with SMA, deletion or mutation of the *SMN1* gene results in *SMN* protein deficiency. Previous research has shown that the presence of the *SMN* protein is required for motor neurons to stay healthy and function properly. However, researchers continue to try and understand more about the timing and cellular pathways involved in motor neuron death caused by *SMN* deficiency.

One of the cellular pathways affected by the loss of the *SMN* protein is called “RNA splicing.” RNA splicing is an important step in the process through which the information encoded in genes is used to direct the assembly of specific proteins.

In his prior research, Dr. Kolb and his lab created an SMA piglet that experiences the same type of *SMN* protein deficiency as is experienced by people with SMA. Dr. Kolb’s current project will utilize this SMA piglet model, along with microscopy and biochemistry methods, to learn more about how loss of the *SMN* protein affects RNA splicing in motor neurons.

By adding to the knowledge about *SMN*’s role in the health and function of motor neurons, Dr. Kolb’s project will enhance the understanding of how current treatments work. The results of this project may also inform future SMA drug development.



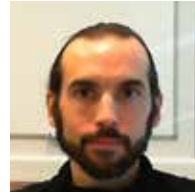
Elana Molotsky, PhD, at the Johns Hopkins University School of Medicine was awarded \$100,000 for her research project, “Identifying developmental and degenerative mechanisms of SMA using single motor neuron nucleus RNA sequencing.”

Dr. Molotsky is a post-doctoral fellow in the lab of Dr. Charlotte Sumner at Johns Hopkins University. After completing her doctoral degree studying spinal and bulbar muscular atrophy (SBMA), Dr. Molotsky wanted to continue to research motor neuron diseases. Working with Dr. Sumner on SMA alongside the other motor neuron disease scientists at Johns Hopkins University was an ideal fit for her career goals.

Dr. Molotsky’s current research focuses on finding out why the loss of the *SMN* protein causes motor neuron death in SMA.

Motor neurons are cells in the central nervous system that relay information from the brain to muscles. In people with SMA, motor neurons can become unhealthy, causing muscles to lose strength and function. Motor neurons contain a chemical messenger called RNA in their nuclei. RNA messages change depending on what is happening inside a motor neuron. For example, the RNA found in a healthy motor neuron will contain different messages than those found in an unhealthy motor neuron.

In her current project, Dr. Molotsky will analyze RNA from the individual spinal cord motor neurons of SMA mice at different stages of disease progression. By determining how RNA messages change as these motor neurons become unhealthy, Dr. Molotsky will learn more about which cellular processes are disrupted in the motor neurons of people with SMA. Her research may also reveal new targets for future SMA drugs.



Michael Tellier, PhD, at the University of Leicester in the United Kingdom was awarded \$114,000 for his research project, “Characterization of the SMN-7SK complex in the regulation of *SMN1* and *SMN2* expression.”

Dr. Tellier became a principal investigator at the University of Leicester in the UK in January of 2023. For many years, his research has focused on molecules that activate genes by binding to them. Recently, Dr. Tellier became involved in SMA research when, together with Dr. Sylvain Egloff, he found that one of the molecules he is studying regulates the activity of the survival motor neuron 1 (*SMN1*) and survival motor neuron 2 and (*SMN2*) genes.

Both the *SMN1* and *SMN2* genes encode the *SMN* protein, which is necessary for motor neuron health and function. In SMA, a mutation in the *SMN1* gene results in low levels of the *SMN* protein, causing motor neuron death. Although the *SMN2* “back-up” gene also encodes the *SMN* protein, most of the *SMN* protein it produces is shortened and unstable.

Dr. Tellier previously discovered that a small, non-coding RNA molecule called “7SK” binds to and activates the expression of the *SMN1* and *SMN2* genes. Furthermore, he found that 7SK also interacts with the *SMN* protein itself to form a complex. In his current research project, Dr. Tellier and his fellow researchers want to determine if the 7SK-*SMN* protein complex plays a role in *SMN1* and *SMN2* gene activation. He will also investigate whether mutations in the *SMN1* gene that cause SMA disrupt the formation or function of this complex.

To accomplish these objectives, Dr. Tellier and his research group will create new cell lines. A cell line is a defined population of cells that share a group of identical traits and can be kept alive, or cultured, in a laboratory for an extended period. These new cell lines will have special characteristics that will allow Dr. Tellier and his colleagues to track the expression of the *SMN1* and *SMN2* genes, as well as the activity of the *SMN* protein.

From the results of this project, Dr. Tellier and his colleagues hope to learn more about the regulation of *SMN1* and *SMN2*, including whether the *SMN* protein increases the expression of its own genes. Because all three currently approved SMA treatments work by increasing *SMN* protein levels, this information will have important implications for current and future SMA treatments. In addition, Dr. Tellier’s new cell lines will not only be useful in this project, they may also be utilized in future SMA research by other scientists.

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.

THANK YOU, SMA COMMUNITY, FOR

100%

2016:

SMA newborn screening pilot starts in New York

FDA approves Spinraza

2017:

Cure SMA nominates SMA for the Federal Recommended Newborn Screening Panel (RUSP)

2018:

The Advisory Committee on Heritable Disorders in Newborns and Children votes to recommend SMA to the federal RUSP

SMA is added to the federal RUSP when the U.S. Department of Health and Human Services adopts the advisory committee's recommendation

Utah becomes the first state to implement a permanent program to screen for SMA

By the end of 2018, 6 states screen for SMA through pilot or permanent programs

2019:

FDA approves Zolgensma

20 states screen for SMA covering 37% of all U.S. newborns

2020:

FDA approves Evrysdi

33 states screen for SMA covering 68% of all U.S. newborns

YOUR NEWBORN SCREENING ADVOCACY!

OF UNITED STATES NOW SCREENING FOR SMA



2021:

38 states screen for SMA covering 84% of all U.S. newborns

2022:

FDA approves Evrysdi label expansion to include infants under 2 months old
47 states screen for SMA covering 98% of all U.S. newborns

2023:

47 states and the District of Columbia screen for SMA covering 99% of all U.S. newborns

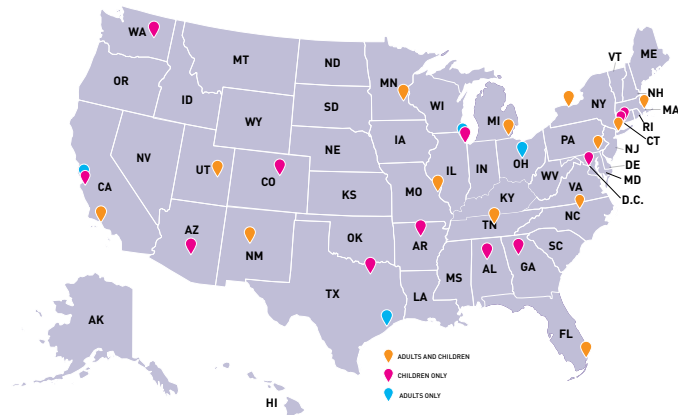
2024:

100% of the United States Now Screening for SMA (all 50 states and the District of Columbia)

CURE SMA CARE CENTER NETWORK

GOAL: To provide the best healthcare for people with SMA, including offering new therapies, and to gather and disseminate new knowledge to advance the SMA standard of care for pediatric and adult persons.

To establish best care, Cure SMA has partnered with hospitals across the U.S. to form the Cure SMA Care Center Network. Centers are geographically diverse and represent a cross section of care for individuals with SMA. Nearly half of these centers provide care to both pediatric and adult patients, four centers provide care focused on adults and 12 centers provide care focused on children. We are not done! With your support Cure SMA plans to expand the SMA Care Center Network from 29 to 60 centers across the U.S.



SMA Clinical Data Registry

The SMA Clinical Data Registry (CDR) is central to our work to collect data to then improve healthcare for people with SMA. Each SMA Care Center Network site consents patients to allow the center to submit information and data to the SMA CDR.

The ability to collect data on a large number of representative individuals living with SMA in a registry is powerful. With more than 1100 participants, the CDR is building a dataset to document changes in SMA over time. The CDR data is analyzed to drive care improvements. The analyses will be used to set the standard of care for SMA. Standard of care is treatment that is accepted by medical experts as a proper treatment for a specific disease or condition and that is widely used by healthcare professionals. The data driven SMA standard of care guidelines will be distributed widely throughout the SMA community and to clinicians and hospitals caring for people with SMA. Keep in mind that data is more compelling than expert opinion.



ADULT and PEDIATRIC CENTERS

- Boston Children's Hospital, Boston, MA
- Columbia University, New York, NY
- Connecticut Children's Medical Center, Hartford, CT
- Duke University Medical Center, Durham, NC
- Gillette Children's Specialty Healthcare, St. Paul, MN
- The Children's Hospital of Philadelphia, Philadelphia, PA
- The University of Michigan, Ann Arbor, MI
- University of Texas, Los Angeles (UCLA), Los Angeles, CA
- University of Miami, Miami, FL
- University of New Mexico, Albuquerque, NM
- University of Rochester Medical Center, Rochester, NY
- University of Utah, Program for Inherited Neuro Disorders, SLC, UT
- Washington University/St. Louis Children's Hospital, St. Louis, MO

ADULT CENTERS

- Baylor College of Medicine, Houston, TX
- Northwestern University, Chicago, IL
- Stanford Health, Palo Alto, CA
- The Ohio State University, Wexner Medical Center, Columbus, OH

PEDIATRIC CENTERS

- Advocate Children's Hospital, Park Ridge, IL
- Arkansas Children's Hospital, Little Rock, AR
- Children's Healthcare of Atlanta, Atlanta, GA
- Children's Hospital Colorado, Aurora, CO
- Children's National Medical Center, Washington, DC
- Children's of Alabama, Birmingham, AL
- Phoenix Children's Hospital, Phoenix, AZ
- Seattle Children's Hospital, Seattle, WA
- Stanford Children's Health, Palo Alto, CA
- University of Texas Southwestern/Children's Health, Dallas, TX
- Vanderbilt University Medical Center, Nashville, TN
- Yale Pediatric Neuromuscular Clinic, New Haven, CT

Acknowledgements

Funding for the SMA Care Center Network was provided in part by the Erin Trainor Memorial Fund and the Tyler William Orr Memorial Fund.

Funding was also provided by the Cure SMA Real World Evidence Collaboration which includes Cure SMA, Biogen, Genentech/Roche, and Novartis.

2023 State of SMA is here

– pick up your copy today!

The report showcases outcomes from Cure SMA's three databases:

- The Membership Database with patient-reported outcomes on over 10,000 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 1,100 patients receiving care from US-based SMA Care Center Network sites
- The SMA Newborn Screening Registry (NBSR) with parent-reported outcomes for over 80 babies with SMA identified through statewide SMA newborn screening

Highlights from the report included:

- Representativeness of our databases
- Demographics of the SMA community
- Prevalence of SMA type and SMN2 copy number
- Data on children, teens, and adults with SMA
- Social determinants of health
- Mental health
- Age at diagnosis of SMA
- Use of SMA treatment
- SMA care and thoughts on telemedicine
- Motor function
- ...and much more!

Grab your copy at the Cure SMA HUB!



If you have not already received a copy of the 2023 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 Real World Evidence Collaboration (RWEC) and the Cure SMA Industry Collaboration (SMA-IC). Lastly, Cure SMA is also grateful to the SMA Care Center Network (CCN) for their commitment to improving care for people with SMA and contributing consented patient data.



HOW TO ADVOCATE AT CONFERENCE

Make this year's conference the most impactful ever!

Consider the following steps on your advocacy journey while at conference:

- ✓ Attend the Cure SMA Advocacy conference workshop to learn how you can take your advocacy journey to the next step
- ✓ Drop by the Cure SMA Hub to:
 - To take an advocacy action
 - Share your advocacy priorities
 - Learn about Cure SMA's new Do It Yourself (DIY) advocacy program

CAREGIVING REPORT

Cure SMA released a national report that chronicles the caregiving challenges experienced by individuals with SMA and their families. This report features first-person experiences and quotes from SMA community members that highlight the essential role caregivers play in their lives. To learn more, grab your copy of the report at the Cure SMA Hub!



Check out the report at: <https://www.curesma.org/advocacy/>

STUCK INSIDE:
A NATIONAL REPORT ON CAREGIVING
FOR INDIVIDUALS WITH SPINAL MUSCULAR ATROPHY



**cure
SMA**



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 SUMMARY

THURSDAY, JUNE 6, 2024

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

1:00PM – 3:00PM NEWLY DIAGNOSED PROGRAM
(For Newly Diagnosed Families Only)

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

6:30PM – 8:30PM MEET AND GREET/ FUN FEST FOR ALL
CONFERENCE ATTENDEES

8:30PM – 11:00PM DAD'S NIGHT OUT ****for dads only****

FRIDAY, JUNE 7, 2024

7:00AM BREAKFAST OPENS

7:15AM – 5:30PM REGISTRATION AND CHECK-IN

7:45AM – 5:30PM EXHIBITORS OPEN

7:45AM – 8:45AM SYMPOSIUM, SPONSORED BY GENENTECH: TAKING CENTER
STAGE: STORIES FROM THE COMMUNITY *Sponsored by Genentech*

8:45AM – 5:30PM SELF-EXPRESSION EXHIBIT *Sponsored by Biogen*

8:45AM – 5:30PM A PIECE OF US *Sponsored by Novartis*

8:45AM – 5:30PM MUSCLE STATION *Sponsored by Scholar Rock*

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

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

11:00AM – 4:45PM TEEN LOUNGE *Sponsored by Luke 18:1 Foundation*
****for all teens ages 12 – 18****

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

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 TEEN SOCIAL *Sponsored by Luke 18:1 Foundation*
 for all teens ages 12 – 18

7:30PM – 11:00PM ADULTS WITH SMA RECEPTION *Sponsored by Biogen and the Dhont Family Foundation*
 for adults with SMA and their attendants

8:30PM – 11:00PM MOM'S NIGHT OUT ***for moms only***

SATURDAY, JUNE 8, 2024

7:00AM BREAKFAST OPENS

7:15AM – 5:00PM REGISTRATION AND CHECK-IN

7:45AM – 5:30PM EXHIBITORS OPEN

7:45AM – 8:45AM SYMPOSIUM, SPONSORED BY BIOGEN: OUR VISION: IMPROVING AIR TRAVEL FOR PEOPLE WITH SMA *Sponsored by Biogen*

8:45AM – 5:30PM SELF-EXPRESSION EXHIBIT *Sponsored by Biogen*

8:45AM – 5:30PM A PIECE OF US *Sponsored by Novartis*

8:45AM – 5:30PM MUSCLE STATION *Sponsored by Scholar Rock*

9:00AM – 11:40AM CHILDREN'S PROGRAM & BABY ROOM
1:00PM – 5:00PM (Drop off opens at 8:30am and 12:30pm)

9:00AM – 5:00PM TEEN LOUNGE *Sponsored by Luke 18:1 Foundation*
 for all teens ages 12 – 18

9:00AM – 5:00PM 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

1:00PM – 2:10PM WORKSHOP SESSION #6

2:30PM – 3:40PM WORKSHOP SESSION #7

4:00PM – 5:00PM WORKSHOP SESSION #8

6:00PM – 7:30PM MOST LIKELY NOT TO... - AN SMA MY WAY MUSICAL EXPERIENCE
Sponsored by Genentech

CONFERENCE SUMMARY

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

7:30PM – 9:30PM TEEN SOCIAL *Sponsored by Luke 18:1 Foundation*
for all teens ages 12 – 18

SUNDAY, JUNE 9, 2024

7:45AM – 8:45AM BREAKFAST OPEN

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

WORKSHOP SESSION #1

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


WORKSHOP SESSION # 2

- Easier Living: Unleashing the Power of Tech in Your Home
- The Role of Therapy PT and OT in your Child's Life – Being Part of the Team
- Financial and Estate Planning with Special Needs Trust
- Parenting With SMA 
- Personal Care Assistants: From Recruitment and Hiring to Day-to-Day Management and Everything In-Between
- What it Means to be a Teen on Wheels
- Healing the Grieving Heart – Part I
- Sharing Your Type 1 Experiences

WORKSHOP SESSION # 3


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

WORKSHOP SESSION #4


- Unpacking Clinical Trials
- Pediatric Yoga for SMA: A 5 Part Therapeutic Yoga Practice
- Empowering Independence: The Benefits of Service Dogs
- The Role of the Multi-disciplinary Clinic - Why might it be helpful for those identified pre-symptomatically
- Beyond High School – from interest to employment
- I Need to Cough, I Need to Breathe
- Taking Charge of Your Health: The Transition from  Pediatric to Adult Care
- University of Utah TRAILS Program: Advancing Adaptive Sports and Innovative Equipment Solutions
- Memory Boxes: Create a Treasure (for children & teens only)

WORKSHOP SESSIONS

WORKSHOP SESSION # 5

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

WORKSHOP SESSION # 6

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

WORKSHOP SESSION # 7

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

WORKSHOP SESSION # 8

- Empowering Women: Sharing Health Tips and Journeys in the SMA Community
- Tech for Seamless Living: Wheelchairs, driving and more
- Q&A Session with the Pulmonary Team
- Mindfulness for Kids
- Early Scoliosis Treatment in SMA
- Must-Love Fundraising: Find Your Perfect Event Match
- Dating Disabled: Navigating the Dating World as a Disabled Person

ADDITIONAL SESSIONS

- Kids Talk it Out (Ages 12 – 17) | Friday, June 7 from 9:00am – 10:30am



PLEASE NOTE

WEAR SUNSCREEN AND KEEP HYDRATED!

As many of you know, June in Texas 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!

ADULTS WITH SMA NETWORKING

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



There are many great opportunities to connect with others in the community at the Annual SMA Conference.

The Adults with SMA Lounge is a great space to refresh throughout the conference days. Take a break and unwind with other adults with SMA and their attendants in the separate space.



