

# DIRECTIONS

SPRING 2018



**cure**  
**SMA**

Make today a  
breakthrough.

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## VISION AND MISSION STATEMENT

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

## OUR VALUES

### Innovation

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

### Balance

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

### Collaboration

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

### Respect

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

### Compassion

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

### Determination

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



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

### Submissions

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

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

### Change of address

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

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

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

*On the Cover, from left: : Jase SMA Type 1, Jeremy, Boaz, Cheryl, Pierce, and Maxwell Yoder.*

*Photo credit to Melissa Joy Photography*



# JOIN US



## Inaugural SMA Clinical Care Meeting & 22nd Annual Researcher Meeting

### SMA Clinical Care Meeting

Clinicians across the country are invited to share experiences, successes and ideas at the inaugural SMA Clinical Care Meeting, to be held on Saturday, June 16, 2018 at the 2018 Annual SMA Conference.

As Spinraza and future FDA-approved treatments extend the lives of those with SMA, care has become even more important. Our goal is not only to extend life, but also to ensure the best possible quality of life.

#### Meeting goals for the SMA Clinical Care Meeting include:

1. Provide an opportunity for SMA healthcare providers across disciplines to share knowledge
2. Facilitate collaborative discussions between healthcare providers to achieve improved care for SMA
3. Foster clinical care research collaboration across care centers
4. Promote interactions between new clinicians and leaders in clinical care
5. Build the SMA clinical care community
6. Promote conversations between families and patients living with SMA, clinicians, researchers and industry partners

### SMA 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.

One of the most important themed sessions each year is our special session. This year's special session is called, 'Clinical and Basic Questions of SMA in the Era of SMN Repletion: Challenge and Opportunity'. The development of additional therapies to be used independently or in combination with SMN enhancing approaches requires understanding more about SMA biology and disease mechanisms. Studying the "new" SMA phenotype after treatment will unveil new, unmet patient need, perhaps including extra-neuronal phenotypes and the need for such therapies. The goal of this session is to discuss these new challenges and opportunities.

**A panel discussion on the drugs in various stages of the SMA drug pipeline is also planned, just for families, and will be open during the Saturday Researcher Q & A session at the Family Meeting.**



# 2018 ANNUAL SMA CONFERENCE

**JUNE 14<sup>TH</sup>-17<sup>TH</sup>, 2018**

**HILTON ANATOLE HOTEL IN DALLAS, TEXAS**

This year's conference will be held at the Hilton Anatole Hotel in Dallas, TX, from Thursday, June 14 through Sunday, June 17, 2018. We are excited to bring the conference to a central location and hope to see you there!

Located in the Market Center district just north of downtown Dallas, the Hilton Anatole is one of the largest hotels in the South and features over 1,000 art objects, including two sections of the Berlin Wall.

Exclusive to hotel guests, the JadeWaters resort pool complex features a leisure pool with swim-up bar, beach-entry family

pool, lazy river, luxury cabanas, a splash zone with two water slides, a full-service restaurant, and more.

We have several new and exciting opportunities planned for 2018, including bringing back the Dance Party on Friday night, in conjunction with the Family Friendly Researcher Poster Session, and the PJ Party & Movie Night on Saturday evening. All of this will take place alongside many beloved favorites such as our adults with SMA and teen socials, Researcher Relay Race, Meet & Greet, and more.



Every year, Cure SMA sponsors a conference to bring together the leading SMA researchers, clinicians, and families living with SMA. Cure SMA has been hosting the Annual SMA Conference since 1988.

We look forward to reuniting as a community at this year's conference in order to lend each other support and strength and to learn about the latest advances in research and care.



## How to Get Involved

Whether you're able to join us in Dallas, TX or not, be sure to like us on Facebook and follow us on Twitter for conference updates.

### We've got lots planned, including:

- A Facebook live-stream of the Family Friendly Poster Session on Friday evening at 7:00pm.
- Regular updates from the conference posted in our news section
- Live-tweeting at 2 Special Sessions
- Sharing photos on all social media channels



If you're posting from or about our conference, be sure to use the hashtags [#cureSMA](#) and [#SMAConference](#).

