

# DIRECTIONS

SPRING 2019

Cover: Amber Bosselman,  
SMA Type II



**cure**  
**SMA**

Make today a  
breakthrough.

Research Update	6
Summit of Strength	8
Advocacy	18
Chapter Highlights	36



# AveXis Receives FDA Approval of Zolgensma, a Gene Therapy, for Spinal Muscular Atrophy for Patients Under Two Years of Age

AveXis, Inc., a Novartis company, recently announced that they have received FDA approval for Zolgensma (formerly AVXS-101), a gene therapy that replaces the survival motor neuron 1 (SMN<sub>1</sub>) gene, which is missing or mutated in individuals with SMA.

This first approval is for intravenous (IV) delivery of gene therapy. The FDA has approved Zolgensma for IV delivery in patients with all forms and types of SMA who are under two years of age at the time of dosing.

In addition, AveXis is currently testing intrathecal (IT) delivery of Zolgensma in clinical trials. IT delivery would allow older patients to receive the therapy. Once these clinical trials are complete, AveXis will determine whether the data supports a separate BLA filing for IT delivery.

“This is an important day for the SMA community. Clinical data shows that a one-time infusion of Zolgensma can change the course of SMA,” said Kenneth Hobby, President of Cure SMA. “We look forward to working with our partners from AveXis and Novartis and with healthcare professionals across the US, to ensure rapid access to Zolgensma according to this FDA approval.

“We also look forward to the additional data coming soon from ongoing clinical trials which could broaden the approval to also cover older SMA patients.”

## Want to learn more about Zolgensma?

Visit [www.cureSMA.org/Zolgensma](http://www.cureSMA.org/Zolgensma) to find information on administration sites, insurance policies and more.

# AveXis Issues Community Statement on Zolgensma Approval

## Dear SMA Community,

We have exciting news to share with you — a major milestone has been reached in the fight against spinal muscular atrophy (SMA)! The US Food and Drug Administration (FDA) has approved ZOLGENSMA® (onasemnogene abeparvovec-xioi) for the treatment of children less than 2 years old with SMA.

This monumental day represents years of collaboration and the perseverance of caregivers and patients, patient advocacy groups, researchers, healthcare professionals, treatment teams, AveXis employees, and the FDA. Because of this collaboration, families now have a new treatment option that targets the genetic root cause of SMA with a one-time-only gene therapy.

“It has been a privilege to work together with the SMA community on this journey to bring ZOLGENSMA to children with SMA. Your partnership has been invaluable at every step,” said Dave Lennon, president of AveXis. “I would like to extend a special thank you to all of the families who participated in the clinical studies—and to those who continue to be a part of our ongoing studies—as we make every effort to assist more people living with SMA. Without you, we would not be here.”

We are working diligently to provide you with additional information about ZOLGENSMA, including how to start treatment and the dedicated support available before, during, and after treatment. Please check [ZOLGENSMA.com](https://www.zolgensma.com) for the latest updates and information.

It is important to understand that ZOLGENSMA can cause acute serious liver injury. In the clinical studies of ZOLGENSMA, the most common side effects were elevated liver enzymes and vomiting.

Everyone in the SMA community should be proud of their contributions. The approval of ZOLGENSMA is just the beginning, and we look forward to continuing our partnership and supporting you at every step of the SMA journey.

**Sincerely,  
The AveXis Team**

**For more information, please visit [Zolgensma.com](https://www.zolgensma.com)**



# Now Approved!

**A one-time-only gene therapy for the treatment of children less than 2 years old with spinal muscular atrophy (SMA).**

## Indication and Important Safety Information

### What is ZOLGENSMA?

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

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

- Liver enzymes could become elevated and cause acute serious liver injury in children who receive ZOLGENSMA.
- Patients will receive an oral corticosteroid before and after infusion with ZOLGENSMA and will undergo regular blood tests to monitor liver function.
- Contact the patient's doctor immediately if the patient's skin and/or whites of the eyes appear yellowish, or if the patient misses a dose of the corticosteroid or vomits it up.

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

- Viral respiratory infections before or after ZOLGENSMA infusion can lead to more serious complications. Contact the patient's doctor immediately if you see signs of a possible viral respiratory infection such as coughing, wheezing, sneezing, runny nose, sore throat, or fever.
- Decreased platelet counts could occur following infusion with ZOLGENSMA. Seek immediate medical attention if a patient experiences unexpected bleeding or bruising.

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

- Talk with the patient's doctor to decide if adjustments to the vaccination schedule are needed to accommodate treatment with a corticosteroid.
- Protection against respiratory syncytial virus (RSV) is recommended.

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

Temporarily, small amounts of ZOLGENSMA may be found in the patient's stool. Use good hand hygiene when coming into direct contact with bodily waste for 1 month after infusion with ZOLGENSMA. Disposable diapers should be sealed in disposable trash bags and thrown out with regular trash.

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

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

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

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

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

**To learn more, talk to your doctor and visit [ZOLGENSMA.com](http://ZOLGENSMA.com).**

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## IMPORTANT FACTS ABOUT ZOLGENSMA® (onasemnogene abeparvovec-xioi)

### USE

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

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

### WARNINGS

#### Acute Serious Liver Injury and Elevated Liver Enzymes

- Liver enzymes could become elevated and cause acute serious liver injury in children who receive ZOLGENSMA. Patients with pre-existing liver impairment may be at higher risk.
- Patients will receive an oral corticosteroid before and after infusion with ZOLGENSMA and will undergo regular blood tests to monitor liver function.
- Contact the patient's doctor immediately if the patient's skin and/or whites of the eyes appear yellowish, or if the patient misses a dose of the corticosteroid or vomits it up.

**Decreased platelet counts** could occur following infusion with ZOLGENSMA. Caregivers should seek immediate medical attention if a patient experiences unexpected bleeding or bruising.

### OTHER IMPORTANT INFORMATION

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

**Vaccination** schedule should be adjusted where possible to accommodate treatment with an oral corticosteroid. Caregivers should talk with the patient's doctor to decide if adjustments to the vaccination schedule are needed during corticosteroid use. Protection against respiratory syncytial virus (RSV) is recommended.

**Viral respiratory infections** before or after ZOLGENSMA infusion can lead to more serious complications. Contact the patient's doctor immediately if you see signs of a possible viral respiratory infection such as coughing, wheezing, sneezing, runny nose, sore throat, or fever.

**Temporarily, small amounts of ZOLGENSMA may be found in the patient's stool.** Use good hand hygiene when coming into direct contact with bodily waste for 1 month after infusion with ZOLGENSMA. Disposable diapers should be sealed in disposable trash bags and thrown out with regular trash.

### COMMON SIDE EFFECTS

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

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

### QUESTIONS?

To learn more, talk to your doctor and you can visit [www.ZOLGENSMA.com](http://www.ZOLGENSMA.com) for Full Prescribing Information.

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AveXis, Inc.

Bannockburn, IL 60015

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# Cure SMA Announces Expanded Phase 3 of SMA Industry Collaboration

## Cure SMA Announces Expanded Phase 3 of SMA Industry Collaboration

In January, we announced the launch of an expanded Phase 3 of our SMA Industry Collaboration.

The SMA Industry Collaboration is a multi-faceted partnership that brings together pharmaceutical companies, Cure SMA, and other nonprofit organizations, to share information, ideas, and data. The SMA Industry Collaboration works together to address scientific, clinical and regulatory topics that are critical to advancing drug development in SMA and will benefit the broader SMA community.

In this third phase, three new members—Novartis, Scholar Rock, and SMA Europe—join existing partners Astellas, AveXis, Biogen, Cytokinetics, and Genentech/Roche. With this expanded structure, Cure SMA and the SMA Industry Collaboration will be able to move forward into several new areas, including clinical trial expansion in Europe.

The pharmaceutical partners in the SMA Industry Collaboration also reflect the diversity of approaches in the SMA drug pipeline. We recently released a new version of this pipeline, showing that both the total number of programs and the number of programs in clinical trials have reached record highs. We know that it will likely take a variety of these drugs, working in combination, to provide the best possible outcome for those at all ages, types, and stages of SMA.

Through the collaboration, developers of muscle drugs will work alongside developer of drugs that target the underlying genetic cause of SMA. Each partner will bring their distinct perspective to shared goals that will benefit the entire SMA community.

## Goals of Collaboration

**The goals for this next phase of the SMA Industry Collaboration include:**

- Publishing the Voice of the Patient Report and results of research on the Benefit-Risk Preferences of parents/caregivers and individuals affected with SMA - Distributed to FDA in January 2018/ Manuscript submitted for publication, October 2018
- Developing patient-reported outcome measures to ensure that SMA clinical trials are measuring the results most important to those affected by SMA - Grant Awarded to Dr. Heatwole, March 2018
- Leveraging partnerships with organizations including the American Academy of Pediatrics, American Academy of Neurology, and the National Organization for Rare Disorders, to further reduce diagnostic delays - Ongoing

- Developing a clinical trial readiness toolkit to increase access to trials by increasing the number of sites that are able to participate. - Completed and shared with trial sites May-Present
- Working directly with sites that are not currently SMA clinical trials sites, to bring them online – 10 Pilot Sites were completed by year end 2018 /Ongoing 2019
- Executing a European clinical trial capacity pilot – Completed, October 2018
- Launching SMArt Moves, a national awareness campaign targeted to both parents and health care professionals, with the goal of reducing the length of SMA “diagnostic odyssey” - Launched November 2018
- Publishing results of research on the on the economic burden of SMA, to increase understanding of the full impact of the disease – 2019
- Past milestones include:
  - Executing a Patient Focused Drug Development Meeting with the FDA
  - Writing and disseminating the SMA Voice of the Patient Report, based on the findings of the PFDD meeting.
  - Conducting and publishing the results of a benefit-risk survey.
  - Conducting an SMA diagnosis needs assessment for families and health care providers
  - Launching a webpage specifically created for parents who suspect their child may have SMA
  - Surveying existing and prospective SMA clinical trial sites to determine barriers to increased participation
  - Developing a clinical trial readiness checklist

*Collaborative industry groups like this one are a rare opportunity to advance goals important to the SMA community. We thank our industry partners for their example of “the strong sense of collaboration that is helping to bring ... therapies for SMA to patients and families,” as Dr. Jonathan Goldsmith of the FDA recently at the SMA Patient-Focused Drug Development Meeting.*



**cure**  
**SMA**

## August is SMA Awareness Month

Be sure to check back at  
[www.CureSMA.org](http://www.CureSMA.org) for the latest  
news & happenings going on  
during the month of August

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# Summit of Strength Program

The 2018 Summit of Strength Program was a great success, and the 2019 Summit of Strength Program has officially begun! Cure SMA is thrilled to continue to provide this special support program to local SMA communities throughout the United States.

The Summit of Strength is a single-day educational event hosted by Cure SMA. These conferences are crafted to provide information for people of all ages and types of SMA, and their loved ones and caregivers. Join us to network with other SMA families and learn from national and local experts about the latest advances in treatment, care, advocacy and support.

This is a free program which includes breakfast, lunch and parking for all attendees. For more info or questions please email [familysupport@curesma.org](mailto:familysupport@curesma.org).



The highly-rated 2018 Summit of Strength Program included 16 one-day mini conferences. Presenters covered over 25 topics, and the average attendance was 79 attendees. These summits were held across 15 states between July 2018 and February 2019:

- |                  |                |                 |
|------------------|----------------|-----------------|
| Cincinnati, OH   | Orlando, FL    | Chicago, IL     |
| Boston, MA       | Milwaukee, WI  | Austin, TX      |
| Little Rock, AR  | Birmingham, AL | St. Louis, MO   |
| Phoenix, AZ      | Anaheim, CA    | Raleigh, NC     |
| Philadelphia, PA | Baltimore, MA  | Santa Clara, CA |
| New York, NY     |                |                 |

Thank you to AveXis for sponsoring the 2018 Summit of Strength Program and thank you to the fantastic speakers and enthusiastic attendees.