THE LOUNGE, HELD ON LEVEL 2 IN THE BRAZOS ROOM, IS OPEN:

Thursday, June 6, 2:30pm – 6:00pm

Friday, June 7, 11:00am – 4:45pm

Saturday, June 8, 9:00am – 5:00pm

ADULTS WITH SMA RECEPTION

Come join other adults with SMA and their attendants for an evening of fun! The Adults with SMA Reception, sponsored by Biogen and the Dhont Foundation, will be held on Friday, June 7th from 7:30pm – 11:00pm on Level 4 in the JW Grand Ballroom 1 - 4. Meet, mingle, and enjoy some light snacks and a cash bar for this evening together.

ADULTS WITH SMA WORKSHOP TRACK



- Personal Care Assistants: From Recruitment and Hiring to Day-to-Day Management and Everything In-Between
- Taking Charge of Your Health: The Transition from Pediatric to Adult Care
- What it Means to be a Teen on Wheels
- Spouses and Significant Others of Adults with SMA Sharing Your Experience
- Dating Disabled: Navigating the Dating World as a Disabled Person
- Therapeutic Yoga for Teens & Adults with SMA
- How to Build Your Presence and Advocate Through Writing & Social Media
- Parenting with SMA
- Medical Management of Adults with SMA
- Adult with SMA Relationships Panel – Relationships through experience
- Navigating the Special Education Process - High School & College
- Young Adults Talk it Out
- Finding a Job, Interviewing and How to Ask for Modifications Panel
- Easier Living: Unleashing the Power of Tech in Your Home
- How to Travel With SMA
- Beyond High School - from interest to employment
- Achieving a Better Life Experience with ABLE Accounts
- Transition to Adulthood Sharing Panel
- Your Mental Health Toolbox
- Adaptive Sport / Recreation Testimonials and Resources
- Shifting Perspectives: Media Representation and the Disabled Community - Roundtable Dialogue for Inclusive Narratives
- Evolving Your Wheels: Driving with SMA
- Personal Care Assistants Sharing Panel
- Empowering Women: Sharing Health Tips and Journeys in the SMA Community
- Tech for Seamless Living: Wheelchairs, driving and more

Be sure to check out these sessions!

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

Genentech
A Member of the Roche Group

SPECIAL EVENTS

MEET AND GREET

THURSDAY 6:30PM – 8:30PM

JW GRAND BALLROOM

KICK OFF TO THE CONFERENCE!

- Annual Relay Race
- Fun Fest/Carnival

FAMILY FRIENDLY RESEARCHER POSTER SESSION

FRIDAY 6:30PM – 8:30PM

JW GRAND BALLROOM

VISIT OVER 30 POSTERS PRESENTED
BY RESEARCHERS

PJ PARTY AND MOVIE NIGHT

SATURDAY 7:00PM – 9:00PM

LONE STAR BALLROOM A - D

MOVIE FOR KIDS AND ADULTS ALIKE!

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





GET STARTED ON YOUR CLINICAL TRIAL

JOURNEY WITH CURE SMA

Cure SMA has **NEW** resources for navigating the evolving landscape of SMA 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.



EMPLOYER GIFT MATCHING



DOUBLE
(or even triple)

your donation to Cure SMA!

Many employers sponsor matching gift programs and will match any charitable contributions made by their employees. Some companies match gifts made by retirees and/or spouses. If you volunteer with us, your employer may also provide Cure SMA with a grant to recognize your ongoing support.



Scan this QR code to search for your employer!

LEAVE A LEGACY

Make a lasting impact by making a planned gift to Cure SMA. There are many ways to give and choosing the right plan can have a major impact on the future of SMA. You and your family can experience the joy of leaving a legacy that will benefit generations to come.

Some of our gift planning options:

- Securities
- Real Estate
- Bequests
- Retirement Assets
- IRA Charitable Rollover
- Life Insurance
- Donor Advised Funds
- Legacy Society
- Major Gift



“Through planned gifts of all types and sizes, you can make a difference in the lives of people with SMA.”

– Jamie Gibson, Chief Development Officer, Cure SMA



Questions? Please reach out to Jamie Gibson: Jamie.Gibson@CureSMA.org or Emily Leitzinger: Emily.Leitzinger@CureSMA.org or by calling 847.709.6343. We are excited to help you make a gift that impacts the future of SMA!

CONFERENCE MEALS INCLUDED WITH REGISTRATION

THURSDAY

DESSERTS AT MEET & GREET:

HOMEMADE CHURROS, ICE CREAM & FROZEN NOVELTIES, CHOCOLATE COVERED STRAWBERRIES, AND WATER.

FRIDAY

BREAKFAST ITEMS:

ASSORTED MUFFINS & CROISSANTS, WATERMELON WEDGES, APPLE 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.

SNACKS AT FAMILY FRIENDLY POSTER SESSION:

LIGHT SNACKS OF SOFT PRETZELS, STRAWBERRY SKEWERS, LEMONADE, AND WATER.

SATURDAY

BREAKFAST ITEMS:

ASSORTED SCONES & MUFFINS, WATERMELON WEDGES, PINEAPPLE SKEWERS, APPLE 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.

SNACKS AT THE PJ PARTY AND MOVIE NIGHT:

POPCORN, ASSORTED MINI CUPCAKES, AND REFRESHMENTS.

SUNDAY

BREAKFAST ITEMS:

ASSORTED BREAKFAST BREADS, WATERMELON WEDGES, APPLE JUICE, AND COFFEE.

There are many dining locations and options available around the hotel, just outside of the hotel, and throughout the city of Austin. Options at the JW Marriott Austin include:

- The Veranda at Dean's
- Corner Restaurant
- Burger Bar Congress
- Starbucks
- JW Marriott Austin Lobby Bar
- Edge Rooftop
- Dean's Italian Steakhouse

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



FOLLOW LAVACA NORTH FOR EASIEST PATH TO UT!!!

JW MARRIOTT



DON'T MISS OUT ON THE SOUTH CONGRESS SHOPPING CENTER!!!



RESTAURANT KEY ON FOLLOWING PAGE

BBQ

- 1) Stubb's BBQ - \$\$ - [737-465-1218](tel:737-465-1218)
- 2) Terry Black's BBQ - \$\$ - [512-394-5899](tel:512-394-5899)
- 3) Cooper's BBQ - \$\$ - [512-474-4227](tel:512-474-4227)

Asian/Sushi

- 4) P.F. Chang's - \$\$ - [512-457-8300](tel:512-457-8300)
- 5) Maiko Sushi Lounge - \$ - [737-236-9888](tel:737-236-9888)
- 6) Sushi Junai Omakase - \$\$\$ - [512-401-3822](tel:512-401-3822)

Pizza

- 7) Desano Pizza - \$\$ - [512-256-2426](tel:512-256-2426)
- 8) Numero 28 - \$\$ - [512-494-5510](tel:512-494-5510)
- 9) The Onion - \$ - [512-476-6466](tel:512-476-6466)
- 10) Roppolo's Pizzeria - \$ - [512-476-1490](tel:512-476-1490)

Italian

- 11) Red Ash - \$\$\$ - [512-379-2906](tel:512-379-2906)
- 12) North Italia - \$\$ - [512-777-5062](tel:512-777-5062)
- 13) Taverna - \$\$ - [512-477-1001](tel:512-477-1001)


TexMex/Tacos

- 14) ATX Cocina - \$\$ - [512-263-2322](tel:512-263-2322)
- 15) Iron Cactus - \$\$ - [512-472-9240](tel:512-472-9240)
- 16) La Condesa - \$\$\$ - [512-499-0300](tel:512-499-0300)
- 17) Torchy's Tacos - \$ - [512-792-5909](tel:512-792-5909)
- 18) Vera Cruz - \$\$\$ - [512-665-2713](tel:512-665-2713)
- 19) One Taco - \$ - [512-527-3002](tel:512-527-3002)

French

- 20) Rotisserie - \$\$ - [512-358-4009](tel:512-358-4009)
- 21) Peche - \$\$\$ - [512-494-4011](tel:512-494-4011)

Lounge/Bar

- 22) The Side Bar - \$ - [512-322-0697](tel:512-322-0697)
- 23) The Aquarium on 6th - \$ - [512-499-8003](tel:512-499-8003)
- ) Elephant Room - \$\$ - [512-473-2279](tel:512-473-2279)
- 25) Firehouse Lounge - \$\$ - [512-201-2522](tel:512-201-2522)
- 26) Austin Club - \$\$\$ - [512-477-9496](tel:512-477-9496)
- 27) Cloak Room - \$\$ - [512-472-9808](tel:512-472-9808)

Contemporary

- 28) Hestia - \$\$\$ - [512-333-0737](tel:512-333-0737)
- 29) Group Therapy - \$\$\$ - [512-542-9292](tel:512-542-9292)
- 30) Fixe Southern House - \$\$\$ - [512-888-9133](tel:512-888-9133)
- 31) Emmer & Rye - \$\$\$ - [512-366-5530](tel:512-366-5530)
- 32) Swift's Attic - \$\$ - [512-482-8842](tel:512-482-8842)

Deli/Sandwiches

- 33) Royal Blue Grocery - \$ - [512-386-1617](tel:512-386-1617)
- 34) Newks Eatery - \$\$ - [512-647-2420](tel:512-647-2420)
- 35) Murphy's Deli - \$ - [512-410-8612](tel:512-410-8612)

Southern

- 36) Gus's Fried Chicken - \$ - [512-474-4877](tel:512-474-4877)
- 37) Moonshine Grill - \$\$ - [512-236-9599](tel:512-236-9599)
- 38) Texas Chili Parlour - \$ - [512-472-2828](tel:512-472-2828)

Sports Bar

- 39) Champions - \$\$ - [512-691-9988](tel:512-691-9988)
- 40) Little Woodrow's - \$\$ - [512-477-2337](tel:512-477-2337)
- 41) BBG's - \$\$ - [512-469-2934](tel:512-469-2934)

Healthy Food

- 42) Modern Market Eatery - \$\$ - [512-666-3099](tel:512-666-3099)
- 43) True Food Kitchen - \$\$ - [512-777-2430](tel:512-777-2430)
- 44) Flower Child - \$\$ - [512-777-2493](tel:512-777-2493)
- 45) The Grove Wine Bar & Kitchen - \$\$ - [512-236-1440](tel:512-236-1440)

European Pub

- 46) Bangers Sausage House - \$\$ - [512-386-1656](tel:512-386-1656)
- 47) The Pub - \$\$ - [512-415-3112](tel:512-415-3112)
- 48) Foxy's Proper Pub - \$\$ - [512-501-6713](tel:512-501-6713)


Greek/Mediterranean

- 49) Peacock Mediterranean Grill - \$\$ - [512-628-1410](tel:512-628-1410)
- 50) Shawarma Point - \$ - [512-621-4550](tel:512-621-4550)

American

- 51) Cedar Door - \$\$ - [512-473-3712](tel:512-473-3712)
- 52) Sandy's Hamburgers - \$ - [512-478-6322](tel:512-478-6322)
- 53) Casino El Camino - \$ - [512-469-9330](tel:512-469-9330)
- 54) Smash ATX - \$\$ - [737-263-0555](tel:737-263-0555)


Steak/Seafood

- 55) Bob's Steak & Chop House - \$\$\$ - [512-222-2627](tel:512-222-2627)
- 56) Perry's Steakhouse - \$\$\$ - [512-474-6300](tel:512-474-6300)
- 57) Fogo de Chao - \$\$\$ - [512-472-0220](tel:512-472-0220)
- 58) Vince Young Steakhouse - \$\$\$ - [512-457-8325](tel:512-457-8325)
- 59) Café Blue - \$\$ - [512-428-5796](tel:512-428-5796)
- ) Dean's Italian Steakhouse - \$\$\$ - [512-608-4490](tel:512-608-4490)

Sweets

- 60) Voodoo Doughnut - \$ - [512-215-8586](tel:512-215-8586)
- 61) Yummi Joy - \$ - [512-296-2195](tel:512-296-2195)
- 62) Nuha's Sinful Desserts - \$ - [512-919-6595](tel:512-919-6595)
- 63) Little Lucy's - \$ - [424-235-8297](tel:424-235-8297)
- 64) Baked Bear - \$ - [512-300-0167](tel:512-300-0167)

Bakery, Breakfast, Coffee, & Snacks

- 65) Jo's Coffee - \$ - [512-469-9003](tel:512-469-9003)
- 66) The Hideout - \$ - [512-476-1313](tel:512-476-1313)
- 67) Halcyon - \$\$ - [512-472-9637](tel:512-472-9637)
- 68) 1886 Café and Bakery - \$\$ - [512-439-1234](tel:512-439-1234)
- 69) Forthright - \$\$ - [512-387-3370](tel:512-387-3370)
- 70) La Café Crepe - \$ - [512-480-0084](tel:512-480-0084)
- 71) Phoebe's Diner - \$\$ - [512-359-8338](tel:512-359-8338)
- ) Corner Restaurant - \$\$ - [512-608-4488](tel:512-608-4488)

Jennifer Miller-Smith, Aaron Smith and Family

The Smith family has consistently proven to be an invaluable asset in the meticulous planning of our Annual SMA Conference. Their generosity over the past several years, notably in donating signage throughout the conference, has been truly commendable. We extend our deepest gratitude to Jennifer Miller-Smith, Aaron Smith, and the entire family for their selfless volunteerism and expertise, which played a pivotal role in making this conference a truly magical and memorable experience.

Expo CCI - Our heartfelt thanks go out to the entire team at Expo CCI, with special recognition to Richard Curran. Their sponsorship and donation of all the remarkable signs and banners that adorned the meeting space added an exceptional touch to the conference. The professionalism demonstrated by Expo CCI, reflected in their impressive signs and banners that showered the entire hotel, was nothing short of outstanding. Their contribution significantly elevated the visual appeal and overall ambiance of our conference, and we are truly grateful for their support.



Jacob Isaac Rappoport Foundation



Since Jacob Rappoport's diagnosis in 2001, Shaina and Adi Rappoport have wholeheartedly committed themselves to advancing Cure SMA's mission. To ensure and establish a lasting legacy for Jacob, the Rappoport Family founded the Jacob Isaac Rappoport Foundation (JIRF) in 2002. Since 2003, the JIRF has been a steadfast partner to Cure SMA and has supported numerous research initiatives, vital support programs, and the Annual SMA Conference.

One significant initiative sponsored by the JIRF at the Annual SMA Conference is the Children's Program, which ensures parents can attend critical workshops and lectures while their children are engaged and secure throughout conference. This program offers a range of entertaining activities, including fun crafts and performances, all facilitated by an exceptional group of volunteers. Beyond its involvement in the Annual SMA Conference, the JIRF extends its support by sponsoring Newly Diagnosed Packages, dispatched to every newly diagnosed family who seeks support from Cure SMA. These packages contain toys and helpful resources, providing valuable support during challenging times.

Further, the JIRF has made substantial contributions to research programs, funding efforts to discover breakthroughs in effective treatments. We extend our heartfelt gratitude to the JIRF for its unwavering commitment over the years, supporting newly diagnosed families, enhancing the Annual SMA Conference experience, and contributing significantly to our growing programs.

Cure SMA thanks the Rappoport Family for their incredible commitment to the SMA community!



fighting spinal muscular atrophy in memory of our shooting star
www.ourshootingstar.com

The Luke 18:1 Foundation



The Luke 18:1 Foundation was founded in 2017 in honor of Luke Stickane with the purpose of finding a cure for SMA. Since 2017, the Luke 18:1 Foundation has been a continued supporter of Cure SMA and has granted over \$2 million dollars to Cure SMA to fund vital research, care, and support programs. This year, the Luke 18:1 Foundation sponsored nearly 200 first-time attendees to attend the 2024 Annual SMA Conference, funded over \$300,000 in basic research grants, supported the UTSW Dallas Care Center Network site, and donated 90 pieces of equipment to the Cure SMA Equipment Pool.

LUKE 18:1

Cure SMA thanks the Stickane Family, Giglio Family, and the Luke 18:1 Foundation for their tireless support of the SMA community!



**Cure SMA thanks The Dhont Family Foundation,
leaders in scientific and social research investment,
for their continued support for those living with SMA,
their families and caregivers.**

HELP KICK-OFF THE 2024 ANNUAL SMA CONFERENCE!



We are looking forward to a great Annual SMA Conference this year and the Meet & Greet is the official kick-off event to the conference. Every registered attendee is invited to join in.

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

Light snacks and desserts will be provided at the event.

COME ENJOY AN EVENING AS THE COMMUNITY COMES TOGETHER!



MEET & GREET

JW Grand Ballroom – Level 4

Thursday, June 6

6:30pm – 8:30pm

Conference Welcome
Introductions, carnival games,
and prizes for all



Annual Relay Race
7:00pm



Conference wristbands must be worn during the entire conference.

You will not be admitted into any conference event or workshop without this conference wristband.

Amy Marquez Scholarship

For the 2024 Annual SMA Conference, the Amy Marquez Scholarship is in its tenth year. The Amy Marquez Scholarship was started in memory of Amy Marquez, who passed away from SMA type I at the age of forty-one. Amy was an active member of the SMA community and was a wonderful source of support and motivation for many SMA families. This scholarship will be awarded each year to an adult with SMA to attend the Annual SMA Conference, in recognition of Amy’s involvement within the SMA Adult community. The scholarship will cover both registration fees and hotel costs











AGENDA | WEDNESDAY, JUNE 5

Please check the Conference App for the most updated agenda.

