

# DIRECTIONS

FALL 2019



**cure**  
**SMA**

Make today a  
breakthrough.

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# 2020 ANNUAL CURE SMA CONFERENCE

THURSDAY, JUNE 11, 2020

**TO** SUNDAY, JUNE 14, 2020

## DISNEY'S YACHT & BEACH CLUB RESORT IN ORLANDO, FLORIDA

Every year, Cure SMA sponsors a conference to bring together the leading SMA researchers, clinicians, and families living with SMA. Cure SMA has been hosting the Annual SMA Conference since 1988. The weekend is filled with a wide variety of workshops, keynote sessions with leading researchers, a family-friendly poster session, a memorable children's program, a meet and greet with a family fun fest, teen and adult social activities, a PJ party and movie night, and a Disney Night at the Park, as well as many opportunities to connect and interact with families and receive first hand updates from the researchers and clinicians.

**We look forward to reuniting as a community at this conference and showing our support for others.**

As always, the Family, Research, and Clinical Care Conferences run alongside each other. This is the largest conference in the world for those affected by SMA, and also for those involved in providing support and care for SMA patients. There is no other program like it. The interactions between the families, researchers, and clinicians at this conference are extremely special.

The annual conference also provides the children an opportunity to make new friends and have a great time. We are expecting another great attendance of over 2,500 attendees.

**Disney's Yacht & Beach Club Resort and Disney's BoardWalk Inn in Orlando, Florida have been carefully selected to meet the needs of the SMA Community for the 2020 Annual SMA Conference.**

**You must complete your conference registration with Cure SMA prior to reserving your hotel room, for the special room rate of \$264 per night plus tax at Disney's Yacht & Beach Club Resort and Disney's BoardWalk Inn.**

Disney's Yacht & Beach Club Resort, where the majority of the conference will take place, is a lakeside resort with an array of New England-style eateries, a full-service exercise and spa facility, and 3 relaxing leisure pools. To top it off, the resort features Stormalong Bay, a three-acre sand bottom pool complete with a shipwreck replica, water slides, lazy river, and a tanning deck. For luxurious spa services, visit Ship Shape, the Yacht Club's massage, salon, and fitness center. For outdoor fun, step right outside to the Bayside Marina where you can rent different watercrafts, take a guided fishing excursion, and go on a pirate adventure cruise!



To register for the Annual SMA Conference,  
please visit [www.cureSMA.org](http://www.cureSMA.org)



# SMA CONFERENCE GOALS

## EXHIBITOR OPPORTUNITIES

The Annual SMA Conference is a wonderful opportunity to promote your company and products to SMA families, medical professionals, and researchers from all over the world. By hosting an exhibitor table or booth, you will be able to personally share the details of your new and existing products with several SMA families and medical professionals, as well as be prominently displayed throughout the conference and online.

For more information, please email [exhibitor@curesma.org](mailto:exhibitor@curesma.org)

## SPONSORSHIP OPPORTUNITIES

The Annual SMA Conference does not happen without a tremendous amount of work and support. Thank you for your consideration and for making a difference in SMA research and for those affected by SMA. Sponsorship is a way of establishing a deeper association and positive brand awareness with the SMA families and researchers.

For more information, please email [sponsorship@curesma.org](mailto:sponsorship@curesma.org)

- To welcome newly diagnosed families into the SMA community.
- To help build an SMA community and help keep that community strong and unified.
- To educate SMA families and provide updates on medical issues, research, and clinical trials.
- To facilitate networking and data sharing between researchers, clinicians, families, and patients.
- To educate researchers and clinicians on the latest research advancements.
- To attract the best researchers and clinicians to the SMA field and encourage collaborations and investments.
- To promote cross-disciplinary dialogue among academic, clinical, and industrial researchers.

## NEWLY DIAGNOSED CONFERENCE PROGRAM

Thanks to the generous funding provided by the Erin Trainor Memorial Fund, Cure SMA covers up to 4 family members' registration fees as well as one hotel room for 3 nights for the Annual SMA Conference. This program is for all families newly diagnosed since the last conference. The mission of the Erin Trainor Memorial Fund (ETMF) is to generate substantial funds to be able to provide conference scholarships, allowing newly diagnosed SMA families/individuals the opportunity to attend the Annual SMA Conference. Our goal is to allow as many newly diagnosed SMA families as possible to attend and experience the benefits of this amazing conference. The meeting gives families the opportunity to gather critical care and daily living information early after diagnosis, learn directly from experienced SMA physicians, and network with other families. This program is automatically offered to all newly diagnosed families that contact Cure SMA.

For more information, please email [familysupport@curesma.org](mailto:familysupport@curesma.org)

## GENERAL CONFERENCE SCHOLARSHIP

For families who are not newly diagnosed, we also have general conference scholarships available to help waive the registration fee costs to attend the conference. Families looking to receive a general conference scholarship are required to apply and can be placed on a scholarship waiting list. They will be notified if they are able to receive a scholarship.

Please email [conference@curesma.org](mailto:conference@curesma.org) for more information.

## SPECIAL MEETING AND CONVENTION THEME PARK TICKETS

Come for the conference and stay for the magic! Make the most of your free time with special Disney Meeting and Convention Theme Park tickets. 2020 Annual SMA Conference attendees are eligible for advance purchase of specially priced discounted Disney Meeting/Convention Theme Park tickets. Ticket information will be provided after you register for the Annual SMA Conference.



Please visit [www.curesma.org](http://www.curesma.org) for more conference information.

The **first** treatment for children and adults with spinal muscular atrophy (SMA)

# WHAT COULD SPINRAZA UNLOCK?



**Sofia**  
age 2.5  
Infantile-onset (Type 1) SMA  
treated with SPINRAZA

The effectiveness of SPINRAZA was evaluated in a well-controlled clinical study of 121 individuals with infantile-onset (Type 1) SMA aged 30 to 262 days and supported by clinical experience across a broad range of ages, SMA types, and level of function.

## Achieving motor milestones

When treated with SPINRAZA, individuals with infantile-onset SMA showed improvements in milestones that are rarely, if ever, achieved in untreated infants.

## Safety considerations

It is recommended that your healthcare provider perform blood and urine testing before starting SPINRAZA and before each dose to monitor for signs of bleeding or kidney damage.



Find out how SMA360° can help with insurance and treatment logistics at [SPINRAZAsupport360.com](https://SPINRAZAsupport360.com)

## INDICATION

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

## IMPORTANT SAFETY INFORMATION

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

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

**The most common side effects of SPINRAZA include** lower respiratory infection, fever, constipation, headache, vomiting, back pain, and post-lumbar puncture syndrome.

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

**For additional Important Safety Information, please see brief summary of full Prescribing Information to the right.**

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



**Lauren**  
age 20  
Later-onset (Type 3) SMA  
treated with SPINRAZA



**Bill**  
age 48  
Later-onset (Type 3) SMA  
treated with SPINRAZA

Individual results may vary based on several factors, including severity of disease, initiation of treatment, and duration of therapy.

## IMPORTANT FACTS ABOUT SPINRAZA® (nusinersen)

### USES

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

### WARNINGS

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

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

### COMMON SIDE EFFECTS

- **The most common side effects of SPINRAZA include** lower respiratory infection, fever, constipation, headache, vomiting, back pain, and post-lumbar puncture syndrome (headache related to the intrathecal procedure).
- Serious side effects of complete or partial collapse of a lung or lobe of a lung have been reported.

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

### OTHER INFORMATION

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

### QUESTIONS?

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

### MANUFACTURED FOR

Biogen  
Cambridge, MA 02142





## 2019 Annual SMA Conference Summary



Thank you to everyone who attended the 2019 Annual SMA Conference at the Disneyland Hotel in Anaheim, California. It was an impactful weekend filled with community, research, and fun! We are happy to announce that, including onsite registration, there were over 2,400 attendees in total – our largest conference to date!

It was such an honor to have SMA families, clinicians, and researchers from 37 countries around the world attend the conference.

The 4-day weekend was filled with special events and workshops. The Newly Diagnosed Program kicked off the conference on Friday, with the Opening General Session welcoming all attendees. Saturday and Sunday were packed full of educational and supportive workshops, as well as the Family Friendly Researcher Poster Session. Finally, the It's A Wonderful Life panel of adults with SMA ended the weekend on a high note. The Meet & Greet, Family PJ Party & Movie Night, and Evening at the Park, sponsored by AveXis, were also conference highlights!

Lastly, at the Monday morning Closing General Session, we announced the location and dates for our 2020 Annual SMA Conference. Mark your calendars for Thursday, June 11 – Sunday, June 14, 2020, as we head to Disney's Yacht & Beach Club Resort in Orlando, Florida!

We extend our thanks to the sponsors and exhibitors who generously supported the 2019 Annual SMA Conference. A special thanks to AveXis, Biogen, and Genentech/Roche for their generosity as presenting sponsors.





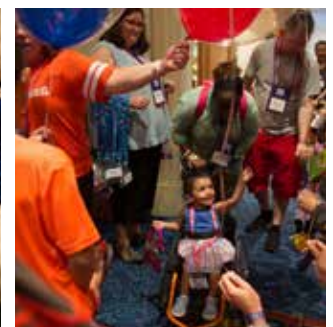
## Meet & Greet

The 2019 Annual SMA Conference began with our signature kick-off event, the Meet & Greet! This tradition welcomes new families, returning families, clinicians, and researchers from all over the world.

It is a special time for all attendees to gather in a fun setting prior to the start of the conference workshops. Everyone at the conference comes together to begin a weekend filled with new friendships and connections, learning the most up-to-date information, and being a part of this wonderful and caring community.

The many games that line the perimeter of the ballroom help to make the Meet & Greet an enjoyable event. Kids and families rotate around to play Bozo Buckets, check out a Treasure Chest, pick a treat from the Lollipop Tree, and much more. The games are adapted for all children to enjoy and win great prizes.

Mickey Mouse, Minnie Mouse, Donald Duck, Daisy Duck, and Wreck-It Ralph were also there to meet the attendees!

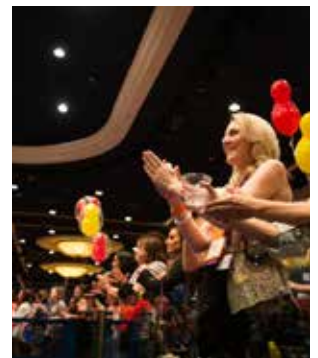




# Researcher Relay Race

The popular Researcher Relay Race is always a highlight at the Meet & Greet, as kids race researchers and clinicians one-on-one to see who can cross the finish line first, with one rule: that the adults have to race in a manual wheelchair!

All of the attendees stand around the course cheering on the racers to see who will win. Try as they may, the researchers and clinicians are always left in the dust!

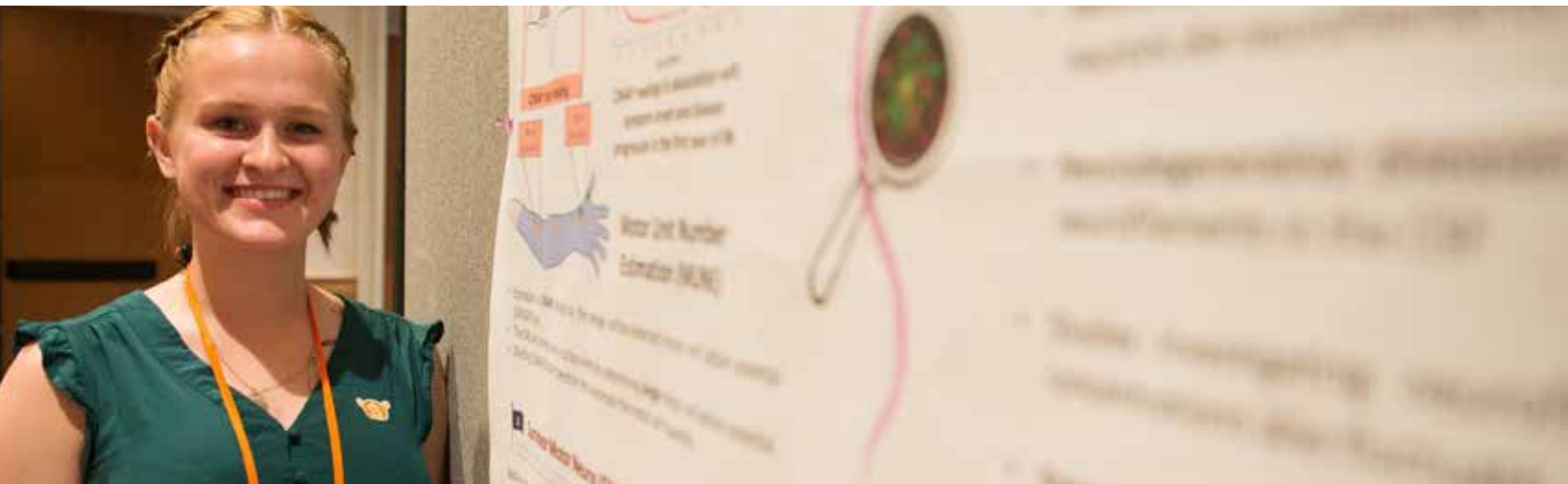




## Workshops

A variety of informative workshops and sessions were offered to all families on Saturday and Sunday, led by some of the leading SMA experts as well as other families affected by SMA. There were more than 55 workshops offered during the conference this year, covering the latest information on critical care and support. Presentations from some of the workshops and sessions offered are available on the Cure SMA website at <https://www.curesma.org/annual-sma-conference/>.





# Family Friendly Researcher Poster Session

The Family Friendly Researcher Poster Session allowed for one-on-one interactions between families and researchers. Cure SMA invited researchers, who were attending the SMA Researcher Meeting, to present family friendly research posters. During the Saturday evening event, families were encouraged to rotate to the different posters to ask questions and learn directly from the researchers involved in each of the projects being presented.

Attendees were also able to stop by the Cuddle Corner to snuggle the therapy dogs kindly brought in by Canine Companions, and meet Disney characters Buzz Lightyear, Woody and Jessie from Toy Story, as well as Pluto.

Family Friendly Researcher Poster Session Posters Included:

**Allison Ebert, PhD from the Medical College of Wisconsin:**  
Understanding SMN Function in Different Cell Types

**Allison Mazzella from Cure SMA:** Assessing Clinical Meaningfulness and Patient Experience in the SMA Teen and Young Adult Populations

**Arthur Burghes, PhD & Anton Blatnik from the Ohio State University:**  
Suppressors of SMN Function and Modifiers of Spinal Muscular Atrophy

**Janice Wong, MD & Kristina Johnson from Biogen:** The Spinraza Clinical Development Program

**Garrett Ingrando, MBA from Biogen:** SPINRAZA Experience in the Real World

**Brunhilde Wirth, PhD from the University of Cologne, Germany:**  
Genetic Modifiers of SMA Help Some People to Remain Asymptomatic; How Can This Knowledge Help All People with SMA?

**Cera Hassinan from Johns Hopkins School of Medicine:**  
Neurofilament as a Biomarker for SMA

**Chad Heatwole, MD, MS-CI from University of Rochester Medical Center:** Measurement of a Patient's Health Status (The SMA-Health Index)

**Geneviève Paris & Andréanne Didillon from the University of Ottawa:**  
SMN and friends: What we can learn from SMN Interactors

**Jen Szegda & Erin Treece, MS from Scholar Rock:** SMA Muscle-Directed Therapy Advancing in Clinical Development.

**Hannah Staunton & Samuel Ewing, EngD from F. Hoffmann-La Roche:** New Measures of Function and Independence in Spinal Muscular Atrophy

**Jamie Shish from Cure SMA:** Cure SMA Newborn Screening Survey and Database

**Reid Garner, Christiano R Alves, PhD, Kathryn J Swoboda, MD from Massachusetts General Hospital & Harvard Medical School:** Circulating Biomarkers for Spinal Muscular Atrophy

**Senam Beckley-Kartey, Marco Castillo, MD & Fani Petridis from F. Hoffmann-La Roche:** Roche and Genentech Spinal Muscular Atrophy Clinical Development Program

**Kevin Kaifer, PhD from the University of Missouri:** Astrocytes Contribute to Motor Neuron Degeneration in Spinal Muscular Atrophy

**Zaida Alipio-Gloria, Arnab K. Chatterjee, Jingxin Wang, Andrew To, Kristen Johnson from Calibr, a Division of Scripps Research:** Innovative Screening Approaches to Identify the Next Generation of SMN-Inducing Compounds

**Frank Bennet, PhD & Kristina Bowyer from Ionis Pharmaceuticals:** Antisense Oligonucleotide Strategies for SMA

**Krysta Engel, PhD from the University of Colorado:** Transcriptome-Wide Interrogation of SMN-mediated RNA Localization Mechanisms in Neurons

**Laxman Gangwani, PhD from Texas Tech University:** Overview and Comparison of SMN-Dependent and SMN-Independent Methods for the Treatment of Spinal Muscular Atrophy

**Lisa Belter from Cure SMA:** Cure SMA Membership: Findings from the 2019 Membership Survey

**Samantha Edell, Darren T. Hwee, PhD, Stacy Rudnicki, MD, Bettina Cockcroft, MD, MBA, Andrew Wolff, MD & Lucie Vu, PhD from Cytokinetics:** Results from Two Pre-clinical Studies: Reldesemtiv in Combination with Nusinersen and in Combination with SMN-C1 Shows Improved Muscle Function in Mouse Model of Spinal Muscular Atrophy

**Mary Schroth, MD, Jamie Shish, Teresa Stewart & Abigail Paras from Cure SMA:** Cure SMA Clinical Care Center Network and SMA Clinical Data Registry

**Doug Sproule, MD from AveXis:** Provide an Overview of ZOLGENSMA Indication, Efficacy, Safety and Dosing for Caregivers

**Kathy L. Poulin, Joshua Del Papa, Hugh J. McMillan, MD, Jodi Warman Chardon, MD, Rashmi Kothary, PhD & Robin J. Parks, PhD from the Ottawa Hospital Research Institute:** Biomarkers for Spinal Muscular Atrophy

**Samuel R. Rosenfeld, MD from Children's Hospital of Orange County:** 20 Year Experience with Segmental Sublaminar Instrumentation for Guided Growth in Early Onset Scoliosis

**Bakri Elsheikh, MD & Sarah Heintzman, RN from the Ohio State University:** The Spinraza Treatment Initiative at The Ohio State University

**Saravanan Arumugam, Michael Kahl, Zhaofa Xu & Yongchao Ma, PhD from Northwestern University:** Targeting Mitochondria, the Powerhouse in Motor Neurons, for Treating SMA

**Fernanda Boulos, PhD and Svetlana Jevtic, DVM, MSc from Novartis:** Branaplam (LMI070) Clinical Program Summary

**Sibylle Jablonka, PhD & Utz Fischer, PhD from the University of Wuerzburg, Germany:** Calcium Channels in SMA: What about the SMN Complex?