# THE SUMMIT OF STRENGTH PROGRAM HAS CONTINUED IN 2019

The Summit of Strength Program has continued in 2019 with 20 new events added from March through November. This will bring the total number of summits to 36, held over just 16 months!

## The dates and cities for the 2019 Summit of Strength Program are:

March 2 | Dallas, TX

March 9 | Fort Lauderdale, FL

March 30 | Seattle, WA

May 4 | Grand Rapids, MI

May 11 | Milwaukee, WI

June 1 | Kansas City, MO

July 20 | Denver, CO

July 27 | Salt Lake City, UT

August 3 | Long Island, NY

August 10 | Chicago, IL

August 24 | Cincinnati, OH

August 31 | Anaheim, CA

September 7 | Philadelphia, PA

September 14 | Rochester, NY

September 21 | Minneapolis, MN

September 28 | Newark, NJ

October 5 | San Ramon, CA

October 12 | Boston, MA

October 19 | Charleston, SC

November 9 | Orlando, FL

Registration is open – Visit the Cure SMA Event Calendar at

[www.curesma.org/get-involved/event-calendar/](http://www.curesma.org/get-involved/event-calendar/)  
to register for your local Summit of Strength today!

*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 their support.*

Is there a moment, anecdote,  
or story from past conferences  
or events that has stood out in  
memory for you and your family?



We want to hear from you!



Share your experiences and  
photos with us by emailing  
[stories@cureSMA.org](mailto:stories@cureSMA.org)!

## July + August Events

SATURDAY 27 <sup>th</sup>	<b>BIRDIES FOR BLAKE GOLF OUTING</b> JULY 27, 2019   LIBERTY TOWNSHIP, OH
SUNDAY 4 <sup>th</sup>	<b>CRAB FEAST AND SILENT AUCTION</b> AUGUST 4, 2019   TOWNSON, MD
SUNDAY 4 <sup>th</sup>	<b>CURE SMA DAY WITH THE TAMPA BAY RAYS</b> AUGUST 4, 2019   TAMPA, FL
MONDAY 5 <sup>th</sup>	<b>CURE SMA DAY WITH THE CHICAGO CUBS</b> AUGUST 5, 2019   CHICAGO, IL
SUNDAY 11 <sup>th</sup>	<b>CURE SMA DAY WITH THE RED SOX</b> AUGUST 11, 2019   BOSTON, MA
SATURDAY 17 <sup>th</sup>	<b>NEW MEXICO WALK-N-ROLL</b> AUGUST 17, 2019   ALBUQUERQUE, NM
SUNDAY 18 <sup>th</sup>	<b>NEW BALANCE FALMOUTH ROAD RACE</b> AUGUST 18, 2019   FALMOUTH, MA
SUNDAY 18 <sup>th</sup>	<b>MICHIGAN TITANIUM TRIATHLON</b> AUGUST 18, 2019   GRAND RAPIDS, MI
SATURDAY 24 <sup>th</sup>	<b>NORTHERN CALIFORNIA CHAPTER WALK-N-ROLL</b> AUGUST 24, 2019   EL SOBRANTE, CA
SATURDAY 24 <sup>th</sup>	<b>CURE SMA 5K RUN/WALK</b> AUGUST 24, 2019   WAKEFIELD, MA
SATURDAY 24 <sup>th</sup>	<b>COLORADO WALK-N-ROLL</b> AUGUST 24, 2019   LITTLETON, CO
SUNDAY 25 <sup>th</sup>	<b>CURE SMA DAY WITH THE CHICAGO WHITE SOX</b> AUGUST 25, 2019   CHICAGO, IL
SUNDAY 25 <sup>th</sup>	<b>CURE SMA DAY WITH THE MILWAUKEE BREWERS</b> AUGUST 25, 2019   MILWAUKEE, WI

## September Events

SATURDAY 14 <sup>th</sup>	<b>BOSTON EVENING OF HOPE</b> SEPTEMBER 14, 2019   BOSTON, MA
SUNDAY 15 <sup>th</sup>	<b>HUMANA ROCK N' ROLL PHILADELPHIA</b> SEPTEMBER 15, 2019   PHILADELPHIA, PA
SATURDAY 21 <sup>st</sup>	<b>ATLANTA WALK-N-ROLL</b> SEPTEMBER 21, 2019   CANTON, GA
SATURDAY 21 <sup>st</sup>	<b>BEAVERDALE BEAVERDASH 5K</b> SEPTEMBER 21, 2019   DES MOINES, IA
SATURDAY 28 <sup>th</sup>	<b>EGGS WITH EVAN</b> SEPTEMBER 28, 2019   LINCOLN, RI
SATURDAY 28 <sup>th</sup>	<b>RALEIGH WALK-N-ROLL</b> SEPTEMBER 28, 2019   CARY, NC

## September Events

SUNDAY 29 <sup>th</sup>	<b>KENNADY'S DREAM WALK-N-ROLL</b> SEPTEMBER 29, 2019   BROOKFIELD, WI
SUNDAY 29 <sup>th</sup>	<b>ZANE'S RUN 5K &amp; WALK</b> SEPTEMBER 29, 2019   MALVERN, PA
SUNDAY 29 <sup>th</sup>	<b>CHICAGO HALF MARATHON &amp; 5K</b> SEPTEMBER 29, 2019   CHICAGO, IL

## October Events

SATURDAY 5 <sup>th</sup>	<b>GREATER FLORIDA WALK-N-ROLL</b> OCTOBER 5, 2019   SAFETY HARBOR, FL
SUNDAY 6 <sup>th</sup>	<b>MO' COWBELL RUN</b> OCTOBER 6, 2019   ST. CHARLES, MO
SATURDAY 12 <sup>th</sup>	<b>CHARLOTTE WALK-N-ROLL</b> OCTOBER 12, 2019   CHARLOTTE, NC
SATURDAY 12 <sup>th</sup>	<b>LUKIE'S FALL FESTIVAL</b> OCTOBER 12, 2019   PEN ARGYL, PA
SUNDAY 13 <sup>th</sup>	<b>NASHVILLE WALK-N-ROLL</b> OCTOBER 13, 2019   NASHVILLE, TN
SATURDAY 19 <sup>th</sup>	<b>VIRGINIA WALK-N-ROLL</b> OCTOBER 19, 2019   WOODBRIDGE, VA
SATURDAY 19 <sup>th</sup>	<b>BALTIMORE RUNNING FESTIVAL</b> OCTOBER 19, 2019   BALTIMORE, MD

## November Events

SUNDAY 3 <sup>rd</sup>	<b>SAN DIEGO WALK-N-ROLL</b> NOVEMBER 3, 2019   SAN DIEGO, CA
SUNDAY 3 <sup>rd</sup>	<b>ALLSTATE HOT CHOCOLATE 15K/5K</b> NOVEMBER 3, 2019   CHICAGO, IL
SUNDAY 3 <sup>rd</sup>	<b>DISNEY WINE &amp; DINE HALF MARATHON</b> NOVEMBER 3, 2019   ORLANDO, FL
SUNDAY 3 <sup>rd</sup>	<b>TCS NEW YORK CITY MARATHON</b> NOVEMBER 3, 2019   NEW YORK, NY
SATURDAY 9 <sup>th</sup>	<b>CNO FINANCIAL INDIANAPOLIS MONUMENTAL MARATHON</b> NOVEMBER 9, 2019   INDIANAPOLIS, IN
THURSDAY 14 <sup>th</sup>	<b>DALLAS EVENING OF HOPE</b> NOVEMBER 14, 2019   DALLAS, TX
SATURDAY 23 <sup>rd</sup>	<b>PHILADELPHIA MARATHON</b> NOVEMBER 23, 2019   PHILADELPHIA, PA



*SAVE THE DATE*



**NATIONAL DISABILITY EMPLOYMENT  
AWARENESS MONTH  
IS IN OCTOBER!**

Cure SMA will be participating in NDEAM activities all month long. NDEAM is a fantastic opportunity to learn about the experiences of adults living with SMA, as they navigate the successes and challenges of job searches and career paths. SMA can take away the ability to walk, eat, or breathe but thanks to new treatments and better standard of care, people with SMA are living longer and stronger. Cure SMA understands the need for more information, services and support for adults living with SMA.

Cure SMA hosted its first NDEAM webinar on October 2018. Four panelists who live with SMA shared their career journey and experiences.

Are you interested in sharing your story during NDEAM? Email us at [stories@curesma.org](mailto:stories@curesma.org)!

# Recognize the symptoms and save a life!



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](https://www.SMArtMoves.CureSMA.org)



# Friday

June 28th, 2019

# TO Monday

July 1st, 2019

# **cure** 2019 ANNUAL **SMA** SMA CONFERENCE

DISNEYLAND HOTEL IN ANAHEIM, CALIFORNIA

Every year since 1988, Cure SMA has hosted a conference to bring together the leading SMA researchers, clinicians, and families living with the disease. The Annual SMA Conference is the largest in the world for those affected by SMA, as well as for those involved in providing support and care for SMA patients. 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 & greet with a family fun fest, teen and adult social activities, Cure SMA Evening in the Park, as well as many opportunities to connect and interact with families and receive first hand updates from the researchers. The conference is an excellent time to reunite as a community and show our support for others.

As always, the Family, Research, and Clinical Care Conferences run alongside each other. 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 affected individuals and children an opportunity to make new friends and have a great time. Over 2,000 people registered for this year's conference at Disneyland Hotel in Anaheim, CA.

## SMA CONFERENCE GOALS

- 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.

To learn more about the Annual SMA Conference, please visit [www.curesma.org](http://www.curesma.org)

# cure SMA 3RD ANNUAL CLINICAL CARE MEETING

As FDA-approved treatments extend the lives of those with SMA, care has become even more important. Goals of the Clinical Care Meeting include promoting interactions between new clinicians and leaders in clinical care, facilitating collaborative discussions between healthcare providers, and encouraging conversations between families and patients living with SMA, clinicians, researchers and industry partners.



## EXHIBITOR OPPORTUNITIES

The Annual SMA Conference is a wonderful opportunity to promote your company and products to SMA families.

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. 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)

## WANT TO GET INVOLVED IN CONFERENCE?

Each year, Cure SMA provides scholarships to help waive the registration fee costs to attend the conference. The Newly Diagnosed Conference scholarship program is generously funded by the Erin Trainor Memorial Fund and is for all families recently diagnosed since the previous year's conference. The scholarship covers up to 4 family members' registration fees as well as one hotel room for 3 nights of the Annual SMA Conference. This program is automatically offered to all newly diagnosed families that contact Cure SMA. General Conference Scholarships are also available to those who are not newly diagnosed.

# cure SMA 24TH ANNUAL RESEARCHER MEETING

The SMA Researcher Meeting is the largest research meeting in the world specifically focused on SMA, with the goal of creating open communication of early, unpublished scientific data, accelerating the pace of research. The meeting also builds productive collaborations—including cross-disciplinary dialogue, partnerships, integration of new researchers and drug companies, and educational opportunities for junior researchers.



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

# 2019 National Partners

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

## National Premier Partners



**Biogen**

**Genentech**  
*A Member of the Roche Group*

## National Platinum Partners



National Gold Partners



National Silver Partner



Resources and Communications Partners





# SMA Newborn Screening Advancements

Thanks to the dedicated advocacy of our community, Cure SMA has been at the forefront of federal and state-level work for newborn screening. Cure SMA is also providing states with grants to help cover start-up costs for SMA screening.