5:00PM – 7:30PM	Registration Open for all Conference Attendees	Griffin Hall Foyer
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AGENDA | THURSDAY, JUNE 6

9:00AM – 6:00PM	Registration Open for all Conference Attendees	Griffin Hall Foyer
1:00PM – 3:00PM Drop off opens at 12:30pm	Newly Diagnosed Children's Program Sponsored by The Jacob Isaac Rappoport Foundation	Lone Star Ballroom E - H
1:00PM – 3:00PM	Newly Diagnosed Program (For Newly Diagnosed Families Only)	Lone Star Ballroom C
1:00PM – 1:15PM	Introduction to Cure SMA and the Community **for newly diagnosed families only** Kenneth Hobby, President Colleen McCarthy O'Toole, Senior Vice President, Community Support	
1:15PM – 1:25PM	Parent Welcome Al Freedman, PhD, SMA Dad Kevin O'Brien, SMA Dad Nick Farrell, SMA Dad	
1:25PM – 1:35PM	Understanding Treatment and Trials Rob Graham, MD	
1:35PM – 1:40PM	SMA Standards of Care Mary Schroth, Chief Medical Officer	
1:40PM – 2:05PM	Life After Diagnosis – Parents Share Their Journey Danyelle Sun, SMA Parent Amy Medina, SMA Parent Marnie Harris, SMA Parent	
2:05PM – 3:00PM	Newly Diagnosed Program Meet and Mingle **for newly diagnosed families only**	
2:30PM – 6:00PM	Adults with SMA Lounge Sponsored by Biogen **for adults with SMA and their attendants**	
6:30PM – 8:30PM	Meet & Greet Includes Annual Relay Race and Games	JW Grand Ballroom
8:30PM – 11:00 PM	Dad's Night Out **for dads only**	Lone Star Ballroom A - D

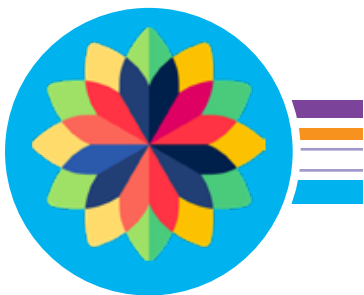
7:00AM	Breakfast Opens		Lone Star Ballroom Foyer & Griffin Hall
7:15AM – 5:30PM	Registration Open for all Conference Attendees		Griffin Hall Foyer
7:45AM – 5:30PM	Exhibitor Tables Open		Griffin Hall
7:45AM – 8:45AM	Symposium by Genentech: Taking Center Stage: Stories from the Community	 <small>A Member of the Roche Group</small>	Lone Star Ballroom A - D
8:45AM – 5:30PM	Self-Expression Exhibit <small>Sponsored by Biogen</small>		Griffin Hall
8:45AM – 5:30PM	A Piece of Us <small>Sponsored by Novartis</small>		Griffin Hall
8:45AM – 5:30PM	Muscle Station <small>Sponsored by Scholar Rock</small>		Griffin 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>		Lone Star Ballroom E - H
9:00AM – 10:30AM	Kids Talk it Out (Ages 12 – 17) Angela Wrigglesworth, Elementary Education Teacher, adult with SMA Al Freedman, PhD, SMA Dad and Child/Family Psychologist 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. <i>**please note, kids in this session will be escorted to the Children's Program in Lone Star Ballroom E- H when the session concludes at 10:30am. Please pick up your kids in Lone Star Ballroom E - H**.</i>		301 & 302
 <h2 style="margin: 0;">Opening General Session: A Cure SMA Update on the Future of SMA</h2> <p style="margin: 0;">Do not miss this opening session where members of Cure SMA's leadership review progress, changes, and our goals for meeting the needs of the SMA community, today and into the future:</p> <p style="margin: 0;">Hear about our next treatments and other possible breakthroughs, including an update on new research investments, see the latest real-world evidence on how SMA is changing and Cure SMA's plans to meet these evolving needs, and learn about new programs and advocacy initiatives underway to break down barriers and improve access to healthcare, treatments, and other everyday living needs.</p> 			
9:00AM – 11:00AM			Lone Star Ballroom A - D
11:00AM – 4:45PM	Adults with SMA Lounge <small>Sponsored by Biogen</small> **for adults with SMA and their attendants**		Brazos
11:00AM – 4:45PM	Teen Lounge <small>Sponsored by Luke 18:1 Foundation</small> **for all teens ages 12 - 18**	<i>LUKE 18:1</i>	303 & 304

11:20AM – 12:20PM Workshop Session #1

	<p>Finding a Job, Interviewing and How to Ask for Modifications Panel Brian Ronningen Doug McCollough Julia Feinberg Sarah Boggess</p> <p>Come to this session to learn more about the experiences, both positive and negative about searching for a job. We look forward to having a lot of open discussion and conversations throughout this session.</p>	<p>JW Grand Ballroom 7</p>
	<p>Pre-symptomatic and Early Diagnosis Experiences Dany Sun, MSW, SMA Mom, Social Work Senior Manager, Cure SMA Diane Murrell, LCSW Marnie Harris, SMA Mom</p> <p>If you're a family who has received an SMA diagnosis either in-utero, through newborn screening, or some other early diagnosis avenue, please join us in this session. You will have an opportunity to hear stories from others who can relate to your experience and to make connections with other parents, too. Professionals in the SMA community who support newly diagnosed families will also provide support, answer questions, and speak to the unique place you may find yourself in with an early or pre-symptomatic diagnosis.</p>	<p>JW Grand Ballroom 3 & 4</p>
	<p>Spouses and significant others of adults with SMA sharing your experience Kyla Pollock, spouse of an adult with SMA</p> <p>A time for spouses and partners of those with SMA to share their unique perspectives, ideas and experiences. This session is intended for spouses, partners, and significant others to those with SMA, only. <i>Time will be allotted for all attendees to ask questions and contribute to the group discussion.</i></p>	<p>201 & 202</p>
	<p>Aquatic Physical Therapy - The Why and How for Individuals with SMA Jennifer Martyn, PT</p> <p>Join us to hear the whys and to hear the whys and hows of aquatic exercise for you or your family member. We will discuss reasons to and not to use the water, what to look for in aquatic facilities, safety, equipment, and exercises. This is a great time to come and see the equipment, mostly dry, and in one place to get the creative juices flowing for how some items might be adapted to be just perfect for your needs. Plenty of time will be available for attendees to ask questions.</p>	<p>Lone Star Ballroom A - D</p>
	<p>Research to Ethics, Angst, Excitement and Realities of SMA Treatments and Research Rob Graham, MD Vanessa Battista, DNP, MBA, MS, RN, CPNP-PC, CHPPN, FPCN</p> <p>A "cure" for everyone? Beyond the "hope and hype" of research, there are ethical, emotional, and practical considerations for the individual with SMA and their family. This session will review factors that may influence decision-making. Extensive time will be allotted for open discussion of research benefits and challenges, access, and distributive justice for newly approved therapies.</p>	<p>JW Grand Ballroom 8</p>
	<p>Navigating Power Mobility Options, While Living with SMA 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., processes for obtaining powered mobility devices, and the best practice for approaches to funding challenges. The presentation will be followed by an audience Q & A.</p>	<p>JW Grand Ballroom 5</p>
	<p>The Difference of Donations: How Fundraising Can Change the Future of SMA Jamie Gibson, Chief Development Officer, Cure SMA Jesse Aynes, Vice President, Development & Events, Cure SMA</p> <p>This session will delve into the transformative power of donations and fundraising efforts in shaping the future landscape of Spinal Muscular Atrophy (SMA). Attendees will gain insights into the impact of their contributions and how they contribute to advancing research, providing support to families affected by SMA, and ultimately, bringing hope for a cure.</p>	<p>JW Grand Ballroom 6</p>

	<p>Healing the Grieving Heart – Part I Fred Troutman, RN, PhD David Sereni, DPT 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>	404
	<p>Parenting With SMA</p> <p><i>Sponsored by Genentech</i></p> <p>Collin Pollock, adult with SMA and father Annah Mobus, adult with SMA and mother Carli Hamilton, adult with SMA and mother Steve Bingman, adult with SMA and father</p> <p>Join a few panelists for a conversation about the rewards and challenges of being a parent living with SMA.</p> 	201 & 202
	<p>Personal Care Assistants: From Recruitment and Hiring to Day-to-Day Management and Everything In-Between Paula Barrett, MBA Carolyn Barrett, MS, adult with SMA</p> <p>This workshop, designed for SMA parents, adults, and teens, will begin with a brief overview on how to get started when hiring and managing you or your child's personal care assistants for the first time. What to look for? Where to look? How to describe your needs? How to train someone on your specific needs? How to transition care management from parents to teens? We'll then dive into common questions, issues, and circumstances that come up while managing complex PCA care (among everything else!). The workshop will conclude with a dialogue on unique challenges, opportunities, and everything in between that comes up when hiring and managing PCA care as an individual with SMA (including recruiting during a tight labour market).</p> <p><i>While this workshop is designed for individuals looking to bring PCA's into their life for the first time or young adults who may be looking to independently manage their team of PCA's, all are welcome.</i></p>	JW Grand Ballroom 6
	<p>What it Means to be a Teen on Wheels Angela Wigglesworth, Elementary Education Teacher, adult with SMA</p> <p>It is hard to be a teenager in today's society. The combination of rapidly changing hormones, peer pressure, and educational challenges are often too much for most young people to handle. If asked to imagine all these factors combined with a diagnosis of SMA, most would probably picture a disaster waiting to happen. But being a teen with SMA is not impossible and in fact can produce some of the most influential and positive times in a young person's life. This facilitated session, led by former teen Angela Wigglesworth, will help to shed light on how to overcome the difficulties of being a teenager and bring forth a smooth segue into adulthood.</p>	301 & 302
	<p>Sharing Your Type 1 Experience <i>(for individuals with SMA type 1 born in 2017 or earlier, and their family)</i> Moderated by, Amy Medina, SMA Parent</p> <p>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.</p>	Lone Star Ballroom A - D
<p>3:25PM – 4:45PM Workshop Session #3</p>		
	<p>Mindfulness for Everyday Life Tara Davenport, SMA parent and mindfulness teacher</p> <p>The recommendation to try mindfulness is very popular these days, but what does it really mean to be mindful or have a mindfulness practice? Join Tara, mother to a 12-year-old with SMA, to explore what mindfulness is and learn easy to use practices to incorporate it into your daily life. Come try for yourself if mindfulness could open the door to a more peaceful life for you!</p>	402 & 403

	<p>Navigating The Special Education Process: Setting our Kids up for Success In Preschool & Elementary School Tina Lewis, Parent of a Child with SMA, and Education Specialist Kimberly Cook, Parent of a Child with SMA</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 my own personal and professional experiences, I 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>	<p>JW Grand Ballroom 3 & 4</p>
	<p>How to Travel with SMA Cory Lee, travel blogger, adult with SMA Sandy Gilbreath, travel blogger, SMA parent</p> <p>Has the travel bug bitten you, but you're not sure how to make traveling with SMA a reality? Or maybe you're caring for someone with SMA and want to know how to see the world with them? Cory Lee, a travel blogger with SMA, and his mom, Sandy, will share how they've explored over 40 countries and all 7 continents together. From navigating air travel with a wheelchair to finding accessible hotels and destinations, they will cover everything you need to know to make your next adventure more stress-free. No matter what your experience is when it comes to traveling, you will undoubtedly want to book your dream trip by the end of this informative session.</p>	<p>JW Grand Ballroom 5</p>
	<p>Physical Therapy for Eating, Speaking and Breathing: HOW and WHEN can a Speech Pathologist help? Renee Roy Hill, MS, CCC-SLP, COM@CLC</p> <p>Muscles are crucial to the development of the oral motor system for eating, speaking and breathing and can be affected or become affected in persons with SMA. A speech pathologist with specialized training in the motor system and swallowing can be a crucial part of the multidisciplinary team. These skills can assist our clients in developing or improving the underlying motor skills needed (habilitation/rehabilitation). Often therapy programs focus on strategies to minimize difficulty (compensatory). While this may be necessary in the short term, understanding how specific muscle based exercises can help improve function is necessary and finding the right therapist is crucial. This course will provide an overview of what an individualized muscle-based program for speech, eating and breathing might look like. In a recent literature review "a comprehensive examination is recommended to evaluate structural and physical impairments...as well as functional and instrumental activities of daily living. Agyenkwa, S. K., et.al (2023). Rehabilitation in Spinal Muscular Atrophy; A Narrative Review. Understanding the role of the speech pathologist and what to ask for can help with navigating support.</p>	<p>JW Grand Ballroom 6</p>
	<p>Taking Care of Business Emily Wolinsky</p> <p>If you're curious about living life and peeing quite freely with little interruption in your daily routine, this workshop will provide information about options for eliminating and increasing your entire sense of independence. You will learn from your peers directly about the pros and cons, the ins and outs, and the ups and downs of taking care of your business.</p>	<p>201 & 202</p>
	<p>Young Adults Talk it Out (Ages 18+) Angela Wrigglesworth, Elementary Education Teacher, adult with SMA Al Freedman, PhD, SMA Dad and Child/Family Psychologist</p> <p>This facilitated session will provide SMA-affected young adults (ages 18+) an opportunity to talk with each other about their lives.</p>	<p>301 & 302</p>




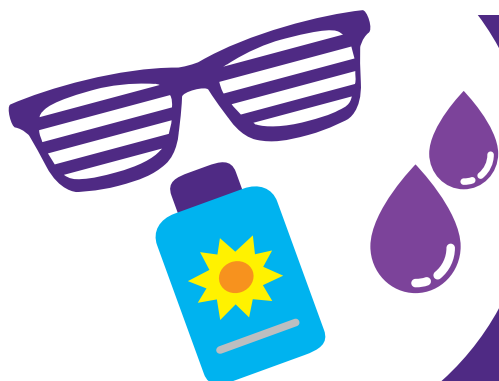
SELF-EXPRESSION EXHIBIT



Biogen's SMA Community Self-Expression Exhibit will offer an opportunity to showcase and engage in creativity in the SMA community on Friday and Saturday this year, with a special focus on traveling. You can peruse the pre-submitted artwork and vote for your top pick in Griffin Hall on Level 2, with the fan-favorite announced during Sunday's Closing Session and featured in Cure SMA's next *Directions* newsletter.

FRIDAY & SATURDAY, 8:45AM – 5:30PM

	<p>Orthopedic Management Brian Snyder, MD, PhD Samuel Rosenfeld, MD Anne Stratton, MD</p> <p>This workshop will focus on life with SMA as it pertains to maintaining the best possible orthopedic management. It will also address the orthopedic complications of SMA. Children with SMA often have musculoskeletal impairments that interfere with mobility, function, and efficiency, and can contribute to restrictive pulmonary disease. Orthopedic intervention can improve or stabilize these impairments and help prevent deterioration in function. Orthopedic surgical procedures can correct hip instability and scoliosis, facilitate orthotic management, and accommodate the demands of continued growth. Musculoskeletal integrative medicine is important in normal development, especially in the child with SMA.</p>	Lone Star Ballroom A - D
	<p>Do-It-Yourself (DIY) Advocacy: Have an Impact on Issues That Matter to You Maynard Friesz, Vice President, Policy and Advocacy, Cure SMA Sarah Bellish, Manager, Policy and Advocacy, Cure SMA, adult with SMA</p> <p>Are you passionate about advocating for issues that impact your everyday life such as caregiving, transportation, housing, or financial security? Want to make a difference for yourself and others with SMA but don't know how or where to start? Cure SMA's Advocacy Team will share DIY tips and resources for connecting with and educating your elected leaders about SMA and SMA community advocacy priorities. Let's make our voices heard together!</p>	JW Ballroom 1 & 2
6:30PM – 8:30PM	<p>Family Friendly Researcher Poster Session</p>	JW Grand Ballroom 5 - 8
7:30PM – 9:30PM	<p>Teen Social Sponsored by Luke 18:1 Foundation <i>LUKE 18:1</i> **for all teens ages 12 – 18**</p>	402 & 403
7:30PM – 11:00PM	<p>Adults with SMA Reception Sponsored by Biogen and The Dhont Family Foundation</p> 	JW Grand Ballroom 1 - 4
8:30PM – 11:00 PM	<p>Mom's Night Out **for moms only**</p>	Lone Star Ballroom A - D



PLEASE NOTE

WEAR SUNSCREEN AND KEEP HYDRATED!