**WE LOOK FORWARD TO SEEING YOU IN DALLAS!**



## 7th Annual “Hope on the Hill” Congressional Dinner

On Wednesday, November 29, 2017 more than 160 people from the SMA community – including government and industry partners – gathered for the 7th Annual “Hope on the Hill” Congressional Dinner in Washington, D.C. Several members of Congress attended the dinner including Rep. Sean Duffy, Rep. Tom Emmer, Rep. Erik Paulsen, and Rep Greg Walden.

The evening included remarks from event co-chairs Greg and Shannon Zerzan, Cure SMA President Kenneth Hobby, and SMA mom Cheryl Yoder. Rep. Greg Walden, Chairman of the United States House of Representatives, Committee on Energy

and Commerce gave a keynote address highlighting the recent milestones in SMA research. Rep. Walden was presented with the Cure SMA Friends and Family Award for his dedication to the SMA community and support of the “Hope on the Hill” Congressional Dinner over the last seven years.

This year’s event raised nearly \$200,000, bringing the event’s cumulative total to over \$1 million raised. We thank our generous sponsors who made the evening possible, particularly our Discovery Sponsors: AveXis, Biogen, Quest Diagnostics, Genentech, and CTIA.



# Clinical Trial and Drug Program Updates

Biogen has provided the following community statement on the final results from CHERISH, a Phase 3 study of SPINRAZA.

## Dear Members of the SMA community,

This past December marked one year since the FDA approval of SPINRAZA® (nusinersen), the first and only treatment option for children and adults living with SMA in the U.S. Since then, SPINRAZA has received regulatory approvals across the globe, including the EU, Japan, Brazil, Canada, Australia, Switzerland and South Korea. We're proud to share that more than 3,200 individuals with SMA are being treated with SPINRAZA worldwide.\*

We are also pleased to share that the final results from CHERISH, a Phase 3 study of SPINRAZA, were published in The New England Journal of Medicine (NEJM). The full manuscript, titled "Nusinersen versus Sham Control in Later-Onset Spinal Muscular Atrophy," appears in the February 15, 2018 publication of NEJM. The results concluded that, among children with later-onset SMA, those who received nusinersen had significant and clinically meaningful improvement in motor function as compared with those in the control group.

Biogen is incredibly thankful to the entire SMA community for their continued support, contributing to both the many regulatory approvals within the last year and the ongoing clinical trial programs. The support of the community has helped thousands of individuals with SMA receive ongoing treatment around the world. Biogen is continuously assessing the possibility of expanding access of SPINRAZA across the globe. Although Biogen may not have plans to bring SPINRAZA to market in every geography we are exploring alternative options for families living with this devastating disease.

We continue to recognize that there is more work to be done to ensure children and adults living with SMA may receive access to SPINRAZA, and we are working on the following to help overcome the current challenges:

- Supporting the growing number of treatment delivery sites: There are now more than 215 sites that have started administering SPINRAZA in the U.S. Physicians and advocacy groups continue to work toward increasing capacity and adding additional sites to administer treatment for pediatric and adult patients.

- Addressing intrathecal access challenges in those with spinal rods and/or fusions: We are continuing to partner with specialists including interventional radiologists, spinal surgeons, neurologists in identifying approaches and techniques best suited to deliver SPINRAZA to all patients who may require treatment. We are also evaluating device collaborations but these are very early efforts and we are working to determine a potential path forward.
- Advancing plans for teens and adults: We are supporting initiatives and study proposals which can further demonstrate the value of SPINRAZA in this patient population.

The CHERISH study is just one part of the largest well-controlled clinical development program conducted to date in the history of SMA, which includes more than five years of data for SMA. Biogen and the physician community continue to collect and evaluate data through SHINE, the SPINRAZA open-label extension study, and we are planning to conduct new clinical research across different SMA populations, which will provide a deeper understanding of SMA and SPINRAZA. As always, we will continue to partner with advocacy groups to ensure the community is aware of new trials as they become available.

Lastly, we continue our commitment to individuals with SMA and their families and our aim to increase the therapeutic options available to treat SMA. In December of 2017, we announced a collaboration with Ionis Pharmaceuticals, Inc. to identify new antisense oligonucleotide drug candidates. These efforts are in the early preclinical stages, but we will be excited to share more information in the coming years.