## Statewide Screening Updates

There are eleven more states with updates on newborn screening for SMA. The SMA community started 2019 with Missouri beginning statewide screening for SMA in January 2019. Rhode Island adopted SMA newborn screening in January 2019. They estimate that screening will begin in a year. Pennsylvania began statewide screening for SMA in March 2019. Arkansas passed legislation to add SMA to their newborn screening panel. Nebraska adopted SMA newborn screening in March 2019. Florida's Genetics and Newborn Screening Advisory Council voted unanimously to add SMA to their state newborn screening panel. We expect Florida to start statewide newborn screening for SMA in May 2020. Oklahoma adopted SMA to their screening panel through a rule change this spring. There is currently no timeline for when SMA newborn screening will begin. Tennessee also adopted SMA this spring to their newborn screening panel and is expected to begin screening in March 2020. Iowa's Center for Congenital and Inherited Disorders Advisory Committee met this April and approved to conduct a pilot for SMA newborn screening. This is the next step in the process before Iowa can permanently implement SMA to their newborn screening panel. There are currently no details on the pilot or when it will begin. In Maine, the Advisory Committee voted to adopt SMA newborn screening in May.

Last but not least, Vermont began statewide screening this May after adopting a proposed regulation to get SMA added to the newborn screening panel.

As of May 2019, over half the states have acted to get add SMA to their newborn screening panels. There are currently six states that are now permanently screening statewide for SMA, four states running SMA screening pilots, and sixteen states that have adopted but not yet implemented newborn screening for SMA.

## Valentine's Day Advocacy Initiative to Support the Newborn Screening Saves Lives Reauthorization Act

Advocates for SMA showed their love for the Newborn Screening Saves Lives Reauthorization Act in February. The SMA community created over 169 Valentine's cards and 78 e-Valentine's that were sent to Capitol Hill. Members of Congress and their staff were thrilled to receive heartfelt and meaningful advocacy cards.





We expect the Newborn Screening Saves Lives Reauthorization Act to be reintroduced to Congress by Representative Lucille Roybal-Allard (D-CA) this spring. In order to give SMA patients the very best treatment, we need to diagnose the condition as soon as possible, which may be long before they start showing symptoms. Newborn screening is the most efficient and effective way to do this. This legislation will renew federal programs and funding to help enhance and improve each of the states newborn screening programs. The Newborn Screening Saves Lives Reauthorization Act is imperative to newborns nationwide.

## How to be an SMA Advocate Webinar

On Wednesday, February 20th Cure SMA's Policy and Advocacy team hosted a webinar to update the SMA community on current advocacy priorities. Advocacy can be confusing and intimidating, but it is critical to making sure that policymakers hear the voice of the SMA Community. Topics covered included:

- Newborn screening and the federal Newborn Screening Saves Lives Reauthorization Act
- Current advocacy priorities
- How to be an effective advocate
- Tips on how to successfully navigate today's political climate as an SMA advocate

**Missed the webinar? Watch it on the Cure SMA YouTube channel.**

## Rare Disease Day on Capitol Hill

The 12th International Rare Disease Day was celebrated on February 28th, 2019. Organizations from across the globe, including Cure SMA, recognize this day as an opportunity to raise awareness of and support for all those affected by rare disease. The theme for Rare Disease Day was 'Bridging Health and Social Care'.

SMA advocates joined other rare disease organizations in the biggest rare disease week ever on Capitol Hill! SMA Adults and families met with their local representatives in Congress to raise awareness of rare diseases and ask for legislators' support for federal newborn screening legislation and increased funding for biomedical research.

**Thank you everyone who continues to advocate for the SMA community in the federal and local level. Our collective voice will continue to create progress in the SMA community. Email [advocacy@curesma.org](mailto:advocacy@curesma.org) to get involved today.**



## Community Spotlight: Amber Bosselman

Amber Bosselman is your typical 24-year-old college senior. She is currently studying Psychology in Idaho and planning to get her master's degree in Industrial Organizational Psychology. Amber's life is similar to that of other students, except she was born with a rare disease called Spinal Muscular Atrophy (SMA).



SMA is a disease that robs people of strength by affecting the motor nerve cells in the spinal cord. "My diagnosis story is probably typical for people with SMA," Amber began. "I was 15 months old and I wasn't meeting the normal benchmarks that a baby was supposed to meet. Twenty-three years ago, most doctors didn't know what SMA was or how to diagnose it. 'Just take her home and love her' doctors would say, but they tried to do their best." Amber reflected.

Amber was born and raised in Wyoming and is the youngest of four children. She believes having a tight-knit family is important to navigating SMA – her family provides a strong support system for her. SMA is the number one genetic cause of death for infants under two years of age. Despite the odds, Amber maintained her strength for a long time. "I have an excellent team of doctors, but it's always a battle of defying the odds," she sighed.

Nonetheless, SMA hasn't stopped Amber from living her best life. Growing up, Amber was never ashamed of her disability, but she wasn't very confident. "People saw the wheelchair and not me. When I got older, I saw the wheelchair

as a part of me. I saw SMA as a part of me that has shaped me for the better," she said. Amber is a resilient, kind, and non-judgmental person. Once Amber made a shift in her approach and embraced her disability, she began to "live a fuller life."

Amber considers herself lucky. "I'm pretty independent for a young adult with SMA," Amber emphasized. SMA doesn't prevent her from going out with friends and living independently. Amber's positivity seems to come from her





parents' optimistic belief of "we try until we fail." Amber loves to sing, paint with water colors, and read books. "I'm currently reading 'The Best Place to Work' but I also enjoy reading science fiction and historical fiction," Amber replied.

Amber recalls going to her first Cure SMA conference in sunny Florida. "It was a pivotal experience for me," Amber began.

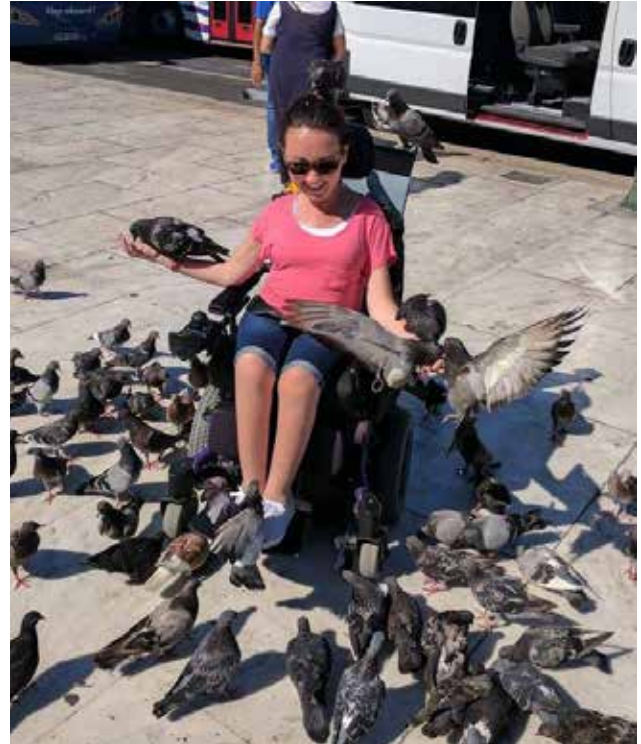
"I learned to embrace my disability. Conference played a strong role. There are not that many people living in Wyoming with a disability, much less SMA." Amber treasures the lifelong friendships she formed at the Conference. She regularly visits with Sandy, who was in her early 50's when they met at the Conference. Amber introduced Sandy to her mom "My mom broke into tears at seeing someone so strong and healthy at her age."



Amber is currently receiving treatment for SMA. "My legs feel stronger; there's more muscle tone. I'm seeing positive results in a short time, yet I'm cautiously optimistic," declared Amber. Her optimism and positivity were clear throughout our conversation. "There's so much hope in the community," Amber said. Sandy is an independent business woman and role model to Amber. The Annual Cure SMA Conference provides

adults and families with the opportunity to meet other people living with SMA. Although SMA is a rare disease, Amber believes that "being part of the SMA community means total acceptance and friends and support in the moments that you need it most."

Amber is excited for the future. "In five to ten years down the road, I envision myself still living independently, renting my own apartment, having been finished with my master's degree, and placed in a job where I begin to give back to the community. I take it very seriously and I'm anxious to give back to the community."



# Community Spotlight: Kyle & Laura Derkowski

Kyle and Laura Derkowski live in Ashburn, Virginia and are co-chairs of the Cure SMA Virginia Chapter. Kyle is originally from Schenectady, New York and Laura from Bethlehem, Pennsylvania; the pair met during their first year in college through a mutual friend and were married in December 2014. The Derkowskis recently shared with Cure SMA their perspective on hope, community and leadership.

At 18 months old, Kyle was diagnosed with spinal muscular atrophy (SMA) type 2. "Throughout my childhood, in the absence of medicine, the only treatment was hope. That hope was found within the SMA community," Kyle said.

He first got involved with Cure SMA back when it was called Families of SMA. "It is a really special community. SMA is such a rare disease but it is a disease that affects people in same ways. We all have similar stories and symptoms, so the best way to adapt is to come together and share information."

SMA is a rare disease; Kyle recalls that little was known about it when he was young. Many medical professionals didn't know what SMA was or had the resources to make the best recommendations for their patients. As a child, Kyle says his family relied on the booklets and pamphlets from Cure SMA to help medical staff understand his needs and to ensure he received the best care. "It's a scary thing to go to a doctor that knows less about your disease than you do. Being able to point them to a place with expert knowledge and advice would be an incredible relief."

Today, Kyle works as a Software Engineer at the Department of Defense. He graduated with his bachelor's degree in computer science and communications from the College of St. Rose and obtained his master's degree in information technology from Rensselaer Polytechnic Institute.

In 2014, Laura attended her first Annual SMA conference with Kyle. "I absolutely loved all of the SMA families and how they come together to support one another. We are so grateful to know them," Laura said.

Kyle reflects on how his role has changed in the SMA community. "Attending [conference] as an adult, made me realize that I could be a positive example for those who were younger than me. When I was a kid I had a couple people with SMA that I looked up to and it gave me a lot of hope. I thought it was my duty to offer a similar example to others," he said.

Since then, Kyle and Laura started the Cure SMA Virginia Chapter. "We were both happy to volunteer. Since the chapter began in 2015, we have held four Walk-n-Roll events and raised nearly \$100,000. We love watching the Walk-n-Roll teams return every year and seeing new teams form, growing the community of families and volunteers."

This year, the Virginia Chapter is hosting the 5th annual Virginia Walk-n-Roll on October 19th and the Inaugural Virginia Evening of Hope on June 13th at the Winery at Bull Run in Centreville, Virginia.

When asked what he would tell his younger self, Kyle said "I would tell myself that all the years of hope will be realized, a treatment will be discovered in my lifetime and someday you are going to meet an amazing girl to share your life with. Also, invest in Google."



Staying hopeful and having a strong support system also inspires Kyle, "The thing I'm most proud of is never truly despairing, even in the darkest of times."

In closing, Kyle shares his advice to youth and other adults in the SMA community: "Don't limit your dreams to what other people tell you that you can or can't do. One of the benefits to having SMA is that you have to develop creativity just to survive. Use every ounce of that creativity to figure out how to do what you want to do and don't give up until you achieve your goals. Always stay positive. Don't waste a second feeling sorry for yourself, you'll only realize your situation is exactly the same as when you started. It is also important to be realistic (I eventually had to give up on my dream of being a running back for the New York Giants) but there are plenty of careers that only require a sharp mind and a strong work ethic. Figure out where your passion intersects with your gifts and go after it. The world has never been more accessible."

The Derkowskis plan to continue turning their passion into action and helping all people affected by SMA.

If you are passionate about helping all people affected by SMA through our SMA Care Center Network, support package programs, equipment pools, information packets, and other care and support services, visit [www.CureSMA.org](http://www.CureSMA.org) to make a donation. Your support will have an immediate impact in the SMA community!