As many of you know, June in Texas 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, JUNE 8 | AGENDA

7:00AM	Breakfast Opens	Lone Star Ballroom Foyer & Griffin Hall
7:15AM – 5:00PM	Registration Open for all Conference Attendees	Griffin Hall Foyer
7:45AM – 5:30PM	Exhibitor Tables Open	Griffin Hall
7:45AM – 8:45AM	Symposium by Biogen: Our Vision: Improving Air Travel for People with SMA	Biogen Lone Star Ballroom A - D
8:45AM – 5:30PM	Self-Expression Exhibit <i>Sponsored by Biogen</i>	Biogen Griffin Hall
8:45AM – 5:30PM	A Piece of Us <i>Sponsored by Novartis</i>	NOVARTIS Griffin Hall
8:45AM – 5:30PM	Muscle Station <i>Sponsored by Scholar Rock</i>	Scholar Rock Griffin Hall
9:00AM – 11:40AM & 1:00PM – 5:00PM <i>(Drop off opens at 8:30am & 12:30pm)</i>	Children's Program <i>Sponsored by The Jacob Isaac Rappoport Foundation</i>	jir FOUNDATION Lone Star Ballroom E - H
9:00AM – 5:00PM	Adults with SMA Lounge <i>Sponsored by Biogen</i> **for adults with SMA and their attendants**	Biogen Brazos
9:00AM – 5:00PM	Teen Lounge <i>Sponsored by Luke 18:1 Foundation</i> **for all teens ages 12 - 18**	LUKE 18:1 303 & 304
9:00AM – 10:10AM Workshop Session #4		
	Unpacking Clinical Trials Rob Graham, MD Thomas Crawford, MD Three treatments are approved for individuals with SMA. More treatments are in development and clinical trials. This workshop brings together a panel of three neurologists who conduct SMA clinical trials for a discussion of how to think about and interpret the results from SMA clinicals trials and how to think about this information when making decisions about treatments.	Lone Star Ballroom A - D
	Pediatric Yoga for SMA – A 5 Part Therapeutic Yoga Practice Anne Buckley-Reen, OTR/RYT, FORKIDS OT 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. A floor practice (on a yoga mat) will guide participants and caregivers to support wellness with a variety of postures and modifications for all functional levels. 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.	JW Grand Ballroom 6

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>Empowering Independence: The Benefits of Service Dogs Katelynne Steinke Jones on the Job</p> <p>Anybody that has typed "service dog" into a search engine knows that it can become overwhelming and confusing easily; distinguishing fact from fiction is difficult unless you already know what you're looking for. This workshop will cover all things service dog related, from what a service dog is and does to acquisition options and handler rights. 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 first-hand knowledge and experience with multiple schools, different breeds and genders, and has a vast amount of working dog knowledge she's ready to share with you. You'll leave with the knowledge 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. 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.</p>	<p>JW Grand Ballroom 3 & 4</p>
	<p>The Role of the Multi-disciplinary Clinic - How can it be helpful for those identified pre-symptomatically Leslie Nelson, PT, PhD, OCS Anne Stratton, MD Danielle Forrest, 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>JW Grand Ballroom 1 & 2</p>
	<p>Beyond high school – from interest to employment Jessica Keough, Founder and President of Faith Above My Ability, adult with SMA</p> <p>Jessica will share her post-secondary journey to help you identify how you can view your disability (or child's disability) as a super power. She'll also share practical steps for student centered transition planning, advocacy tips, employment accommodations, and ways you can empower yourself or your child. For ages 13 and up, working professionals with SMA, parents of teens who have IEPs.</p>	<p>JW Grand Ballroom 8</p>
	<p>I Need to Cough, I Need to Breathe Oren Kupfer, MD Peter Schochet, MD Jane Taylor, MD</p> <p>In this workshop, we will discuss how cough works and why it is important, why cough strength is diminished in SMA, how we can measure cough strength, and how we can help cough function and limit respiratory infections and hospitalizations. We plan to discuss the medical literature, share our experiences, and hear from the audience. Individuals with SMA are at risk for difficulty breathing due to muscle weakness. We will also discuss why the muscle weakness causes difficulty breathing during illness and after surgery, and how to know when breathing support machines such as BIPAP should be considered. We will talk about the modalities available to use at home and in the hospital, as well as strategies to help your care team support respiratory health at home. There will be opportunities after the presentation to ask general questions about breathing complications and to share experiences that have improved the health of those with SMA. Bring your questions and experience to this interactive session and we hope to have our whole pulmonary team there!</p>	<p>JW Grand Ballroom 5</p>
	<p>Taking Charge of Your Health: The Transition from Pediatric to Adult Care <i>Sponsored by Genentech</i> Vanessa Battista, DNP, MBA, MS, RN, CPNP-PC, CHPPN, FPCN Bakri Elsheikh, MBBS, FRCP Julianne Meiser, MSW, LSW</p>  <p>This workshop will focus on the following aspects of transition from pediatric to adult healthcare: Understand the importance of "why" transition; identify some of the transition skills needed before transferring to adult care; a single clinic study on advance directives; and, an adult provider's perspective on adult clinics and differences you might anticipate. This session is ideal for parents, adolescents, and young adults who are preparing transitioning from pediatric to adult care.</p>	<p>201 & 202</p>

	<p>University of Utah TRAILS Program: Advancing Adaptive Sports and Innovative Equipment Solutions Melissa McIntyre, DPT Januel Gomez, avid skier, adult with SMA</p> <p>The TRAILS program at the University of Utah is dedicated to meeting the recreational, wellness, and educational needs of individuals with complex physical disabilities. Established in 2005 by Dr. Jeffery Rosenbluth and Tanja Kari, TRAILS has been at the forefront of developing groundbreaking adaptive equipment, enabling athletes to engage in sports previously inaccessible to them.</p> <p>In this workshop, we will delve into the rich history of TRAILS, exploring its evolution over the years. We will then turn our focus to the diverse programming offered and the cutting-edge equipment available through the program. Lastly, we will discuss our current outreach initiatives and provide opportunities for engagement and involvement. Join us as we celebrate inclusivity and empower individuals to thrive through adaptive sports and innovative solutions.</p>	402 & 403
	<p>Memory Boxes: Create a Treasure (for children & teens only) Jennifer Lemisch, MA, ATR-BC, LPC</p> <p>Grieving a loss young is not an easy process and a different experience for everyone. This workshop will provide bereaved children/teens an opportunity to create a box to hold memories of their loved one. Artmaking provides an outlet for expression of feelings and children/teens will be encouraged to share together while creating their box. Children/teens are welcome to bring photos of their loved ones to use. There will also be a printer available to print a few photos.</p>	305

10:30AM – 11:40AM Workshop Session #5

	<p>The Being in Doing: Making Your To-Do List Work for YOU! Wendy Godfrey, ST Wellness</p> <p>Come explore how your trusty To-Do List can naturally heighten self-awareness, help you be more intentional with resources and even improve work-life balance. In this program we will discover the connection between the To-Do List and personal values, explore how to individualize our lists, connect tasks with our core values, commit to task completion by supporting core values. Join me to discover how you can decrease stress and become more resilient by understanding the "why".</p> <p>Oh, and please bring YOUR To-Do List!</p>	JW Grand Ballroom 6
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	<p>How to Build Your Presence and Advocate Through Writing & Social Media <i>Sponsored by Genentech</i></p> <p>Kevin Schaefer, Writer, Podcaster, adult with SMA Allie Williams, Writer, Vlogger, adult with SMA Brianna Albers, Author, Advocate, adult with SMA Candis Welch, Advocate, adult with SMA Connie Chandler, Social Media for We Carry Kevan, adult with SMA Shane Burcaw, adult with SMA Jose Flores, Corporate Speaker, #1 Best-Selling Author, Global Motivator, and Workshop Facilitator, adult with SMA</p> <p>In this workshop, moderator Kevin Schaefer speaks with several published authors and influencers in the SMA community. These panelists talk about their writing, storytelling techniques, social media platforms and how their work coincides with disability advocacy. They also share tips for getting your work out in the world and the importance of representation in media. An audience Q&A will follow the main conversation.</p>	 JW Grand Ballroom 5
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GENENTECH'S MOST LIKELY NOT TO... – AN SMA MY WAY MUSICAL EXPERIENCE




Genentech and SMA My Way will be bringing a taste of Broadway to the conference this year, celebrating highlights from the witty and relatable Most Likely Not To... Musical, which will take place in the JW Grand Ballrooms 5-6 on Level 4 on Saturday evening. Attendees will be able to enjoy show-stopping original songs and video clips from the live event which took place in New York City on Rare Disease Day this year and hear from cast members about their experiences as well.

SATURDAY, 6:00PM – 7:30PM

	<p>Incorporating Exercise into Your Life Leslie Nelson, PT, PhD, OCS Anne Stratton, MD Tina Duong, PT, 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>	<p>JW Grand Ballroom 1 & 2</p>
	<p>Keepsake Creation: Grieving Through Art Jennifer Lemisch, MA, ATR-BC, LPC</p> <p>Grieving a loved one is not an easy process and is a different experience for everyone. This workshop will provide participants an opportunity to create keepsakes and share memories of their loved one while artmaking. Participants are encouraged to bring photos of your loved one for use in the workshop. There will also be a printer available to print a few photos if brought digitally.</p>	<p>305</p>
	<p>Achieving a Better Life Experience with ABLÉ Accounts Mark Fry, J.D., CPA (Inactive); Louisiana Board Certified Legal Specialist in Estate Planning and Administration</p> <p>This workshop will provide attendees with basic and advanced information on the use of ABLÉ accounts to expand the financial empowerment for individuals with exceptionalities. The workshop will explore with the attendees the various limitations, income tax benefits, and asset protective aspects associated with the ABLÉ accounts, and will compare the use of these accounts with the use of special needs or supplemental care trusts.</p>	<p>JW Grand Ballroom 3 & 4</p>
	<p>Preventing Emergencies – Daily Care, Contingencies and Response in the Community Rob Graham, MD Michael Manchester, Emergency Manager</p> <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>	<p>JW Grand Ballroom 8</p>
	<p>Time is Neurons: Exploring Legacy Giving for SMA Jamie Gibson, CNP, Chief Development Officer, Cure SMA Emily Leitzinger, Director, National Leadership Giving, Cure SMA</p> <p>This session will focus on legacy and planned giving, exploring ways for individuals to leave a lasting impact on the SMA community. Attendees will learn about various options for including Cure SMA in their gifts of the future, ensuring their support continues to make a difference for generations to come.</p>	<p>JW Grand Ballroom 7</p>
	<p>Transition to Adulthood Panel Amber Bosselman Ryan Manriquez Megan DeJarnett Andrew Cherico</p> <p>This session is a 2nd part to the Taking Charge of Your Health: The Transition from Pediatric to Adult Care in the previous session. You will now hear from Adults with SMA who have been through the transitioning to adulthood phase. Hear their experiences and come with questions!</p>	<p>201 & 202</p>

	<p>Kids Talk it Out (Ages 6 – 11) Angela Wigglesworth, Elementary Education Teacher, adult with SMA Al Freedman, PhD, SMA Dad and Child/Family Psychologist</p> <p>This facilitated session will provide SMA-affected children (ages 6-10) 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>	301 & 302
<p>11:40AM – 1:00PM Lunch Griffin Hall, Lone Star Ballroom Foyer</p>		
<p>1:00PM – 2:10PM Workshop Session #6</p>		
	<p>Adults with SMA Relationships Panel – Share your experience Angela Wigglesworth and Justin Titcombe Jenna Coburn and Tanya Vega Spencer Cook and Michaela Arzola Collin Pollock and Kyla Pollock</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>	JW Grand Ballroom 6
	<p>Spinal Muscular Atrophy Nutrition – Food for Thought Rebecca Hurst Davis, MS, RD, CSP, CD, CNSC Stacey Tarrant, BS, RD, LDN Laura Watne, MS, RD, CSP</p> <p>In this workshop, we will discuss nutrition for people with SMA of all ages, from birth to adulthood, whether food is eaten by mouth, provided by tube-feeding, or a mixture of both. We will address the unique nutritional needs of infants, toddlers, school-aged children, teenagers, and adults. We will also discuss how disease-modifying therapies continue to impact our nutrition recommendations.</p>	JW Grand Ballroom 8
	<p>Get To The Art of It: Community Art Time Jennifer Lemisch, MA, ATR-BC, LPC</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>	JW Grand Ballroom 7
	<p>Your Mental Health Toolbox Amber Bosselman, Disability Life Coach</p> <p>This brand-new workshop with disability life coach Amber gives you the top tools you need to strengthen your mental well-being. You will get actionable steps you can start doing right now, and resources specifically designed for people with SMA to help you navigate life's challenges with resilience.</p>	JW Grand Ballroom 3 & 4
	<p>Navigating The Special Education Process: Transitioning to Middle School, High School, and College Tina Lewis, Parent of a child with SMA, and Education Specialist Kimberly Cook, Parent of a child with SMA</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 my own personal and professional experiences, I 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>	Lone Star Ballroom A - D
	<p>Adaptive Sport / Recreation Testimonials and Resources Charlie Zerzan, wheelchair basketball player Marley Robinson, volt hockey player Kurt Beach, Adaptive Sports Director at the University of Michigan Ed Bronsdon, moderator</p> <p>Listen and learn from the personal testimonials of individuals with SMA who are active in various adaptive sport and recreation programs. What activities have proven particularly rewarding / challenging / fun for others? What are some examples of accommodations that can be made to adapt an activity to your abilities? What resources are available to get started? How costly are various activities? Are they safe? What benefits may come from being active in sport and recreation? How can you get involved? After learning more from the panelists, attendees will be able to individually ask questions to gain more insight into adaptive sport and recreation options for themselves and their families.</p>	JW Grand Ballroom 1 & 2

	<p>Healing the Grieving Heart – Now What? Part II Fred Troutman, RN, PhD David Sereni, DPT Natasha Abruzzo, RN</p> <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>	404
	<p>Shifting Perspectives: Media Representation and the Disabled Community - Roundtable Dialogue for Inclusive Narratives Sponsored by  Kevin Schaefer, Writer, Podcaster, adult with SMA</p> <p>What kind of disability representation is there in mainstream media? How are wheelchair users portrayed in stories? Come share and discuss your thoughts on this subject as we look at both positive and negative examples of representation.</p>	JW Grand Ballroom 5
	<p>Siblings Talk it Out (Ages 12 to 17) 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 12-18 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>	305
<p>2:30PM – 3:40PM Workshop Session #7</p>		
	<p>Evolving Your Wheels: Driving with SMA Jill Sclase, CTRS, CDRS</p> <p>The workshop will look at home and community activities to assist in building appropriate skills for the potential of being a driver. We will also look at the cognitive and social skills required for driving as well as identifying the adaptive driving equipment available to assist with the physical limitations associated with SMA. The workshop will include sharing stories of various clients with SMA who are successfully driving.</p>	Lone Star Ballroom A – D
	<p>Personal Care Assistants Discussion Panel Emily Wolinsky Annie Heathcote Spencer Cook TK Small</p> <p>Step into the world of caregiving in this workshop. Those in the SMA community looking for more information on personal care assistants can come together to share their diverse perspectives, experiences, and insights. Join us for an enriching discussion as we explore the profound impact of caregiving, exchange practical strategies, and foster a supportive community.</p>	JW Grand Ballroom 6
	<p>Grandparents Coffee and Share Your Experience Moderated by Sylvia and Ramiro Resendez, Grandparents</p> <p>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.</p>	JW Grand Ballroom 8
	<p>Medical Management of Adults with SMA Bakri Elsheikh, MBBS, FRCP Tina Duong, PT, PhD</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>	JW Grand Ballroom 1 & 2

	<p>Therapeutic Yoga for Adults and Teens with SMA Anne Buckley-Reen, OTR/RYT, FORKIDS OT Peyton Tansey, Adult with SMA</p> <p>The workshop will introduce you to the benefits of yoga for adults and teens with SMA. Anne and her Co-host Peyton will discuss the physical, emotional, respiratory, cognitive and immunological benefits of yoga. The workshop will include a chair practice modeled by Peyton and all are invited to participate. The workshop will conclude with a review of a typical yoga routine which includes circle of song, eye exercises, postures, progressive relaxation and breathing exercises. Learn about the many benefits of yoga practice for SMA including stress reduction, balanced energy, joint mobility, respiratory support and more!</p>	<p>JW Grand Ballroom 5</p>
	<p>Genetics and Reproductive Options for SMA Families Harvey J. Stern, MD, PhD, FACMG, FAAP Melissa Gibbons, MS, CGC</p> <p>This workshop will provide an introduction to the genetics and inheritance of SMA. Our objective is to provide a better understanding of the role SMN1 and SMN2 play in SMA and to discuss the different genetic testing options available for SMA. These tests allow us to diagnose 5q-SMA in infants and adults, identify SMA carriers, and determine if your unborn child has SMA. The wide range of reproductive options for couples who are at-risk for having children with 5q-SMA will be discussed including Preimplantation Genetic Testing (PGT-M) with in vitro fertilization (IVF), Sperm/Egg Donation, Chorionic Villus Sampling, Amniocentesis, Newborn Screening and at birth diagnostic testing.</p>	<p>402 & 403</p>
	<p>Supporting the Emotional Health in SMA Families Julia Feinberg, PsyD</p> <p>We all know physical health is important and have some idea of how to take care of our bodies. We've learned the skills from our SMA doctors, clinics, family, friends, and our own experiences. However, emotional wellbeing isn't emphasized nearly as much in SMA care, even though it is critical to living a meaningful, joyous life. In this workshop, we will take space for you to reflect on how your physical and emotional health are interlinked, the factors that impact your emotional wellbeing, and ways to support your mental health. You will come away with greater understanding of how SMA impacts your emotional health and the things you can do in your own life to improve your emotional wellbeing</p>	<p>JW Grand Ballroom 3 & 4</p>
	<p>Siblings Talk it Out (Ages 5 to 11) 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 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 make friends and have fun!</p>	<p>305</p>
<p>4:00PM – 5:00PM Workshop Session #8</p>		
	<p>Empowering Women: Sharing Health Tips and Journeys in the SMA Community Megan DeJarnett Angela Wigglesworth Cory Jacobson Carli Hamilton</p> <p>Calling all women, from adolescents to seniors, to join us for an enriching session focused on empowerment in our daily lives. This gathering is an opportunity to delve into a dialogue where we exchange invaluable health tips and personal journeys within the SMA community. Together, we'll explore and celebrate the remarkable resilience and strength inherent in every woman. Join us to share, learn, and uplift one another on our unique paths.</p>	<p>JW Grand Ballroom 5</p>



NOVARTIS' "A PIECE OF US"



Novartis will be offering an engaging activity on Friday and Saturday to highlight the ongoing learning and collaboration that the SMA community continues to achieve together. Head to Griffin Hall on Level 2 to contribute to a message wall by decorating a personal puzzle piece, expressing what the SMA community means to you. Your thoughts and drawings will contribute to this collective celebration of the SMA community's unity and strength.