**Erin Kelly from Cure SMA:** The SMA Patient and Family Voice: Impacting our Community and Stakeholders Through Advocacy, Clinical Care, Research, and Industry Partnerships

**Josh Noone, PhD, Sarah Whitmire, MS, Daniel Buchenberger, MS, Rosalina Mills, Christine Pozniak, PhD & Er Chen, MPP from F. Hoffmann-La Roche:** Impact of SMA on Caregivers' Daily Activities and Health-Related Quality of Life





## PJ Party and Movie Night



On Saturday evening after the Family Friendly Researcher Poster Session, families were invited to cozy up and enjoy Toy Story on the big screen! It was a relaxing end to the evening, after a full day of workshops.





## Cure SMA Evening at the Park

All attendees were invited to enjoy the magical Disneyland Park together on Sunday evening. It was a beautiful evening to raise awareness and be together at the theme park after a fun day of workshops! The Cure SMA Evening in the Park was generously sponsored by AveXis.



SPONSORED BY AVEXIS





## Adult Programs

A new Adults with SMA Lounge was offered on both Saturday and Sunday as a fun space for adults with SMA to mingle and unwind. This lounge, generously sponsored by Biogen, offered a relaxing space with snacks, refreshments, and television.

The Adults with SMA Receptions were another opportunity for adults with SMA and their families to spend time together in a friendly social setting. These receptions, held on both Friday and Saturday evenings, were graciously sponsored by the Dhont Family Foundation.

Another special addition to this year's conference was the scholarship for adults with SMA, sponsored by Genentech/Roche, which offered travel stipends for both an adult with SMA and their aide/attendant, as well as up to three nights hotel stay. The Dhont Family Foundation also provided registration scholarships for adults with SMA.



**Genentech**  
A Member of the Roche Group

THE  
**DHONT**  
FAMILY FOUNDATION

*"My husband and I were so impressed and energized by the conference and by Cure SMA. I have followed the website for years but gained new appreciation for the organization and its work at the conference. My husband and I both attended many conferences of various types in our careers and both of us felt this was the best organized, best thought out, and well run conference we have ever attended."*

*I was also impressed with the equal care and thought given to adults with SMA as well as, the families and children. It is really refreshing to see Cure SMA's commitment to adults, as well as the forward thinking regarding changing needs in this new era where treatments are available."*

*-The Johnson Family*

*"Our trip to Disneyland just coincided with your conference. I didn't know about SMA before but I saw all these absolutely amazing people and their families/caretakers doing their thing at life. I am going to donate and post an awareness note/link in my Facebook page so people can understand and be inspired."*

*Thanks for the massive inspiration. Please pass this sentiment onto everyone with SMA you can on my behalf."*

*-Molly*

## Quotes from Around the Community on the 2019 Annual SMA Conference

*"It was incredible to see and hear the data for the current therapies and the therapies coming down the road for these patients. Also, to experience firsthand the collaborative approach taken to ensure patients and families are on the forefront of therapeutics for SMA. Truly remarkable and what I perceive as a gold standard approach to disease awareness and research."*

*-John McGuire*

*"Neither of us are new to industry events or scientific conferences but this was one of the most dedicated scientific gatherings we have seen. We discussed several times during the conference how impressed we were with the sheer number of field experts and the dedication of the clinicians to finding treatments for these families. It was truly awe inspiring."*

*-Buffy Nelson*

*"We want to say a huge thank you to Cure SMA, The Dhont Foundation, Genentech, and to all the volunteers for making it possible, for my family to attend this year's conference. It was such a positive experience for my kids to be around people who are similar to their mom. We had such a wonderful time! I finally met people in person that I've been talking to for years online and reunited with individuals I had met at last year's conference. I especially loved the opening session message of one community. Thanks again for an amazing time!"*

*-The Ammons Family*

*"Our son, Alexander, hasn't stopped talking about conference and his SMA friends that he met while out there!"*

*-The Enderlin Family*



## Children's Program

This year's Children's Program was another huge success! Thanks to our incredible volunteers, all the children had a fabulous time. Kids stayed busy with countless arts and crafts projects, toys, live entertainment, exciting movies, fun activities, video games, build-a-bear stations, and so much more. A highlight was the caricature artist who drew photos for the kids to take home as a conference memento.

The Annual SMA Conference would not be possible without the assistance of our fantastic volunteers. From setting up decor, working in the Children's Program, preparing and running games at the Meet & Greet, to any of the other countless jobs, our volunteers were amazing once again.







## 23<sup>rd</sup> Annual SMA Researcher Meeting

**The SMA Researcher Meeting is the largest research meeting in the world specifically focused on SMA, and seeks to create open communication of early, unpublished data to accelerate the pace of research.**

The meeting also furthers research by building collaborations—including cross-disciplinary dialogue, partnerships, integration of new researchers and drug companies, and educational opportunities for junior researchers. This year, more than 675 researchers attended the meeting—a record number! The SMA Researcher Meeting runs alongside the family conference, but is held separately for researchers to engage with each other. We then provide opportunities throughout the conference for both the researchers and families to come together for events such as the Meet & Greet, Family Friendly Researcher Poster Session, Evening at the Park, and more. The interactions from both sides of the conferences are so special and is what make the Annual SMA Conference such a unique and valuable weekend for everyone involved.



To view the highlights and summaries specifically from the SMA Researcher Meeting, please visit the SMA Researcher Meeting page <http://www.curesma.org/research/for-researchers/research-conference/>.



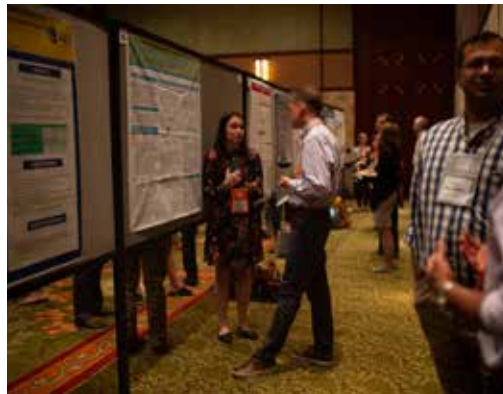
## Clinical Care Meeting

**On Thursday, June 27, Cure SMA hosted its 2nd Annual SMA Clinical Care Meeting, as part of the Annual SMA Conference. This meeting is the third component to the Annual SMA Conference – with the researcher meeting, family meeting, and clinical care meeting all happening in one place at the same time. This allows us to make new connections and interactions that are much more valuable.**

The Clinical Care Meeting provided a valuable opportunity to share knowledge and network among clinical attendees representing 19 countries and 70 different institutions. Attendees also had the opportunity to network with other members of the SMA community, including persons with SMA, families, and researchers.

The goals of this meeting were to provide an opportunity for SMA healthcare providers across various disciplines to share knowledge, discuss improved care for SMA, foster clinical care research collaboration across care centers, promote interactions between new clinicians and leaders in clinical care, build the SMA clinical care community, and promote conversations between families and patients living with SMA, clinicians, researchers, and industry partners.

More than 375 healthcare providers who diagnose and care for people affected by SMA were able to participate this year. This included physicians, nurse practitioners, physician assistants and nurses, pediatric and adult specialists – including neurologists, pulmonologists, rehabilitation medicine, orthopedic surgery, palliative care, physical and occupational therapists, speech and language pathologists, nutritionists, social workers, respiratory therapists, and trainees in the above disciplines.



# 2019 National Partners

Thank you to our National Partners for their continued support of Cure SMA!  
Without it, many of our events and programs wouldn't be possible.

## National Premier Partners



**Biogen**

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*A Member of the Roche Group*

## National Platinum Partners



**NOVARTIS**

## National Gold Partners



## National Silver Partner



## Resources and Communications Partners





# Community Spotlight

## Angela Wigglesworth

**October was National Disability Employment Awareness Month. Throughout the month, we shared stories about adults in the workforce who live with SMA. We are pleased to share this story from Angela Wigglesworth of Texas.**

On the first day of each new school year, Angela Wigglesworth explains spinal muscular atrophy (SMA) to her students. “It [SMA] normalizes very quickly after that,” she says.

Angela, a self-described “student whisperer,” is a 42-year-old elementary school teacher from Houston, TX, who was diagnosed with SMA as an infant. Throughout her years in the classroom, she’s learned that SMA helps her establish bonds with her students, especially some of the more challenging ones. “They all want to help me, and I use it to my advantage. I have an abundance of teacher assistants,” Angela explains.

While she views teaching an energetic bunch of third graders as her ideal career, Angela began college as a business major. During a challenging day on Texas A&M’s campus, she got stuck on the railroad tracks that separated her from the business school. “I was quite unhappy, as you can imagine. I changed my major to education the next day because I would never have to cross those tracks again,” says Angela.

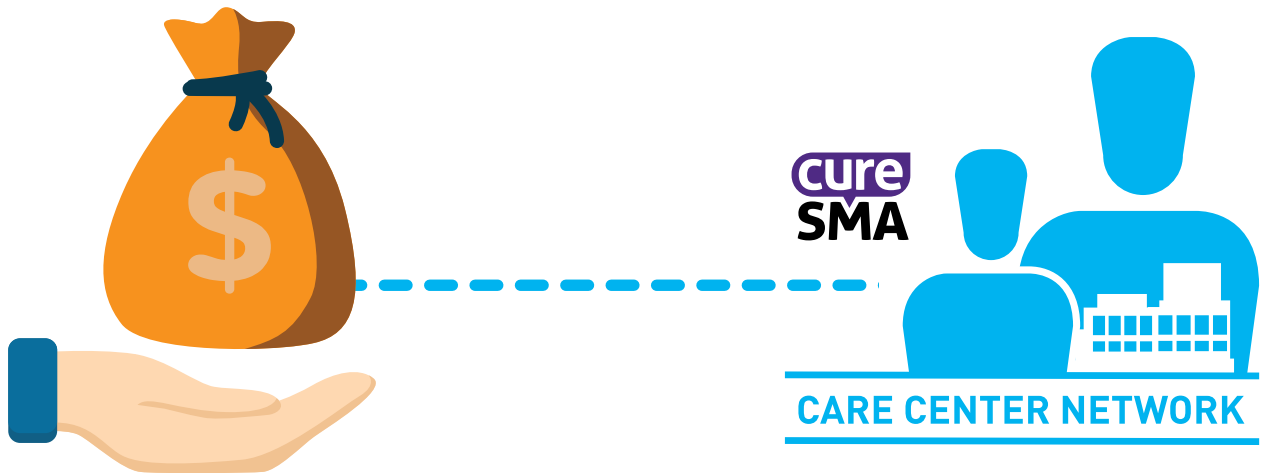
Angela earned a Bachelor of Science in Elementary Education from Texas A&M, and went on to earn a Master of Education in Multicultural Urban Special Education.

Because SMA affects individuals physically, Angela makes accommodations to her day-to-day routine. She uses a document camera instead of writing on the board, and she has a teacher’s aide half the day to help her complete the bigger, more physical tasks. Like most teachers in America, Angela also works from home at least a couple hours on weeknights, grading assignments and completing other administrative tasks.

“It’s a wonderful job if you’re able to be an entertainer from your chair. Kids need you to be ‘on’ the entire day,” Angela said. “Up until I started treatment with Spinraza, I had to fake stamina.”

Asking for accommodations at work is nerve-racking but Angela’s advice is simple: “Be confident. The worst thing they can say is ‘no’. When interviewing with my last boss, I told him, ‘I know it’s expensive to hire me, but I’m worth it’. Be worth it in whatever career you choose.”

*Are you a teen or an adult in the SMA community and would like to receive a Teen and Adult Support Package at no cost? Visit <https://www.curesma.org/teens-and-adults/> for more information.*



# Cure SMA Receives \$150,000 Grant from the Oscar G. and Elsa S. Mayer Family Foundation

Cure SMA is pleased to announce a \$150,000 grant over three years, awarded by the Oscar G. and Elsa S. Mayer Family Foundation, to support continued development of the Cure SMA Care Center Network.

## The mission of the Cure SMA Care Center Network is to:

1. Improve SMA clinical care and disease management, leading to creation of evidence to support a robust standard of care for SMA.
2. Standardize care across the U.S. to improve healthcare delivery, decrease healthcare costs and burden of disease, improve the patient experience, and facilitate more rapid therapeutic development.
3. Develop clinical care center capacity to deliver new therapies to individuals with SMA and increase patient access to new treatments.
4. Increase the number of sites for SMA clinical trials.
5. Provide a resource for local patient services and family support and regional healthcare providers.

## The Cure SMA Care Center Network has expanded to 18 centers across the U.S.:

- Advocate Children's Hospital, Park Ridge, IL
- Arkansas Children's Hospital, Little Rock, AR
- Children's of Alabama, Birmingham, AL
- Children's Medical Center Dallas/UT Southwestern, Dallas, TX
- Children's National, Washington, DC
- Connecticut Children's Hospital, Hartford, CT
- Duke University Medical Center, Durham, NC
- Gillette Children's Hospital, St. Paul, MN
- Lucile Packard Children's Hospital, Palo Alto, CA
- Nemours Children's Hospital, Orlando, FL
- Phoenix Children's Hospital, Phoenix, AZ
- Seattle Children's Hospital, Seattle, WA
- Stanford Medical Center, Stanford, CA
- University of Missouri Health Care, Columbia, MO
- University of Rochester Medical Center - Strong/Golisano Children's Hospital, Rochester, NY
- University of Utah, Utah Program for Inherited Neuromuscular Disorders, Salt Lake City, UT
- Vanderbilt University Medical Center, Nashville, TN
- Yale New Haven Hospital, New Haven, CT



# Cure SMA Summit of Strength Program

The 2019 Summit of Strength Program was a huge success, with more than 135 speakers sharing their expertise on numerous highly rated and unique topics. We would like to thank these wonderful speakers and all attendees for making this year's program so engaging and insightful.

Summits of Strength are single-day, educational events providing information for people of all ages and types of SMA, as well as their loved ones and caregivers. These "mini conferences" give attendees the opportunity to network and learn from national and local experts about the latest advances in support, treatment, care, and advocacy. They can also meet their Cure SMA chapter leaders and connect with others in the local SMA community!

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

**In just the last 16 months, Cure SMA has hosted 36 Summits of Strength reaching 2,900 registered attendees. The 2018 and 2019 Summits of Strength included:**

Anaheim, California  
Austin, Texas  
Baltimore, Maryland  
Birmingham, Alabama  
Boston, Massachusetts  
Charleston, South Carolina  
Chicago, Illinois  
Cincinnati, Ohio  
Dallas, Texas  
Newark, New Jersey  
Orlando, Florida  
Philadelphia, Pennsylvania  
Phoenix, Arizona  
Raleigh, North Carolina  
Seattle, Washington

Denver, Colorado  
Fort Lauderdale, Florida  
Grand Rapids, Michigan  
Kansas City, Missouri  
Little Rock, Arkansas  
Long Island, New York  
Milwaukee, Wisconsin  
Minneapolis, Minnesota  
New York City, New York  
Rochester, New York  
Saint Louis, Missouri  
Salt Lake City, Utah  
San Ramon, California  
Santa Clara, California

*Thank you to the 2019 Summit of Strength Program's National Presenting Sponsors: AveXis, Biogen, and Genentech/Roche. We would also like to recognize Platinum Sponsor, Scholar Rock, for its support.*



# 2020 SUMMIT OF STRENGTH PROGRAM

Be sure to register for the Summit of Strength in your area!  
The 2020 Summit of Strength series will be held in the following cities:

Anaheim, California	Grand Rapids, Michigan	New Orleans, Louisiana
Baltimore, Maryland	Houston, Texas	New York City, New York
Boston, Massachusetts	Indianapolis, Indiana	Orlando, Florida
Chicago, Illinois	Jacksonville, Florida	Philadelphia, Pennsylvania
Cincinnati, Ohio	Kansas City, Missouri	Raleigh, North Carolina
Dallas, Texas	Louisville, Kentucky	San Francisco, California
Des Moines, Iowa	Minneapolis, Minnesota	Seattle, Washington

Please see the Cure SMA website for an updated list of cities and dates.  
For more information or questions, please email [familysupport@curesma.org](mailto:familysupport@curesma.org)



[instagram.com/curesmaorg](https://www.instagram.com/curesmaorg)



[twitter.com/cureSMA](https://twitter.com/cureSMA)

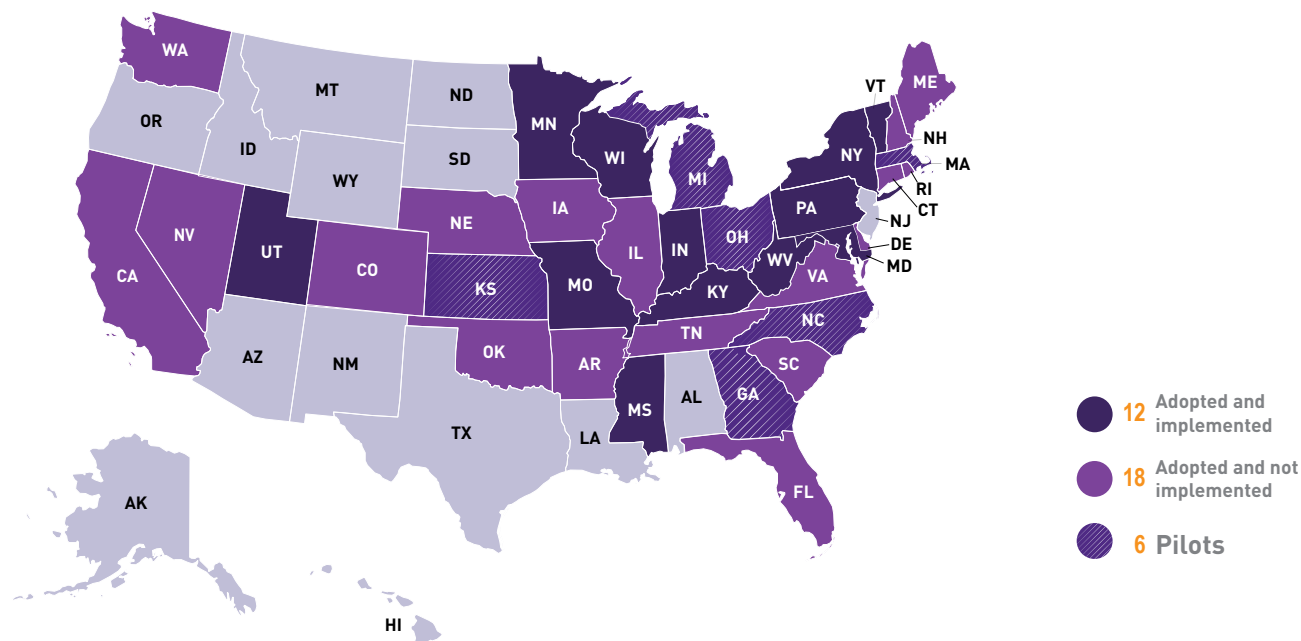


[facebook.com/cureSMA](https://www.facebook.com/cureSMA)



[www.youtube.com/c/CureSMA](https://www.youtube.com/c/CureSMA)

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



## States Continue to Make Progress Toward SMA Newborn Screening Adoption and Implementation

Cure SMA and our community of individuals, families, and partners across the country continue to work in support of state adoption and implementation of newborn screening for SMA.