We thank everyone for their feedback, continued support and enthusiasm around SPINRAZA. We remain a dedicated partner to this community and will continue to provide updates in the future.

## Thank you,

The Team at Biogen

*\*Based on commercial, Early Access Program and clinical trial participant patients as of December 31, 2017.*

**Biogen recently announced new interim Phase 2 results from NURTURE, the ongoing open-label, single-arm study evaluating the efficacy and safety of SPINRAZA, or nusinersen, among pre-symptomatic infants with spinal muscular atrophy. Additionally, data from a case series conducted on SPINRAZA-treated teens and young adults was also released. The main findings of which are summarized below:**

- NURTURE study results reported that all study participants (25 infants) were alive, did not require permanent ventilator, and experienced improved motor function as of July 5, 2017, compared to a decline seen in SMA natural history
- One-hundred percent of NURTURE participants achieved the age-expected World Health Organization motor milestone of sitting without support – a development never seen with SMA Type 1
- In a case series conducted on SPINRAZA-treated teens and young adults with SMA Type 2 and 3 (17 to 19 years old upon their last visit) demonstrated stable or improved motor function and improved quality of life

**To read more about the NURTURE and SPINRAZA-treated teen data, visit: [www.curesma.org/news/biogen-nurture-results.html](http://www.curesma.org/news/biogen-nurture-results.html)**





## AveXis has provided the following community statement on AVXS-101.

### Dear SMA Community,

AveXis, the gene therapy company developing a new approach to treat SMA known as AVXS-101, is pleased to initiate screening for the remaining patients to be enrolled in the pivotal trial of AVXS-101 for SMA Type 1, known as STR<sub>1</sub>VE.

This next step in the STR<sub>1</sub>VE study comes after a review of the information gathered from the first three patients who were dosed in the trial. There was at least a four-week interval scheduled between dosing the first three patients to allow review of the safety analysis as well as early signals of efficacy.

### **STR<sub>1</sub>VE is designed to evaluate the efficacy and safety of a one-time intravenous (IV) infusion of AVXS-101.**

- **OVERVIEW:** STR<sub>1</sub>VE is an ongoing study of AVXS-101 in patients with SMA Type 1, studied at multiple centers across the U.S. which began enrolling in September 2017.
- **ADMINISTRATION:** In STR<sub>1</sub>VE, AVXS-101 is given one-time through a needle inserted into a vein, known as an intravenous (IV) infusion.
- **WHO:** STR<sub>1</sub>VE will enroll a minimum of 15 patients with SMA Type 1 who are less than six months of age at the time of gene therapy administration, and who have one or two copies of the SMN2 backup gene and bi-allelic SMN1 gene deletion or point mutations.

We know there is an urgent need for new treatment approaches, and we are eager to rapidly enroll the remaining patients in the pivotal trial as we further our clinical understanding of AVXS-101.

If you have any questions about STR<sub>1</sub>VE, please contact us at [medinfo@avexis.com](mailto:medinfo@avexis.com).

Sincerely,  
The AveXis Team

## FREQUENTLY ASKED QUESTIONS

### **When will AVXS-101 be approved by the FDA?**

We cannot speak on behalf of the FDA regarding whether and when they will decide to approve AVXS-101. The goal of the ongoing and planned studies is to enhance our understanding of how well AVXS-101 works and, more importantly, its safety profile in a broad range of people with SMA. The FDA then uses the information collected in these clinical studies to help determine whether AVXS-101 should be approved, and, if so, for what type(s) of patients.

### **Who should I contact to see if my child is eligible for STR<sub>1</sub>VE?**

For more information about STR<sub>1</sub>VE, please visit [StudySMANow.com](http://StudySMANow.com), or contact us at [medinfo@avexis.com](mailto:medinfo@avexis.com).

### **I saw reports that gene therapy may not be safe. Does that apply to AVXS-101?**

We understand that a recently published paper discussing a small, early-stage study of AAVHu68 in animals may have raised some concerns. It is important to know that this does not have implications for AVXS-101, primarily because AAVHu68 is a different vector than AAV9 – the adeno-associated virus in AVXS-101. Therefore, direct comparisons of the two cannot be made.