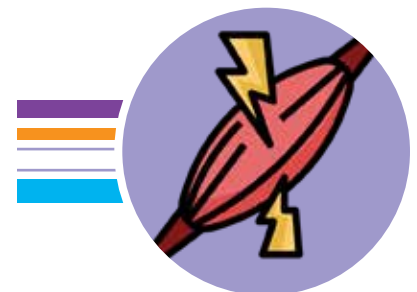
FRIDAY & SATURDAY, 8:45AM – 5:30PM

	<p>Tech for Seamless Living: Wheelchairs, Driving and More Kevin Schafer, Writer, Podcaster, adult with SMA Tyler Dukes, DevOps Manager, adult with SMA Jenna Coburn, Social Media Manager, adult with SMA Jose Flores, Corporate Speaker, #1 Best-Selling Author, Global Motivator, Workshop Facilitator, adult with SMA Amber Bosselman, Certified Life Coach, adult with SMA</p> <p>In this panel discussion, five 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>	<p>JW Grand Ballroom 6</p>
	<p>Dating Disabled: Navigating the Dating World as a Disabled Person Maylan Chávez, BS in Psychology, adult with SMA Michael Hazel, Film Major, adult with SMA</p> <p>This workshop will discuss and dismantle the happiness and heartbreak of dating as a disabled person. Adults with SMA will be exploring the obstacles, challenges, logistics, and stigmas surrounding the dating world in an open, round-table type discussion with all attendees. Ages 16+ are highly encouraged to attend. The workshop will be answering questions, sharing experiences, anonymously and in person, for those who have doubts, need advice, or simply want encouragement and uplifting with navigating dating.</p>	<p>JW Grand Ballroom 1 & 2</p>
	<p>Mindfulness for Kids Tara Davenport, SMA parent and mindfulness teacher Claire Miles, SMA patient (x-linked)</p> <p>When you're a child with SMA, the challenges you face can create anxiety and fear in areas even unrelated to SMA. Join us as we explore ideas on how kids can use mindfulness-based techniques to help with those hard times. We will share many ideas so families can pick and choose what to try! All ages are welcome to join us!</p>	<p>301 & 302</p>
	<p>Q and A Session with The Pulmonary Team Oren Kupfer, MD Peter Schochet, MD Jane Taylor, MD</p> <p>Over the last few years, disease-moderating medications have become available to treat patients with SMA. These agents have positively altered the day-to-day living of children and adults with SMA and are improving the prognosis of this illness. Respiratory and sleep changes are amongst the benefits seen. In our 2024 Annual Cure SMA Family conference, the pulmonologists and sleep physicians who serve on the MAC are holding sessions on airway clearance, respiratory support, optimizing sleep health and an open free flowing Q and A session. Come meet our pulmonologists and be ready with your questions, as our experts look forward to answering them while giving you updates on what to expect in the coming years.</p>	<p>Lone Star Ballroom A - D</p>

SCHOLAR ROCK'S MUSCLE STATION



Scholar Rock introduces the very first Muscle Station in Griffin Hall on Level 2, where you can enjoy a range of activities and treats. Focus on your muscles through educational sessions led by a physical therapist, and savor delicious smoothies and frozen treats. Make sure to stop by Scholar Rock's booth to pick up a flyer detailing the schedule for these special activities.




FRIDAY & SATURDAY, 8:45AM – 5:30PM

SATURDAY, JUNE 8 | AGENDA

	Early Scoliosis Management in SMA Samuel Rosenfeld, MD Brian Snyder, MD This workshop will focus on care of early scoliosis with SMA including monitoring and management considerations and strategies.	JW Grand Ballroom 8
	Must-Love Fundraising: Find Your Perfect Event Match Cure SMA Development and Events Department This speed dating themed workshop-style session will nourish your time, talents, and treasures to take your fundraising efforts to the next level. This session will showcase Cure SMA's diverse fundraising campaigns, including Walk-n-Roll, DIY, Endurance, Corporate Giving, and Distinguished Events. Attendees will have the opportunity to explore each campaign's unique features, success stories, and ways to get involved, empowering them to support Cure SMA's mission in their own creative ways.	JW Grand Ballroom 7
6:00PM – 7:30PM	Most Likely Not to... - An SMA My Way Musical Experience <i>Sponsored by Genentech</i> 	JW Grand Ballroom 5 & 6
7:00PM – 9:00PM	PJ Party and Movie Night	Lone Star Ballroom A - D
7:30PM – 9:30PM	Teen Social <i>Sponsored by Luke 18:1 Foundation</i> <i>**for all teens ages 12 - 18**</i> 	303 & 304

SUNDAY, JUNE 9 | AGENDA

7:45AM	Breakfast Opens	Lone Star Ballroom Foyer & Griffin Hall
9:00AM – 11:15AM (Drop off opens at 8:30am)	Children's Program <i>Sponsored by The Jacob Isaac Rappoport Foundation</i> 	Lone Star Ballroom E - H
9:00AM – 11:15AM	It's a Wonderful Life/Closing General Session	Lone Star Ballroom A - D

Thank you to our 2024 Annual SMA Conference Speakers and Panelists

A heartfelt expression of gratitude to every speaker who played a crucial role in reuniting our community in person at the 2024 Annual SMA Conference! Your dedication to volunteering your time and expertise to educate the community on the latest developments related to SMA is truly commendable. The impact of your contributions reverberates throughout our community, providing valuable insights and fostering a sense of unity. We recognize the selfless commitment each speaker demonstrated, and we want to emphasize that the success of this year's conference hinged significantly on your collective efforts. Your willingness to share knowledge, insights, and experiences has not only enriched the event but has also contributed to the overall well-being of individuals and families affected by SMA.

Your passion for advancing understanding and awareness in the SMA community has undoubtedly left a lasting impression. We extend our sincerest thanks for being an integral part of the 2024 Annual SMA Conference. Your commitment to fostering education, connection, and support has made a significant impact, and we look forward to future collaborations that continue to strengthen our community.

FAMILY FRIENDLY RESEARCHER POSTER SESSION

FRIDAY JUNE 7 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:

SMA ASTROCYTES IMPACT MOTOR NEURON FUNCTION

Allison Ebert, PhD, Medical College of Wisconsin

SCHOLAR ROCK'S SMA PROGRAM

Ameet Khara, PharmD; Christabella Cherubino, DC, MS, CME, Scholar Rock

GONE FISHING: USING SMN MUTANTS TO CATCH TARGETS FOR ADDITIVE THERAPEUTICS FOR SMA

Anton J Blatnik III, PhD, The Ohio State University College of Medicine

THECAFLEX DRX™ SYSTEM: IMPLANTABLE INTRATHECAL CATHETER AND SUBCUTANEOUS PORT PLATFORM FOR REPEAT INTRATHECAL DELIVERY OF NUSINERSEN

Cassandra N Dennys, PhD, Melissa Breedlove, Catalina Troche, John McGuire, Alcyone Therapeutics

RESILIENT- EFFICACY AND SAFETY OF TALDEFGROBEP ALFA IN SPINAL MUSCULAR ATROPHY

Cliff Bechtold, Biohaven

THE DIFFERENCE OF DONATIONS: HOW FUNDRAISING CAN CHANGE THE FUTURE OF SMA

Cure SMA Development Team, Cure SMA

CHARACTERIZING THE REVERSIBILITY OF CELLULAR AND MOLECULAR DEFECTS OF SMN-DEFICIENT MUSCLE

Elana Molotsky, PhD, Michelle Harran Chan-Cortes, PhD, Kamran Eslami, BS, Bhavya Ravi, PhD, Stephen Brown, BS, Ramzi Khairallah, PhD, Charlotte Sumner, MD, Johns Hopkins University

HOW DOES DUAL THERAPY AFFECT OUTCOMES OF SMA IN SYMPTOMATIC CHILDREN

Elicia Estrella, MS, LCGC, Dept. of Neurology Boston Children's Hospital/Harvard Medical School

INSIGHTS INTO THE HEALTH AND WELL-BEING OF ADULTS LIVING WITH SPINAL MUSCULAR ATROPHY

Erin F Welsh, MPH, Cure SMA

LOCAL RNA TRANSLATION TO RESCUE SMA MOTONEURONS

Florence Rage, PhD, IGMM, CNRS, Montpellier

IMPROVEMENTS IN MOUTH OPENING AMONG PATIENTS WITH SMA FOLLOWING ORASTRETCH THERAPY

Katlyn Elizabeth McGrattan, PhD, University of Minnesota

LEARN ABOUT SPINRAZA® AND THE LATEST REAL-WORLD EVIDENCE IN ADULTS

Kevin Conway, Marketing Director, Biogen

CHARTING NEW HORIZONS: A PATHWAY TO EARLY ASSESSMENT FOR NEWBORN SCREENING IN SMA

Kristin J Krosschell, PT, DPT, PCS, Northwestern University Feinberg School of Medicine, Allison Cullen, BS, The Children's Hospital of Philadelphia

GETTING STARTED ON YOUR CLINICAL TRIAL JOURNEY WITH CURE SMA - NEW RESOURCES AND TOOLS TO IMPROVE COMMUNITY AWARENESS

Lauren Eisenman, MS, Cure SMA

THE IMPACT OF PATIENT-PROVIDER COMMUNICATION ON STRESS IN A HOSPITAL SETTING

Linsey Wehner MPH, Jeremy Orr MD, Amy Bellinghausen MD, University of California, San Diego Health, Department of Medicine, Division of Pulmonary, Critical Care, Sleep Medicine & Physiology

ESTIMATING THE PREVALENCE OF SMA. CURE SMA'S MODEL FOR PREVALENCE AND DEMOGRAPHICS OF THE U.S. SMA POPULATION

Lisa Belter, MPH, Cure SMA

INVESTIGATING MOTOR NEURON RECOVERY USING MOUSE MODELS OF SMA

Lyndsay Murray PhD, University of Edinburgh

CURE SMA CARE CENTER NETWORK

Mary Schroth, MD, Erica Jorgensen, Cure SMA

CURE SMA: ADVANCING ACCESSIBLE AIR TRAVEL THROUGH LEGISLATIVE ADVOCACY

Maynard Friesz, Cure SMA, Sarah Bellish, Cure SMA

SMA COMMUNITY-BASED EXPERIENCE WITH THE 12-TIER FUNCTIONAL ABILITY SCALE FOR EVOLVING SPINAL MUSCULAR ATROPHY

Meghan Moore Burk, PT, DPT, NCS, Children's Hospital Colorado

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

Melissa Bowerman, Ph.D., Keele University

AN UPDATE ON FERTILITY IN MEN WITH SMA: THE IMPACT OF SMA AND SMN2 SPLICING MODIFIERS

Natan Bar-Chama MD, Department of Urology The Mount Sinai Hospital / Reproductive Medicine Associates of New York

THE SMA EFFORT: IMPROVING THE ASSESSMENT OF EXPERIENCED FATIGABILITY

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

A DESCRIPTIVE EVALUATION OF DISEASE MANAGEMENT TRENDS AND TRANSITION OF CARE AMONG TREATED AND NEVER-TREATED PATIENTS WITH SPINAL MUSCULAR ATROPHY (SMA) USING US CLAIMS DATA

Randal Richardson, MD, MMS, Gillette Children's

GENE REPLACEMENT THERAPY: OVERVIEW AND LATEST UPDATES

Sandra P. Reyna, MD; Nayla Mumneh, MD, Novartis Gene Therapies, Inc.

REAL WORLD TREATMENT PATTERNS OF INDIVIDUALS INITIATING SMA TREATMENT AS TEENS OR ADULTS IN THE SMA CLINICAL DATA REGISTRY

Sarah Whitmire, MS, Cure SMA

NIFEDIPINE AND ELECTRICAL SIGNALS IN SMA

Saravanan Arumugam, PhD, Department of Medical Physiology and Biophysics, School of Medicine, University of Seville, Spain

THE JOURNEY BEYOND CLINICAL STUDIES: REAL-WORLD EXPERIENCE WITH RISDIPLAM TREATMENT

Sheila Shapouri, PharmD, MS, Senior Health Economist, Genentech

ROCHE/GENENTECH CONTINUED EFFORTS TO ADVANCE CARE IN SMA

Travis Dickendeshner, PhD, Principal Medical Science Director, Genentech

IDENTIFYING THE TOP 10 UNANSWERED RESEARCH PRIORITIES FOR SPINAL MUSCULAR ATROPHY

Vanessa Christie-Brown, SMA Europe

THE NMD670 SYNAPSE-SMA PHASE 2 STUDY, A MUSCLE-TARGETED ORAL DRUG THERAPY FOR AMBULATORY ADULTS WITH SMA

Vera Kiyasova, MD, NMD Pharma

August is SMA Awareness Month!

While we work year-round to raise awareness and funds for SMA, August is our time to shine a brighter spotlight on SMA and the SMA community.

Join Cure SMA in preparing for the biggest #SMAAwarenessMonth yet!

Here are the best ways to get ready for August:

- Our annual candle lighting takes place on Saturday, August 10th. Purchase your Cure SMA candle at curesmaorg.myshopify.com
- Do you have a story you'd like to share about your SMA journey? Or are you a social media superstar who'd like to help us create interesting and engaging social media content? Contact stories@curesma.org and let us know how you'd like to help
- Become a Cure SMA advocate and act on 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!

CHILDREN'S PROGRAM ENTERTAINMENT SCHEDULE

Be sure to check out **Cartoon You Caricatures** so a caricaturist can draw a photo of you to take home as a fun conference memento!
Will be available all-day Friday, Saturday and Sunday during children's program hours!



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 7, 2024

CHILDREN'S PROGRAM MORNING SESSION

9:00AM – 12:20PM

9:00AM – 12:20PM

Cartoon You Caricatures Stop by this fun station so a caricaturist can draw a photo of you to take home as a fun conference memento!

11:00AM – 12:00PM

Watts-up This "electrifying" event demonstrates the exciting world of electricity. Prepared to be transformed to the molecular level as you learn what happens to electrons in an atom. The audience is surprised with flying objects and a shocking display!

CHILDREN'S PROGRAM AFTERNOON SESSION

1:45PM – 4:45PM

1:45PM – 4:45PM

Cartoon You Caricatures Stop by this fun station so a caricaturist can draw a photo of you to take home as a fun conference memento!

3:30PM – 4:30PM

Marvels of Motion In this high energy event, children see Newton's three laws of motion in action. You will get to try exciting experiments, compete in crazy competitions, and learn the physics behind some of your favorite sports.

SATURDAY, JUNE 8, 2024

CHILDREN'S PROGRAM MORNING SESSION

9:00AM – 11:40AM

9:00AM – 11:40AM

Cartoon You Caricatures Stop by this fun station so a caricaturist can draw a photo of you to take home as a fun conference memento!

10:30AM – 11:30AM

Up, Up and Away! This spellbinding special event introduces you to the principles of air and pressure. You will get to see an incredible exothermic reaction take place and even get the chance to watch a hovercraft in action!

CHILDREN'S PROGRAM AFTERNOON SESSION

1:00PM – 5:00PM

1:00PM – 5:00PM

Cartoon You Caricatures Stop by this fun station so a caricaturist can draw a photo of you to take home as a fun conference memento!

1:30PM – 2:30PM

Bubble Show This interactive show features all sorts of bubbles! From giant bubbles to small bubbles to bubbles inside of bubbles, bubble expert Katya will leave you amazed!

3:45PM – 4:45PM

Fire and Ice Show This spectacular show thrills audiences with impressive science experiments. The event includes foggy dry ice storms and demonstrates how giant beach balls can float in the air. Everyone will be amazed by a rainbow in a bottle and special bubbly showers!

SUNDAY, JUNE 9, 2024

CHILDREN'S PROGRAM MORNING SESSION

9:00AM – 11:15AM

9:00AM – 11:15AM

Cartoon You Caricatures Stop by this fun station so a caricaturist can draw a photo of you to take home as a fun conference memento!

Sponsored by





HOW DO BATHROOM BREAKS WORK?

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

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

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

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

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

WHAT DO VOLUNTEERS ASSIST WITH THROUGHOUT THE DAY?

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

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

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

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

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

WHEN IS THE CHILDREN'S PROGRAM OPEN?