To date, 12 states (IN, KY, MD, MN, MO, NY, PA, UT, VT, WI, WV, MS) have fully implemented newborn screening of SMA, while another six states (GA, MA, MI, NC, KS, OH) have initiated pilots. An additional 18 states have added SMA to their newborn screening panel and are now working toward implementation (AR, CA, CO, CT, DE, FL, IA, IL, ME, NE, NH, NV, OK, RI, SC, TN, VA, WA).

**This fall and winter, we expect to see more states take positive steps toward newborn screening for SMA, including the following state actions:**

- Wisconsin: screening of all babies for SMA is expected to begin in October 2019;
- Michigan: SMA newborn screening is expected to start in March 2020. This summer, Cure SMA provided \$75,000 in grant funds to assist the state in its efforts to implement;

- Colorado: the state's Board of Health added SMA to its newborn screening panel. The changes take effect on January 2020;
- New Hampshire: the Governor and Executive Board are expected to consider an amendment to its newborn screening laboratory contract to include SMA. If approved and funded, SMA screenings would begin shortly thereafter; and
- Arkansas: final rule-making steps are expected by the end of 2019 with SMA newborn screening to begin as early as 2020.

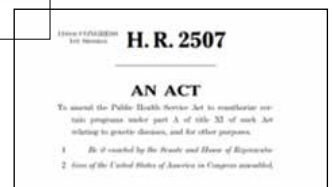
Cure SMA advocates in Nebraska, New Jersey, Iowa, Oregon, Washington, and other states have been working in recent months to help advance adoption and implementation of SMA newborn screening in their states. Thank you for all your efforts!

Want to get involved with local and national advocacy efforts around newborn screening for SMA? Contact the Cure SMA Advocacy Team at [advocacy@curesma.org](mailto:advocacy@curesma.org).



# Newborn Screening Reauthorization Bill Awaits Final Action

The Newborn Screening Saves Lives Reauthorizations Act (H.R. 4378 / S. 2158) is still awaiting approval in the U.S. Senate. The U.S. House of Representatives approved its version of the Newborn Screening Saves Lives Act earlier this summer. The reauthorization of this bill will renew newborn screening activities and funding nationally, extending screening activities through fiscal year 2024 and recommending \$30 million in new funding for state newborn screening implementation and evaluation. Separately, Congress approved a funding measure that would temporarily fund existing newborn screening activities while it works on the reauthorization bill.



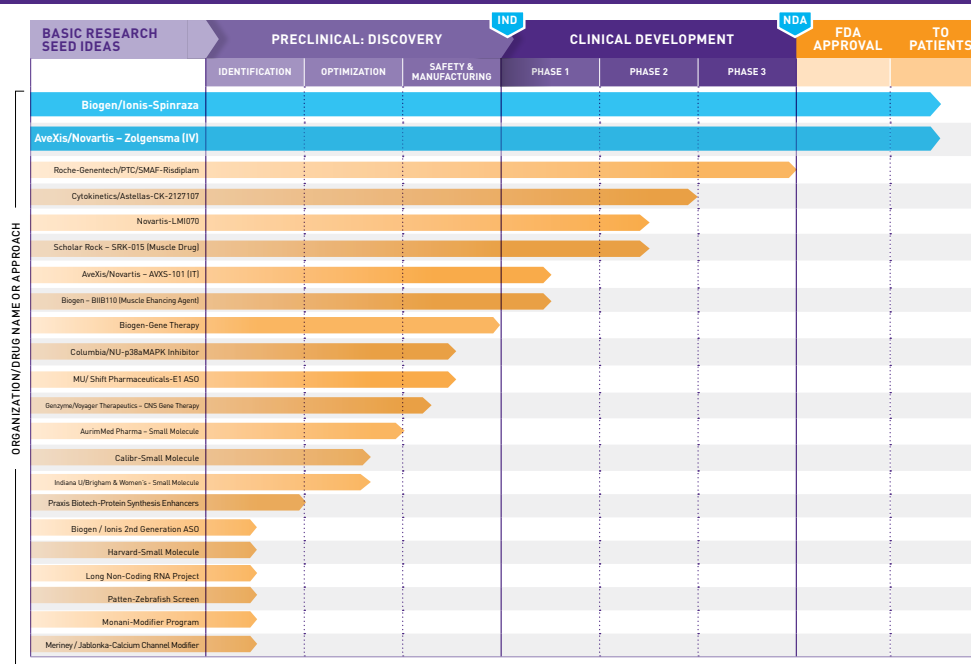
**Ask your Senators to support the Newborn Screening Saves Lives Reauthorization Act today!**

**Visit [www.curesma.org/actioncenter](http://www.curesma.org/actioncenter) to show your support for newborn screening.**

We've recently released an update to the SMA drug pipeline.

This latest version includes:

- 23 active programs, including two approved therapies.
- 15 pharmaceutical partners.
- 6 programs in clinical trials.
- An ever-increasing breadth of potential treatment approaches to SMA.



# Updated SMA Drug Pipeline

## Effective Treatments for All Ages, Stages, and Types of SMA

The updated version of this pipeline reflects our community's progress in gaining access to Zolgensma and Spinraza, as well as the progress of 21 additional programs currently in development.

There are a number of systems, pathways, and processes that are affected in SMA, and there may be additional ways to treat SMA that work on these other areas—collectively referred to as “non-SMN” approaches. These non-SMN approaches include drugs that work on the muscles and nerves.

Research strongly suggests that a combination of SMN-enhancing and non-SMN approaches is the best route to treat all ages, stages, and types of SMA. This allows us to attack SMA from all sides and ensures that comprehensive, effective treatments are available. Because of this, Cure SMA's strategic research model is focused on the complementary goals of increasing the total number of programs in the drug pipeline and increasing the diversity of programs in the pipeline.

## Balance of Therapeutic Approaches

In order to find more treatments and a cure for SMA, we know it's crucial to attack SMA from all sides. As with all

scientific research, it's difficult to predict which SMA drug programs might be successful. By investing in diverse of approaches, we maximize our chances for success. If one drug candidate or one approach fails, we have others to take its place.

## The Cure SMA drug pipeline identifies four possible treatment targets:

1. Replacement or correction of the faulty SMN<sub>1</sub> gene.
2. Modulation of the low functioning SMN<sub>2</sub> “back-up gene.”
3. Neuroprotection of the motor neurons affected by loss of SMN protein.
4. Muscle protection to prevent or restore the loss of muscle function in SMA.

The therapeutic approaches section of our website describes each of these approaches in more detail.

## Thank You

The dedicated support of our community has made all this possible. Whether families raising funds and awareness, researchers investigating new potential treatments, or pharmaceutical and regulatory partners helping us take the next steps—everyone has a role to play. Thank you to everyone for their hard work and dedication.



## Community Spotlight: PAUL GUARINO

**Paul Guarino was ahead of his time when he started PG Sports as a Twitter page in 2011. Initially, the West Haven, CT native created a simple logo and shirts to promote the newly formed brand. As Guarino gained followers and interest grew in the shirts, he knew it was time for an upgrade.**

After predicting the exact score of Super Bowl XLVI, the Giants vs the Patriots, Guarino connected with a graphic designer, Corey Jeppesen. Jeppesen created the logo PG Sports uses today. Once the logo was official, Guarino began reaching out to athletes via social media. The ask was simple, PG Sports would send the gear and in return the athletes would tweet it out to their followers or send Guarino a picture he could use to promote the brand. A common practice used by brands in 2019, Guarino's method was innovative by 2011 standards.

The first few athletes connected to PG Sports were former MLB All-Star Chuck Knobloch, former NFL player Rob Jackson (West Haven native), MLB All-Star Brandon Phillips and WNBA All-Star Renee Montgomery. Since then, Paul has made a lot of connections in the sports world. Today, PG Sports' accounts have a combined social media following of 42,000 people. What started as a Twitter page has turned into a multifaceted brand, complete with custom apparel, a regular podcast, and a YouTube show called the My Why Series.

PG Sports' slogan, Everywhere & Anywhere, is universal and relatable to almost everyone. That was intentional. "I feel like a lot of people like/want to be Everywhere & Anywhere," said Guarino.

When Paul is looking for fresh apparel ideas, his life serves as the inspiration. At 10 years old, Paul was diagnosed with SMA. "I always knew I wasn't physically the same as most when I was

younger ... Now it is what it is. I adapt and figure it out," Paul said.

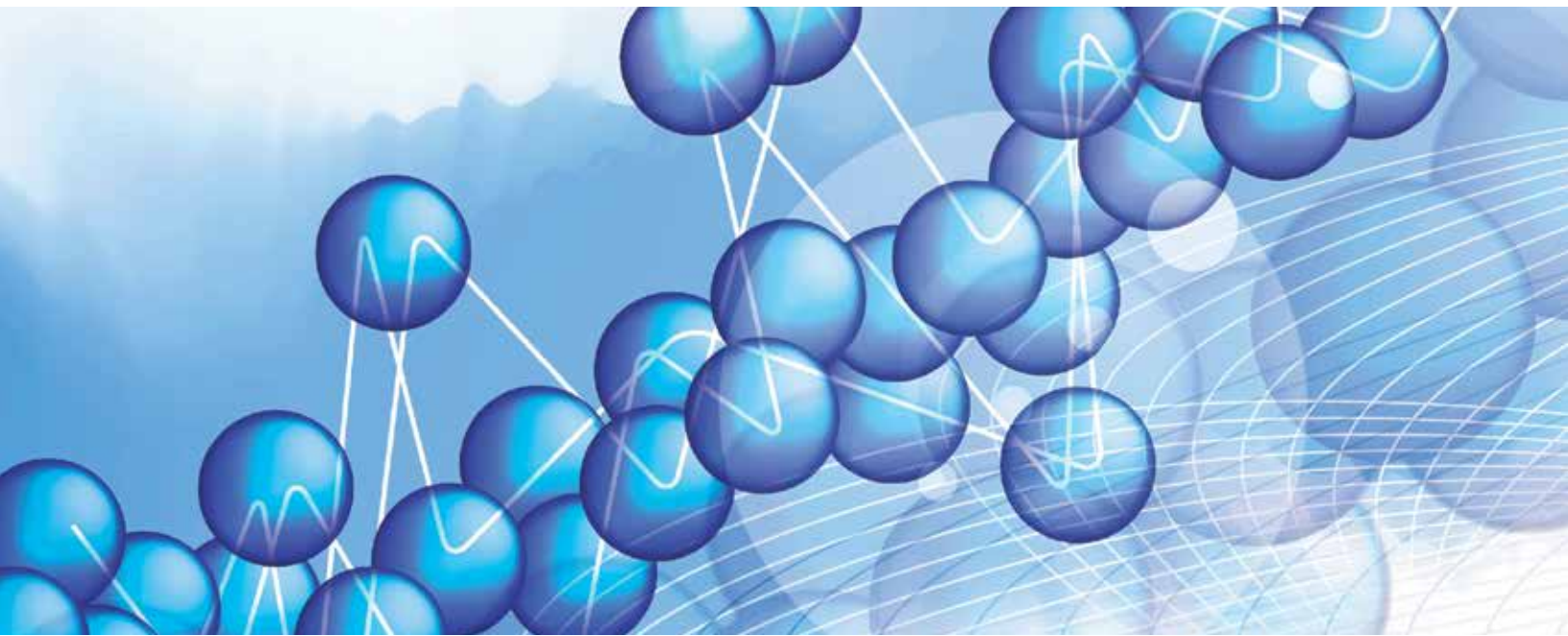
"The 'Chip on My Shoulder' tee literally has quotes on the back of the design with stuff companies said to me when I got rejected from jobs," said Guarino. "I think you get inspiration from everything you do."

Guarino's business partner, Aaron Burrell, conceptualized the idea behind the "My Why Series", a YouTube show that regularly features a variety of athletes. Guarino produces the show and sets up everything behind the scenes. "The interviews show the athletes in a great, relatable light which I think is very important because then people can relate to them more," said Paul.

Aside from meeting Brandon Phillips, a "pinch-me" moment for Guarino was getting to interview David Beckerman on his podcast, Average to Savage. Beckerman is the founder of one of the 90's most prolific sports apparel brands, Starter. "It was great to pick his brain," said Paul of the fellow Connecticut local.

For those thinking about becoming entrepreneurs in the sports world, Guarino has some advice. "Consistency is key. You're going to have ups and downs in business just like in life."

Paul Guarino is still looking for his big "why" but in the meantime, you can find him Everywhere & Anywhere.



# Cure SMA Awards Grants to Four States to Expedite the Implementation of SMA Newborn Screening

On July 3, 2018, the U.S. Health and Human Services (HHS) Secretary, Alex Azar, approved the recommendation that newborn screening for SMA be implemented nationwide. This recommendation was issued on February 8, 2018, by the Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC). With Secretary Azar's signature, SMA becomes part of the Recommended Uniform Screening Panel (RUSP), a list of 35 core conditions that all newborns born in the U.S. are recommended to be screened for.

Each state must determine whether they will implement SMA screening, and how quickly they will implement it. While this RUSP decision is not a requirement for states to begin screening, many states were waiting for the decision to be made. On average in the U.S., one baby each day is born with SMA. Each day represents an opportunity to save a life through newborn screening and early treatment.

Cure SMA is pleased to announce the following grants to newborn screening programs to help expedite the adoption and implementation of SMA to their statewide newborn screening panels.

## **\$150,000 to the Iowa Newborn Screening Program**

This grant is to help fund Phase 1 of implementation of SMA newborn screening. Phase 1 involves the development of infrastructure to screen for SMA including: development of the laboratory test, development of short-term follow up protocols, development of IT resources for both lab and follow-up, and development of long-term follow up capability. It is anticipated that Phase 1 will be completed in 6 to 9 months with Cure SMA grant funding. Completion of Phase 1 will

allow the start of Phase 2, which is pilot screening for all infants in Iowa, and clinical evaluation and treatment for infants identified as presumptive positive by the screen and receiving a confirmed diagnosis of SMA.

### **\$75,000 to the Michigan Department of Health and Human Services**

This grant will allow for Michigan to upgrade their LIMS (Laboratory Information Management) system to include SMA and will help support the hiring of molecular scientists to work on SMA newborn screening. SMA newborn screening is approved but not yet implemented in Michigan with a target start date of March 2020.

### **\$150,000 to the Virginia Division of Consolidated Laboratory Services**

This grant will allow for the purchase of PCR machines needed to perform the SMA newborn screening assay. The Virginia newborn screening program is preparing to implement SMA screening when the regulations have been fully approved by the Governor. \$150,000 to the Research Triangle Institute, a North Carolina Nonprofit Corporation

RTI is currently running the early check program. Early check is a free screening study designed to identify children with rare health conditions before symptoms appear and study the benefits of early treatments. New and expectant mothers may enroll in the program online from their second trimester until 4 weeks after their child's birth. This grant will allow for labor support for recruiters and the generation of recruitment materials to inform new parents and caregivers about early check in order to increase awareness of and enrollment into the program. Early check hopes that their SMA newborn screening will help bridge the gap until statewide SMA newborn screening implementation occurs in North Carolina.

***Cure SMA would like to thank AveXis for helping support these grants.***

ORDER YOURS TODAY!

STELLA FROM PELLA AND HER MAGIC SHOE

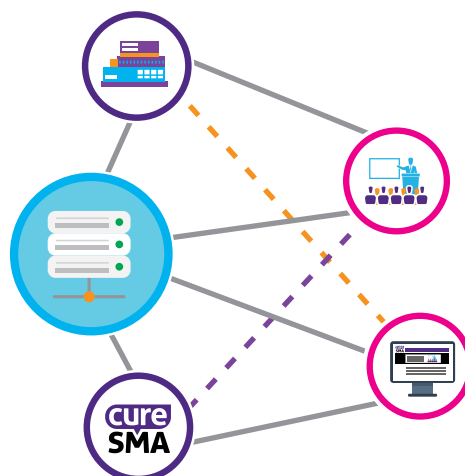


This Holiday Season

give the gift of an imaginative children's story!  
Stella from Pella and Her Magic Shoe is about a little girl who lives with SMA. Stella defies the odds and is given a magical gift that will be sure to put a smile on your face, teaching us a universal truth...the mind is a powerful thing.

Thanks to the generosity of the author,  
\$1 from the sale of each book  
will be donated to Cure SMA.

Purchase your new copy from Amazon today!