## STRONG Update and Expanded Clinical Trials – JAN 2018

- **OVERVIEW:** STRONG is an ongoing study of AVXS-101 in patients with SMA Type 2, studied at multiple centers across the U.S. which began enrolling in December 2017.
- **ADMINISTRATION:** In STRONG, AVXS-101 is given one time through what is known as an intrathecal (IT) injection near the lower end of the spinal cord. STRONG is the first time AVXS-101 is being administered this way. Data from STRONG will help us understand how to best design the planned study, REACH.
- **WHO:** STRONG will enroll 27 infants and children who are symptomatic with a generic diagnosis consistent with SMA, including the bi-allelic deletion of SMN1 and three copies of SMN2 without the SMN2 genetic modifier who are greater than 6 months and less than 5 years old. Patients enrolled in STRONG must be able to sit but cannot stand or walk, and cannot have previously been able to stand or walk.

### Planned Studies

#### STR1VE EU

- **OVERVIEW:** STR1VE EU is expected to start enrolling patients in the first half of 2018 in patients with SMA Type 1, studied at multiple centers across the European Union.
- **ADMINISTRATION:** In STR1VE EU, AVXS-101 is administered through a one-time IV infusion.
- **WHO:** STR1VE EU will enroll approximately 30 patients with SMA Type 1 who are less than six months of age at the time of gene therapy administration.

#### SPRINT

- **OVERVIEW:** SPRINT is a multi-national trial expected to start enrolling patients in the first half of 2018 in pre-symptomatic patients with SMA Types 1, 2 and 3.
- **ADMINISTRATION:** In SPRINT, AVXS-101 is administered through a one-time IV infusion.
- **WHO:** SPRINT is expected to enroll approximately 44 patients with two, three and four copies of SMN2 who are less than six weeks of age and pre-symptomatic at the time of genetherapy administration.

#### REACH

- **OVERVIEW:** REACH is a multi-national trial expected to start enrolling patients late in 2018 or early 2019 in SMA Types 1, 2 and 3.
- **ADMINISTRATION:** In REACH, AVXS-101 is administered through a one-time IT injection. Data from STRONG (the first study of AVXS-101 delivered through IT injection) will help determine the final study design.
- **WHO:** REACH is expected to enroll approximately 50 patients with SMA Types 1, 2 and 3 who are between approximately six months and 18 years of age.



## Genentech/Roche Update – Firefish Trial

PTC Therapeutics, Inc. recently announced the presentation of early interim data from Part 1, the dose-finding portion of the FIREFISH study. RG7916 has been safe and well tolerated at all doses and there have been no drug-related safety findings leading to withdrawal. In addition, data on the ability to swallow and requirements for tracheostomy or permanent ventilation, together with overall survival were also presented. Previously published natural history data indicate that in a comparable historic cohort the median age of event-free survival for SMA Type 1 infants to be between 8 and 10.5 months.

**Roche has provided the following community statement on RG7916 and Olesoxime investigational programs.**

### Dear SMA Community,

We are very pleased to share an update of the Roche SMA program. We have two investigational molecules in development for people with SMA, olesoxime and RG7916. Both molecules are given by mouth (or g-tube) and work in different ways.

### RG7916

RG7916 is an SMN2 splicing modifier and is being studied in three ongoing clinical studies, FIREFISH, SUNFISH and JEWELFISH.

RG7916 is developed in collaboration with PTC Therapeutics and the SMA Foundation.

FIREFISH for babies with Type 1 SMA – Start of Part 2  
FIREFISH is evaluating RG7916 in babies aged 1-7 months with Type 1 SMA. It is an open label study, all babies receive RG7916 and there is no placebo.

FIREFISH has two parts: Part 1 assessed the safety profile of RG7916 at different dose levels and demonstrated that RG7916 was safe and well tolerated at all dose levels. In Part 1 we also measured the concentration of RG7916 and the SMN protein level in blood. This has allowed us to confirm the dose of RG7916 to be investigated in Part 2. Participants in Part 1 continue to receive RG7916 in an open-label extension phase.

Part 2 of FIREFISH is now underway and will assess the efficacy and safety of RG7916 in approximately 40 babies. Part 2 of the trial has a duration of two years, after which all babies will continue to receive RG7916 until it is available in their country. The primary

analysis of the efficacy and safety of RG7916 is taking place after all patients have completed 1 year of treatment.