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



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. The level of enthusiasm each volunteer provides throughout the day in the children's program and during the evening events is endless and even contagious! Every volunteer has a major impact on the success and atmosphere of our conference and every 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. 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 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 34 YEARS

George Ghorbanian
Chicago Police Officer



VOLUNTEER FOR 24 YEARS

Lance Northcutt
Lawyer



VOLUNTEER FOR 32 YEARS

Patti Slojkowski
Dental Hygienist



VOLUNTEER FOR 24 YEARS

Kelly Basso
Electrologist



VOLUNTEER FOR 25 YEARS

Kelly Milito
Hair Stylist



VOLUNTEER FOR 23 YEARS

Katlyn O'Brien
Teacher

THANK YOU TO OUR VOLUNTEERS



VOLUNTEER FOR 23 YEARS

Mary Blume
Caregiver for Grandkids Mason and Ava



VOLUNTEER FOR 22 YEARS

Noreen Reilly
IT Project Manager



VOLUNTEER FOR 22 YEARS

Traci O'Brien
Organic Skincare Entrepreneur + Creative Marketer



VOLUNTEER FOR 15 YEARS

Jackie Bohl
Event Planner



VOLUNTEER FOR 14 YEARS

Patrick Hogan
High School Social Studies Teacher and Coach



VOLUNTEER FOR 14 YEARS

Jackie Graney
Studio 22 Dance Director



VOLUNTEER FOR 13 YEARS

Patti Northcutt



VOLUNTEER FOR 13 YEARS

Joy Martin
Physical Therapist



VOLUNTEER FOR 13 YEARS

Donna Budil
Preschool Director



VOLUNTEER FOR 12 YEARS

Jennifer Walsh
Business Systems Analyst



VOLUNTEER FOR 12 YEARS

Hayley Miller
Product Manager, Esri



VOLUNTEER FOR 12 YEARS

Kelly Gibbons
Corporate Wellness Benefits



VOLUNTEER FOR 12 YEARS

Kayla Forsythe
Registered Nurse



VOLUNTEER FOR 11 YEARS

Laura Kroll
2nd Grade Teacher



VOLUNTEER FOR 11 YEARS

Georgia Slojkowski
Elementary Orchestra Teacher



VOLUNTEER FOR 10 YEARS

Patrick Slojkowski
Associate Scientist at PepsiCo



VOLUNTEER FOR 9 YEARS

Raphi Milito
Sales Specialist



VOLUNTEER FOR 9 YEARS

Ralph Milito
Real Estate Agent

THANK YOU TO OUR VOLUNTEERS



VOLUNTEER FOR 9 YEARS

Michael Milito
Project Engineer



VOLUNTEER FOR 9 YEARS

Daniela Milito
Chef



VOLUNTEER FOR 9 YEARS

Sally McCarthy
Retired Nurse



VOLUNTEER FOR 8 YEARS

Alanna Woods



VOLUNTEER FOR 8 YEARS

Michele Rubenstein
Assistant Teacher at Therapeutic Preschool



VOLUNTEER FOR 8 YEARS

Emma Rubenstein
Student at Marist College



VOLUNTEER FOR 8 YEARS

Rebeka Nekolova
Videographer/Video Editor



VOLUNTEER FOR 7 YEARS

Isabella Hernandez
Student



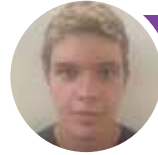
VOLUNTEER FOR 7 YEARS

Cara Freedman
Sr. Research Assitant at NORD



VOLUNTEER FOR 7 YEARS

Katie Dieckhoff
Case Manager



VOLUNTEER FOR 6 YEARS

Will Reilly
Student



VOLUNTEER FOR 6 YEARS

Morgan Ramirez
Student



VOLUNTEER FOR 5 YEARS

Dan Melko
Retired



VOLUNTEER FOR 5 YEARS

Sarah Grimson
Retail Manager



VOLUNTEER FOR 3 YEARS

Alison Williams
Student at the University of Missouri



VOLUNTEER FOR 3 YEARS

Cathy Staples
Orthodontal Assistant



VOLUNTEER FOR 3 YEARS

Dave Richmond
Property Manager



VOLUNTEER FOR 3 YEARS

Molly Ramirez
Student at Nebraska Wesleyan University

THANK YOU TO OUR VOLUNTEERS



VOLUNTEER FOR 3 YEARS

Steve Paoletti
Law Student & US Army Reserve Soldier



VOLUNTEER FOR 3 YEARS

Sally O'Toole
College Student



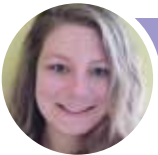
VOLUNTEER FOR 3 YEARS

Daisy Ortiz
Server



VOLUNTEER FOR 3 YEARS

Jack Olech
Student



VOLUNTEER FOR 3 YEARS

Lexi Nickols
Social Worker



VOLUNTEER FOR 3 YEARS

Kay McGovern
Private Investigator



VOLUNTEER FOR 3 YEARS

Terry McGovern
Vice President, Atlas Forms and Graphics



VOLUNTEER FOR 3 YEARS

Kristi Lazic
Registered Nurse



VOLUNTEER FOR 3 YEARS

Stacy Hernandez



VOLUNTEER FOR 3 YEARS

Lola Hernandez
Student



VOLUNTEER FOR 3 YEARS

Paul Enwia
Middle School Social Studies Teacher



VOLUNTEER FOR 3 YEARS

Logan Dimitriou
Student



VOLUNTEER FOR 3 YEARS

Lily Carlson
Student



VOLUNTEER FOR 3 YEARS

Eric Berghoff
Sports Medicine Intern for Ivy Rehab and Physical Therapy



VOLUNTEER FOR 3 YEARS

Lena Ahrens
Student



VOLUNTEER FOR 2 YEARS

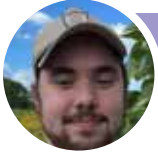
Jack Koteles
Student



VOLUNTEER FOR 2 YEARS

Makenna Stalter
Early Head Start Classroom Manager

THANK YOU TO OUR VOLUNTEERS



VOLUNTEER FOR 2 YEARS

Sam Rossi
Software Engineer



VOLUNTEER FOR 2 YEARS

Sam Olech
Student



VOLUNTEER FOR 2 YEARS

Kathleen O'Hare
Associate Director DePaul
University



VOLUNTEER FOR 2 YEARS

Jayne O'Brien
Retired RN



VOLUNTEER FOR 2 YEARS

Liz Molbeck
Food Service Director



VOLUNTEER FOR 2 YEARS

Mackenzie Maloney
Nurse



VOLUNTEER FOR 2 YEARS

Frank Magnelli
Chicago Territory Manger for Aura
Healthcare



VOLUNTEER FOR 2 YEARS

Braden Gebavi
Chief Product Officer at Bet Caddy



VOLUNTEER FOR 2 YEARS

Ben Goldberg
Kitchen Manager



VOLUNTEER FOR 2 YEARS

Ronna Fernandez
Senior Business Manager,
Northeastern Illinois University



VOLUNTEER FOR 2 YEARS

Ricardo Fernandez
Chicago Police Officer



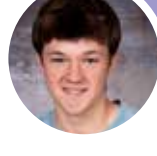
VOLUNTEER FOR 2 YEARS

Vince Coughlin
Teacher



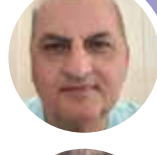
VOLUNTEER FOR 2 YEARS

Neena Campos
Student



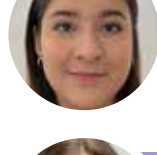
VOLUNTEER FOR 2 YEARS

Matt Breslin
Student



VOLUNTEER FOR 2 YEARS

Atour Bethishou
Retired Police Sergeant



VOLUNTEER FOR 2 YEARS

Regina Ballesteros
Student



VOLUNTEER FOR 2 YEARS

Bryn Bahnks
Student at Washington University



Kelly Milito VOLUNTEER FOR 25 YEARS

The 2024 Annual SMA Conference marks a huge milestone for one of our longest returning volunteer, Kelly Milito! Kelly volunteered at her first conference 25 years ago and has been involved ever since! Every year she takes time away from her family and job to travel and support the Children's Program and over the years has even gotten her adult children and husband now involved as well as volunteers! 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!





TREATMENT FOR LIFE IN ACTION

Evrysdi is the only oral, non-invasive, at-home treatment for SMA

- ✓ Delivered to your door
- ✓ No needles, sedation or hospital stays required to take Evrysdi
- ✓ No required monitoring or laboratory testing
- ✓ Can be taken at home, at work, or when on the go*
- ✓ A global community of more than 11,000 strong have chosen Evrysdi†

*If refrigeration is not available, Evrysdi can be kept at room temperature up to 104°F for a combined total of 5 days. Please refer to the Instructions for Use for additional information about storage and administration.

†Based on individuals with SMA receiving Evrysdi worldwide as of July 2023.

What is Evrysdi?

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

Important Safety Information

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

MEET US FOR A COMMUNITY SYMPOSIUM

TAKING CENTER STAGE: STORIES FROM THE COMMUNITY
FRIDAY, JUNE 7: 7:45 AM - 8:45 AM

- ✓ Hear first-hand perspectives from people taking Evrysdi
- ✓ Review the science of SMA and how Evrysdi works

STOP BY OUR BOOTH

FRIDAY, JUNE 7: 7:45 AM - 5:30 PM | SATURDAY, JUNE 8: 7:45 AM - 5:30 PM



Important Safety Information (cont'd)

- 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.

Genentech
A Member of the Roche Group

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Patient Information
EVRYSDI® (ev-RIZ-dee)
(risdiplam)
for oral solution

What is EVRYSDI?

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

Before taking EVRYSDI, tell your healthcare provider about all of your medical conditions, including if you:

- 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:
 - 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.evrysdipregnancyregistry.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.

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.

How should I take EVRYSDI?

See the detailed Instructions for Use that comes with EVRYSDI for information on how to take or give EVRYSDI 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.
- 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.

Taking EVRYSDI

- 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.
- 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.
 - Take EVRYSDI exactly as your healthcare provider tells you to take it. Do not change the dose without talking to your healthcare provider.
- Take EVRYSDI 1 time daily after a meal (or after breastfeeding for a child) at approximately the same time each day. Drink water afterwards to make sure EVRYSDI has been completely swallowed.
- Do not mix EVRYSDI with formula or milk.
- If you are unable to swallow and have a nasogastric or gastrostomy tube, EVRYSDI can be given through the tube.
- If you miss a dose of EVRYSDI:
 - If you remember the missed dose within 6 hours of when you normally take EVRYSDI, then take or give 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.

Reusable Oral Syringes

- Your pharmacist will provide you with the reusable oral syringe(s) that are needed for taking your medicine and explain how to use them. Wash the syringes per instructions after use. Do not throw them away.
- Use the reusable oral syringe(s) provided by your pharmacist (you should receive 1 or 2 identical oral syringes depending on your prescribed daily dose) to measure your or your child's dose of EVRYSDI, as they are designed to protect the medicine from light. Contact your healthcare provider or pharmacist if your oral syringe(s) are lost or damaged.
- When transferred from the bottle to the oral syringe, take EVRYSDI right away. Do not store the EVRYSDI solution in the syringe. If EVRYSDI is not taken within 5 minutes of when it is drawn up, EVRYSDI should be thrown away from the reusable oral syringe, and a new dose should be prepared.

What are the possible side effects of EVRYSDI?

The most common side effects of EVRYSDI include:

- **For later-onset SMA:**
 - fever
 - diarrhea
 - rash
- **For infantile-onset SMA:**
 - fever
 - runny nose, sneezing, and sore throat
 - constipation (upper respiratory infection)
 - diarrhea
 - lung infection (lower respiratory infection)
 - vomiting
 - rash
 - cough

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.

How should I store EVRYSDI?

- Store EVRYSDI in the refrigerator between 36°F to 46°F (2°C to 8°C). Do not freeze.
- 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).

Keep EVRYSDI, all medicines and syringes out of the reach of children.

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.

What are the ingredients in EVRYSDI?

Active ingredient: risdiplam

Inactive ingredients: ascorbic acid, disodium edetate dihydrate, isomalt, mannitol, polyethylene glycol 6000, sodium benzoate, strawberry flavor, sucralose, and tartaric acid.

Genentech

A Member of the Roche Group

EVRYSDI® (risdiplam)

Distributed by:

Genentech, Inc.

A Member of the Roche Group

1 DNA Way

South San Francisco, CA

94080-4990

EVRYSDI is a registered trademark of Genentech, Inc.

M-US-00007143(v6.0)

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For more information, go to www.EVRYSDI.com or call 1-833-387-9734.

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

Approved: 3/2023

Cure SMA offers resource guides to support those with SMA and their communities. These resources cover a range of topics to enrich daily living at home and in the community. Below are some sample topics currently available, but topics covered in these guides continue to grow so stay tuned for more to come!

- Protected Savings Options Comparison Chart
- Guide to Talking with Children about Disabilities
- Educator's Guide to SMA
- Sample School Letter Guide
- Travel Guide
- Adaptive Equipment List
- Driving - Becoming Licensed
- Accessible Vehicle Options and Considerations
- Home Modifications Guide
- Bathroom Accommodations
- Bathroom Equipment List
- DEI Children's Book Recommendations
- Guide to Advertising for & Interviewing PCAs
- Guide to Hiring & Maintaining PCAs
- Surgery & Hospital Stay Guide



Make today a
breakthrough.

To request a copy of any of these resources, please email communitysupport@curesma.org.

BOARDING PASS to see the potential



SMA →

You're invited to see how Biogen discussions to make the travel accessible for people with SMA

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.**

©2024 Biogen. All rights reserved. 03/24 SMA-US-1264
225 Binney Street, Cambridge, MA 02142

al future of travel with SMA



AUS

en is facilitating
experience more

A.

Passenger: You

Date: June 6–9, 2024

Destination:
2024 Annual Cure SMA
Conference

Austin, TX



Biogen.



Biogen.

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.

Let's celebrate the past, present, and future faces of ZOLGENSMA!

Please join us as we celebrate every child who has been—or may be—treated with ZOLGENSMA® (onasemnogene abeparvovec-xioi) suspension, for intravenous infusion.

Stop by our booth and meet our Family Ambassadors for support and resources. And be sure to snap a photo to commemorate your visit with the ZOLGENSMA team at Cure SMA 2024 in Austin, Texas.

CELEBRATE WITH US AT THE ZOLGENSMA BOOTH IN GRIFFIN HALL

Results vary among children based on several factors, including how far SMA had progressed prior to receiving treatment.

Indication and Important Safety Information for ZOLGENSMA

What is ZOLGENSMA?

ZOLGENSMA is a prescription gene therapy used to treat children less than 2 years old with spinal muscular atrophy (SMA). ZOLGENSMA is given as a one-time infusion into a vein. ZOLGENSMA was not evaluated in patients with advanced SMA.

What is the most important information I should know about ZOLGENSMA?

- ZOLGENSMA can increase liver enzyme levels and cause acute serious liver injury or acute liver failure which could result in death.
- Patients will receive an oral corticosteroid before and after infusion with ZOLGENSMA and will undergo regular blood tests to monitor liver function.
- Contact the patient's doctor immediately if the patient's skin and/or whites of the eyes appear yellowish, if the patient misses a dose of corticosteroid or vomits it up, or if the patient experiences a decrease in alertness.

What should I watch for before and after infusion with ZOLGENSMA?

- Infections before or after ZOLGENSMA infusion can lead to more serious complications. Caregivers and close contacts with the patient should follow infection prevention procedures. Contact the patient's doctor immediately if the patient experiences any signs of a possible infection such as coughing, wheezing, sneezing, runny nose, sore throat, or fever.
- Decreased platelet counts could occur following infusion with ZOLGENSMA. Seek immediate medical attention if the patient experiences unexpected bleeding or bruising.
- Thrombotic microangiopathy (TMA) has been reported to generally occur within the first two weeks after ZOLGENSMA infusion. Seek immediate medical attention if the patient experiences any signs or symptoms of TMA, such as unexpected bruising or bleeding, seizures, or decreased urine output.

- There is a theoretical risk of tumor development with gene therapies such as ZOLGENSMA. Contact the patient's doctor and Novartis Gene Therapies, Inc. (1-833-828-3947) if a tumor develops.

What do I need to know about vaccinations and ZOLGENSMA?

- Talk with the patient's doctor to decide if adjustments to the vaccination schedule are needed to accommodate treatment with a corticosteroid.
- Protection against influenza and respiratory syncytial virus (RSV) is recommended and vaccination status should be up-to-date prior to ZOLGENSMA administration. Please consult the patient's doctor.

Do I need to take precautions with the patient's bodily waste?

Temporarily, small amounts of ZOLGENSMA may be found in the patient's stool. Use good hand hygiene when coming into direct contact with patient body waste for one month after infusion with ZOLGENSMA. Disposable diapers should be sealed in disposable trash bags and thrown out with regular trash.

What are the possible or likely side effects of ZOLGENSMA?

The most common side effects that occurred in patients treated with ZOLGENSMA were elevated liver enzymes and vomiting.

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

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

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



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Bannockburn, IL 60015



For US audiences only.
02/2024 US-ZOL-24-0010

IMPORTANT FACTS ABOUT ZOLGENSMA® [onasemnogene abeparvovec-xioi]

USE

ZOLGENSMA is a prescription gene therapy used to treat children less than 2 years old with spinal muscular atrophy (SMA).

- ZOLGENSMA is given as a one-time infusion into a vein.
- ZOLGENSMA was not evaluated in patients with advanced SMA.

WARNINGS

Acute Serious Liver Injury, Acute Liver Failure or Elevated Aminotransferases

- ZOLGENSMA can increase liver enzyme levels and cause acute serious liver injury or acute liver failure which could result in death.
- Patients will receive an oral corticosteroid before and after infusion with ZOLGENSMA and will undergo regular blood tests to monitor liver function.
- Contact the patient's doctor immediately if the patient's skin and/or whites of the eyes appear yellowish, if the patient misses a dose of corticosteroid or vomits it up, or if the patient experiences a decrease in alertness.

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

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

Thrombotic microangiopathy (TMA) has been reported to generally occur within the first two weeks after ZOLGENSMA infusion. Seek immediate medical attention if the patient experiences any signs or symptoms of TMA, such as unexpected bruising or bleeding, seizures, or decreased urine output.

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

OTHER IMPORTANT INFORMATION

Patients should be tested for the presence of anti-AAV9 antibodies prior to infusion with ZOLGENSMA.

The patient's doctor may need to adjust the vaccination schedule to accommodate corticosteroid treatment. Protection against influenza and respiratory syncytial virus (RSV) is recommended and vaccination status should be up-to-date prior to ZOLGENSMA administration. Consult the patient's doctor.

Temporarily, small amounts of ZOLGENSMA may be found in the patient's stool. Use good hand hygiene when coming into direct contact with patient body waste for one month after infusion with ZOLGENSMA. Disposable diapers should be sealed in disposable trash bags and thrown out into regular trash.

COMMON SIDE EFFECTS

The most common side effects that occurred in patients treated with ZOLGENSMA were elevated liver enzymes and vomiting.

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

QUESTIONS?

To learn more, talk to the patient's doctor and you can visit www.zolgensma.com for Full Product Information.

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10/2023 US-ZOL-20-0121 V6

We are proud to support Cure SMA and the 2024 Conference, and we are grateful to the patients, caregivers, sites, investigators, and advocacy groups for their support of our clinical trials. With your help, we are working to advance a potential promising new muscle-targeted approach for SMA.

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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!
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Cure SMA is celebrating its 40th year!

This organization, originally called Families of SMA, began in 1984 to be a place where those affected by spinal muscular atrophy could turn to for support. Thank you to the entire community for your continuous and unwavering support that has led to the breakthrough in research, treatment, care, and support we now know today!