## 8th Annual “Hope on the Hill” Congressional Dinner Raises \$200,000

The 8th Annual “Hope on the Hill” Congressional Dinner was held on Tuesday, November 27, 2018 at The Willard Hotel in Washington, DC. More than 170 people from the SMA community – including government and industry partners – attended the dinner which raised \$200,000 to fund advocacy efforts, research, and family support services. Since 2011, the “Hope on the Hill” Congressional Dinner has raised over \$1.2M for Cure SMA.

The evening included remarks from event co-chairs, Greg and Shannon Zerzan, Cure SMA President, Kenneth Hobby, and from keynote speaker, Walter Robb, Principal, Stonewall Robb Advisors & former Co-CEO of Whole Foods Market. Walter spoke about his personal connection to SMA and about his hope for the future,

We were pleased to have Congressman Kevin Yoder from Kansas and Senator Debbie Stabenow from Michigan join us for the event. Senator Stabenow has long been an advocate for the rare disease community. She supported legislation to create new innovative research opportunities at the National Institutes of Health, and to increase access to clinical trials.



Cure SMA remains focused on educating and engaging all groups in our community: families affected by SMA, governmental and regulatory groups, insurance and payers, and the biotech and pharmaceutical companies that are developing and testing SMA drugs. It is more important now than ever to make certain that regulators, payers, and industry partners understand the impact of SMA.

*Special thanks to our generous sponsors and event attendees for making this event possible. For information about the 2019 “Hope on the Hill” Congressional Dinner, please reach out to Erin Kelly at [erin@curesma.org](mailto:erin@curesma.org)*

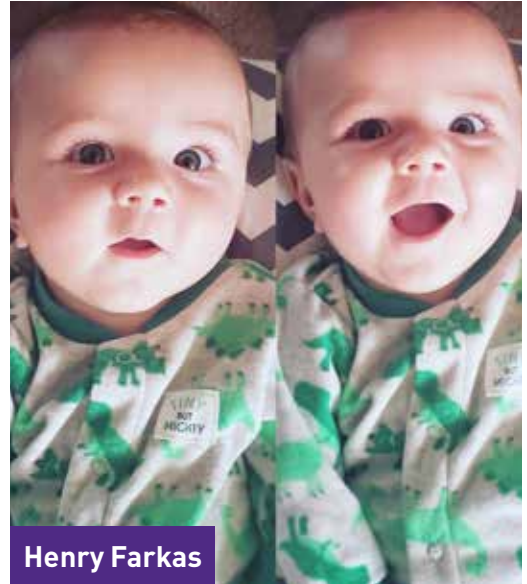
# Sharing Photos



Assim Mehila



Christopher Pantier



Henry Farkas



Max Lasko



Dima Hameed



Mia Browning



Emilano Giordano



Lincoln DellaMaggiora

# Sharing Photos



Winnie Stanley



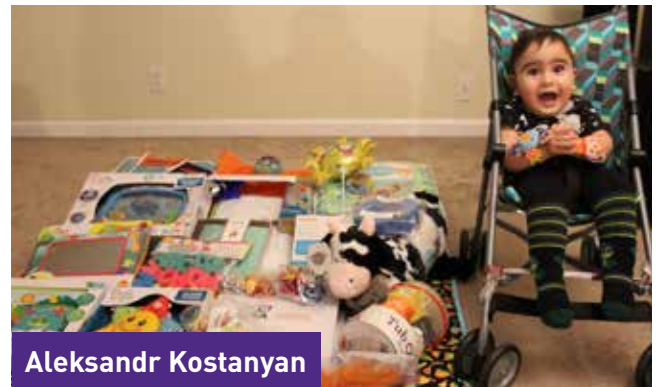
Alexandria Barker



Porter Larsen



Ella Schnell



Aleksandr Kostanyan



Yana Sobashko



Tori Haws



Pantier Family



Theo Roggenburg



# Care Packages



Thank you to Kathy Phillips for donating these adorable blankets to the care package program in honor of her grandson, Colin Watson!



These beautiful handmade blankets have been generously donated in honor of Charlotte Metter.



A big thank you to the Adams family for their fantastic donation of Infantino tub toys and Smarty Phonebook toys in honor of Ava Adams!



Thank you so much to Holly Sontag for donating these wonderful books to the care package program in honor of her daughter, Mila Thomas.

# CURE SMA FAMILY SUPPORT APP IS NOW AVAILABLE FOR YOUR MOBILE DEVICE!



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!

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



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



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

**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.**

# In Memoriam

Mailee Rose | March 26, 2013 - March 9, 2018

## Always And Forever Loving Memories Of You Til We Hold You Again

"let the little children come to me.  
And he took them up in His arms,  
put His hands on them and blessed them." Mark 10:14 – 16

*Beyond the clouds and stars above...You sent to us a Higher Love...  
Her smiled filled with sunshine bright...Her heart of the purest light...  
All the Love you sent to us, was more than just a dream...  
God's precious little Angel, above all means...*

## Mailee Rose

*We look up in the sky at night, to find your shining star...  
To give us peace and comfort, to remind us your not to far...  
Baby Girl, you're in Heaven now, with Jesus by your side...  
He tells us all to keep our faith; and always to abide...  
Prayers flowing up for mommy...Asking Jesus to carry her each day...  
He is the only one who knows her pain, as He wipes her tears away...  
She knows how much He loves her, and He knows her heart so dear...  
He lets her know His love and all her prayers He hears...  
We'll always miss your touch and how you feel to hold...  
We hope you're singing praises, where the streets are paved in Gold...  
With everyday that passes by... Memories of you we keep alive...  
Beyond the clouds and stars above... You sent to us a Higher Love...  
Her smile filled with sunshine bright... Her heart of the purest light...  
All the Love you sent to us, was more than just a dream...  
God's precious little Angel, above all means...*

Love,  
Nanna



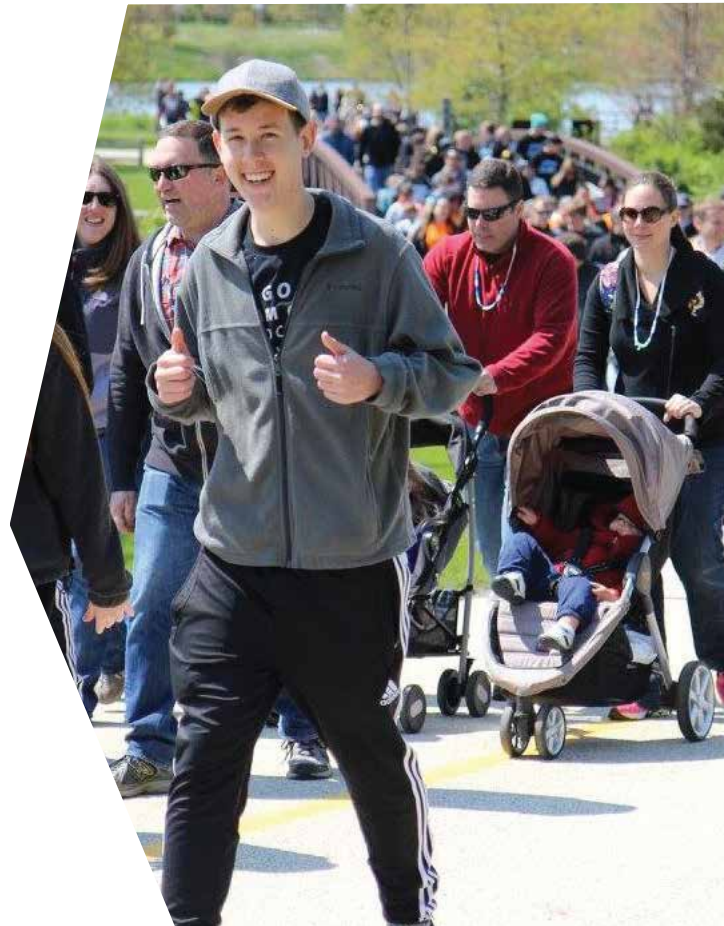


# GET INVOLVED WITH YOUR LOCAL CHAPTER

**Cure SMA has 34 volunteer chapters throughout the United States.**

Our chapters provide support for affected families and adults 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 <http://www.curesma.org/get-involved> to find your local chapter.



## Family Letters



Cure SMA,  
We received the box of toys and gifts from the parents in memory of their babies, each toy will be loved and their memories will live on.

**With gratitude,**  
**Kristina, Matthew, and Sophia Kleeh**



Dear Cure SMA:  
We are beyond thankful for the very generous gifts. Ella is very happy and I can't thank you enough! From the bottom of my heart, I thank you and the SMA organization!

**Thank you,**  
**Mary Schnell**



To Cure SMA:  
I am happy to see my son, Jason, smile when he received the care package. He was so excited to see so many bright and colorful things to use. I am really grateful for all of the support from each of you. The information packet is a great guide to help me understand more about SMA.

Thank you once again for all your support

**Thank you,**  
**Guzman Family**



Thank you CURE SMA for the care package, we loved it. Thank you for everything.

**Thanks,  
The Dedic Family**



Dear Friends from Cure SMA,

We received the care package; my son Aleksandr and our family really enjoy this care package. We are so thankful to you for all your help.

**All my best,  
The Kostanyan Family**

Cure SMA,  
We received our care package and information packet – Thank you so much!!! We feel so fortunate to have an amazing organization ties to this disease. We appreciate all of the support.

**Thank you,  
Melissa Gutridge**

Dear Cure SMA,  
We have received our packets. Thank you so much. We truly appreciate all the information and Jackson loved the toys.

Thank you for your kindness and support.

**Thank you,  
Kathy Fulkerson** *(Grandmother of Jackson Schultheis)*

**Good afternoon,**

Our family would like to thank you for such an amazing package. Mehkai was so excited to open his toys. We really appreciate all the information you sent as well. We want to wish the whole organization a wonderful holiday.

**Thank you,  
The Rodriguez Family**



Cure SMA,

I really can't express how much the package meant to us, knowing that other people care and wanted to support him made us all cry. I can't tell you enough how much it meant. Personally, I have never been so moved by a kind act of stranger who wanted to comfort Porter.

He has loved playing with all the toys and the care package couldn't have come at a better time.

**Thank you,  
The Larsen Family**

Cure SMA,

We received Phoenix's care package and it was so much more than we had ever even imagined! We actually assumed it was the car bed and put it in the closet until we had time to get it set up and then realized it was the care package when the actual car bed came in. We are so beyond grateful for everything these families have donated! Not only is Phoenix super happy with everything she received, but so is her big brother! Thank you so much! To both the Cure SMA team and to the SMA families that have raised the funds for these donations! There were so many great items that we're very excited to enjoy with her and I loved seeing the beautiful faces of other SMA stars!



**Thank you,  
Dorothy Hunt**

To Cure SMA:

Thank you all so much for the unbelievably thoughtful care package! It was really the sweetest thing ever :) It brought a huge smile to my son's face (and to his older brother too!). The handmade blanket is something we will cherish a long time to come.

I can't say thank you enough.

**Warmest regards,  
Sabrina Singh Uppal**



Cure SMA,

Thank you so much for the incredible care package! It was a ray of light during this difficult time. Christopher dug in right away! My family and I are so grateful for your organization.

**Thank you again,  
Ashley Pantier**

Hi Cure SMA,

We received the care package. Yana really likes the stickers collection and coloring pad. Thank you so much for sending the package and your support.

**Kind regards,  
Nataliia Sobashko**

Everyone at Cure SMA,

Thank you so much for the care package and all the toys! I can't wait for Peyton to play with them! They will help her so much with her physical therapy!

**Thanks so much!  
Danielle Finizio**

# 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)



# Join us for a Cure SMA Walk-n-Roll



The Cure SMA Walk-n-Roll is a fun, family friendly event that supports Cure SMA's mission of driving breakthroughs in treatment and care and providing families the support they need for today. We welcome you to join us as an individual or start a team with your family, friends, co-workers, and neighbors.