# Cure SMA's Newborn Screening Registry (NBSR)

In 2018, SMA was added to the federal Recommended Uniform Screening Panel (RUSP), a panel of diseases that newborns in the United States are recommended to be screened for. However, the decision on whether to implement newborn screening for a specific condition is up to each state. Since SMA's inclusion on the RUSP, many states have implemented newborn screening. As evidence has shown, early diagnosis and treatment leads to better outcomes.

Cure SMA has developed a data registry for children with SMA who were identified through newborn screening. The Newborn Screening Registry (NBSR) is a secure, online registry established to collect and analyze information on patients diagnosed with SMA through newborn screening. This information will help families, healthcare providers, and researchers learn more about SMA, better manage symptoms over time, and develop new treatments.

We intend to use this information, along with the information in our clinical data registry, to better understand the impact of SMA newborn screening on SMA, and develop evidence-based standards of care for SMA.

If you are a parent or caregiver of a child with SMA who was identified through newborn screening, we invite you to participate in our registry.

To learn more about Cure SMA's newborn screening registry, visit [www.curesma.org/NBSR](http://www.curesma.org/NBSR).



## Cure SMA Offers Teens and Adults Support Package

After years of providing newly diagnosed care packages to parents navigating life with SMA, Cure SMA launched a new support package specifically for adults and teens living with SMA. And the response has been incredible! Since early 2019, we have shared more than 1,000 support packages with teens and adults living with SMA!

Thanks to a generous grant funded from Biogen, Cure SMA is thrilled to continue offering this wonderful program to those individuals who have still not received this valuable support package. The package is filled with helpful items that have been recommended by adults living with SMA, including:

- Medical Fleece Ease Sheepskin – provides relief of bed sores and pressure points when in one position for long periods of time and keeps you cool/warm.
- Amazon Echo Plus – connects and controls compatible smart devices (i.e., light bulbs, door locks, switches, plugs) and makes calls when you can't access a phone.
- Telescopic Back Scratcher – between 6-1/2" and 20-1/4" long, it helps with out-of-reach items, and it great for moving items close enough to grasp.
- Long Grabber Reacher Tool – with an ergonomic handle trigger design and magnetic tip, this helps pick up small objects and assists with dressing.

- Gooseneck phone or tablet mount – flexible phone and tablet stand allows you to watch your device hands free or mount it in an accessible location.

- Etekcity Remote Control Outlet Switch Kit – remote-control outlets work from 100 feet away and help switch on/off hard-to-reach appliances and devices.

- EZ-Shampoo Hair Washing Basin – wash hair without having to leave the bed. This is perfect for traveling when you are not able to use an accessible bathroom.

- Neck & Shoulder Heating Pad – this perfect neck and shoulders warmer helps to relieve stiffness, knotted muscles, tightness, and inflammation.

- Sisu Positioner Pillow – molds to the exact shape of your body, reducing discomfort caused by long periods of sitting or lying down.

Many of the items shown above have been found to make activities of daily living easier for those with SMA. They also help those living with SMA to gain independence with certain tasks they might not have been able to do on their own.

If you are a teen or adult with SMA and are interested in receiving a Cure SMA support package, please email [supportpackage@curesma.org](mailto:supportpackage@curesma.org) to request one at no charge. Please note you must have a confirmed SMA diagnosis, be 13 years of age or older, live within the U.S., and have not already received a support package through this program to qualify.

# UNLOCK POSSIBILITIES AT A SPINRAZA EVENT

Get knowledge and resources about the first treatment for spinal muscular atrophy (SMA)



## SPINRAZA for SMA

Learn about SPINRAZA treatment from a healthcare provider (HCP)



## Treatment Journey

Hear inspirational stories and build connections with the SMA community



## Support Services

Understand what resources may be available for you



Visit [SPINRAZAevents.com](https://SPINRAZAevents.com) or call 1-888-615-4343 to sign up for the next free educational webcast or live event near you

### INDICATION

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

### IMPORTANT SAFETY INFORMATION

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

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

**The most common side effects of SPINRAZA include** lower respiratory infection, fever, constipation, headache, vomiting, back pain, and post-lumbar puncture syndrome.

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

**For additional Important Safety Information, please see brief summary of full Prescribing Information on the next page.**

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



Individual results may vary based on several factors, including severity of disease, initiation of treatment, and duration of therapy.

### IMPORTANT FACTS ABOUT SPINRAZA® (nusinersen)

#### USES

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

#### WARNINGS

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

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

#### COMMON SIDE EFFECTS

- **The most common side effects of SPINRAZA include** lower respiratory infection, fever, constipation, headache, vomiting, back pain, and post-lumbar puncture syndrome (headache related to the intrathecal procedure).
- Serious side effects of complete or partial collapse of a lung or lobe of a lung have been reported.

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

#### OTHER INFORMATION

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

#### QUESTIONS?

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

#### MANUFACTURED FOR

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Cambridge, MA 02142

revised 05/18



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# CURE SMA TEEN AND ADULT SUPPORT PACKAGE

The Cure SMA Support Package for teens and adults is filled with helpful items that have been recommended by adults living with SMA. Many of these items included in the package have been found to make activities of daily living easier for those with SMA.

They also help those living with SMA to gain independence with certain tasks they might not have been able to do on their own.

If you are a teen or adult with SMA and are interested in receiving a Cure SMA support package please visit <http://events.curesma.org/supportpackage> to request one at no charge.



## Care Packages



These handmade blankets were donated in honor of Charlotte Facchini. Cure SMA would like to thank Charlotte's great grandma and Great Aunt JoJo for donating these blankets to include in our care packages.



Thank you to the Meyers Family for donating this fun array of toys on behalf of their daughter, to "bring joy to the other children like they did for Charlie."



These adorable unicorn and cloud soft chimes were donated in honor of Liv Harlow McDonald from her grandparents, Debbie and Richard Butler! Thank you for such a generous and thoughtful gift!

# Sharing Photos



Ella Savko



Grimes Girls



Emilia Villaescusa



The Wolff Family



Max Lasko



Jayceon Jackson



Lincoln Schwartz



Titus Alston



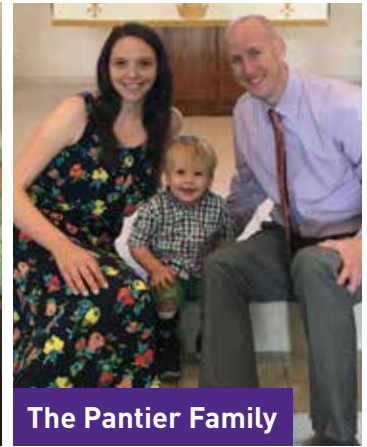
Aggie Frisch



Christopher Pantier



Jazaria Frederick



The Pantier Family



Annie Dooling



Celine Domalski



Abraham Bergman



Hana Arafat Hatata



Dalton Wintin



Delanie Clayton



Filomena Petrak



Max Lasko



Kaiden Martin



Jase Hobby



## Family Letters



Dear Cure SMA,

Just received our care package and our Autumn Clair is loving her mirror and feather! Thank you all so very much!

**Thank you!**  
**Katherine Doell**



Hi Cure SMA,

Oh, my goodness, I'm so overwhelmed and touched by this care package! What an incredible thing for you guys to do for people! Please know we are so grateful! I'm looking forward to going through the binder. Thanks again!

**Makell Burgoyne**



Friends at Cure SMA,

Thank you so much for the bountiful care package we received for Isaac! It was a bright spot in what has been a hard week.

**Thank you,**  
**Michelle, Ben, and Isaac Olthoff**

Everyone at Cure SMA,

Thank you so much for the care package of goodies for our daughter, Harper. Her favorite thing is the Play-Doh set. She will play with it while she is in her standing table for hours! We have used each and every item multiple times and really cherish the handmade blanket. Thank you so much for all your do for families!

**Thank you,**  
**Leah and Zach Preiss**



Our Friends at Cure SMA,

We received Lindsay's care package for teens and adults! All I can say is "wow"! It has some very helpful things. She loves the Amazon Echo and connecting it with lights will be so helpful. There were many items I had never thought of that will really make life a little easier. Our family just wants to say thank you!!

**Thank you,  
Walt, Tracy, Trent, and Lindsay Cochran**



Everyone at Cure SMA,

Thank you so much for the generous care package! Aiden loves all his new toys!

**The Kew Family**

Dear everyone at Cure SMA,

I recently received a teen and adult support package. Everything inside is perfect for my needs and is so useful! Being a teen, I am trying to become more independent and do things on my own. These items, especially the remote outlet switches, help me in becoming self-sufficient. The fleece cushion is so comfortable to sleep on! It helps me sleep through the night by keeping me cool.

I would like to thank all of the volunteers and staff of Cure SMA for making this package possible. It is such a great idea and is a life changer for me!

**Thank you again,  
Amelia Wong**

Hi Cure SMA,

Thank you so much for the gifts for our little girl!

We are so blessed to have found your organization.

Again, thank you for being such a big part of our family.

**Ellie Villaescusa**

Thank you so much for our daughter Charlie's new diagnosis box. She loved everything inside!

**Thank you again,  
The Meyers Family**



Dear Cure SMA,

Thank you for this amazing box of goodies! Kaden loves the frog balloon!

**Wilson and Elva Martin**



Hello Cure SMA,

My daughter, Tori, received her care package and we are blown away by everything she received. She especially loved the balloon, rings, touch tablet, and lullaby polar bear. Reading the dedications of donations from other families was very emotional for me. We can't thank everyone enough for all the support we've gotten through this very tough time.

**Warmest regards,  
Melinda Cannon-Haws**



Hi Cure SMA,

I just wanted to let you know that Mary is loving the bambino. From the moment I took it out of the box I could tell it would be a winner. It's so light weight and easy to push. She's able to move herself around our house. With the other chairs that we had borrowed from other places she was having a lot of trouble moving around. This chair has given her more independence and we are so thankful for it.

Thanks for all of your hard work and thank you to everyone you work with. You've made our girl happier!

**Katie Carnehl**

Dear Cure SMA,

I just wanted to let you know that the Panthera Micro arrived yesterday and Nemue loves it! She was able to get the hang of it right away and has been cruising around the house. Exploring and playing hide and seek. My husband and I both were brought to tears seeing her with this independence and confidence. No words can really describe how grateful we are for all that you do and how you have given us not only support like this, but also a community to grow with.

**All our gratitude and love,  
Carla**



Hello Cure SMA!

I've attached some pictures of our sweet girl with some toys from her care package! She also loves the otteroo, made mom and dad cry happy tears seeing her legs move around! Thank you all so much for your hard work!

**Thank you,  
The Evans/Fristsch**



Everyone at Cure SMA,

We are so thankful to be connected to Cure SMA. We received the informational packet, care package, and binder. We were so overwhelmed by the generosity of Cure SMA and donors for the care package. It arrived at such a stressful time and helped us know we are not alone in this. Our son Evan is enjoying all of the fun toys. We use the handmade quilt daily during tummy time.

**Julie Menk**



Cure SMA,

We have been using the Splashy seat for a couple of months now and Henry loves it! It can sit up or go flat, so I do feel this seat would work for all the kiddos regardless of their strength or ability to sit upright. This seat has allowed Henry to play in the bathtub with his younger brother which they both love. As always, we are so appreciative of all Cure SMA has done for our family!

With the warmer weather, we were able to try the Splashy seat in our little pool outside and Henry loved it! We are excited to take it to our neighborhood pool soon (maybe even the beach this summer). This has been so much fun, thanks again!

**Valerie White**

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



[twitter.com/cureSMA](https://twitter.com/cureSMA)



[@curesmaorg](https://www.instagram.com/curesmaorg)



[facebook.com/cureSMA](https://facebook.com/cureSMA)



[youtube.com/user/FamiliesofSMA1](https://youtube.com/user/FamiliesofSMA1)



[www.linkedin.com/company/families-of-sma](https://www.linkedin.com/company/families-of-sma)





Make today a  
breakthrough.

**You may be gone from  
my sight, but you are never  
gone from my heart.**

**In remembrance of all of the lives  
lost to Spinal Muscular Atrophy.**

*Photo of Tonya Willingham and her daughter, Hanna*

# In Memoriam

Alexandra Meigs | October 24, 2007 – January 1, 2008

Alexandra, in her pretty blue dress with her pretty braided hair, “walked” over to John and said, “I often come to this place and look for you and mommy.” When John asked how often, Alexandra responded “all the time,” (as if to say, “of course!”). A few weeks ago, John woke up from this very dream and was surprised to have seen her looking so healthy and happy and resembling her big sister Avery in the face.

As we were preparing to celebrate Alexandra’s 12th birthday on October 24th, we agreed that this dream was a true reminder that she is still with us and watching. She remembers us, as we remember her. We could only wish that the medical breakthroughs of today were available when she was here in 2007-2008. Unfortunately, they were not, and she passed away from SMA Type 1, as her lungs and body got weaker and gave out.

That said, 12 years later, we are just so thankful for all of our friends and family who have supported us over the years – both financially and emotionally. In 2008, there was only 1 company investing in a SMA drug program. Today, there are two FDA approved treatments and 21 additional programs in development, including six in clinical trials. So, basically, when Alexandra was here, there was no treatment nor cure.

Today, we are amazed that there are treatments and a cure in the foreseeable future. When I went to Capitol Hill for Cure SMA’s Day on the Hill last year and saw a child with SMA walking, I was AMAZED! As much as I prayed and dreamed, I wasn’t sure that I would really live to see this day and I know that we simply could not have seen this medical progress without everyone’s financial help.

To that end, we reached to as many family and friends that we knew and raised over \$20,000 for Cure SMA in honor of Alexandra’s 12th birthday. This brings our total since 2008, to over \$150,000 for medical research and support services for families facing this terrible disease.

All I can say is that I know you are watching, Alexandra. I hope you are proud of mommy and daddy and, to our friends and family, Alexandra truly appreciates your donations, as do we. So, thank you for remembering our baby girl’s 12th birthday on October 24th and giving true meaning to her very short-lived life on earth.

Lovingly,

Andrea & John Meigs



# Thank you!



**Cure SMA would like to thank everyone who participated in SMA Awareness Month.**

Whether you made an advocacy visit, attended an MLB awareness game, sent in photos or videos, or simply shared messages on social media, we appreciate the community effort to spotlight SMA and look forward to next year.



**Make today a  
breakthrough.**

# Thank You!

TO ALL OUR EVENTS THAT MAKE CURE SMA SO GREAT



In 2019, dedicated volunteer committees hosted 48 Walk-n-Rolls in communities across the country. Together these events raised over \$1.48 million for Cure SMA! We would like to shine a special spotlight on these top five walks, Pennsylvania, Northern California, Walk-n-Roll in Honor of Graham, New England, and Cincinnati.

In addition, our Cure SMA Walk-n-Roll programs would not be successful without the countless teams and participants that come out rain or shine to support our cause. In 2019, our top five teams went above and beyond to support Cure SMA.

We would like to congratulate Team Murphy, \$36,330, and Mac's Pack, \$18,510, with the New England Walk-n-Roll, Pete's Flying Eagles, \$26,605, with the Pennsylvania Walk-n-Roll, Team Hammerin' Hank, \$23,475, with Charlotte Walk-n-Roll, and Annie's Magical Fairies Team, \$20,525, with Northern California Walk-n-Roll.

**A special thank you to the dedicated captains that led their teams to success at walk-n-rolls across the country!**



WANT TO JOIN US AT OUR NEXT EVENT?

Visit our website [www.cureSMA.org](http://www.cureSMA.org)  
Click on events to find the next Walk-n-Roll in your area



# GET INVOLVED WITH YOUR LOCAL CHAPTER

**Cure SMA has 36 volunteer chapters throughout the United States.**

Our chapters provide support for affected families through networking, fundraising events, and advocacy. As representatives of Cure SMA, chapter leaders spread SMA awareness in their local communities and generate support for our organization.



**VOLUNTEER OPPORTUNITIES ARE AVAILABLE NATIONALLY**

Please contact [fundraising@curesma.org](mailto:fundraising@curesma.org) for more information.

Visit [www.curesma.org/chapters](http://www.curesma.org/chapters)



# Cure SMA Awareness Games

This year, we had 16 baseball awareness games across the country. Cure SMA families came decked out in their Cure SMA gear and cheered on their teams as they raised awareness for SMA. From being featured on the scoreboard to running the bases after the game, our families had a blast attending these games. The mascots loved taking pictures with the kids too!

- 2019 SJYPA Night at the Ball Park with the Phillies – May 29
- Cure SMA Day with the Baltimore Orioles – June 2
- 2019 SMA Day with the Tampa Bay Rays – August 4
- Cure SMA Day with the Chicago Cubs – August 5
- 2019 Cure SMA Day with the Omaha Storm Chasers – August 10
- Cure SMA Day with the Boston Red Sox – August 11
- Cure SMA Day with the Birmingham Barons – August 18
- Cure SMA Day with the Dayton Dragons – August 21
- Cure SMA Day with the Jacksonville Jumbo Shrimp – August 25
- Cure SMA Day with the Chicago White Sox – August 25
- Cure SMA Day with the Milwaukee Brewers – August 25
- 2019 SMA Awareness game with the Quad Cities River Bandits – August 25
- Cure SMA Day with the Miami Marlins – August 25
- 2019 SMA Awareness game with the New Hampshire Fisher Cats – August 25
- Washington Nationals Awareness Game – September 15
- SMA Day with the Seattle Mariners – September 29

**We hope to see everyone out at the games next year as we continue to educate the community on SMA!**



# Chapter Highlights

## 2019 Alabama Walk-n-Roll

### Alabama Chapter

On March 30, 2019, the 2019 Alabama Walk-n-Roll took place at Tannehill Park in McCalla, AL. Over 65 people enjoyed a beautiful walk through the park, family-friendly activities like crafts, and a great silent auction. The delicious lunch was donated by Southern Food Service. The event committee was instrumental in making this event happen, which raised just over **\$16,000**.

A big shout out goes to Jennifer Patrick (and family), Patti Kemp, Maggie Moore, and Linda Russo, for all their help in planning this successful event!