NMD Pharma proudly support CureSMA and we are excited to join the research and clinical community following the inspiration of the adults with SMA and the entire SMA community!

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

The Cure SMA Board and Committee Members

These individuals exemplify unwavering dedication as they stand for every family impacted by SMA. Their commitment lies in steering the organization's focus while actively seeking innovative ways to aid those with SMA, support families, and generate funds for research and care. We express gratitude to these devoted volunteers for their exceptional ideas and tireless efforts that extend beyond expectations to benefit the entire community.

Nick Farrell

Nick, as the Chair of the Board for Cure SMA, demonstrates remarkable involvement and passion, investing his full effort in every undertaking. Continuously striving for improvement, promotion, and assistance within the SMA community, he consistently seeks ways to enhance its well-being. We feel fortunate to have such an outstanding leader in our corner, and we extend our gratitude to him for his ongoing support.

The Cure SMA Chapter Leaders

We express immense gratitude for the representation of our organization across the U.S., courtesy of these dedicated and supportive individuals. Their embodiment of community spirit resonates across states, as they generously offer their time, attentive ears, and enthusiastic efforts in contributing to the quest for an SMA cure. The success our organization has achieved wouldn't be possible without each one of them. Thank you for everything!

The Cure SMA Medical Advisory Council Members

We feel fortunate to have a distinguished group of SMA medical and clinical experts in the U.S. as integral members of our community. The Medical Advisory Council consistently engages in brainstorming sessions to promote awareness about SMA in the medical community, enhance care for SMA patients and their families, and pursue various other initiatives. These dedicated professionals, with their wealth of knowledge, volunteer their time outside their clinics and family commitments to organize conference workshops and educate families on diverse medical aspects of SMA. We are deeply grateful for the invaluable support and expertise that each of you contributes to Cure SMA.

The Cure SMA Scientific Advisory Board Members

Each year, the Scientific Advisory Board diligently evaluates all research grant applications and plays a crucial role in shaping the agenda for the Annual Researcher Meeting. We extend our gratitude to the SAB members for their expertise. Their tireless dedication and hard work are truly appreciated, as they ensure that Cure SMA funds the most outstanding 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 to 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 Cure SMA Translational Advisory Council Members

In the journey from initial academic research to the clinical and medical phases of discovering an SMA cure, these individuals hold a pivotal position. Translational research, the essential intermediate stage, transforms research ideas into practical solutions for patients. We express heartfelt gratitude to all members of the TAC for dedicating their time to the challenge and responsibility of supporting Cure SMA in this crucial role.

The Trainor Family

We extend our gratitude to the Trainor Family for their enduring support throughout the years. It is your generosity that has propelled Cure SMA and the Annual Conference to their current positions of prominence. Thank you for making a lasting impact.

The Dhont Family Foundation

It's a great honor for us to offer sponsorship to any adult with SMA, enabling them and an aide to attend the conference this year, thanks to the generous support and funding from the Dhont Foundation. We deeply appreciate your commitment to providing this opportunity to many in the community, as well as sponsoring the highly anticipated Adults with SMA Social throughout the conference! We value your support to ensure the Annual SMA Conference is a space for all in the community.

Jacob Isaac Rappoport Foundation

We express heartfelt gratitude to this incredible foundation for its unwavering support over the years, particularly for newly diagnosed families, the conference, and beyond. Your remarkable contribution is what makes the Children's Program at the conference possible. We sincerely appreciate your kindness and generosity.

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

Our gratitude extends to this family for their consistent contributions to the conference, year after year. Cure SMA values and cherishes their willingness to assist in any capacity. Thank you for transforming this conference into a truly special event with your exceptional signage, support, and kindness.

Luke 18:1 Foundation

We are thrilled to be able to offer a special place for teenagers at this year's Annual SMA Conference. A special thank you goes to the Luke 18:1 Foundation for sponsoring the Teen Lounge and Teen Social, providing a unique space for teens to connect, mingle, and forge lasting friendships. Your support has made this initiative possible and is truly appreciated.

The Nunemaker Family

We express our sincere gratitude to the Nunemaker family for their generosity and commitment to funding research for SMA. It is through your support that we continue funding research projects in our quest to drive the next generation of SMA treatments.



Celebrating a Remarkable Milestone: 20 Years of the Cincinnati Walk-n-Roll!

In 2024, we proudly mark two decades of unwavering commitment and tireless dedication to the cause of Cure SMA through the Cincinnati Walk-n-Roll event. Spearheaded by the determined Lockwood Family, including Elizabeth, Bob, Rob, Kevin, Beth, Emma, and Nicholas, this event stands as a beacon of hope and solidarity for families affected by SMA. Their passion has propelled Cure SMA forward, raising vital funds and awareness for spinal muscular atrophy research.

As we reflect on this milestone, we extend our deepest gratitude to the Lockwood Family and all those who have supported this remarkable journey. Together, we envision a better future for the SMA community, fueled by the spirit of compassion and community. Here's to 20 years of making a difference, and to many more strides towards a cure.

OFFICIAL CURE SMA MERCHANDISE

Items will be on sale at the merchandise table next to registration on Level 2 of the hotel in the Griffin Hall Foyer. Make sure to stop by and check it out while supplies last!

5 Brand New Items Debuting at Conference!

- Cure SMA Tie-Dye T-shirt (infant, toddler, youth and adult sizes available!)
- Reusable Grocery Bag
- Cure SMA 40th Anniversary Key Chain
- Men's Performance Polo
- Women's Performance Polo

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

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



Share a photo on your social media of you sporting your Cure SMA gear during this week's Conference using hashtag #2024SMACONFERENCE

Accessories:

- Adhesive Cell Phone Wallet
~~\$10~~ **NOW \$5**
- Cookie Cutter Set
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- Car Magnet
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- Embroidered Plush Blanket
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- License Plate Frame
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- Push Pop Fidget Game
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- Vinyl Decal
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- Adult & Youth Bracelet
~~\$2~~ **NOW \$1**
- Tuffy the Plush Puppy
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- Wheelchair joysticks
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- NEW** Cure SMA 40th Anniversary Keychain
~~\$6~~ **NOW \$5**

Stickers:

- Circle Sticker
- Est 1984 Sticker
- Logo Sticker
- Black Square Sticker
- Blue Square Sticker
- Light Purple Square Sticker
- Orange Square Sticker
- Pink Square Sticker
- Purple Square Sticker
- CURE Sticker with SMA Repeating

****All stickers on sale for \$1 each!**

Drinkware:

- 40oz Orange Travel Mug
~~\$30~~ **NOW \$25**
- Purple Water Bottle
~~\$15~~ **NOW \$10**
- Stainless Steel Wine Tumbler
~~\$20~~ **NOW \$15**

Bags:

- Black Belt Bag
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- Large Cooler Bag Backpack
~~\$45~~ **NOW \$35**
- NEW** Reusable Grocery Bag
~~\$10~~ **NOW \$8**

Hats:

- Gray Adjustable Baseball Hat
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- Black Performance Baseball Hat
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- Gray Bucket Hat
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- Cure SMA Striped Pom Beanie
~~\$25~~ **NOW \$18**

Toddler & Youth Apparel:

- Youth We Can Cure SMA Crewneck Sweatshirt (Small-XLarge) ~~\$25~~ **NOW \$20**
- NEW** Tie-Dye Cure SMA Infant Onesie (6mon, 12 mon, 18mon) ~~\$20~~ **NOW \$18**
- NEW** Tie-Dye Cure SMA Toddler T-shirt (2T-4T) ~~\$30~~ **NOW \$24**
- NEW** Tie-Dye Cure SMA Youth T-shirt (Small-XLarge) ~~\$30~~ **NOW \$24**

Adult Apparel:

- NEW** Tie-Dye Cure SMA T-shirt (Small-3XLarge) ~~\$30~~ **NOW \$24**
- NEW** Unisex Heathered Purple Performance Polo (Small-2XLarge) ~~\$35~~ **Now \$28**
- Unisex Full Zip Purple Hoodie (Small-2XLarge) ~~\$49~~ **Now \$40**
- Unisex Black Performance Full-Zip Fleece (Small-2XLarge) ~~\$49~~ **NOW \$40**
- Unisex Dark Lavender Long Sleeve Tee (Small-2XLarge) ~~\$30~~ **NOW \$25**
- Unisex Black Long Sleeve Circle Tee (Small-2XLarge) ~~\$30~~ **NOW \$25**
- Women's Performance Racerback Tank (Small-2XLarge) ~~\$25~~ **NOW \$20**
- Women's White Reflective Performance Half Zip (Small-2XLarge) ~~\$49~~ **NOW \$40**
- Women's White Cropped Logo Crewneck Sweatshirt (Small-2XLarge) ~~\$35~~ **NOW \$30**
- Women's We Can Cure SMA Cropped Crewneck Sweatshirt (Small-2XLarge) ~~\$35~~ **NOW \$30**
- NEW** Women's Heathered Purple Performance Polo (Small-2XLarge) ~~\$35~~ **NOW \$28**

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Dell Children's Pediatric Neuromuscular Disease Center

The Pediatric Neuromuscular Disease Center is a specialty program within UT Health Austin Pediatric Neurosciences at Dell Children's, a clinical partnership between Dell Children's Medical Center and UT Health Austin. Our team diagnoses and manages the care of children and adolescents with neuromuscular disorders, including inherited neuropathies, muscular dystrophies, congenital myasthenic syndromes, congenital myopathies, and spinal muscular atrophy (SMA). We offer gene therapy for SMA and Duchenne muscular dystrophy and provide on-call support for newborns who screen positive for SMA, coordinating their care as they grow. We also offer the region's only MDA-affiliated muscular dystrophy clinic, staffed by a multidisciplinary team of neurologists, pulmonologists, cardiologists, and physical therapists.



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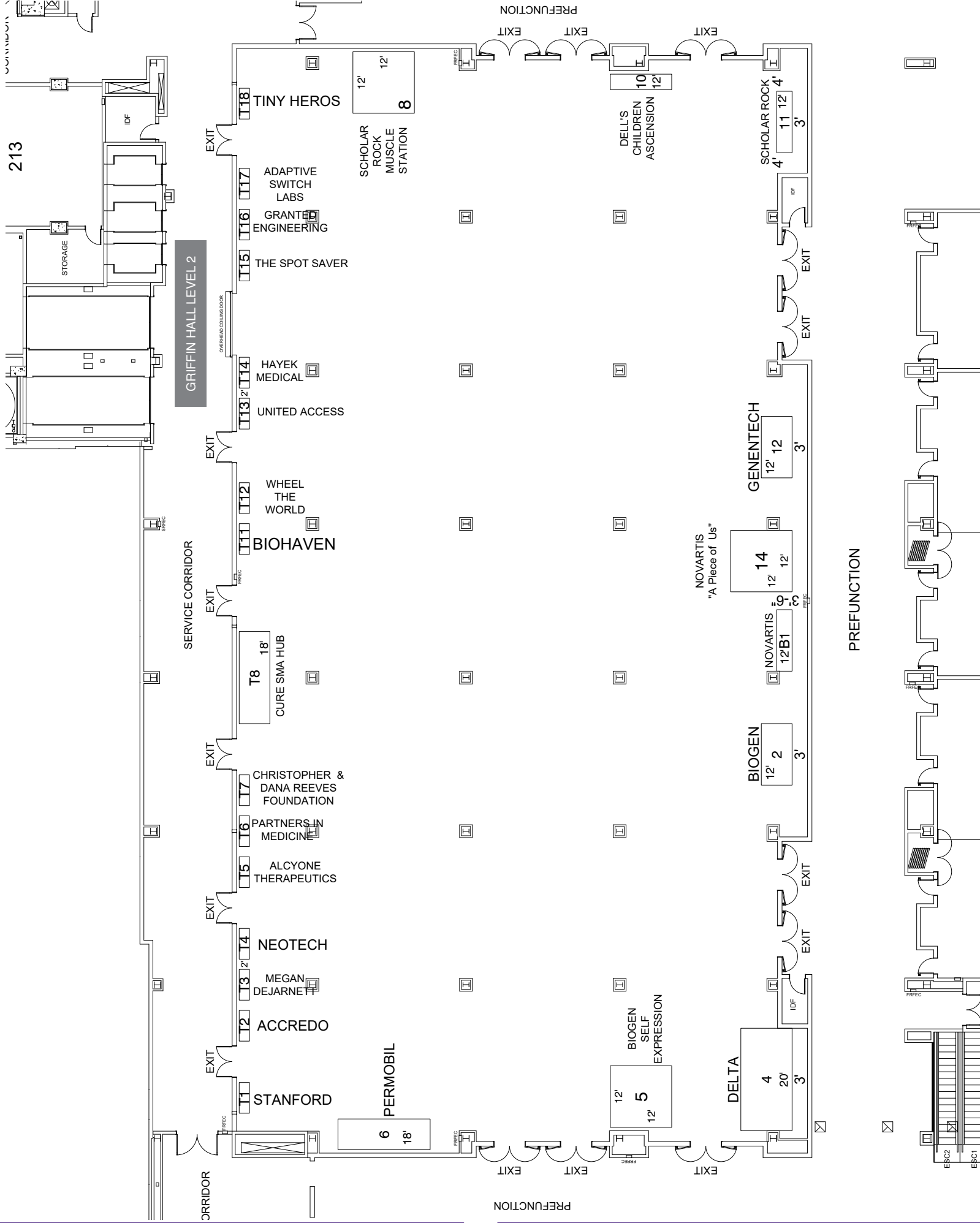
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EXHIBITOR KEY

- **Accredo - #T2**
- **Adaptive Switch Laboratories, Inc. - # T17**
- **Alycone Therapeutics - # T5**
- **Biogen - # 2**
- **Biogen Self Expression Exhibit - #5**
- **Biohaven - # T11**
- **Christopher & Dana Reeves Foundation - # T7**
- **Cure SMA Hub – # T8**
- **Dell Children’s Ascension - # 10**
- **Delta Airlines - # 4**
- **Genentech - # 12**
- **Granted Engineering - # T16**
- **Hayek Medical A United Hayek Company - # T14**
- **Megan DeJarnett Speaker, Author + Disability Advocate - # T3**
- **Neotech Home Health - # T4**
- **Novartis - # B1**
- **Novartis “A Piece of Us” - # 14**
- **Partners in Medicine LLC - # T6**
- **Permobil - # 6**
- **Permobil Repair Center - # 6**
- **Scholar Rock - # 11**
- **Scholar Rock Muscle Station - # 8**
- **Stanford Neuromuscular Clinic and Research - # T1**
- **The Spot Saver - # T15**
- **Tiny Heroes: Recruiting Infants for SMA Research - # T18**
- **United Access - # T13**
- **Wheel the World - # T12**



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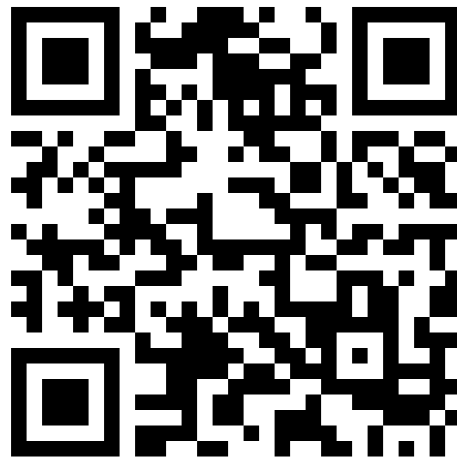
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we ♥ our volunteers



OUR VOLUNTEERS ARE THE ROOT OF WHO WE ARE.

As representatives of Cure SMA, volunteers spread awareness of SMA in their local communities by supporting local events, advocating for SMA-related policies, and generating support for our organization.

We want to thank our dedicated volunteers for providing their time and efforts to further the mission of Cure SMA. Their support allows us to offer programs and services to every individual in our community, as well as continue to fund and direct comprehensive research that drives breakthroughs in treatment and care.



ARE YOU LOOKING TO VOLUNTEER WITH CURE SMA?

We are always searching for volunteers who want to make an impact in the SMA community, and there are a variety of ways to get involved:

- Become an advocate
- Join a planning committee, or volunteer on event day, at one of our 50+ Walk-n-Roll events across the country
- Engage your community and host your own event supporting Cure SMA



LEARN MORE ABOUT HOW YOU CAN GET INVOLVED!



COME VISIT THE CURE SMA HUB!



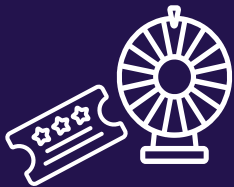
Learn more about peer-to-peer fundraising, special events, and how you can power our progress in funding breakthroughs in research, care, and support!



Register for an upcoming fundraising event and start your fundraising journey today!



Become a Cure SMA advocate and learn about important advocacy initiatives that the SMA community are propelling forward!



Enjoy games, win exclusive prizes, and connect with your Cure SMA team!



We can't wait to see you!

Join us in the Griffin Hall to experience our Cure SMA Hub!

CHAPTER LEADERS

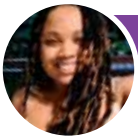
Below we would like to help you put a face to a name and recognize all of our current Chapter Leaders across the U.S.! Please make sure to say hello to those in attendance (noted by * next to their name) and introduce yourself if you haven't met them already.