The Walk-n-Roll is a fun filled day celebrating the strength of the SMA community. By supporting a Walk-n-Roll and raising money, you will help fund programs that will continue to change the course of SMA for everyone affected – from infants to adults – and eventually lead to a cure.

## WANT TO JOIN US AT OUR NEXT EVENT?



Visit [events.curesma.org/WalknRoll](https://events.curesma.org/WalknRoll)  
to find an event near you!



## Chapter Highlights

### 2018 Arizona Walk-n-Roll

#### Arizona Chapter

The 13th Annual Arizona Walk-n-Roll was held on November 10, 2018, at Steele Indian School Park in Phoenix, AZ. Teams of families and friends, sponsors, and vendors came out to make the day a huge success. This year's event raised **\$23,083** in support of a cure for SMA. Participants enjoyed various activities, games, and an amazing raffle. A special thank you to the volunteers that came out to the event. A huge thank you to Angel Wolff and her committee for another wonderful walk in Arizona!



#### Arkansas Chapter

### 2018 Turkey Trot Booth

On October 12, 2018, Cure SMA was represented by a booth at the Turkey Trot Festival in Yellville, AR. The booth included a raffle that raised over \$285 for Cure SMA! Thank you to Lisa May for raising funds and spreading awareness in memory of her grandson, Cason Bauss, and Ember and Solara Hinson.

*Note: The amounts raised and shown are totals as of February 12, 2019 and may differ from current fundraising totals by the time you get this newsletter.*

## Carolinas Chapter



### 2018 Charlotte Walk-n-Roll

North Carolina

The inaugural Charlotte Walk-n-Roll took place on October 6, 2018, at Reedy Creek Park in Charlotte, NC. The morning included a catered breakfast, pumpkin painting, live music, and family fun. This first-year walk raised **\$36,196** for Cure SMA! Thank you to the amazing planning committee, Anne and Mark Davis, Holly Bolton, Eleanor Bolton, Lauren Evans, Lindsey Quinn, Lindsay Salamon, and Ann Lundsford, for all their hard work.



### 2018 Raleigh Walk-n-Roll

The 6th Annual Raleigh Walk-n-Roll occurred on September 29, 2018, once again at the beautiful Anderson Point Park in Raleigh, NC. This event raised **\$21,432** for Cure SMA! It was a great day for friends and families to come together to celebrate the SMA community. There was a catered lunch by PDQ, DJ, games, and a symbolic walk around the park. Thank you to the hard-working planning committee, Jennifer Lee, Marla Kasper, Amy Hoke, Carrie Ann Boles, Remona Sandridge, Rebekka Mastin, Kristen Bathe, and Abby Quinn.



### 2019 Hayes' Heroes Evening of Hope

South Carolina

The 4th Annual Hayes' Heroes Evening of Hope was a wonderful evening held on February 24, 2019, at a new location, the Country Club of Lexington, in Lexington, SC. Guests enjoyed a fun evening with a large silent auction, live auction hosted by award winning journalist, Brandon Taylor, a wine pull, live music by the Jumpstart Band, great food, and dancing. This event raised its highest total yet, at **\$33,232** and counting! A huge thank you to the amazing planning committee, Keri Johnson, Kathy Cooper, Kari Taylor, Jamie Wingard, Dawn Hyatt, and Joyce Sireno. This event would not be possible without their hard work and dedication every year.

### 2018 Cure SMA Mistletoe Jam

Families and friends joined together for the 7th Annual Mistletoe Jam at the Southside Smokehouse and Grille in Landrum, SC, on December 7, 2018. This is always a fun night filled with live music by local bands all while raising money for Cure SMA in honor of Alexandra Genovese. This year's event raised **\$6,245** for Cure SMA! Thank you to Chris Genovese and Don McInerney for hosting this event year after year!

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Northern California Chapter



**Vineyard Christian Middle School Game-a-Thon**

The Vineyard Christian Middle School in Woodbridge, CA, hosted a game-a-thon in honor of Harper Hale on November 2, 2018, raising \$8,000 for Cure SMA! Thank you to Karen Hale and Jammie Morton for planning this special fundraiser!



**August is SMA Awareness Month**

Be sure to check back at [www.CureSMA.org](http://www.CureSMA.org) for the latest news & happenings going on during the month of August

925 Busse Road, Elk Grove Village, IL 60007 • 800.886.1762 • Fax 847.367.7623 • [info@curesma.org](mailto:info@curesma.org)



**Our Lovely Angels Inaugural Crab Feed**

Our Lovely Angels hosted the inaugural Crab Feed in Stockton, CA, on February 22, 2019. They raised \$3,600 for Cure SMA, in memory of Jessica and Jaylin Gayle. Due to the great turn out, planning has already started for next year's event! Thank you to Gloria Lopez and Priscilla Gutierrez for hosting this special fundraiser!

*Note: The amounts raised and shown are totals as of February 12, 2019 and may differ from current fundraising totals by the time you get this newsletter.*

## In Loving Memory of Chapter Leader, Dick Wolff

We remember the life of Richard Wolff, devoted Cure SMA volunteer and grandfather to Madison Wolff. Dick will be remembered for his dedication and amazing support of the Northern California Chapter Walk-n-Roll the past 10+ years. He was instrumental in the details and organization of the walk for many years. He kept the Northern California Family List updated, edited the Faces of SMA newsletter, and was the detail person, along with his wife, Pat. Dick passed away during the night on Thursday, October 11. Dick and his family will always be in our hearts at Cure SMA!



# Thank You to Our Volunteers

Each year, Cure SMA puts on over 300 local events, the Annual SMA Conference, and sends out hundreds of care packages and other resources. Without our wonderful volunteers, the success of these events would not be possible. Volunteering empowers people to find their purpose, to take their passion and turn it into meaningful change. Thank you to all of our chapter leaders, event organizers and families for their hard work and dedication to Cure SMA. **We truly couldn't do it without you!**

*Note: The amounts raised and shown are totals as of February 12, 2019 and may differ from current fundraising totals by the time you get this newsletter.*

## Southern California Chapter



## 2018 San Diego Walk-n-Roll

The inaugural San Diego Walk-n-Roll took place on November 4, 2018, at spacious Liberty Station NTC Park. Over 150 participants and 18 teams gathered together to raise **\$14,956!** The day included arts and crafts, an awesome face painter, a visit from the Naked Juice Food Truck and a 2 mile walk around beautiful, NTC Park. Cure SMA is looking forward to next year's event on November 3, 2019!

Thank you to our sponsors Mobility Works and Home Advisor. Also, a huge thank you to our event organizers, Autumn and Rickk Montoya and Brittany and Michael Sattari, we couldn't have done it without you!

## Ruby's Diner

Thank you, Lynn De Blasio, for hosting another successful Dine & Donate event at Ruby's Diner, in memory of Jamie Ramsey on November 14, 2018. This event raised \$1,234, all of which was donated to Cure SMA!

## Kendra Scott

On November 29, 2018, Nikki McIntosh held a Kendra Scott Gives Back party in Newport Beach, CA. Thank you, Nikki, for hosting this event and donating \$540 of the proceeds to Cure SMA!

## Remembering Alexandra Nina Meigs' 11th Birthday

On October 24, 2018, the Meigs Family from Los Angeles, CA, remembered the life of their beautiful daughter Alexandra and celebrated her 11th birthday. While they miss her dearly, they continue to honor her memory by contributing to Cure SMA on her birthday each year – determined to help find a cure for this terrible disease that took her life too soon.

Since Alexandra passed in 2008, Andrea and John have raised over **\$135,000** for Cure SMA. They thank their family and friends for the tremendous support given so generously to them, both emotionally and financially! This year, in their fundraising, they shared a video clip of one of Alexandra's final days with us on earth. The response was incredible, and they were able to raise **\$20,860** this year alone for Alexandra's 11th birthday!

The Meigs' Family wants to say thank you from the bottom of their hearts for remembering Alexandra's birthday. They hope that everyone will continue to support the great work of Cure SMA and hope that, one day, there will be a cure, so no baby will suffer from this disease like Alexandra.

- John and Andrea Meigs



*Note: The amounts raised and shown are totals as of February 12, 2019 and may differ from current fundraising totals by the time you get this newsletter.*

## Chesapeake Chapter



## 2018 Our Little Jewels Golf Tournament

Maryland

On September 21, 2018, Jimmy Lewis held the Our Little Jewels Golf Outing at The Links at Challedon in Mt. Airy, MD. The organization donated \$2,500 of the golf tournament funds to help fund critical research for the SMA community. Our Little Jewels is led by Jimmy Lewis, in honor of his grandson, Julian Lewis, who is affected by SMA. Thank you to Jimmy and the Our Little Jewels generous supporters for their continued support of Cure SMA and the Chesapeake Chapter!

## Steamboat Landing Bingo Fundraiser

Thank you to Steamboat Landing Camp Ground in Milton, DE, for hosting another successful bingo fundraiser on August 11, 2018. Cure SMA is grateful to the owners of Steamboat Landing, Rusty and Linda Pride and the Calvert Family for organizing this event and raising \$1,400 in honor of Olivia Calvert.



## 3rd Annual Cookout in Memory of Owen

The 3rd Annual Cookout in loving memory of Owen Jonas Close was held on August 11, 2018, in Accident, MD. Those who attended gathered for a candle lighting ceremony in memory of Owen and all of those affected by SMA. Thank you to Ashley Close for hosting the party during SMA Awareness Month and raising over \$1,300 for Cure SMA.



## 22nd Annual Arnold Family Golf Outing

West Virginia

On October 8, 2018, the Arnold Family Golf Outing celebrated its 22nd year! Thank you to Linda, Kevin, and Eric Arnold for their unwavering support and continuing to organize this event at The Berry Hills Country Club in Charleston, WV. This year's golf outing was one of their most successful years, raising **\$12,000** for Cure SMA.

*Note: The amounts raised and shown are totals as of February 12, 2019 and may differ from current fundraising totals by the time you get this newsletter.*

## Connecticut Chapter



## Craft for a Cause

On February 2, 2018, Connecticut Chapter member, Yvette Haas, invited family and friends to “Craft for a Cause.” It was an enjoyable afternoon of creating one-of-a-kind valentines. Together, they wrote 26 cards to Congress in support of newborn screening and raised \$150 for Cure SMA!

The proceeds of her event will support the Connecticut Walk-n-Roll this spring. Thank you to Yvette and her community for supporting advocacy efforts while fundraising for Cure SMA!

## Georgia Chapter

## Erin’s Muscle Hustle Walk

On December 1, 2018, Erin Allen hosted Erin’s Muscle Hustle Walk in Evans, GA, for her senior project to bring awareness to SMA. People who formed teams and reached their goal received an event t-shirt. The day of the walk, participants ran laps around the school gym and collected beads every time they finished a lap. The people with the most beads received a prize. With the help of her friends, family, and classmates, she raised over \$5,000 for Cure SMA!



## 2018 Atlanta Walk-n-Roll

The inaugural Atlanta Walk-n-Roll was held on October 27, 2018, at Etowah River Park in Canton, GA, and was a huge success! Over 90 participants and six teams joined this year. Together they raised more than \$13,500 for Cure SMA! A special thank you to the event organizers, Tara Ragan and Valerie White, for their continued dedication to making this an awesome first event in this area.

Thank you to the amazing teams for their fundraising this year: Believe for Brooklyn, Caleb’s Crew, Lehmann’s, Team David, Team Henry, and Team Mikaela. Next year’s event will take place on September 21, 2019, at Etowah River Park in Canton!

## Greater Florida Chapter



## 18th Annual Costume Crusade

The Village Early Learning Center in Brandon, FL, hosted the 18th Annual Costume Crusade on October 25, 2018, where over 175 families participated, dressing up and parading around in costume. Costume Crusade began with a gift basket fund-raiser that ran for two weeks. Costume Crusade culminates in a wheelchair race, costume parade, carnival style games, and silent auction, with the winners of the baskets and the silent auction announced at the close of the event. The event raised \$3,800 for Cure SMA. Thank you to Susan and Joe Miller for creating this great event.