## Chapter Update

This past year, a very important Chapter Leader from Alabama stepped down from her position after many years; Jennifer Patrick. Thank you to Jennifer Patrick for her 11 years of service to the Alabama-Mississippi Chapter of Cure SMA! Jennifer took over as President of the chapter in 2008, with the support of her friends and family. Since then she dedicated her time to being a great resource for newly diagnosed families and the essential part of the annual walk-n-roll, raising over **\$200,000** for Cure SMA.

Jennifer wanted to be a Chapter Leader to help find a cure for her son, Logan, who passed away in 2012. She wanted to share what did and didn't work for her son with other families. Jennifer continued to support Cure SMA because she saw firsthand how important the organization is for networking with other families and healthcare providers, access to the equipment pool, and most importantly for supporting research to find a treatment and ultimately a cure! We wish Jennifer and her family the very best as she takes a break from chapter leadership but will remain a strong support of the chapter.



*Note: The amounts raised and shown are totals as of August 15, 2019 and may differ from current fundraising totals by the time you get this newsletter.*

## Arizona Chapter

### 2019 Arizona Evening of Hope

The 3rd Annual Arizona Evening of Hope – Wine Tasting and Art Auction was held on May 11, 2019, at Su Vino in Scottsdale, AZ. Sixty-six attendees gathered together to enjoy an elegant evening out consisting of local wines from Su Vino Winery, delicious hors d'oeuvres, and both a live and silent auction. This year's event raised over \$8,800 for Cure SMA.

A special thank you to Bo Buchanan, Angel Wolff, and their committee for spearheading this event!



### Arizona Dine to Donate Events

Thank you to the Arizona Chapter for hosting fundraisers at Fuddruckers and Chipotle in the Phoenix area in August for SMA Awareness Month! A special thank you to Angel Wolff for coordinating these events.

## Arkansas Chapter

### 2019 Arkansas Chapter Walk-n-Roll

The 2nd Annual Arkansas Chapter Walk-n-Roll was held on May 18, 2019, at The Crossing at Angel Court in Little Rock, AR. Despite the cold weather, over 95 participants attended and raised \$8,647 for Cure SMA. The event featured a scenic one-mile walk, family games, activities, a DJ, and refreshments!

Thank you to the Chapter Leaders Kelly and Jason Alexander, DeAnna and Sean Dillon, and Sylvia Wheeler for their hard work and dedication to making this event a success. Thank you to all the amazing families, participants, donors, and sponsors, for their support and generosity!



## Carolinas Chapter

### Campaign in Honor of Sonya Patel

North Carolina

Thank you to the Patel family for fundraising for Cure SMA in honor of their daughter, Sonya Patel! Sejal and Shashin Patel of Wilmington, NC, rallied their family and friends together through a letter writing campaign and raised nearly \$4,000 in April 2019.

### Awareness Events in Plymouth

Thank you to Crystal Hill and her family for hosting events and participating in the local parade to spread SMA awareness in Plymouth, NC, during July and August 2019!

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## Chesapeake Chapter

### 26th Annual Chesapeake Crab Feast and Silent Auction Maryland

The Chesapeake Chapter celebrated its 26th Annual Crab Feast and Silent Auction on Sunday, August 3, 2019, in Townson, MD. Nearly, 350 people came together to celebrate another remarkable year as well as to raise funds for Cure SMA. This year's event was the grand finale for event organizers Barb & Gene Trainor, Beverly & Dan Venedam, and John & Katy Nolan. Longtime supporters came from far and wide to be part of this special day and celebrate this event. Thank you to the chapter leaders, attendees, and longtime volunteers, for their unwavering support over the past 26 years. This event started in memory of Erin Trainor, only months after she passed away. With such passion and dedication, the crab feast grew for 26 years to become one of the longest running fundraising events for Cure SMA. The Trainor and Venedam families, along with John and Katy Nolan, celebrate a job well done!



The event raised **\$44,805** for the Chesapeake Chapter and the Erin Trainor Memorial Fund. Attendees enjoyed the silent auction, wine and dine raffle, laydown games and beer wheel, along with plenty of Maryland blue crabs from Captain Bob's. Many thanks to the ticket captains who contributed to a sold-out event; Charles Nolan, Mike Demchak, Anthony Nolan, Stephen Nolan, Matt Brunner, Derek Lewis, Eugene Trainor, Bob Cawley, Billy Owings, Joe Maher, Patrick Farace, and Mary Kate Venedam. Special thanks to the Knight of Columbus #5208 for managing the wheels and raffles for all 26 years!

The Erin Trainor Memorial Fund is an endowment established to provide scholarship for newly diagnosed families to attend The Annual SMA Conference. Cure SMA has been coordinating this conference since 1980 and in this time it has become the SMA conference to attend on an annual basis for families, clinicians, and researchers.

### 2019 Chesapeake Chapter Walk-n-Roll

The Chesapeake Chapter celebrated its 7th Annual Chesapeake Chapter Walk-n-Roll this year on Saturday, April 27, 2019, at Old National Pike Park in Mount Airy, MD. The event was a huge success and was attended by 13 incredible teams and 150 attendees who surpassed the event fundraising goal by raising **\$24,447**. They had games, face painting, music, and raffle items! A special thank you to those who donated their time to make the event more special; Stacey Markel, the event photographer, Charles Nolan, Katy Nolan, and Dan Venedam, for grilling food for all the participants.

A huge thank you to the event day volunteers and especially the event organizers; Tina and Derek Lewis, Kim Heinrich, Barbara White, Melissa Wayland, and Beverly Venedam, for hosting another amazing event and generous local sponsors: Starcom Construction, Our Little Jewels, 2-Fold Collective, John Hopkins Homecare Group, and AMT Consulting Engineers.



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## 4th Annual SMA Awareness Party in honor of Owen Close

Thank you to Ashley Close for hosting the SMA Awareness Party in memory of her son, Owen Close, during SMA Awareness Month. The fundraiser was held at the Close Family home in Accident, MD, and raised \$1,000 for Cure SMA.



## 2019 West Virginia Walk-n-Roll

West Virginia

Thank you to the West Virginia community for organizing the 2019 West Virginia Walk-n-Roll on May 18, 2019, in Star City, WV, at Edith Barill Riverfront Park. Over 140 walkers and rollers participated from West Virginia, Pennsylvania, Ohio, and Maryland. The day consisted of a walk along the Caperton Trail, an incredible raffle, characters like Spiderman and WV Mascot Musket, and the chance for so many families to come together and support those affected by SMA. This event raised **\$13,572** to support Cure SMA's ongoing efforts to continue to fund research and family support programs.

Cure SMA would like to recognize the committee for making this incredible event possible; Ashley Close, Julie Coddington, Caressa Delaney, Renee Hunter, Janice Kress, Ann Stanley, and Candace Strader. They could not do this without all the hardworking and passionate attendees, donors, and event day volunteers. Thank you to the face painter, Rose Kraftick, and live band, JGBB. Thank you to the generous loyal and local business supports; Mylan Pharmaceutical, Cardinal Pediatrics, United Bank, and Pineview Gynecology.

## Cycling Fundraiser for Winnie Stanley

Thank you to Ann Stanley and Candace Strader, for organizing the second cycling fundraiser in the Chesapeake Chapter for SMA Awareness Month. Twenty-five participants came together on August 23, 2019, at the Zenergy Cycling Studio in Charleston, WV, in honor of Winnie Stanley raising \$400 for Cure SMA.

### Connecticut Chapter



## 2019 Connecticut Chapter Walk-n-Roll

This year's annual Connecticut Walk-n-Roll was held on June 2, 2019, at Northwest Park in Manchester, CT. The community gathered together for a one-mile walk on a path along the river with food, music, and raffles. Friends, families, coworkers, care-providers, and supporters, all came to show their support for Cure SMA.

This year's walk raised over **\$11,000**, nearly tripling last year's amount! Special thanks to Team Approve Bill No. 7282, who raised nearly \$3,000, Team Jules, who raised over \$2,700, and Team Wild Ones, who raised over \$2,600!

A huge thank you goes out to the incredible organizers; Macie Tozzoli, Yvette Haas, Maria Eleni Kaloidis, and Carissa Decelles, for all their dedication to this successful event. Can't wait to see everyone in May 2020!

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## Connecticut Family Fun Day

The Connecticut Family Day was a huge success! On August 10, 2019, families from across Connecticut joined together at Chapter 126, an accessible facility, to play sports, eat food, and socialize as a community. Thank you to Kate McBride for all her hard work in organizing this event! Looking forward to this event again next year!



## Connecticut Family Picnic

This year's family picnic at Camp Harkness in Connecticut was a great time! Nearly 40 people came out on August 18, 2019, to enjoy a fun and relaxing day at the beach. New and old families alike joined together to support each other and grow the Connecticut Chapter community. Thank you to Yvette Haas for all her hard work in making this event happen. They hope to see everyone again next year for a great day with fellow SMA families!

## Greater Florida Chapter



## Filipino Student Association at the University of Central Florida Bake Sale

On August 8, 2019, students in the Filipino Student Association at the University of Central Florida in Orlando, FL, hosted a bake sale, raising \$120 to benefit Cure SMA. Members of the Filipino Student Association wanted to reach out to organizations they were passionate about. Many of the members are excited to enter the medical field and thought Cure SMA would be an ideal partnership. Thank you to Kaitlin Altamirano, Philanthropy Director, for supporting Cure SMA!

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## Capital Region New York Chapter

### 2019 Cure SMA Albany Pub Crawl

The Inaugural Albany Pub Crawl with Brooks Wolfe Pack was held in Downtown Albany on April 13, 2019. Over 40 friends and family members of those affected by SMA gathered together visiting multiple bars throughout the day along with a raffle to raise \$3,850 for Cure SMA.



Thank you to the participating bars; Ama Cocina, The Hollow, Pearl Street Pub, Loch and Quay, and Dawn's Victory. A special thank you to Allie Wolfe for organizing this fun event in honor of her son, Brooks Wolfe.

### Phil Sweeney Memorial Tournament

The Phil Sweeney Memorial Tournament is a softball tournament created to honor the memory of teammate and friend, Phil Sweeney, who suffered a fatal heart attack while pitching in a game on May 16, 2010. Phil was a veteran pitcher who competed on the local, state, and national level for over 30 years. He was the ultimate competitor and an unselfish teammate.

During the weekend of June 22, 2019, the 10th Annual Phil Sweeney Memorial Softball Tournament was held at Knickerbocker Park, in Troy, NY. Cure SMA was selected as the benefit charity for this year's event raising \$2,125. Thank you to the Sweeney Family and Jeff Miter for organizing this softball tournament and supporting Cure SMA.



### Germantown Central School Fundraiser

Thank you to Germantown Central School and Megan Dodge in Germantown, NY, for donating their teacher fundraiser proceeds to Cure SMA. The fundraiser was held at the end of the 2019 school year and \$492 was donated in honor of Lincoln Schwartz.



### Lake Pleasant 4th of July Parade

The Braunius and Dunkley families gathered for the July 4th parade in Speculator, NY, to create a float. The theme was, "Oh the Places You'll Go in the Adirondacks," and they adapted it to, "Oh the Places You'll Roll." The families kicked off their fundraising for Team Lenna Strong for the NY Capital Region 5K/Walk-n-Roll, by raising awareness and collecting \$150 at the 4th of July Celebration. Thank you to the Braunius and Dunkley families, for their continued support of Cure SMA in honor of Lenna.

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## Greater New York Chapter



## 2019 Greater NY Chapter Golf Outing

On May 20, 2019, the Greater NY Chapter Golf Outing was held at The Hamlet Golf and Country Club in Commack, NY. The golfers enjoyed another year of beautiful weather, lunch, on-course beverages, dinner, raffle and beat-the-pro contest all while supporting an incredible cause! The day also featured a live auction with opportunities to bid on tickets to six different supporting events, a set of custom-fit Calloway irons from PGA Professional Mike Meehan, and top shelf liquor donated by SGSW.

The golf outing exceeded the fundraising goal and by raising **\$44,445**. A special thank you to the Rubenstein family, Sparacino family, Fagerland family, and Bonner family, for making the event possible. Cure SMA would like to also thank the event organizers, Erin Bonner, Debbie Cuevas, and Catherine Martin, for putting together another successful golf outing.

## 2019 New York Evening of Hope

On May 8, 2019, Cure SMA hosted the 2019 New York Evening of Hope held at local Meatpacking District staple restaurant, Bistrot Bagatelle, in New York City. It was a special evening attended by 100 guests who enjoyed an open bar, hors d'oeuvres, raffle, and silent auction!

Cure SMA is grateful to the many families and friends who attended and helped raise **\$35,503**! The evening would not have been possible without the incredibly generous local supporters and sponsors; Benefit Finance Partners, Edelman, The Geller Family, Genesis Exhibits, Macy's, Sema4, Strategies for Wealth, and Voya Investment Management.

Lastly, thank you to the hardworking and passionate volunteer event committee, Chris and Kelly Jankowski, Rebecca Kostyuchenko, Alexandra Lakhman, Kate McCue, and Michele Rubenstein. Together, a cure will be found for SMA!



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## Illinois Chapter



### 2019 Tee Off with the Drive to Cure SMA in Honor of Ryan

On May 18, 2019, over 85 golfers gathered for 18 holes, dinner, raffles, and fun at Gleneagles Country Club in Lemont, IL, for the Tee Off with the Drive to Cure SMA in Honor of Ryan! This event is in its 6th year and held in honor of Ryan Manfre, an outgoing and all-around amazing 12-year-old with SMA. With the help of generous sponsors, volunteers, and golfers the event raised over **\$33,062** for Cure SMA!

Cure SMA would like to give special thanks to Jeanne Emerson, Becky & Brian Manfre, and Susan and Steve Fedea, for organizing this annual event and their continuous support!



### 2019 Cure SMA Western Suburbs Walk-n-Roll

The Western Suburbs Walk-n-Roll was held on May 18, 2019, at Ty Warner Park in Westmont, IL. It was a beautiful day for a walk-n-roll, which had over 150 participants in attendance. The day was filled with snacks, activities, raffle items, special guests, such as characters from Star Wars and the local high school marching band. Due to everyone's efforts, over **\$29,000** was raised and a total of 20 teams participated!

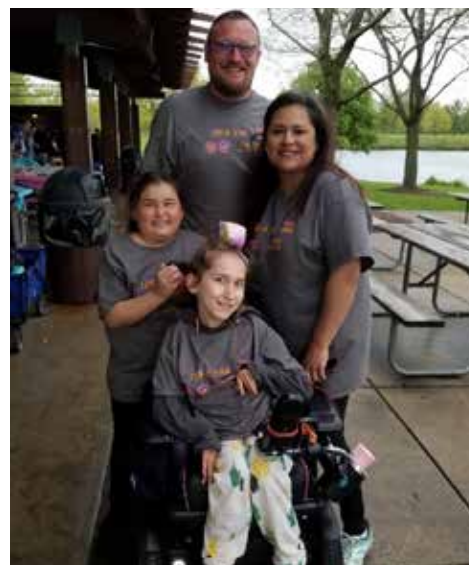
Thank you to the event committee; Danielle Plotke, Kathy Heinrich, Joana Susul, and Mindy Wiley, for their hard work and dedication to making this event a success. Thank you to all the amazing families, participants, donors, and sponsors, for their support and generosity!

### 2019 Cure SMA Libertyville Walk-n-Roll

The Illinois Chapter hosted the Libertyville Walk-n-Roll on May 19, 2019, at Independence Grove in Libertyville, IL. Despite the windy weather, they had a wonderful turnout. Everyone enjoyed snacks and activities in the pavilion and walked the beautiful lake at the park.

Special thanks to all the amazing teams, participants, sponsors, and donors, for making the Libertyville Walk a great success. As a result of everyone's efforts over **\$20,250** was raised and a total of 11 teams participated!

Cure SMA would like to give a big thank you to the walk's event organizer, Janet Schoenborn! A special thank you to Cynthia Annel, Maria Marusich, and everyone else who helped plan this year's event.



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## Iowa Chapter

### 2019 Cure SMA Evening of Hope in Honor of Miracle for Madi



The 4th Annual Evening of Hope in Honor of Miracle for Madi took place on April 12, 2019, at the Hotel Blackhawk in Davenport, IA, in honor of Madi Ramirez. The dinner event featured a silent auction, sip n' sparkle, pass the purse, step and repeat, plated dinner, live music, and dancing.

The event was a huge success, raising over **\$44,780** for Cure SMA!

A big thank you to Megan Ramirez and her friends and family for organizing this event and making the evening possible! A special thank you to the generous sponsors, donors, attendees, and volunteers, for their support!

## Kansas City Chapter

### 2019 St. Louis Walk-n-Roll

Missouri

The 4th Annual St. Louis Walk-n-Roll took place on May 5, 2019, at Tower Grove Park in St. Louis, MO. SMA families and supporters gathered together to support the event and enjoyed a scenic one-mile walk and run, activities, and refreshments.



Thank you to our eight teams and over 85 participants who raised **\$13,568** for Cure SMA.

A special thank you to Jan Hutchinson and Valerie Giglio, for their hard work behind the scenes! A big thank you to Kathy Goodyear and Rita Schmidt for their help on event day.



### Asher's 1st Birthday Party Fundraiser

Super Asher Wilcox celebrated his 1st birthday on Sunday, August 4, 2019, in Missouri, with a big gathering of family, friends, caregivers, and fans. His party included a fundraiser (online and off-line) for Cure SMA that collected over \$1,000! Guests also signed a letter to senators urging them to pass the Newborn Screening bill that just made it through congress. Everyone who attended or donated online was entered into a drawing for some cool Cure SMA gear, and Asher showed off his fine motor skills by choosing the names himself. Thank you to the Wilcox family for putting on a great event!

### Ackerman Elementary School

Nebraska

Thank you to Ackerman Elementary School in Omaha, NE, for holding a week of fundraising in honor of one of their students! Students donated a dollar each day to participate in the daily theme (pajama day, stuffed animal day, crazy day, hat day) ending in a "purple out," where everyone wore purple to school. They also made shirts, sent flyers home, and shared awareness videos and information to each staff member. Together they were able to raise \$1,708 for SMA research and family support programs!