ALABAMA



ALABAMA CHAPTER

Linda Russo* | 29 Years



ALABAMA CHAPTER

Shaakira Thomas*

ARKANSAS



ARKANSAS CHAPTER

DeAnna Dillon* | 7 Years



ARKANSAS CHAPTER

Sean Dillon* | 7 Years

ARIZONA



ARIZONA CHAPTER

Cassandra Thompson



ARIZONA CHAPTER

Angel Wolff* | 13 Years

CALIFORNIA



NORTHERN CALIFORNIA CHAPTER

David Sereni, Jr* | 26 Years



SOUTHERN CALIFORNIA CHAPTER

Autumn Montoya | 13 Years



SOUTHERN CALIFORNIA CHAPTER

Rickk Montoya* | 13 Years

COLORADO



ROCKY MOUNTAIN CHAPTER

Lyza Weisman | 3 Years

CONNECTICUT



CONNECTICUT CHAPTER

Kathryn McBride | 3 Years

*attending Conference

CHAPTER LEADERS

FLORIDA



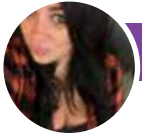
GREATER FLORIDA CHAPTER

Audra Butler | 14 Years



GREATER FLORIDA CHAPTER

Katie Kerns* | 14 Years



GREATER FLORIDA CHAPTER

Jennifer Smith



SOUTH FLORIDA CHAPTER

Maylan Chavez* | 4 Years



SOUTH FLORIDA CHAPTER

Jennifer Miller Smith* | 15 Years



SOUTH FLORIDA CHAPTER

Fiorenna Fuentes Stark | 12 Years

GEORGIA



GEORGIA CHAPTER

Tara Ragan* | 6 Years



GEORGIA CHAPTER

Valerie White | 7 Years

IOWA



IOWA CHAPTER

Megan Ramirez* | 8 Years

ILLINOIS



ILLINOIS CHAPTER

Kathleen Heinrich* | 5 Years



ILLINOIS CHAPTER

Jill Zmaczynski* | 3 Years

INDIANA



OKI CHAPTER

Holly Sontag* | 5 Years



OKI CHAPTER

Adrienne Vollmer* | 7 Years

KENTUCKY



OKI CHAPTER

Kristen DeLuca | 15 Years



OKI CHAPTER

Alex Haas * | 2 Years



OKI CHAPTER

Courtney Ogletree* | 6 Years

CHAPTER LEADERSHIP IS A FUN AND REWARDING WAY TO WORK WITH THE SMA COMMUNITY.

If you would like to learn more about becoming a chapter leader or looking for a fun way to connect with the SMA community, please contact Shannon O'Brien at shannon@dcuresma.org.

**attending Conference*

CHAPTER LEADERS

MASSACHUSETTS



NEW ENGLAND CHAPTER

Kristen Farrell



NEW ENGLAND CHAPTER

Barbara Jean Mirabile | 14 Years

MARYLAND



CHESAPEAKE CHAPTER

Kim Heinrich



CHESAPEAKE CHAPTER

Derek Lewis* | 13 Years



CHESAPEAKE CHAPTER

Tina Lewis* | 13 Years

MICHIGAN



MICHIGAN CHAPTER

Gretchen Dorer* | 6 Years



MICHIGAN CHAPTER

Aryn Manni * | 2 Years

MINNESOTA



MINNESOTA CHAPTER

Matthew Czech* | 8 Years



MINNESOTA CHAPTER

Melanie Dennison | 6 Months



MINNESOTA CHAPTER

Kayla Yaeger | 6 Years

NORTH CAROLINA



CAROLINAS CHAPTER

Mimi (Xiachun) Chan (Yu) | 10 Years

NEW HAMPSHIRE



NEW ENGLAND CHAPTER

Deodonne Bhattarai* | 8 Years

NEW JERSEY



NORTH JERSEY CHAPTER

Alexandra Lakhman | 6 Years



NORTH JERSEY CHAPTER

Laura Watson * | 7 Years

*attending Conference

CHAPTER LEADERS

NEW MEXICO



NEW MEXICO CHAPTER

Natasha Abruzzo* | 15 Years



NEW MEXICO CHAPTER

Annie Wiseman* | 5 Years



NEW MEXICO CHAPTER

Joe Wiseman* | 5 Years

NEW YORK



NEW YORK CAPITAL REGION CHAPTER

Amy Cunniff Bleau | 13 Years



NEW YORK CAPITAL REGION CHAPTER

Allie Wolfe | 5 Years



WESTERN NEW YORK CHAPTER

Mary Boguhn* | 19 Years

OHIO



OKI CHAPTER

Stephanie Hall | 11 Years



OKI CHAPTER

Beth Lockwood | 21 Years



OKI CHAPTER

Kevin Lockwood | 21 Years



OKI CHAPTER

Elizabeth Lockwood | 21 Years

OKLAHOMA



OKLAHOMA CHAPTER

Amanda Chaffin | 6 Years

PENNSYLVANIA



PENNSYLVANIA CHAPTER

Emily Farkas* | 3 Years



PENNSYLVANIA CHAPTER

Christina Murray



PENNSYLVANIA CHAPTER

Gina Perri

PUERTO RICO



PUERTO RICO CHAPTER

Brenda Luciano | 6 Months



PUERTO RICO CHAPTER

Ramon Rivera Vega* | 6 Months



PUERTO RICO CHAPTER

Keishla Rolon* | 6 Months



PUERTO RICO CHAPTER

Natasha Santiago* | 6 Months



PUERTO RICO CHAPTER

Elizabeth Serrano* | 6 Months

**attending Conference*

CHAPTER LEADERS

SOUTH CAROLINA



CAROLINAS CHAPTER

Idalmis Vivar

TENNESSEE



TENNESSEE CHAPTER

Sarah Boggess*



TENNESSEE CHAPTER

Rondi Kauffmann | 6 Years



TENNESSEE CHAPTER

Keri Tarantino | 6 Years

TEXAS



TEXAS CHAPTER

Beth Moore* | 10 Years



TEXAS CHAPTER

Kate Nelson* | 6 Years



TEXAS CHAPTER

Sapna Pringle* | 5 Years



TEXAS CHAPTER

Kristen Resendez* | 6 Years

VIRGINIA



VIRGINIA CHAPTER

Laura Derkowski | 9 Years



VIRGINIA CHAPTER

Kyle Derkowski | 9 Years



VIRGINIA CHAPTER

Jackie Lackey* | 6 Months



VIRGINIA CHAPTER

Sam Lackey | 6 Months



VIRGINIA CHAPTER

Debra Schaefer | 9 Years

VERMONT



NEW ENGLAND CHAPTER

Susan O'Neill | 9 Years

WASHINGTON



PACIFIC NORTHWEST CHAPTER

Mark Courteau* | 2 Years

WISCONSIN



WISCONSIN CHAPTER

Kim Banach | 5 Years



WISCONSIN CHAPTER

Ashley Baumeister* | 6 Years



WISCONSIN CHAPTER

Kristin Jennings * | 6 Years

*attending Conference



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STREAM FOR A PURPOSE

CURE SMA IS LIVE!

Earlier this year, we launched Stream Away SMA—an innovative program where you can utilize the power of streaming to raise funds and awareness for spinal muscular atrophy (SMA).

Professional creators, recreational gamers, and supporters who are brand new to the streaming community are all welcome to participate by hosting a charity stream. Whether you're gaming, making art, playing music, or just chatting, you can help unlock new levels of impact with Cure SMA by channelling your skills and passions into a force for good.

During your charity stream, you'll have the opportunity to inspire your viewers to take action in real time to help fund vital research and support programs that are changing the landscape of SMA today—all while they stream their favorite content!



WILL YOU BE OUR PLAYER 2?

TOGETHER, WE CAN POWER UP THE FIGHT AGAINST SMA.

Level up your fundraising with a charity stream!
Have questions? Post to our Discord channel or reach out to us at fundraising@curesma.org for assistance.



 @CURE_SMA

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.

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

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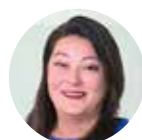
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In memoriam, we honor Peter Pingerelli for his service to the Adult Advisory Council.

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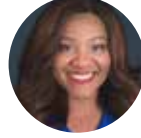
**Vanessa Jackson,
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**Alissa deRamus,
Executive Assistant**



**Jeanette Figueroa,
Revenue Accountant**



**Latesa Reynolds, Specialist,
Data Systems**



DONATE

Your Birthday to Cure SMA

Celebrate your special day with a birthday fundraiser for Cure SMA!
You can create an impactful virtual fundraiser in three simple steps.

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



Register to Fundraise

Create a fundraising page through Cure SMA's DIY website.



Tell Your Story and Spread the word

Write down your unique story filled with lived experiences, inspiring anecdotes, and why you're choosing to raise funds for Cure SMA.



Share the Link to Your Fundraising Page

Connect with the people around you - your family, friends, colleagues, classmates, and communities.

If all of our conference attendees raised \$100 for their birthday, we'd be able to raise over \$200,000 for the SMA community.

Let's celebrate YOU in 2024 together!



With Do It Yourself (DIY) fundraising, the possibilities are endless. Reach out to us at diy@curesma.org for help getting started or to receive branded marketing and materials.

Cure
SMA

DO IT YOUR WAY

FUNDRAISING



WALK-N-ROLL

JOIN THE MOVEMENT: CURE SMA'S WALK-N-ROLL

Stand Strong with the
SMA Community:
Register or Donate today!



Whether you walk, roll, or simply donate, your involvement in our Walk-n-Roll program is a powerful way to make a difference for individuals with spinal muscular atrophy (SMA).



Cure SMA introduces the 2024 Exclusive Legacy Club:

Raise \$5,000 or more and receive a custom 40th Anniversary special embroidered letterman jacket. Join today!

THANK YOU TO OUR SPONSORS

National Presenting Sponsors



National Supporting Sponsor



National Title Sponsor



Boost your fundraising and stay up to date!

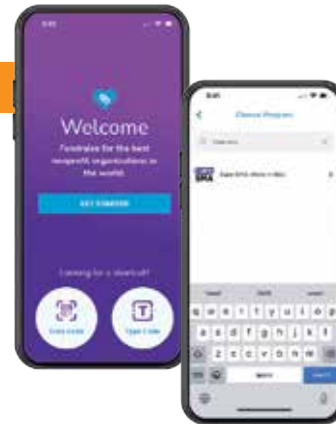
The DonorDrive Charity Fundraising App is a powerful tool to help you raise funds and awareness for the SMA community. Download the app today to connect with your community and go the extra mile in your fundraising.



HOW TO GET STARTED

1 Install the DonorDrive App

- Download the DonorDrive Charity Fundraising app from the Google Play or Apple App store.
- Open the app and tap **Get Started**.
- Search for **Cure SMA** at the top search bar.
- Select **Cure SMA**.
- Tap **Log in** and use the same email address and password you used when you registered for your event.



2 Fundraise



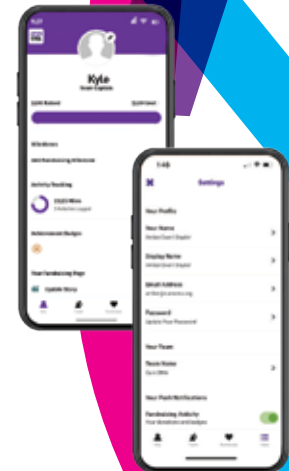
The app will help you complete key actions that can boost your personal and team fundraising.

From the **“You”** tab you can:

- Create a Facebook Fundraiser.
- Display your QR Code to allow others to directly access your fundraising page.
- Update and share your page with friend and family for donations.
- And more!

From the **“Team”** tab Team Captains can:

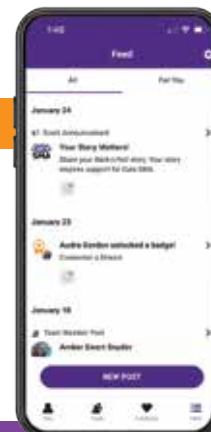
- View the team roster.
- Send an updates to team members via email or through a feed post.



3 Stay Up To Date

Check out the Feed tab for important event information and updates.

- See and react to updates from your Team Captain.
- Hear updates from Cure SMA about the impact of your fundraising.
- Check out tips to boost your support for the Walk-n-Roll.



Fill out the conference survey

FILL OUT THE CONFERENCE SURVEY FOR YOUR CHANCE TO
WIN AN APPLE WATCH OR 2025 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 your conference folder. Please drop your completed surveys into the many bins throughout the meeting space, at your workshops or at the Registration Area.

All participants who complete the surveys by 10:30am on Sunday, June 9, 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 2025 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 9, at the Closing General Session/It's a Wonderful Life. All participants who complete the surveys by 10:30am on Sunday, June 9, will have their name entered into a raffle.



You can also fill out the survey online at
<https://survey.alchemer.com/s3/7757341/2024-Annual-SMA-Conference-Austin>



Summits are one day educational events, crafted to provide people of all ages and types of SMA and their caregivers the opportunity to network and learn about the latest advances in treatment, care, advocacy, and support.

Atlanta, GA | February 3
Brooklyn, NYC, NY | February 17
Philadelphia, PA | March 2
Detroit, MI | April 13
Chicago, IL | April 27

Sanibel, FL | July 13
Boston, MA | July 20
Norfolk, VA | August 3
San Antonio, TX | September 7
Orlando, FL | September 21

Phoenix, AZ | September 28
Houston, TX* | November 2
Anaheim, CA | November 23
New Orleans, LA | December 7
San Jose, CA | December 14

**Both English and Spanish Sessions!*

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

Summit of Strength Webinar Series

Cure SMA offers a variety of educational online content specifically tailored for individuals and families living with SMA. Check out our YouTube channel at youtube.com/@CureSMA for all of these valuable webinars!



REGISTER TODAY!

Thank you to the sponsors for the 2024 Summit of Strength Program

PRESENTING SPONSORS



VISIONARY SPONSOR



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JW MARRIOTT AUSTIN LEVEL MEETING SPACE GUIDE

LEVEL 2

- **Griffin Hall** – Exhibitors; Meals; Seating
 - **Brazos** – Adults with SMA Lounge
 - **201 & 202** – Workshop
 - **Griffin Hall Foyer** – Registration; Merchandise Sales
-

LEVEL 3

- **Lone Star Ballroom E – H** – Children’s Program & Baby Room
 - **Lone Star Ballroom A – D** – Symposia; General Session; Workshop; PJ Party; Mom’s Night; Dad’s Night
 - **301 & 302** – Kids Talk it Out; Workshop
 - **303 & 304** – Teen Lounge
 - **305** – Workshop; Siblings Talk it Out
 - **Lone Star Ballroom Foyer** – Children’s Program Registration; Some Food Buffets for Breakfast & Lunch
-

LEVEL 4

- **JW Grand Ballroom 1, 2, 3, 4, 5, 6, 7, 8** – Workshops; Meet & Greet; Poster Session; Adults with SMA Reception
- **401** – Workshop
- **402 & 403** – Workshop; Teen Social

LEVEL 2 - JW MARRIOTT AUSTIN



LEVEL 3 - JW MARRIOTT AUSTIN

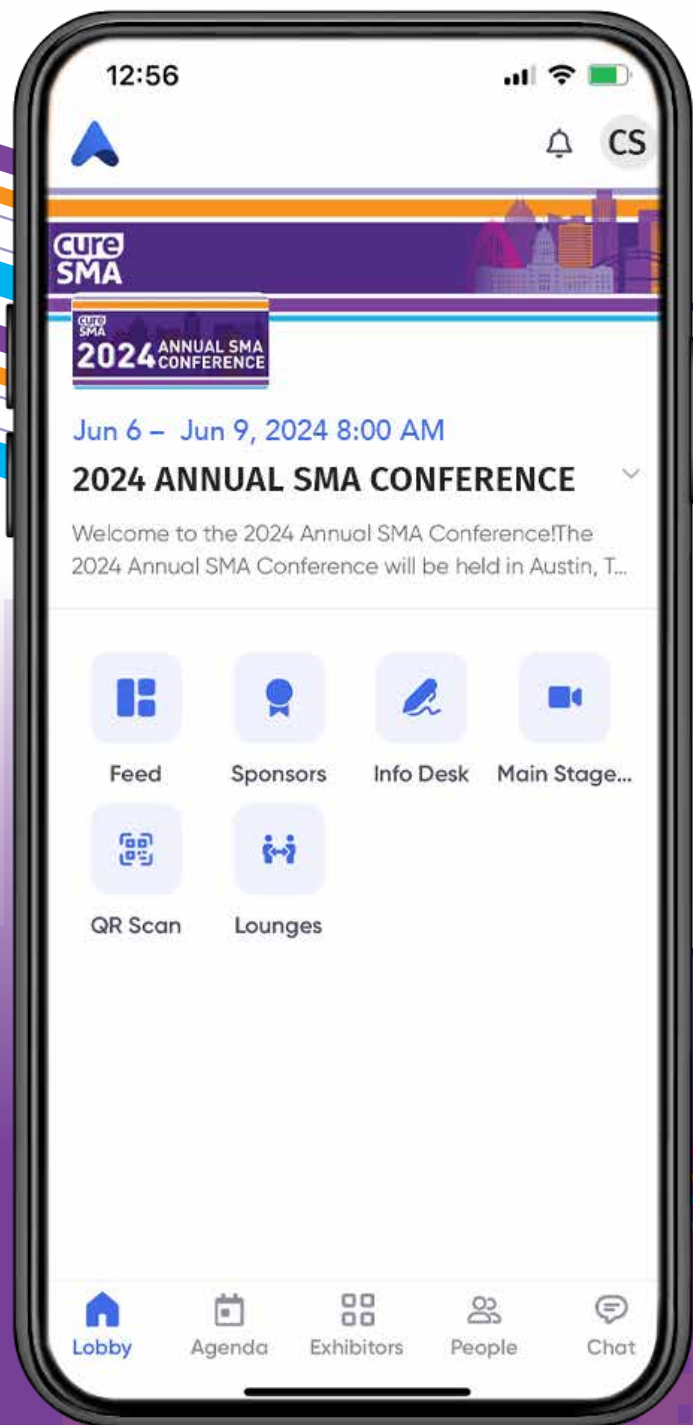


LEVEL 4 - JW MARRIOTT AUSTIN



The Annual SMA Conference App

The 2024 Annual SMA Conference App is the perfect tool to keep you up to date on everything happening at conference!



Features you will find on the app:

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

**cure
SMA**