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## 2018 Greater Florida Chapter Walk-n-Roll

The 10th Annual Greater Florida Chapter Walk-n-Roll, presented by the Outback Bowl, was held on November 17, 2018, at Fort Desoto State Park in St. Petersburg, FL, and was a huge success! Over 170 participants and 15 teams joined this year for a beautiful walk along the coast, family-friendly activities such as, a craft corner, tattoos, and strolling magician, while celebrating how well they fundraised for a cure. A raffle was the highlight with the big prizes being a one-night stay at the Don Cesar Hotel and tickets for four people to Busch Gardens. Lunch was generously donated by PDQ.

Together, the sponsors and teams raised more than **\$23,000** for Cure SMA! A special thank you to the event organizer, Katie Kerns, and the committee for all their hard work and dedication.

Thank you to all the outstanding teams for their fundraising this year: Allison Wonderland, Amiya's Circle, Andy's Army, Arms for Asher, Brooks Wolfe Pack, Emma's Entourage, House of K, Jaceys Journey, Joey Strong, Joie's Cure Crew, Muscle Up for Maia, Team 2 Angels, Team Gabby, Team Riley, and TeamEd.

Next year's event will take place on October 5, 2019, at Philippe Park in Safety Harbor!



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## Greater New York Chapter



## 2018 Cure SMA Greater New York Chapter Walk-n-Roll

On October 21, 2018, the Greater New York Chapter celebrated the 14th Annual Greater New York Walk-n-Roll, in memory of Javier Brookes. Despite the crazy winds, more than 160 participants attended the walk at Long Beach Boardwalk in Long Beach, NY. The day was a great success and the ten teams worked to raise **\$26,328** for critical SMA research and family support programs. It was a bittersweet day as the chapter acknowledged Debbie Cuevas' 15 years of service to the Greater New York Chapter and welcomed the new Chapter Co-Chairs, Erin and Kevin Bonner.

Cure SMA thanks Debbie and her family for their support and hard work for the SMA community. The dedication Debbie has shown over the years has helped countless families and Cure SMA would not be where we are today without her. Under her leadership, the Greater New York Chapter raised over \$1.9 million!

## Ski Away SMA

The Hailey Mae Foundation hosted the Ski Away SMA fundraiser on March 17, 2018, at Magic Mountain in Londonderry, VT. After taking a couple winters off due to the lack of snow, supporters were eager to get back on the slopes and raised **\$16,000** in memory of Hailey Smelser who would have been 16 this year.



Thank you to Marie and Taylor Smelser for their generous support in honor of their daughter and continuing the fight to cure SMA.

## New York Mets Awareness Game

The SMA community and supporters had a wonderful day cheering on the NY Mets at Citi Field on September 30, 2018, in Flushing, NY. Not only was it a day of fun at the ballpark, but the Greater New York Chapter raised awareness by accepting the Spirit Award on the field before the game. After, the kids ran and rolled around the bases during the Mr. Met Dash. Thank you to everyone who came out to show your support.

## Capital Region Satellite Chapter



## 2018 Capital Region 5K & Walk-n-Roll

On September 29, 2018, the Capital Region Chapter held its 7th Annual 5K & Walk-n-Roll in memory of David Cuniff. The walk was held at Colonie Mohawk River Park, in Colonie, NY, and was one of their biggest years yet raising **\$36,348!** The community celebrated another year of breakthroughs including the state of New York screening newborns for SMA on October 1, 2018. In addition, the chapter welcomed its newest chapter leader, Allie Balleau, to the Capital Region Chapter leadership team.

Thank you to all the local sponsors and teams; Brooks Wolf Pack, Caleb's Dream Team, Grace to Race, Team Greyson, Team Izzac Whaley, Team Josephine, #LennaStrong, The Patient Experience Project, and Team Whalen Chevrolet. A very special thank you to Amy Cuniff-Bleau and Allie Balleau, for their support of the Cure SMA families in the capital region and making this a special event.

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## Dave's 40th Birthday Bash

Ken and Deb Cunniff honored their son, Trooper David Cunniff, by celebrating his 40th birthday with a fundraising bash in his memory. On November 3, 2018, Dave would have been 40 years old. Sadly, he was taken almost five years ago in a tragic accident while on duty on the NYS Thruway. Dave's goal was to raise a million dollars to help find a cure for SMA, and his family has continued to fundraise in his name and honor his dream. This past November, the Cunniff's fundraised \$3,050 for this milestone birthday.



Thank you to Ken and Deb for never giving up and continuing to support Cure SMA and the Capital Region Chapter that Dave started through events like the 5K and Walk-n-Roll and an annual ice fishing tournament.

## 6th Annual David Cunniff Ice Fishing Tournament

The 6th Annual David Cunniff Fishing Tournament was held at the Dockside Restaurant, in Lake George, NY, on Glen Lake, on January 26, 2019. Through partnering with the NYS Signal 30 Fund, the day was a



great success and raised \$2,648. The NYS Signal 30 Fund is an organization that supports the members of the New York State Troopers who have been killed in the line of duty like Trooper Cunniff. Thank you to Walt Cunniff and Christine Mozal for their hard work and efforts to start, promote, and run this ice fishing tournament.

## Illinois Chapter



## 2018 Evening of Hope in Honor of Cameron Lily Shish

The Evening of Hope in Honor of Cameron Lily Shish took place on November 1, 2018, at the Oak Brook Bath & Tennis Club in Oak Brook, IL. Guests enjoyed cocktails, hors d'oeuvres, music, a wine raffle, and a silent auction, that included popular items like Chicago Cubs tickets and spa packages!

In its first year, the event raised over **\$20,000**. The proceeds of this event will support scholarships to the 2019 Cure SMA Conference this summer in Anaheim, CA. A huge thank you to Jamie Shish for her work to put this event together and her dedication to fundraising for Cure SMA. Please join Jamie and her community again at the 2nd annual event in the fall!

## 2018 Illinois Chapter Holiday Party

The Illinois Chapter hosted a holiday party on December 15, 2018, at Lurie Children's Hospital in Chicago, IL. More than 100 family members and friends came together for an afternoon full of holiday fun! Lunch was provided and there was music, cookie decorating, and ornament making available for all the kids to enjoy! We also had a special visit from Santa who came and took pictures with each kid.



Cure SMA would like to give a special thanks to AveXis for sponsoring this fun get-together for SMA families! We would also like to thank Anna Goldberger and Michelle Erford from Lurie Children's for their help in organizing this fun family event!

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## 4th Annual Chicago Gala of Hope

On February 22, 2019, over 280 guests gathered at the Ivy Room in Chicago, IL, for the 4th Annual Cure SMA Chicago Gala of Hope. This incredible evening raised over **\$165,000** in support of Cure SMA. This fun event brought together families, researchers, doctors, business leaders, as well as generous supporters to raise funds to find treatments and a cure for SMA. The evening featured cocktails, hors d'oeuvres, a silent auction, live auction, and live entertainment. Comedian, Brett Walkow, was the MC and the band, Shout Out, performed live and kept everyone on the dance floor all night!

A special thank you to the title sponsor, AveXis, for their generous support of the 4th Annual Chicago Gala. Cure SMA would also like to thank the other sponsors who generously supported this event: Biogen, Ivy Room, Alight, Project Farma, Pivot Design, and Atlas Forms & Graphics Inc.

Thank you to all the committee members and volunteers for their hard work, dedication and commitment to the success of this event, especially Maria Marusich and the O'Brien family and friends.





**Friday**  
June 28th, 2019  
**TO Monday**  
July 1st, 2019

**cure SMA** 2019 ANNUAL SMA CONFERENCE

DISNEYLAND HOTEL IN ANAHEIM, CALIFORNIA

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

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## Iowa Chapter



## 22nd Annual Beaverdale Beaverdash

The 22nd Annual Beaverdale Beaverdash took place on September 15, 2018 in Des Moines, IA. Five teams and over 198 participants took part in the Timed 5K, Untimed 1 Mile Frolic and Beaver Trot, raising over \$9,120 for Cure SMA.



Thank you to the Mercy Medical Center volunteers for their help and a special thank you to Julie Greenwood for organizing this year's event!

## 97X WXLQ Quad Cities Tribute Fest

The 97X WXLQ Quad Cities Tribute Fest took place on September 29, 2018, in Davenport, IA. The event included performances by five tribute bands, a silent auction, 50/50 raffle and bake sale. The event was a huge success and raised **\$10,782** towards the 2019 Evening of Hope in Honor of Miracle for Madi. A special thank you to Greg Dwyer for his continued support!

## Kansas City Chapter



## 15th Annual Bommarito Z Club Show

Missouri

The 15th Annual Bommarito Z Club Car Show took place on September 2, 2018, at Bommarito Nissan in Hazelwood, MO. With over 86 cars, the event continues to grow every year! The day included a DJ, door prizes, a raffle, food, and a variety of cool cars. This year, the event honoring Brittany Carpenter and in memory of Madeline Schmidt, Michael Goodyear, and Brian Goodyear, raise **\$23,029!**



A very special thank you to Janet Hutchinson, all the members of the Gateway Z Club, and the Bommarito Automotive Group, for their continued support of Cure SMA and our mission. Their unwavering support through this incredible event has raised over \$150,000 for Cure SMA in the last ten years!

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## 3rd Annual Forest Hills Country Club Charitable Foundation Gala

The 3rd Annual Forest Hills Golf Charitable Foundation Gala took place on January 26, 2019, in Chesterfield, MO. Items auctioned on behalf of Cure SMA raised \$4,750!

Thank you to Valerie Giglio for choosing Cure SMA as her charity of choice for this event in honor of her grandson, Luke, and the Luke 18:1 Foundation.

## 2018 Phi Tau Omega Trivia Night

The Annual Phi Tau Omega Trivia Night took place in October 2018, in St. Louis, MO. Thank you to Kathy Goodyear and the Delta Phi Chapter of Phi Tau Omega for raising \$2,249 in honor of Brittany Carpenter and in memory of Michael and Brian Goodyear.

## 2018 Scare Away SMA

The 2018 Scare Away SMA took place on October 28, 2018, in Chesterfield, MO. \$1,854 was raised in honor of Matilda (Tilly) McRoberts. Thank you to Leslie Derrington for her continued support of Cure SMA!

## Minnesota Chapter



## 2018 Minnesota Chapter Walk-n-Roll

Minnesota

The 2018 Minnesota Chapter Walk-n-Roll took place on September 8, 2018, at Central Park in Roseville, MN. The day included family games and activities, a raffle, silent auction, and food sale. With 15 teams and over 289 people in attendance the event was a huge success, raising over **\$26,563!**

A special thank you to Chapter Leaders, Kara Forcier, Matt Czech, and Jon Schwerr for helping organize the event. Thank you to the sponsors, team captains, participants, volunteers and donors for making the day such a success!

## Team Kayley T-shirt Sale

South Dakota

Thank you to Kayley Shade in Hartford, SD, for holding her second fundraiser of 2018 by selling Team Kayley t-shirts in August and September, raising \$308.

Thank you for spreading awareness and fundraising for Cure SMA!

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## New England Chapter

### 2nd Annual Evening of Hope in honor of Natalia

Massachusetts

The 2nd Annual Evening of Hope in Honor of Natalia took place on October 13, 2018 at the Knights of Columbus in North Easton, MA. Guests enjoyed cocktails, hors d'oeuvres, music, dancing and a silent auction that included popular items, like Shawn Mendes concert tickets and an autographed Bobby Orr jersey!