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### Louisiana Chapter

## 2019 Evening of Hope Singer-Songwriter Night

On April 4, 2019, the Louisiana Chapter hosted the 4th Annual Cure SMA Singer-Songwriter Night at the Trademark in Baton Rouge, LA. The evening featured cocktails, hors d'oeuvres, silent auction, wine pull, dinner, and a live performance by professional singer-songwriter, Terri Hendrix with Lloyd Baines.

The evening was a huge success, raising **\$45,220** for SMA research and family support programs.

A special thank you to Krista Scurria for chairing the event, as well as the dedicated chapter leaders, committee members, generous sponsors, and amazing volunteers, for making this day possible.



## 2019 Louisiana Chapter Rock-n-Bowl

The 2019 Louisiana Chapter Rock-n-Bowl was held on July 7, 2019, at the Rock-n-Bowl New Orleans, in New Orleans, LA. The day was filled with bowling, silent auction and raffle, food and refreshments. This event raised over \$5,000. Thank you to Shawn Audibert for helping to make this event a success!

### Michigan Chapter



## 2019 Cure SMA Michigan Chapter Walk-n-Roll

Thank you to everyone who participated in the annual Michigan Chapter Walk-n-Roll. Over 100 people gathered at Kensington Metro park in Milford, MI, on June 2, 2019, to celebrate the strength of the SMA community and fundraise to support Cure SMA. Thanks to the support of the event's 14 teams, over **\$23,975** was raised! Thank you to Marianne Hunderman and Gretchen Dorer for help with making this event a huge success!

A special shout out to Team Abbey House as the top fundraising team with a grand total of over \$8,900!

Thank you to the Dorer and Hunderman families for their help with this year's walk.

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## Minnesota Chapter



### 2019 Minnesota Evening of Hope

The 2019 Minnesota Evening of Hope took place on April 6, 2019, at the Rosemount Community Center in Rosemount, MN. Guests enjoyed cocktails, hors d'oeuvres, music, wine raffle, silent auction, and an amazing live auction that had everyone on their feet!

In its first year, the event raised over **\$78,000**. A huge thank you to the Bigelow family for their work to put this event together and their dedication to fundraising for Cure SMA. We would also like to thank the committee who helped make this event possible! Please join the Bigelow family and the committee again at the 2nd annual event in the spring!



### Inaugural Madisyn's Skate-Away SMA

The 2019 Madisyn's Skate-Away SMA took place on June 2, 2019, at Cheap Skate Roller Rink in Coon Rapids, MN. It was a wonderful day filled with Bones Brothers BBQ, skating, games, exciting silent auction, and more!

In its first year, Madisyn's Skate-Away SMA raised over \$3,000! Thank you to Madisyn, Jamie, Jason, and the rest of the Mevissen family, for making this event a success.



### Claire Bear Day

On May 4, 2019, the Pruet family held an ice cream social fundraiser in memory of their daughter, Claire. They raised over \$1,600 during the event! Thank you to the Pruet family for putting on this event.

### Chaska Middle School East Fundraiser

Thank you to Chaska Middle School East in Chaska, MN, for holding a student fundraiser in the month of March in honor of one of their students, raising \$155 for Cure SMA!

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## New England Chapter



## 2019 New England Chapter Walk-n-Roll

Massachusetts

On May 11, 2019, the New England Chapter held their 19th Annual Cure SMA Walk-n-Roll at DCR Wompatuck State Park in Hingham, MA. This fundraiser and annual reunion brought nearly 300 people and 22 teams together to raise funds for Cure SMA. This year, the community raised over **\$93,000**.

A big thank you goes out to the top three teams: Team Murphy, who raised over \$36,000, Mac's Pack, who raised over \$18,000, and Kelsey's Krew, who raised over \$10,000. Thank you to the hard-working teams, this couldn't have been done without them!

Cure SMA looks forward to seeing everyone at next year's 20th Annual New England Walk-n-Roll in May 2020.

## 2019 Cure SMA 5K Run/Walk, Wakefield, MA

This year on August 24, 2019, nearly 150 people came together for the 6th Annual Wakefield 5K Run/Walk. It was a perfect day filled with runners, walkers, and rollers, who all enjoyed a beautiful trip around Lake Quannapowitt in Wakefield, MA. Participants received t-shirts and tried their luck with the raffle, which included gift certificates, prizes, and gift baskets! The course was chip timed by Race Wire and everyone enjoyed food and drinks after the event.



This year, over **\$15,000** was raised for Cure SMA! Thanks to everyone who ran, walked, strolled, rolled, supported, volunteered, and donated. Special thanks to Kristen Farrell, for all her hard work to pull off such a successful event!

## Oskar's Jam for Cure SMA

This year, on June 15, 2019, people gathered together in Oskar's backyard in Newton Centre, MA, for a wonderful afternoon of music, dancing, and refreshments. Oskar and family entertained their friends with a variety of music, such as jazz, pop, rock, and blues. Any musician in attendance was invited to take the stage and show off their skills! Because of their hard work, they earned over **\$11,000** for Cure SMA! Thanks to Ima and David Jonsdottir for their hard work in organizing this awesome event for their son, Oskar!

## 7th Annual Rogo Cup to Cure SMA Golf Tournament



The 7th and final Rogo Cup was held on June 3, 2019, at the Atlantic Country Club in Plymouth, MA. The Rogowicz, Butler, Spiegel, and Scully families held this tournament in memory of Mark Butler and in honor of Billy Spiegel and Lauren Rogowicz.

The wonderful golfers and volunteers braved the rainy weather for a great turnout! A big thank you to everyone for their contributions to this event, raising over **\$32,000** this year and bringing the seven-year total to nearly \$275,000! Thanks to the sponsors, donors, golfers, and volunteers for all their hard work!

Special thanks to Joe Scully and his incredible work in organizing this golf tournament and raising funds for Cure SMA!

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## 2019 Vermont Walk-n-Roll

Vermont

Another successful walk-n-roll in Burlington, VT, happened on May 18, 2019. This year's walk featured a DJ, face painting, raffles, food, and fun. Both new and familiar faces came together from across Vermont with the common goal to contribute to finding a cure for SMA.

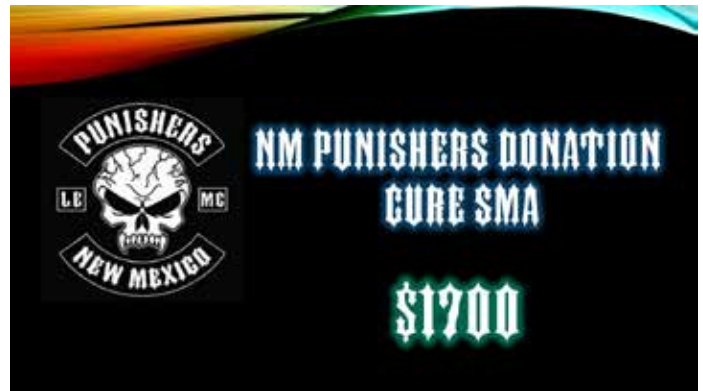
This year, nearly **\$17,000** was raised, making it the biggest year yet! A huge thank you to SMA Domination, who raised over \$5,300, Team Baby O and Gruffalo Seekers, who raised over \$5,000, and Team Sharks, who raised over \$1,700. Special thanks to Sue O'Neill and Margot Vanscoy, for all their hard work to make this event a success.

### New Mexico Chapter

## 2019 New Mexico Walk-n-Roll

The Inaugural New Mexico Walk-n-Roll was a fun day for all! Nearly 120 participants representing 10 teams joined on August 17, 2019, at Balloon Fiesta Park in Albuquerque, NM. The event raised over \$8,500 for Cure SMA!

A special thank you to Mariah Rascon and her family, for organizing this amazing day. Congratulations to the top three fundraising teams; Claire's Crowd, Team Luis, and Old School New Styles Barber Shop.



## Punisher's Ride for Cure SMA

Thank you to the Punishers in New Mexico for hosting a fundraiser for Cure SMA! The group hosted a ride in Albuquerque, NM, on August 31, 2019. In addition, the Punishers had a great presence at the Inaugural New Mexico Walk-n-Roll! Thanks to their generous support, \$1,700 was raised for Cure SMA!

## Be a Part of the Breakthrough



Cure SMA Events play an important role in raising funds to support research and programs that impact families. Join our community in making a difference by visiting our events calendar to see a list of events near you!

[curesma.org/cure-sma-events/](https://curesma.org/cure-sma-events/)

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## Northern California Chapter



## 2019 Cure SMA Concert for a Cure

The Cure SMA Concert for a Cure took place on May 10, 2019, at Diablo Country Club in Diablo, CA. This year's theme was "Jazz & Jeans," and attendees enjoyed a live jazz performance during dinner. Over 275 guests came together and celebrated the SMA community's recent successes and raised over **\$190,000** to fund research into a cure for SMA.

Danny McHale, son of Joe and Mary McHale, was diagnosed with SMA in February 2001.

"When Joe and Mary asked what could be done for little Danny, the physician said "Nothing. Take him home and love him in the time you have left." He wasn't expected to see his first birthday. Unwilling to accept this prognosis, that afternoon the McHale's called "Families of SMA" who told them "Yes, there is hope."

Soon after, a friend of the McHale's, learned of Danny's diagnosis. Although she had met them only once, she really wanted to do something to help. She offered to host an evening of music and put together a few auction items, inviting friends and neighbors to

join in. That night, back in June of 2001, more than 50 people came together in the Book's backyard. They raised \$7,500 for Cure SMA to help further the research and development of a treatment."

Since 2001, Concert for a Cure has grown with the help of community support! The McHale and Dindzans families joined forces together to create the largest event on the west coast for Cure SMA. During the evening guests enjoy raffles, a huge silent auction, balloon pop, and "Sip & Sparkle," before gathering together in the ballroom for dinner, live jazz performance, and live auction featuring items such as a luxury cruise, fighter pilot experience, and Stephen Curry autographed Warriors jersey, among many other fabulous packages! The program included research updates, an SMA video, and a speech by Mary McHale.

Cure SMA would like to say a thank you to Mary McHale, Nancy Dindzans, Valerie Phelps, and Cathy Barsotti, along with their dedicated committee! This event would not be possible without the incredible dedication and help of all the committee planning members, event day volunteers, and sponsors!



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## 2019 Northern California Walk-n-Roll

The 17th Annual Northern California Chapter Walk-n-Roll took place on August 24, 2019, at Kennedy Grove Regional Recreation Area in El Sobrante and reached a very exciting milestone. After combining many years of fundraising and hard work, this event has raised over \$1 million! This year alone, over 350 participants and 31 teams raised over **\$100,000** for Cure SMA.

The day began with a fun, dance warm up and announcements, then friends and families took a short walk around the beautiful park. Sandwich lunches were served following the walk, along with juice from in-kind sponsor, Barsotti Juice Co. Everyone enjoyed the picnic area, balloon artist, face painter, and memorial area hosted by the Live RhysStrong Foundation, and new this year, Queen Bee Photo Booth donated their services and families

enjoyed taking photos with fun props. The day concluded with a raffle featuring popular Star Wars items!

This walk would not be possible without the help from the event committee, volunteers and sponsors. A huge thank you goes out to Pat Wolff, Krisie Nguyen, David and Lisa Sereni, Linda Shively, Marge Shively, and Cathy Barsotti, among the many volunteers who helped out with setup, making sandwiches, and cleanup!

Each year, this event grows bigger and bigger because of their dedication. Cure SMA and the Northern California Chapter appreciate everything they do!



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## North Florida Chapter



## 2019 St. Augustine Walk-n-Roll

On March 2, 2019, the inaugural St. Augustine Walk-n-Roll took place at the Riverview Club at St. Augustine Shores. Over 200 people joined the North Florida Chapter in its first event. Participants enjoyed a beautiful walk through Canopy Shores Park, family-friendly activities like face painting and crafts. The event committee was instrumental in reaching and exceeding our goal of \$15,000, with 16 teams, they raised just over **\$22,000**.

A big shout out goes to Kevin Campbell, Corinne Romano, Coral Friend, Maureen Ford, Kim Storms, Hannah Williford, and Ruby Gill, for all their help in planning this successful event! Mark your calendar for next year's event on Saturday, February 29, 2020.

## North Jersey Chapter

## 2019 North Jersey Walk-n-Roll

The Cure SMA North Jersey Chapter hosted the 4th Annual Walk-n-Roll on June 22, 2019, at Roosevelt Park in Edison, NJ. Thank you to all the dedicated teams and individual participants who helped make this day a success

and helped raise over **\$19,220**. This fun-filled event included activities for the whole family to enjoy, such as a balloon artist, face painting, games, comedy acts, and more!

A special thank you to Anna Pham, Kristen Smith, and Laura Watson for all their hard work in planning this event!



## 2019 Cure SMA Walk-n-Roll in honor of Katherine Santiago

On May 18, 2019, the Cure SMA Walk-n-Roll in Honor of Katherine Santiago took place at Slayton Field in Millburn, NJ, raising \$5,335. The walk was initially for Katherine – as sister, best friend, daughter, and passionate Harry Potter fan. However, over the last 11 years the walk has grown and is now for the countless SMA families, uniting together to get closer to a cure.

Thank you to Julia, Alma and Efren Santiago, and Allie Mazzella, for holding this annual event.

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## 2019 Cure SMA Walk-n-Roll in honor of Matthew Munch and Zianna Shamsi

On May 18, 2019, the students at Shongum School and their families, gathered at Shongum in Randolph, NJ, to walk or roll in honor of their fellow classmates, Matthew Munch and Zianna Shamsi. Over 200 participants gathered in the school gym and raised \$4,723 in support of Cure SMA. This wonderful event was organized and led by Matthew's teacher, Mrs. Susan Miessler. Thank you, Susan, for spearheading this event!

## 2019 Italian Dinner to Benefit Cure SMA

The 8th Annual Italian Dinner to Benefit Cure SMA was held on June 15, 2019, at the local Immaculate Conception Church Gym in Secaucus, NJ. This annual event is hosted by the local Knights of Columbus and is held in honor of Daniel Cevallos. Cure SMA is thankful for the \$3,630 raised for SMA research and support programs. Thank you to Giovanni and Paulina Recalde for organizing this event!

## John's Day to Dance Away SMA

On April 27, 2019, individuals gathered in Far Hills, NJ, for a dance performance by In Motion and In Motion II Dance Companies, to help find a cure for SMA. The event raised \$2,500 to help fund Cure SMA's research efforts and program services. Thank you to Kathie Kececi for spearheading this event year after year!



## Jeans Day in honor of Ava Finelli

Thank you to everyone at Chiesa Shahinian & Giantomasi PC Attorneys at Law Office in West Orange, NJ, for participating in the office jeans day in honor of Ava Finelli in August 2019! Together they raised \$450 for Cure SMA.

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## OKI Chapter



## 2019 Cure SMA Walk-n-Roll for Graham

The 2019 Walk-n-Roll for Graham took place on May 10, 2019, at Ritz Charles in Carmel, IN. This year's event exceeded all expectations by raising **\$104,184** for Cure SMA and rallying together over 750 people.

This event has something for everyone, including a beautiful walk through the trails of Coxhall Gardens, raffle items, silent auction, a tattoo station, a kid's zone with endless games and prizes, a DJ, great food and drinks, and so much more!

This event would not be possible without all the hard work and dedication of the amazing planning committee; Melody Braun, Ashley Goldman, Lisa Hiers, Lindsay Holt, Jen Juon, Leslieanne Maggart, Caity Sams, Allison Starr, Erin Watts, and Kristen Weaver.

A special thank you to the event chairs, Adrienne and Nick Vollmer. Adrienne and Nick founded this event in honor of their son, Graham, who is affected by SMA. This family works tirelessly to support Cure SMA and the entire SMA community each day.

Many groups hosted fundraisers to support this event. Cure SMA extends a thank you to Wheatfield Elementary and Cathy Vollmer, for hosting Silly Spray for SMA to support this event!



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## 2019 Louisville Walk-n-Roll

Kentucky

Over 235 people joined us in a celebration of the strength of the SMA community at the inaugural Louisville Walk-n-Roll! The event, held on April 27, 2019, at Broad Run Park in Louisville, KY, raised over **\$30,000** for Cure SMA!



A big thank you goes out to the event committee, Kristen DeLuca, Sara Harlan, and Courtney Ogletree, for their tireless efforts in making the Louisville Walk-n-Roll such a success!

Congratulations to our top three fundraising teams: Delaney's Defenders, Team Lucy, and LouCity Power Soccer!



## 2019 Rock The Bay

Rock the Bay was held on August 17, 2019, at the Kentucky Lake Subdivision, in Paducah, KY. Everyone had a great time enjoying food, drinks, and live music from the band MurMur. Attendees supported the event by purchasing Rock the Bay t-shirts, burgers, hotdogs, ice cream, bubbles, and tattoos. Guests also bid on great silent auction items and entered the 50/50 raffle drawing! The event raised over **\$17,000** for Cure SMA!

A huge thank you to Alex Durbin and Aaron Haas and their family and friends for hosting this wonderful event and for their continued passion and support for Cure SMA.

## Deacon Alexander Memorial Car Show

In its 6th year, the Deacon Alexander Car Show was held at the First Baptist Church of Walton, KY, in August 17, 2019. This year there was a great turn out, and \$970 was raised for Cure SMA! Thank you to Amanda Perry, her family, church family, and friends for making this happen every year.



## Lemonade & Cookie Stand in Honor of Emma & Nick

Thank you to Grant and Cole Galloway for hosting a cookie and lemonade stand in honor of their cousins Emma and Nick Lockwood in June 2019 in Berea, KY! Thanks to their hard work and dedication to Cure SMA they raised over \$215.

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## 2019 Cincinnati Walk-n-Roll

Ohio

The annual Cincinnati Walk-n-Roll was held on June 1, 2019, at the Xavier University Cintas Center, in Cincinnati, OH. In its 16th year the event raised an amazing **\$90,804** for Cure SMA! This event is always filled with fun family activities, lots of fundraising, and most importantly, hope. This year the kids were able to enjoy a petting zoo, face painting, and lots of games! It was a beautiful morning filled with friendship, passion, and support.

A huge thank you to Beth and Kevin Lockwood and Bob and Elizabeth Lockwood, who spend countless hours soliciting sponsors, supporting families, and organizing logistics to make the walk-n-roll a huge success.

A special thank you to Ron and Janet Merkle, Marilyn Pater, Gloria Logeman, Linda Schwabb, Nicole and Mark Haake, and Amy Trojanski, for their important role in this event.

Thank you to our raffle and food committees for all their help! Cure SMA appreciates all the teams, families, sponsors, and volunteers, who helped make this event a success.



## 2019 Birdies for Blake Golf Outing

The 2019 Birdies for Blake Golf Tournament took place on July 27, 2019, at Green Crest Golf Club in Liberty Township, OH. This year's event raised a total of **\$39,500** for Cure SMA! It was a beautiful day out on the green! Everyone back at the clubhouse had a great day playing bingo.

A huge thank you to Mark and Nancy Farrell, Nick and Kacey Farrell, and Kate and Sam Queen, for planning this wonderful event each year, and for their continued support and dedication to finding a Cure SMA.



## 2019 Cleveland Walk-n-Roll

The 2019 Cleveland Walk-n-Roll took place on May 5, 2019, at beautiful Lakeview Park in Lorain, OH. The event raised an impressive total of **\$19,230** for Cure SMA! Despite the gloomy skies, it was still a beautiful morning filled with family fun including fun games, an extra special visit from the Superheroes to Kids in Ohio, and a fantastic acapella performance! A huge thank you to Laura Shepherd, Kaila Phan, and their families for helping to plan and execute this event.

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## Will's Day at the Bay

Thank you to everyone at the Put in Bay Boat Line Company for fundraising for Cure SMA! On June 12, 2019, the company hosted Will's Day at the Bay in honor of Will Blumensaadt. The event raised over \$6,000 for Cure SMA! Thank you to the Blumensaadt family for their generous support of Cure SMA.

## The Ladies of Philoptochos of Dayton Ohio Fundraiser

Thank you to The Ladies of Philoptochos in Dayton, OH, for fundraising for Cure SMA! As part of their Community Care Ministry, the group hosted an event at Skyline Chili and collected donations from generous parishioners totaling \$1,800! Thank you to the May Chairs Margarita Ronayne and Michelle Zois for all for all their hard work fundraising in honor of Blake Farrell!

## Bishop John King Mussio Schools Dress Down Day in honor of Gianni Braccone

Thank you to the students and staff at Bishop John King Mussio Schools in Steubenville, OH, for hosting a dress down day in honor of Gianni Braccone in April 2019! Together they raised nearly \$780 for Cure SMA.

## Lemonade Stand in Honor of Cambrie Bentley

Thank you to the second-grade class at Prospect Elementary School in Girard, OH, for hosting a fundraiser in June 2019! The class sold lemonade in honor of their classmate, Cambrie Bentley!

# WE NEED YOU!



## START AN EVENT

Fundraising events help support Cure SMA programs and bring together the SMA Community. There are many different and meaningful event options, from a Walk-n-Roll to a jeans day.

Get started by filling out a Fundraising Interest Form!  
[curesma.org/fundraise](https://curesma.org/fundraise)

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## Pennsylvania Chapter



## 2019 Cure SMA Pennsylvania Chapter Walk-n-Roll

The 16th Annual Pennsylvania Chapter Walk-n-Roll brought together more than 540 participants to walk-n-roll to support Cure SMA. The event surpassed its original goal, by raising **\$120,085!**

The cloudy skies cleared, and participants had a beautiful morning at Penn Park in Philadelphia, PA, on June 2, 2019.

Twenty-five teams recruited participants and raised funds to help make the event a success. Congratulations to the event's top five fundraising teams: Pete's Philadelphia Eagles, Team Hammerin' Hank, Team Saxton, Team William, and Team Madison.

Thank you to the committee members who planned every detail of this event, recruited sponsors, and inspired the local community to support Cure SMA: Gina Cannady, Allyson Henkel, Karen McRory Negrin, Tara Maida, Christina Murray, Stephanie Reese, Paula Saxton, Olivia Santiago, and Sue Davis.



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## 2019 Muscles for Mckenna Gala

The 2019 Muscles for Mckenna raised over **\$77,650**! One hundred and sixty-six guests gathered at the Crystal Tea Room in Philadelphia, PA, on March 22, 2019, for the seventh annual event to raise funds for Cure SMA.

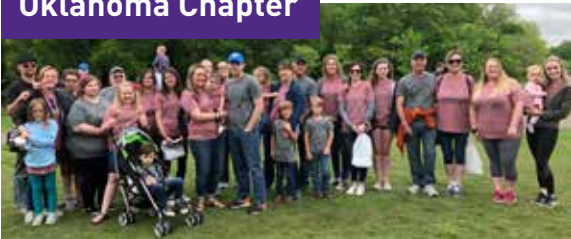
Guests enjoyed an evening full of fun with live music by the Heartbeats, a spirited live auction, selfie station, and great food! Guests generously raised their paddles during the Fund-a-Need portion of the evening.

A special thank you to event chairs Jim and Amy Ellixson, as well as the entire committee, who made this year's event such a success: Bill & Maureen Bell, Dave & Kim Carlin, Jane & Tom Pedicone, Dennis & Melanie Ellixson, Kellie & Mike Keenan, Coleen McLaughlin, Nancy & Steve Mckenzie, Jane & Tom Pedicone, Scott & Jocelyn Setzman, Emily & Dan Tomlinson.

## New Hope Middle School Walk-a-Thon

Thank you to the students at New Hope Middle School in New Hope, PA, for hosting a school walk-a-thon in June 2019! Thanks to their dedication, over \$1,100 was raised for Cure SMA!

### Oklahoma Chapter



## 2019 Oklahoma Walk-n-Roll

Thank you everyone who participated in the 2019 Oklahoma Walk-n-Roll. Over 230 people gathered at Bluff Creek Park in Oklahoma City, OK, on May 4, 2019, to celebrate the strength of the SMA community and fundraise to support Cure SMA. Thanks to the support of the event's 12 teams, over **\$19,600** was raised! Thank you to Amanda Chaffin, Lauren Lockhart, Shanna Culbertson, Kristen Griffen, and Kimberly McIntosh, for helping make this event a huge success!

### Rocky Mountain Chapter

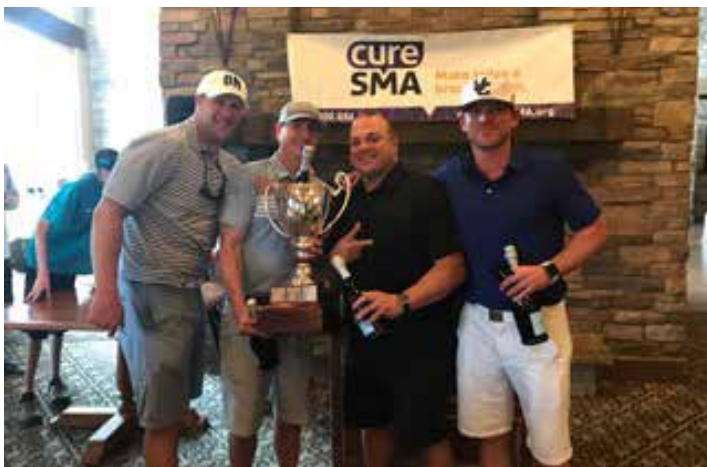
## 2019 Colorado Walk-n-Roll

Colorado

On August 14, 2019, the Rocky Mountain community gathered in Littleton, CO, at Clement Park for the annual Colorado Walk-n-Roll. This year's walk raised over **\$42,100** to help in the fight against SMA and hosted over 300 participants! Thank you to the top teams; Team Levi, Team Jack Colorado, and Hope for Hannah!

A special thank you to Michelle Pritekel, Sherri Casas, and Julie Lino, for their roles in organizing and planning this yearly event.

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## 2019 Rocky Mountain Charity Golf Tournament

The 16th Annual Rocky Mountain Charity Golf Tournament took place on July 1, 2019, at the beautiful Club at Pradera in Parker, CO. With the support of this year's sponsors, donors, and players, the event raised **\$33,875** to help find a cure for SMA!

Cure SMA would like to extend a special thank you to event organizer, Gillian Faith and her committee for hosting the tournament.



## 2019 Colorado Evening of Hope

The 6th Annual Colorado Evening of Hope was another great success for the Rocky Mountain Chapter. Instead of a beer and cheese pairing, this year featured a BBQ buffet and pop culture trivia night hosted by Chain Reaction Brewing Company and Brain Reaction Trivia on March 22, 2019, in Denver, CO. Thank you to all the friends and families of the Rocky Mountain SMA community for their continued support.

The event raised \$9,130! Cure SMA sincerely appreciates all the donations – in-kind, services and more – that were given to the event.

Thank you to Marynell Larson for organizing this annual event.

## Southern California Chapter



## 2019 Los Angeles Walk-n-Roll

The 2nd Annual Los Angeles Walk-n-Roll took place on May 2, 2019, at Griffith Park in Los Angeles, CA. The morning included a walk along the Equestrian Trail, refreshments, a raffle, and more! Over 85 people participated in a day of fun raising over \$9,800 to fund critical SMA research and valuable family support programs.

Thank you to Autumn Montoya, Ruby Mercado, and Rosa Gonzalez for their hard work in making this event such a success again this year! Mark your calendars for the 3rd Annual Los Angeles Walk-n-Roll in May 2020!



## 2019 Southern California Walk-n-Roll

On April 13, 2019, families gathered together at TeWinkle Park in Costa Mesa for the Southern California Walk-n-Roll. The morning was filled with a walk around the park, lunch, and a great raffle. Thanks to the following teams for helping raise over \$8,500 for Cure SMA: Nothing Stops Neely, Evelyn's Fight, Team Kennedy Montoya, Princess Ava's Squad, Project Farma, WheelyQ, ELFinator, Team AveXis, and Team Charlie.

Thank you to Autumn and Rick Montoya for planning this walk each year.

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## Margaret Horvath Birthday Party Fundraiser

Cure SMA would like to thank Andras and Margaret Horvath for using their special anniversary to honor their grandson, Joshua Briseno. In lieu of gifts, they asked their friends and family to donate to cure SMA and were able to raise \$1,665.



## 2019 Fitness After Dark

The Camp Transformation Center - Menifee hosted its 4th Annual John Robert Ekman Cure SMA Fitness After Dark event on August 23, 2019 in Menifee Lakes, CA. The night was filled with love of family, fitness, and a strong sense of belonging for everyone who attended. The Camp Transformation Center and Cure SMA continue to partner up to raise funds and increase awareness for SMA. John Robert (J.R.) Ekman and his family participated in full force as a very heart felt speech by J.R. resonated with everyone in attendance. JR spoke about the benefits of finding a cure, the treatment that he has been receiving, the positive impact it has had on him, and the importance of being proactive in fitness and not taking one's health for granted.

The Camp Transformation Center, and its owners Chad and Jenn Burleson would like to thank Cure SMA for the great work that they do in their communities and the selfless nature of everyone involved in the organization who choose to put the needs of others often times before their own.

"We are very privileged to work alongside such an amazing group of people and to have such awesome members here at The Camp who rallied around this great cause; together we can Cure SMA and that is exactly what we plan to do."

Thank you to the Camp Transformation Center, Chad and Jenn Burleson, and everyone who participated for all their hard work in raising funds and awareness for Cure SMA. Thanks to their efforts, they raised over \$800 for Cure SMA!



## 2019 Surf Away SMA

The 2019 Surf Away SMA with Ricochet took place on August 2, 2019, at La Jolla Shores in La Jolla, CA. This annual event is hosted by Ionis Pharmaceuticals and brings together the SMA community in Southern California during SMA Awareness Month.

Families got to enjoy surfing with Ricochet the SURFice dog on an adapted surfboard with professional surfer, family friendly entertainment, lunch, and more. This year was the largest year yet with over 42 people registered and 20 surfers!

Thank you to Ionis and their generous volunteers for making this possible, and an extra special thank you to Ricochet for making this event so unique!



## Southern California Candle Lighting

The Southern California Chapter gathered on the evening of August 10, 2019 to remember those we have lost to SMA and honor those living with SMA. The chapter released lighted balloons at sunset and hosted a potluck for families to spend time with each other during SMA Awareness Month.

Thank you to Autumn and Rick Montoya for organizing this special event!

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## South Florida Chapter



## 2019 Miami Walk-n-Roll

On April 27, 2019, the inaugural Miami Walk-n-Roll took place at Amelia Earhart Park in Hialeah. Over 100 people joined the South Florida Chapter in its first walk-n-roll in the Miami area. Participants enjoyed a beautiful walk through the park, and family-friendly activities like yard games and crafts. The event committee was instrumental in reaching and exceeding our goal of \$15,000, with 6 teams, they raised over **\$24,000**. A special thanks goes to Team Ravi who raised over \$15,000!

A big shout out goes to Idalmis Del Toro and Maylan Chavez for all their help in planning this successful event! Next year's event will be held on Saturday, March 14, 2020.

## Bayview Elementary Community Compassion Day for SMA

On August 28, 2019, Bayview Elementary in Fort Lauderdale, FL, celebrated Compassion Day in honor of Mia Fuentes-Israel. Students at the school were able to support Cure SMA by donating \$1 to wear purple to school that day. Donations totaled \$800 to Cure SMA. Thank you to Mia and Fiorenna Fuentes-Israel, as well as Bayview Elementary for supporting Cure SMA!



## Tennessee Chapter

## Shake Shack Fundraiser

Thank you to Rondi Kauffmann and Keri Tarantino for organizing a Dine to Donate partnership with their local Shake Shack in Nashville, TN, on June 11, 2019! The event raised \$125 for Cure SMA.

## Chapter Update



This past year a very important Chapter Leader from South Florida stepped down from her position after many years; Jennifer Miller-Smith. A big thank you to Jennifer Miller-Smith for her years of dedicated service to Cure SMA!

Jennifer founded the South Florida Chapter when her daughter, Madison, was diagnosed in 2007. As a leader in the SMA community for 11 years, Jennifer dedicated countless hours to helping newly diagnosed families, parents, and adults with SMA connect with each other and local resources. Through her service, she has touched the lives of hundreds of families. During her tenure, Jennifer co-chaired the

Gala of Hope, in addition to numerous other fundraisers, which have raised over \$1 million for Cure SMA.

Thank you to Jennifer for her endless support! Jennifer will continue to be a proud community member of the South Florida Chapter, and we wish her all the best in her future endeavors.

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## Texas Chapter

### 2019 Links 4 Luke

The 2nd Annual Links4Luke Golf Tournament took place on April 29, 2019, at Timarron Country Club in Southlake, TX. This annual event benefits the Luke 18:1 Foundation, whose mission is to work together as a community to find a cure for SMA through raising awareness, funding research, and supporting individuals and families with SMA.



Players enjoyed 18 holes of golf with activities like Hole in One, Closest to the Pin, Putting Contest, and Longest Drive, along with refreshments provided along the way by sponsors. There was also a silent auction and a Kendra Scott jewelry pull in the clubhouse. Thanks to the generosity of the sponsors, players, and community, the Luke 18:1 Foundation was able to donate **\$200,000** to Cure SMA to benefit research programs and the equipment pool.

Thank you so much to the Stickane family for everything they've done to make this event a success!



### 2019 Dallas Walk-n-Roll

The inaugural Dallas Walk-n-Roll was held on March 30, 2019, at the beautiful Parr Park in Grapevine, TX. Although the day was a little chilly and rainy, the walkers and rollers enjoyed a short walk, along with a face painter, snacks, a raffle, crafts, and life-size bowling! Families, friends, coworkers, and community members all came out to show their support for Cure SMA. Thanks to the hard work of our 13 teams, sponsors, and generous donors, the Dallas Walk-n-Roll raised over **\$15,000**!

Special thanks to Kate Nelson and Janet Kelley for their hard work and dedication to making this event so successful! Next year's event will be in the spring of 2020.



### 2019 Houston Walk-n-Roll

The 3rd Annual Houston Walk-n-Roll was held on April 27, 2019, at a new location for this year, Lost Creek Park in Sugar Land, TX. The day couldn't have been better! It was warm and sunny for the walkers and rollers! Attendees enjoyed a walk around the exterior of the green, along with a face painter, snacks, a raffle, coloring for the kids, and life-size bowling! Families, friends, coworkers, and community members all came out to show their support for Cure SMA. Shout out to all 10 teams for their fundraising efforts, and thanks to everyone who was able to attend the walk, the Houston Walk-n-Roll raised over **\$13,500**!

Special thanks to Sapna Pringle and Samantha Valdez for all their help in making this event such a success! Next year's event will take place on April 25, 2020.

### 2019 Cure SMA Fayetteville 5K in Honor of Annabelle and Jude

The 4th Annual Fayetteville 5K in Honor of Annabelle and Jude Combs was held on April 13, 2019, at Oak Thicket Park in Fayetteville, TX. With over 120 participants, the event raised over **\$13,000** for Cure SMA! Attendees enjoyed a 5K run or walk, refreshments, entertainment, a raffle, and a chance to connect with the local community.



The 5K race celebrated Annabelle, who turned four, and baby brother Jude! Shout out to the top three fundraising teams Team Anthony, Mile SMashers, and #KickSMA for their fundraising efforts!

Thank you to Alyssa Combs for another great event and all 13 sponsors for supporting the race!

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## Virginia Chapter



## 2019 Virginia Evening of Hope

The inaugural Cure SMA Virginia Evening of Hope was held on June 13, 2019 and raised **\$14,000** for Cure SMA! It was a beautiful summer evening at the Winery at Bull Run in Centreville, VA, featuring live music, raffles, a silent auction, appetizers by Purple Onion Catering, delicious desserts, and unlimited wine and beer.

Thank you to all the attendees, volunteers, donors, vendors, and well-wishers! The event could not have raised these funds without their support and the Virginia Chapter is so grateful to all who donated their time and talents, to help those living with SMA. A special thank you to Meghan Moore, the Band SAMA, Bernadette Dalgetty of An Endless Pursuit photography, and Shannon Zerzan of Anatomy of a Pineapple, for donating their time to make the event an even greater success.

Lastly, this event would not have been possible without the support of Laura Derkowski and Maureen Farace. Thank you for your countless hours of hard work and bringing this new event to Northern Virginia. Cure SMA hopes to make the Virginia Evening of Hope an annual event, so stay tuned for ways to help and get involved!