This event was started by Marisa Boidi in honor of her daughter, Natalia, who was diagnosed with SMA at eight weeks old. This year, her event raised over **\$54,000!** In just two years, Marisa and her generous community have raised over **\$116,000** to fund critical SMA research and family support programs. A huge thank you goes out to Marisa for her tireless work to put this event together and her dedication to fundraise for Cure SMA. We hope to see everyone again at the 3rd annual event in the fall!



### 5th Annual Cure SMA Medfield Pub Crawl

Thanks to Joe and Renee Romanowski, the Johnson family and their family and friends, the 5th and final Medfield Cure SMA Pub Crawl, in honor of William Johnson took place on November 3, 2018. Over 150 "crawlers," made their way in teams through the streets of Medfield stopping at designated bars along the way and

raising over **\$10,000** for Cure SMA. It has been an incredibly fun and effective fundraiser each fall, so thank you to the Romanowskis, the Johnsons and their incredible community for their hard work and dedication over the past five years! It was a great end to a very special event.

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## 12th Annual Ride for Alex

Thanks to Tammy Foisy and everyone who helped make the 12th Annual Ride for Alex such a success! This event took place on September 18, 2018, in Freetown, MA, and was attended by over 100 people in Alex's community! This event combines a motorcycle poker run, raffles, music, food, and vendors to raise funds that are split between Alex Pateakos' family and Cure SMA. This year they generously donated over \$1,200 to Cure SMA. Thanks again to everyone who helped make this event a success!



## 2018 Cure SMA Hike for a Cure

New Hampshire

Thanks to Natalia and Jason Wylie and Gunstock Mountain Resort of Gilford, NH, for teaming up for the 2nd Annual Cure SMA Hike for a Cure in honor of Sofia Wylie. Thanks to their hard work it was a huge success yet again, raising over \$16,000 for Cure SMA! On September 9, 2018, more than 110 eager hikers, walkers and rollers enjoyed a day of fun for a great cause. Sofia and her family began the event with a joyous send off to the hikers and runners that would climb to the summit of Gunstock Mountain, as well as the walkers and rollers who took a stroll through the Gunstock Campground.

The hikers were treated to a scenic chairlift ride back down the mountain and the rest of the registrants were given the opportunity to take a ride on the chairlift too. The weather was clear and sunny, offering beautiful views of the mountains and lakes. After the hike and walk, everyone was invited back to the lodge for lunch, yard games, raffle and silent auction, plus a complimentary ride on the Mountain Coaster for those who were interested. It was a fun day!

Join other New Hampshire friends and families for the 3rd annual event in fall of 2019!

## Rhode Island Chapter

## Cure SMA Eggs with Evan

Rhode Island held a new event this year for Cure SMA, called Eggs with Evan! On September 29, 2018, about 175 friends from Rhode Island and Massachusetts gathered at Kirkbrae Country Club to "brunch," their way to a cure. The guests enjoyed an omelet station, buffet brunch and even a donut wall. They were entertained by a DJ, face painting, a craft table, and Declan Murphy's Cure SMA games. A silent auction and raffle helped fundraise for Cure SMA. The speaking program included an update on drug development for SMA and the status of newborn screening for SMA in Rhode Island.



Thanks to the hard work on behalf of the Vaudry family and the support of their community, Eggs with Evan raised \$26,000 for Cure SMA. Join them for the 2019 Eggs with Evan on September 28, 2019!



## Working On Walking Annual Fundraiser

On August 3, 2018, in Wrentham, MA, Working On Walking (WOW) held its 9th annual gala fundraiser for SMA. With a celebration full of hope and love on the agenda, hundreds gathered for food, raffles, dancing and so much more, to help pave the way to cure SMA. As a result of the outpouring generosity and support from their guests, WOW generously donated \$20,000 to support Cure SMA's efforts.

Working On Walking is a nonprofit organization founded by Alyssa Silva, a woman living with SMA. Established in 2014, WOW's mission is to continuously provide the SMA community with funds, awareness and hope, which all play an integral role on their journey to the ultimate goal—a cure. Thank you to Alyssa Silva for her generosity and her community for supporting this event!

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## 2018 Bugaboo WOD New Mexico

On October 27, 2018, dozens of CrossFit enthusiasts came out to CrossFit Albuquerque in Albuquerque, NM, to work out for Cure SMA! Participants completed a fun workout on the day. Thanks to the generous support of participants, nearly \$4,500 was raised for Cure SMA!

A special thank you to Joe Vigil and Natasha and Ben Abruzzo for all their hard work organizing this event.

### OKI Chapter



## Vikings Say Cure SMA Kentucky

A big thank you to Alex and Aaron Haas, and their family and friends, for hosting a fundraiser benefitting Cure SMA during a basketball game at St. Mary's High School in Paducah, KY, on February 1, 2019. It was a great turnout that raised \$1,140 for Cure SMA!

## Cassano's Cares Golf Outing Ohio

The Cassano's Cares Foundation aims to use the influence and history of the Cassano's brand to impact the community for the better. Each year the foundation hosts a golf outing to benefit a charitable organization of their choosing. This year, the Foundation chose Cure SMA, in honor of their friends Nora and Scott Monnin and their two girls. The outing took place at Heatherwood Golf Club in Springboro, OH, on September 17, 2018. With the incredible amount of hard work from Chris Cassano and Chip Cassano, along with their friends and family, this year's event was able to raise a total of **\$40,000** for the Cure SMA OKI Chapter! They cannot be thanked enough for their amazing support towards Cure SMA's mission!

## Rise Pies Fundraiser

Thank you to Rebekah Marsteller for hosting a fundraiser at Rise Pies in Youngstown, OH, for the Cure SMA OKI Chapter! This event occurred on November 30, 2018 and raised a total of \$280 for Cure SMA!

### Pacific Northwest Chapter

## Wreaths of Hope Washington

The 13th Annual Wreaths of Hope took place in November 17, 2018, in Chehalis, WA. Guests enjoyed crafting holiday wreaths, live music, caroling, baked goods, and hot cocoa, raising over \$2,250.

Thank you to Sybil Kuhn for her dedication to making this event such a success each year!

## SMA Day with the Seattle Mariners

The Pacific Northwest Chapter came together for SMA Day at T-Mobile Park in Seattle, WA, for a game against the New York Yankees. Families enjoyed a day out at the ballpark, spread awareness, and fundraised a portion of proceeds from each ticket purchased.

Thank you to Jennifer Stack for her help organizing this event and to everyone who came out for this SMA day at the ballpark.

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## 10th Annual Zane's Run

Pennsylvania

Congratulations to the entire Zane's Run committee for hosting a successful 10th event!

Five-hundred and thirty-five people came out to Great Valley Middle School in Malvern, PA on September 30, 2018, to celebrate the milestone 10th Zane's Run. It was an incredible day filled with fun for everyone!

Over **\$46,700** was raised to support Cure SMA! A huge thank you to the 14 fundraising teams that helped make this year such a success: Cooper Can, Freedom Tribe, GVHS Girls Tennis Team, JDT, Mead/Kwon Family, Peter's Philadelphia Eagles, Run for Roman, Team Brave, Team Joey Strong, Team PAO, Team Sadie, Trisomy 18, Wheels for Jimmy, and Team Whitcomb.

Through this event, the Sweet Baby Zane Fund supports Cure SMA's equipment pool for purchases of car beds, bath chairs, and Panthera wheelchairs.

A special thank you to Hillary & Keith Schmid, the Dunlap Family, Meridith Bebee, and Carrie Kane for their outstanding service to Cure SMA and years of dedication to this event.



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## 15th Annual Lukie's Fall Festival

Thank you to Lukie's Crew for another incredible Lukie's Fall Festival. The event celebrated its milestone 15th anniversary on October 6, 2018. The event was once again held at Weona Park in Pen Argyl, PA.

Despite the rainy weather, everyone had a great time treasuring those special moments and raising money for Cure SMA! The event featured food, games, raffles, live music, entertainment, a pie eating contest, kid's costume parade, face painting, hay rides, clowns, balloons, mini golf, historic carousel, pumpkins, bake sale, sand art, and lots of fun for everyone!

This year nearly **\$12,400** was raised for Cure SMA!

A special thank you to Tara and Joe Maida for their continued dedication to Cure SMA's mission and Lukie's Fall Festival. Thank you to all the Maida's friends and family who put in countless hours of work to make this event such a success each year.



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## 2018 Ultimate Granite Golf

Thank you to everyone who supported the 6th Annual Ultimate Granite Surface Golf Outing held on September 14, 2018, in Butler, PA. The tournament raised a record breaking **\$10,000** for Cure SMA! This tremendous event is held each year in memory of Benjamin Piper.

Thank you to Janet Bartley and the entire staff at Ultimate Granite for their continued support of Cure SMA.



## 15th Annual Lily Kennedy Golf Tournament

Thank you to Dr. Mark Lynch, Heather Kennedy and all the dedicated volunteers who made the 2018 Lily Kennedy Golf Outing a success. This event is held each year in memory of Lily Kennedy. This year's event, held on September 30, 2018, in Roaring Spring, PA, raised \$6,250 for Cure SMA!

A special thank you to Saint Francis University's Social Work Department and Social Work Club for choosing Cure SMA as their charity of choice and putting so much work into hosting this event each year.

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## Rocky Mountain Chapter



### 2018 Concert for Cash Colorado

The Cash Scanlon Phillips Foundation hosted the 11th Annual Concert for Cash on January 26, 2019, at the Denver Field House in Denver, CO. The Foundation generously sponsors Cure SMA's type II newly diagnosed care package program, in addition to sponsoring the Colorado Evening of Hope and the Colorado Walk-n-Roll.

In May 2007, Tess and Page Phillips lost their 5-month-old baby to SMA. Though devastated, the couple refused to crumble, embarking instead on a quest to live every moment in tribute to their son, Cash Scanlon Phillips. In January of 2008, joined by a fervent following of family and friends who called themselves "Team Cash," the couple launched the first ever Concert for Cash.

Ten concerts later, the Cash Scanlon Phillips Foundation has built the much-loved Healing Garden at Children's Hospital and has provided support for other programs there, including the Bereavement Program, the International Adoption Clinic and the Heart Program. They have also provided adoption assistance to Colorado families and funding to Cure SMA.

Attendees of Concert for Cash enjoyed grooving to the band Boogie Machine, live and silent auctions, dinner, and dancing. Everyone had a wonderful time while celebrating the life of Cash and raising money for Cure SMA. Thank you so much to Tess and Page for their tireless efforts in making this event such a success year after year!

## South Florida Chapter



### South Florida Chapter Holiday Party

The South Florida Chapter Holiday Party was held on December 5, 2018, at Sway Nightclub in Fort Lauderdale, FL. Over 50 people enjoyed food donated by Carrabba's Italian Grill, family photos donated by Kim Ruoff Photography, a light show, music, presents provided by District Mgmt. and a surprise guest – Santa!

Thank you to Jennifer Miller-Smith and Fiorenna Fuentes-Israel for planning this fun event!

## Tennessee Chapter



### 2018 Nashville Walk-n-Roll

The 4th Annual Nashville Walk-n-Roll took place on, October 14, 2018, once again at beautiful Centennial Park in Nashville, TN. The annual event brings together many local families and friends connected through the SMA community. The morning included fun for everyone with a DJ, games and pumpkin painting. This year's event raised **\$17,328** and is possible because of the hard work put forth by Kayla Harbin and her family and friends.

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## 2018 Bentley's Smiles for Miles 5K

This year's Bentley's Smiles for Miles 5K changed locations to the Ewtonville Baptist Church in Dunlap, TN. This annual event took place on September 22, 2018, raising a total of **\$11,429** for Cure SMA! The morning consisted of a timed 5K race to raise money, increase awareness, and provide hope for those affected by SMA. Thank you to Carie Whitaker and her family and friends for making this event a success year after year in memory of her daughter, Bentley!

### Virginia Chapter



## 2018 Virginia Chapter Walk-n-Roll

The 2018 Virginia Chapter Walk-n-Roll was held on October 13, 2018, at Gar-Field High School in Woodbridge, VA. More than 180 participants and 12 teams from across the region were in attendance, raising over **\$25,876!** It was a fun filled day with an incredible raffle organized by Debbi Schaefer, face painting, a racecar, outdoor games, and DJ. Thank you to the incredible sponsors and teams for their support; the A Team, Bennett's Village, Team Daryn, Team Eakin, Gabby's Crew, Hope for Hudson, Team Jack Jack, Knock Out SMA, Mia's Milers, Peyton's Pacers, Team Sherlin, and Virginia is for Fighters.

To see photos from event day, check out the chapter Facebook page [www.facebook.com/cureSMAVirginia](http://www.facebook.com/cureSMAVirginia) for pictures by Kloepping Photography who generously donates their time each year.

Lastly, thank you to the Virginia Chapter Leaders for putting on another successful event: Kyle and Laura Derkowski, Jim Ferry, Amy Knodell, Jessica White and Debra Schaefer.

## 2018 Cure SMA 5K Jogging for Joshua

The 2018 Cure SMA 5K & Walk-n-Roll Jogging for Joshua was held on November 10, 2018, at First Landing State Park in Virginia Beach, VA. The event was a huge success and over 150 participants attended, raising **\$17,027** for Cure SMA. It was a beautiful day along the Cape



Henry Trail accompanied by an incredible raffle and silent auction from the support of the many local Virginia Beach businesses.

Thank you to Bayley and Nathan Bullock for their hard work and dedication in bringing the Hampton Roads community together for this event in memory of their son, Joshua Bullock. Thank you to all the new families, participants, donors and sponsors for their support and generosity!

### Western New York Chapter

## 2018 Cake Pop Fundraiser in Memory of Saydee Smith

Thank you to Dawn Smith from Niagara Falls, NY, for organizing a fundraiser in memory of her daughter, Saydee. Dawn raised \$380 from her cake pop fundraiser for Saydee's 3rd birthday on January 6, 2019. Cure SMA is grateful to Dawn and her community for donating these funds to our care package program.

### Wisconsin Chapter

## 8th Annual Kennady's Dream Walk-n-Roll

On September 23, 2018, families from all over Wisconsin gathered on a beautiful morning for the 8th Annual Kennady's Dream Walk-n-Roll which is held each year at Fox Brook Park in memory of Kennady Quinell. All guests enjoyed the walk around the park, a delicious lunch, and a great silent auction that was filled with some great prizes. With help and lots of love from friends, family, and supporters, the event raised **\$21,000!** This money will go towards providing wagons to other SMA families, as well as research and education to continue working towards finding a cure for SMA!

Thank you to all the teams that came out to help raise money, and a huge thank you to Corey, Erin and Charlotte Quinell for all their hard work in planning this great event. We hope to see everyone next year on September 22, 2019!



# cure SMA 2019

CURE SMA MERCHANDISE



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



# August is SMA Awareness Month

Be sure to check back at  
[www.CureSMA.org](http://www.CureSMA.org) for the latest news &  
happenings going on during the month of August



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# JOIN TEAM CURE SMA

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)!

## UPCOMING TEAM CURE SMA EVENTS

August	2019 New Balance Falmouth Road Race August 18, 2019 Falmouth, MA
	2019 Michigan Titanium Triathlon August 18, 2019 Grand Rapids, MI
September	2019 Humana Rock n' Roll Philadelphia September 15, 2019 Philadelphia, PA
	2019 Chicago Half Marathon & 5K September 29, 2019 Chicago, IL
October	2019 MO' Cowbell Run October 6, 2019 St. Charles, MO
	2019 Baltimore Running Festival October 19, 2019 Baltimore, MD

November	2019 Allstate Hot Chocolate 15K/5K November 3, 2019 Chicago, IL
	2019 Disney Wine & Dine Half Marathon November 3, 2019 Orlando, FL
	2019 TCS New York City Marathon November 3, 2019 New York, NY
	2019 CNO Financial Indianapolis Monumental Marathon November 9, 2019 Indianapolis, IN
	2019 Philadelphia Marathon November 23, 2019 Philadelphia, PA



# 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.

## Featured Events

### 2018 Chicago Half Marathon & 5K

Thank you to the 24 incredible Team Cure SMA participants that ran and fundraised in the 2018 Chicago Half Marathon & 5K on September 23. Together, the runners successfully raised **\$11,135** for Cure SMA. Cure SMA would like to thank all of the runners for their hard work and dedication. Special shout out to Team Goin' for Koen for raising over \$9,000 for Cure SMA.

### 2018 New Balance Falmouth Road Race

20 runners took on the 2018 New Balance Falmouth Road Race on August 19. 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 \$54,663 for Cure SMA. Cure SMA would like to thank all of the runners for their hard work in fundraising and training for this race. Special shout out to Rachael Brown for raising over **\$19,000** and to Tricia Michalovicz for raising over \$11,000 for Cure SMA.

### 2018 Philadelphia Marathon

Thank you to the 5 amazing runners that took part in the 2018 Philadelphia Marathon on November 18. The Philadelphia Marathon is one of the top 10 marathons in the U.S. Together, Team William successfully raised **\$14,000** for Cure SMA. Special thanks to Shannon Hostetter, Christopher Jankowski, Nicholas Jankowski, Rick Jankowski and Diane Mei for their hard work and dedication.

### 2018 TCS New York City Marathon

Thank you to the 6 runners that took part in the 2018 TCS New York City Marathon on November 4. The TCS New York City Marathon is an annual marathon that courses through the five boroughs of New York City. It is the largest marathon in the world, with 52,812 finishers in 2018. Thanks to the incredible dedication of these runners they were able to raise **\$25,645** for Cure SMA. Special thanks to Sarah Bromley, Andrew Mayer, Joseph Mayer, Brittany Moncure, Matthew Pembroke and Helen Weston for their hard work and dedication.





# SPECIAL THANKS

to all Team Cure SMA athletes for participating in the following events

### 2018 Allstate Hot Chocolate 15k/5k Chicago Race

Special thanks to Steven Bidochka, Brett Kinley, Jamie Leavitt, Sarah McCall, Michelle Pantoja and Abby Paras.

### 2018 CNO Financial Indianapolis Monumental Marathon

Special thanks to Carrie Ammerman, Tami Bowman, Trista DeBolt, Ashley Goldman, Leah Hill, Lindsay Holt, Jaima Kinsler, Caitlin Sams, Brendan Smith, Holly Sontag, Adrienne Vollmer and Erin Watts.

### 2018 Humana Rock n Roll San Antonio Marathon and Half Marathon

Special thanks to Kurt Garrison, Tricia Garrison, Deric Nicholes, Jeffrey Pacini, Tammy Pacici and Laura Sepeda.

### 2018 MO' Cowbell Run

Special thanks to Alysa Bainter, Andrew Boyd, Callie Bushmeyer, Bryce Bushmeyer, Kim Bushmeyer, Brittany Meyer, Dustin Patterson, Amber Platt, Stefanie Rennecker, Jacob Schneider and Stephanie Schneider.

### 2018 Rehoboth Beach Marathon

Special thanks to Jason Moyer, Jessica Moyer and Denise Robinson.

### 2018 Rock 'n' Roll Denver Half Marathon

Special thanks to Angela Powers.

### 2018 Savannah Rock 'n' Roll Marathon & Half Marathon

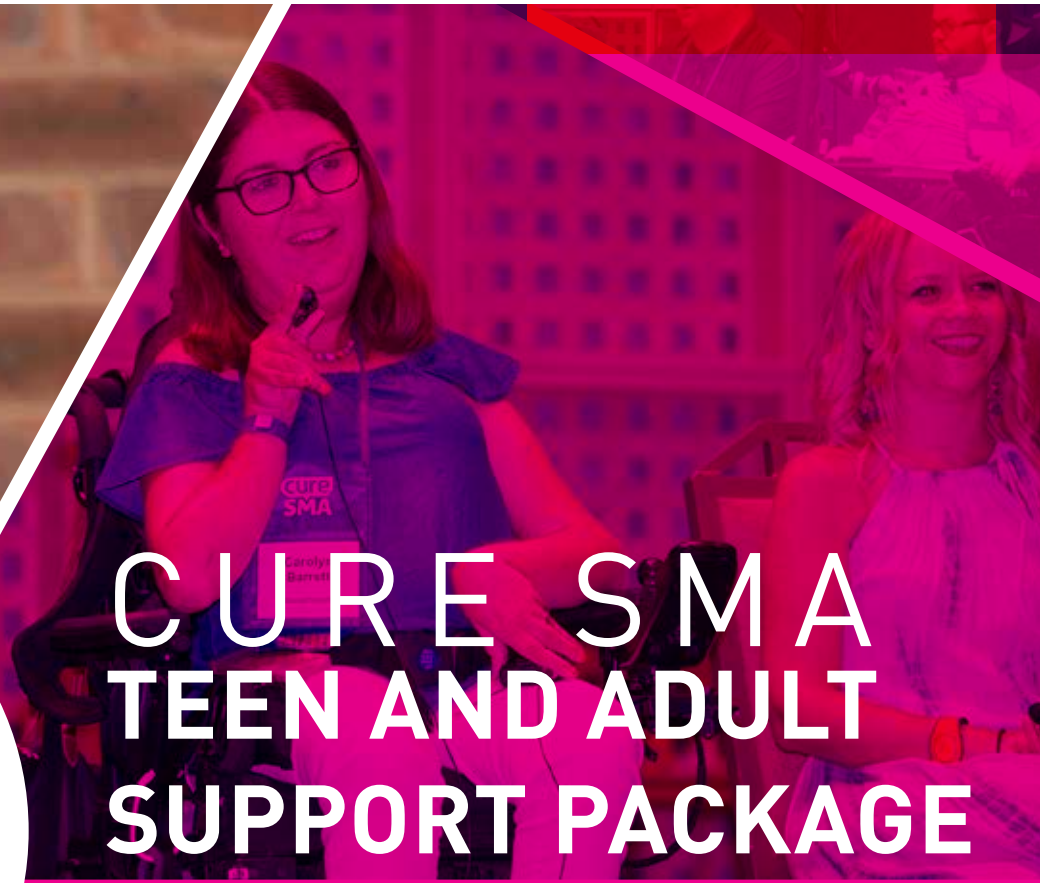
Special thanks to Jennifer Doyle and Carol Kelly.

### 2019 Rock 'n' Roll Arizona Marathon

Special thanks to Vanesa Flores.

### 2019 United Airlines Rock 'n' Roll Washington DC Marathon

Special thanks to Erin Bonner, Robert Buchanan, Terence Johnson, Darius Oxley and Katie Ursel.



# 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 [www.events.curesma.org/supportpackage](http://www.events.curesma.org/supportpackage) to request one at no charge.



Cure SMA  
925 Busse Road  
Elk Grove Village, IL 60007  
1.800.886.1762

Non-Profit Organization  
U.S. Postage  
PAID  
Permit No. 126  
Elgin, IL

# ACT NOW! TRANSFORM TOMORROW >>

## MAKE AN IMPACT AND HELP CURE SMA

- Demonstrate your commitment to meeting the ever-changing needs of the SMA community by supporting our local Summit of Strength symposiums and new Adult and Teen Support Package program.
- An unprecedented level of support is needed to expand the SMA Care Center Network, so all individuals affected by SMA across the US have access to treatments and the best possible care.
- We must act now to ensure people living with SMA get the school and workplace accommodations they need, that health insurers cover SMA treatments, and the immediate and long term needs of everyone affected are addressed.

**Please make a donation today**  
that will help provide these and other programs to everyone affected by SMA.

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

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**



Questions about your donation, matching gifts,  
or other ways to get involved?  
Please email us at [fundraising@curesma.org](mailto:fundraising@curesma.org)