## Jawbox Punk Band Reunion Fundraiser

On June 29, 2019, the Little Salon at the Showroom in downtown DC, held a benefit celebration of DC creativity with a special tribute to DC post-punk legends, Jawbox, who performed a pair of reunion shows in DC the same weekend. The many attendees enjoyed music, interactive art, photo exhibitions, craft beer, and the chance to contribute to a meaningful and productive cause. All proceeds from the show were donated to Cure SMA in honor of Jawbox lead singer, J Robbins' son who is affected by SMA.

Thank you to Chris Maier, J Robbins, and Jawbox, for organizing this event in honor of Callum Robbins, raising \$1,300 for Cure SMA. Lastly, a special thank you to the Little Salon for making this event possible (#LittleSalonDC).



## Western New York Chapter

## Kinsley's Day for SMA

Thank you to Cheryl Weidman, who hosted the 2019 Kinsley's Day for SMA at her home in Columbus, NY, on August 10, 2019. It was a fun filled day with games, raffle, face painting, tattoos, rock painting station, and a barbeque. Not even the rain could stop them as they commemorated those affected by SMA with a candle lighting ceremony for SMA Awareness Month. This wonderful event raised over \$1,000 for SMA in memory of Kinsley Weidman, in the hopes that no other family will have to say goodbye. Thank you to everyone for continuing the fight to cure SMA!



*Note: The amounts raised and shown are totals as of August 15, 2019 and may differ from current fundraising totals by the time you get this newsletter.*



## Pig Roast

On June 8, 2019, in Lockport, NY, the Western New York Chapter held the 5th Annual Pig Roast SMA. The Justice League of WNY, a non-profit group that entertains at children functions, were part of the entertainment at the 5th Uncle Brad's Pig Roast. It was a great day with the sun shining and warm weather. Many fish were caught in the stocked pond. Even the Justice League, dressed as Ghost Busters and Scooby Doo took part in the fun. Everyone brought a dish to pass, including desserts, snacks, salads, and delicious pork. This year the, "Give a Dream," winner to a SMA child was Charlie with a wish for a new phone. Everyone had a great time and the Western New York Chapter looks forward to next year's event!

Cure SMA would like to thank the Western New York chapter leaders and Brad Shiesley, for hosting this wonderful event for the community and raising **\$1,560**.

## Wisconsin Chapter



## 2019 Cure SMA Wisconsin Chapter Bowl-a-Thon

The Wisconsin Chapter Bowl-a-Thon was held on April 13, 2019, in New Berlin, WI. This year it was another great success, raising **\$7,967**.

A special thank you to Kim Banach, Ashley Baumeister, and Amy Medina, for all their hard work planning this year's event and making it such a success.

## Tori Stevens Memorial Race

Thank you to Ashley Hedges for once again planning the Tori Stevens Memorial Night to support Cure SMA! This year's event took place on June 3, 2019. Each year Ashley rallies the town of Tomahawk, WI, to come together at the Tomahawk Speedway to remember her dear friend, Tori. Through the generosity of the local community, over **\$700** was raised for Cure SMA!



# HAVE YOU CHECKED OUT THE CURE SMA APP?

The Cure SMA Guide app is a family support program that takes a new approach to provide useful tools and information related to SMA care, to use at home and on-the-go. The app is now available to download from your Apple or Android device.

The app contains important information about SMA, including all of the SMA Care Series booklets, and acts as a quick way to have SMA care information available at your fingertips.

## Access important information such as:

- Downloadable PDFs of all SMA Care Series booklets, in both English and Spanish
- Resources for physicians, nurses, therapists, and other healthcare providers
- Local chapter contact information
- General medical and emergency recommendations and tools
- Much more!



Please download our app directly from the Apple Store or Google Play Store for Android devices.



*The Cure SMA Guide is your portable source for SMA care and support. Access valuable information at the touch of a button. Share resources with your family, friends, and care providers.*



Cure SMA would like to thank Genentech for generously funding a grant to support the Cure SMA Guide app resource for the SMA community!



# JOIN TEAM CURE SMA

RACING FOR A BREAKTHROUGH

Interested in joining Team Cure SMA? Check out our upcoming events and email Alyssa Zavislak at [alyssa.zavislak@curesma.org](mailto:alyssa.zavislak@curesma.org) to get involved!

## UPCOMING TEAM CURE SMA EVENTS

### NOVEMBER:

Allstate Hot Chocolate 15K/5K

Philadelphia Marathon

TCS New York City Marathon

CNO Financial Indianapolis Monumental Marathon

Disney Wine & Dine Half Marathon Weekend

Detroit Free Press Marathon

### DECEMBER:

Rock N' Roll San Antonio

Rehoboth Beach Race

Little Rock Ugly Sweater Race

St. Jude Memphis Marathon

### JANUARY:

Rock N Roll Arizona Marathon

### MARCH:

United Airlines New York City Half Marathon

Bank of America Shamrock Shuffle 8K

Portland Shamrock Run

Publix Georgia Marathon & Half Marathon

Rock 'n' Roll Washington DC Marathon Series

Napa Valley Marathon & Half Marathon\*

### APRIL:

Coastal Delaware Running Festival and Delaware Marathon

Novo Nordisk New Jersey Marathon & Half Marathon

Rock N' Roll San Francisco Half Marathon

Rock N' Roll Nashville

Raleigh Half Marathon\*

### MAY:

Dick's Sporting Goods Pittsburgh Marathon

Lake Minnetonka Half Marathon

Wisconsin Marathon

Flying Pig Marathon

Vermont Marathon

### JUNE:

San Diego Rock N' Roll Marathon and Half Marathon

Rock N' Roll Seattle

Bike the Drive Chicago\*

The Denver Century Ride\*

North Shore Classic Half Marathon\*

### JULY:

Ragbrai Race

### AUGUST:

New Balance Falmouth Road Race

IRONMAN Boulder

Michigan Titanium Triathlon

### SEPTEMBER:

Chicago Half Marathon & 5K

Rock n Roll Philadelphia

### OCTOBER:

Mo' Cowbell Run

Baltimore Running Festival



TEAM CURE SMA

RACING FOR A BREAKTHROUGH

# **cure** **SMA** TEAM CURE SMA

RACING FOR A BREAKTHROUGH



## Endurance Highlights

### About Team Cure SMA

Team Cure SMA is an endurance program designed to connect runners and cyclists with Cure SMA. Team Cure SMA athletes from across the country can choose to run or bike in an endurance event all while raising money and awareness for SMA.

## Top Performing Team Cure SMA Events

### 2019 United Airlines New York City Half Marathon

Thank you to the 10 incredible Team Cure SMA participants that ran and fundraised in the 2019 United Airlines New York City Half Marathon in March. Together, the runners successfully raised \$15,000 for Cure SMA. Cure SMA would like to thank all of the runners for their hard work and dedication.

### 2019 Dick's Sporting Goods Pittsburgh Marathon

Thank you to the 10 amazing runners that took part in the 2019 Dick's Sporting Goods Pittsburgh Marathon in May. Special shout out to Brett Chieze and his team successfully raised over \$11,000 for Cure SMA.

### 2019 Reebok Ragnar Great Midwest

Thank you to the 15 runners that took part in the 2019 Reebok Ragnar Great Midwest. Team Biogen successfully raised over \$14,000 for Cure SMA while running in the 200-mile relay race starting in Waukegan, Illinois and finishing in Madison, Wisconsin over the course of 30 hours. The all-star team included: Brian Bieller, Cari Henry-Holm, Chad Mierau, Dan Pucci, Danielle Conley, Derk Holder, Jeff Combs, Katie Heggemeier, Kim DeRobertis, Leanne Vaughn, Nate Greene, Sarah Jennison, Shane Dorfman, and Tracy Parker.

### 2019 Vermont City Marathon

Thank you to the amazing runners that took part in the 2019 Vermont City Marathon in May. Special shout out to sisters, Regina Philipps and Amanda McKenna, who successfully raised over \$17,000 for Cure SMA.

### 2019 New Balance Falmouth Road Race

20 runners took on the 2019 New Balance Falmouth Road Race on August 18. The Falmouth Road Race is an annual 7.1-mile road race on Cape Cod from Woods Hole, a village in the town of Falmouth, Massachusetts, to Falmouth Heights. Thanks to the incredible dedication of these runners they were able to raise over \$55,000 for Cure SMA. Cure SMA would like to thank all the runners for their hard work in fundraising and training for this race. Special shout out to Rachael Brown for raising over \$20,000 for Cure SMA.

### 2019 Chicago Half Marathon & 5K

Thank you to the 20 incredible Team Cure SMA participants that ran and fundraised in the 2019 Chicago Half Marathon & 5K on September 29. Together, the runners successfully raised \$12,000 for Cure SMA. Cure SMA would like to thank all of the runners for their hard work and dedication. Congratulations Team Goin' for Koen for raising over \$9,000 for Cure SMA.

## Additional Team Cure SMA Events

### 2019 Bank of America Shamrock Shuffle

Great job to first time Team Cure SMA runners Aliberskys Benso, Michael Benso, Vincent Benso, Robyn Berto, Jessica Cook, Emily Crumpton, Jennifer Dawson, Phil Delamothe, John Kesselring, Ethan Marrow, Sean Maynard, Philip Salome, Julia Taicsich, Izabella Tyszler, Helen White and Kyle Wu.

### 2019 Flying Pig Marathon

Congratulations Team Cure SMA runners Lisa Davison, Kathryn Farrell, Danielle Miller, Kate Queen and Suzanne Spears.

### 2019 Lake Minnetonka Half Marathon

Thank you Team Cure SMA runners Rory Philstrom and Shannon Stolt.

### 2019 Novo Nordisk New Jersey Marathon and Half Marathon

Great job to our seasoned Team Cure SMA runners Valerie Boyle, William Boyle, Christine Cassu, Nena Ciambotti, Heather Fehn, Ryan Kastner, Stacy Kidd and Lisa Maver.

### 2019 Portland Shamrock Run

Congratulations Team Cure SMA runners Cheryl Grabham, Wren Grabham, Dana Hawkes, Aaron Johnson and Katrina Yuen.

### 2019 Publix Georgia Marathon and Half Marathon

Special shout out to Team Cure SMA runners Mandy Abercrombie and Leslie Cash.

### 2019 San Diego Rock N' Roll Marathon and Half Marathon

Congratulations Team Cure SMA runners Brian Basista, Joanna Burch, Brad Colonna, Dasha Knobel and Alexis Martinez.

### 2019 United Airlines Rock n' Roll San Francisco Half Marathon

Amazing work Team Cure SMA runner Kelly Gross participating in our first ever San Francisco Half Marathon race.

### 2019 Wisconsin Marathon

Congratulations Team Cure SMA runners Deb Bozewicz, Jessica Collins-Gonzalez, Gina Dillon, Hamlet Gonzalez, Jacob Janiszewski, Lola Janiszewski, Meaghan Martin, Michael Martin, Bill Morris, Charlotte Morris, Aaron Rooker, Alicia Rooker, Dean Rooker, Michael Schmidt, Alexandria Smith, Anne Smith, Emily Vossman, Jeremy Vossman, Bradley Zajork and Molly Zajork.

### 2019 DIY Endurance

Way to go Team Cure SMA runners Jeremy Burkhart, Ibon Hernandez, Abby Paras, Carice Smith, Megan Starkey and Jonni Winegardner.



# cure SMA 2019

CURE SMA MERCHANDISE



Support our mission and raise awareness by purchasing Cure SMA merchandise through our online store. We love seeing all of our supporters wearing our Cure SMA gear so please email [familysupport@curesma.org](mailto:familysupport@curesma.org) to share your photos for a chance to be featured in a future publication and our next issue of Directions!

[www.curesma.org/merchandise](http://www.curesma.org/merchandise)



# CURE SMA MERCHANDISE PRICING AND SIZE GUIDE

## ACCESSORIES:

<b>\$2</b> Adult Bracelet	<b>\$6</b> Fidget Spinner	<b>\$17</b> Stainless Steel Vacuum Insulated Bottle
<b>\$2</b> Youth Bracelet	<b>\$15</b> Notecards	<b>\$20</b> Canvas Tote
<b>\$4</b> Oversized Magnet	<b>\$10</b> Popsocket	<b>\$20</b> Purple Zippered Tote
<b>\$5</b> Flat Holiday Ornament	<b>\$15</b> Purple Ceramic Mug	
<b>\$5</b> Vinyl Decal		

## HATS:

<b>\$20</b> Marble Knit Beanie	<b>\$20</b> Gray Adjustable Baseball Hat	<b>\$20</b> White Performance Baseball Hat
<b>\$25</b> Striped Pom Beanie	<b>\$20</b> Black Performance Baseball Hat	

## APPAREL:

### TODDLER & YOUTH APPAREL:

<b>\$24</b> Youth Grey Crew Neck Tee (Small-XLarge)
<b>\$24</b> Toddler Grey Crew Neck Tee (2T-4T)
<b>\$24</b> Youth Est 1984 Purple Jersey Tee (XSmall-XLarge)
<b>\$18</b> Onesie (6mon, 12mon, 18mon & 24mon)
<b>\$25</b> Youth Baseball Tee (XSmall-XLarge)
<b>\$25</b> Youth We Can Cure SMA Crewneck Sweatshirt (XSmall-XLarge)

### WOMEN'S APPAREL:

<b>\$24</b> Women's Est. 1984 Purple Jersey Tee (Small-2XLarge)
<b>\$28</b> Women's Purple Performance Polo (XSmall-4XLarge)
<b>\$49</b> Women's Performance Half Zip (Small-4XLarge)
<b>\$49</b> Unisex Full Zip Purple Hoodie (XSmall-2XLarge)
<b>\$24</b> Unisex Grey Crew Neck Tee (XSmall-4XLarge)
<b>\$24</b> Unisex Orange V-Neck Tee (XSmall-2XLarge)
<b>\$32</b> Unisex V-Neck Purple Scrub Top (Small-3XLarge)
<b>\$25</b> Unisex Baseball Tee (Small-2XLarge)
<b>\$30</b> Unisex We Can Cure SMA Crewneck Sweatshirt (Small-3XLarge)
<b>\$35</b> Windbreaker Full Zip Jacket (XSmall-3XLarge)

### MEN'S APPAREL:

<b>\$24</b> Men's Est 1984 Purple Jersey Tee (Small-3XLarge)
<b>\$28</b> Men's White Performance Polo (Small-4XLarge)
<b>\$49</b> Men's Performance Half Zip (Small-4XLarge)
<b>\$49</b> Unisex Full Zip Purple Hoodie (XSmall-2XLarge)
<b>\$24</b> Unisex Grey Crew Neck Tee (XSmall-4XLarge)
<b>\$24</b> Unisex Orange V-Neck Tee (XSmall-2XLarge)
<b>\$32</b> Unisex V-Neck Purple Scrub Top (Small-3XLarge)
<b>\$25</b> Unisex Baseball Tee (Small-2XLarge)
<b>\$30</b> Unisex We Can Cure SMA Crewneck Sweatshirt (Small-3XLarge)
<b>\$35</b> Windbreaker Full Zip Jacket (XSmall-3XLarge)

**SHOP NOW**

Items can be ordered  
on our website at  
[www.curesma.org/merchandise](http://www.curesma.org/merchandise)

# Recognize the symptoms and save a life!



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EARLY ACTION, EARLY TREATMENT, SAVES LIVES.

Motor delays or missed milestones may signal serious conditions like SMA (spinal muscular atrophy). There is new hope, but it's important to act swiftly and make SMarT Moves.



[SMarTMoves.CureSMA.org](http://SMarTMoves.CureSMA.org)

## VISION AND MISSION STATEMENT

Cure SMA leads the way to a world without spinal muscular atrophy, the number one genetic cause of death of infants. We fund and direct comprehensive research that drives breakthroughs in treatment and care, and we provide families the support they need for today.

## OUR VALUES

### Innovation

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

### Balance

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

### Collaboration

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

### Respect

There is no “right way” to live with a disease like spinal muscular atrophy. 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 affected by SMA and communicate openly and honestly, giving them clear and accurate information.

### Determination

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

**The production of this newsletter was supported by a grant from Biogen.**

On the Cover: The Enderlin Family



We are a non-profit, 501(c)3 tax exempt organization. Funds will be specifically directed to scientific, educational or literary purposes in keeping with a charitable organization. The organization is proud to provide funding to the Cure SMA newsletter and website, which provides information and networking opportunities.

### Submissions

To submit articles or make other contributions to our newsletter, please contact us at: [newsletter@curesma.org](mailto:newsletter@curesma.org).

Digital images are encouraged! Send your digital pictures to: [newsletter@curesma.org](mailto:newsletter@curesma.org).

### Change of address

Send changes, including ZIP code to: [info@curesma.org](mailto:info@curesma.org) or call 800.886.1762 or mail to: Cure SMA, 925 Busse Road, Elk Grove Village, IL 60007

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Cure SMA does not support or endorse any particular treatment or therapy. Information contained in this newsletter should not be used as a substitute for consultation with a qualified healthcare professional.



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## MAKE A DONATION TO CURE SMA TODAY!

### Your support will fund:

**SMA Care Center Network** – Double the number of sites in our network and data registry from 12 to 24 centers by the end of 2020. This growth is vital to meeting our end-goal of an evidence-based standard of care for SMA.

**Basic Research Initiatives** – Advance new research for non-SMN targeted therapies that will work together with existing FDA-approved treatments to create the best possible outcomes for all ages and stages of SMA.

**Local Support Services** – Help us reach more than 60% of the SMA community in 2020 through customized support programs, including the Summit of Strength event series. Today we are reaching approximately 40% of the community with these essential services.

Questions about your donation, matching gifts, or other ways to get involved?

Please email us at [fundraising@curesma.org](mailto:fundraising@curesma.org)

To send a donation by mail, send your donation to:  
**Cure SMA 925 Busse Road, Elk Grove Village, IL 60007**

COMMUNITY  
on the



Visit us at [www.cureSMA.org](http://www.cureSMA.org) and click the donate button.  
To make a donation by phone, call us at 800.886.1762