Recruitment into FIREFISH Part 2 has begun in Belgium, France and Italy. Additional countries and sites will be progressively opened following Health Authority and Ethics Committee approvals.

If positive, data from FIREFISH may be used to support Health Authority submissions and potential approval and access to RG7916.

### Studies for people with Type 2 and 3 SMA

SUNFISH is a clinical study for people with Type 2 and 3 SMA, non-ambulant, aged 2-25 years. SUNFISH is also a two part study. Part 1 has already been completed. In Part 2, we are assessing the safety and efficacy of RG7916 in type 2 and 3 SMA. Part 2 is ongoing in Europe and additional countries and sites will be opened throughout 2018, following Health Authority and Ethics Committee approvals. If positive, data from SUNFISH may be used to support Health Authority submissions and potential approval and access to RG7916.

JEWELFISH is an exploratory study assessing safety and tolerability of RG7916 in people with Type 2 and 3 SMA who have previously taken part in a study with another SMN2-targeting molecule. Recruitment is ongoing in study centers in Europe and in the US.

RG7916 has been well tolerated in all studies to date and no participants have left a study due to drug-related safety findings. We will be sharing more information from all ongoing studies at scientific conferences in the coming months.

### OLESOXIME

Olesoxime supports the function of mitochondria, the power houses of cells, therefore supporting the continued function of cells.

The OLEOS study is an ongoing open-label extension study with non-ambulant Type 2 and 3 SMA patients who took part in earlier olesoxime studies. Patients will be followed over several years. We are working on plans for a phase 3 study with olesoxime and will update you on these plans in the second half of 2018.

You can find further information and recruiting study centers for both RG7916 and olesoxime on <http://www.clinicaltrials.gov/> (search for SUNFISH, FIREFISH, JEWELFISH or olesoxime)

Thank you to the patients and families participating in clinical studies. Thanks also to the Patient Organizations for your contribution to advancing research in SMA. With your support, we progress our clinical studies in SMA with utmost speed and quality, and we look forward to providing further updates to the community.

**Best regards,**

**Sangeeta Jethwa, MD, on behalf of the Roche SMA team**



## Cytokinetics

### Cytokinetics Update – CK-2127107

Cytokinetics is currently conducting a Phase 2 clinical trial of CK-2127107 – now referred to by the generic name, reldesemtiv – which is designed to assess the investigational agent's effect on multiple measures of muscle function in both ambulatory and non-ambulatory patients with SMA. The trial includes two cohorts of varying doses of reldesemtiv.

Cytokinetics, Inc. recently announced the publication of results from three early clinical trials in healthy volunteers that evaluated safety, tolerability, pharmacokinetics, and pharmacodynamics of CK-2127107. The data supports the ongoing Phase 2 trial of the drug in patients with spinal muscular atrophy (SMA). CK-2127107 is an investigational next-generation fast skeletal muscle troponin activator (FSTA) which Cytokinetics developed in collaboration with Astellas Pharma. The compound aims to act as a muscle activator by slowing calcium signaling in fast skeletal muscle fibers.

The results showed that CK-2127107 increased the force generated versus placebo in response to nerve stimulation. Single doses of CK-2127107 were well-tolerated in healthy volunteers at doses up to 4000 mg. No serious adverse effects (SAEs) were reported and adverse effects (AEs) were all mild or moderate. The publication, titled **“CK-2127107 Amplifies Skeletal Muscle Response to Nerve Activation in Humans,”** is published online in *Muscle & Nerve*.

#### Cure SMA Funding for Combination Therapies

The clinical trials for CK-2127107 came about because of early seed funding from Cure SMA, supporting research focused on the potential application of these types of skeletal muscle activators to SMA. In 2014, Cytokinetics released encouraging data from preclinical studies conducted with our funding. The data showed this approach had positive effects in preserving muscle strength and reducing muscle fatigue, setting the groundwork for the ongoing clinical trials.

The progress of this program also highlights the importance of developing combination therapies to treat SMA. The goal is that CK-2127107 will show positive results in preserving muscle strength in human clinical trials, and may lend itself to combination with other SMA therapies, particularly those that address the SMN protein deficiency caused by the SMN1.



## SCHOLAR ROCK

### Scholar Rock Update - SRK-105

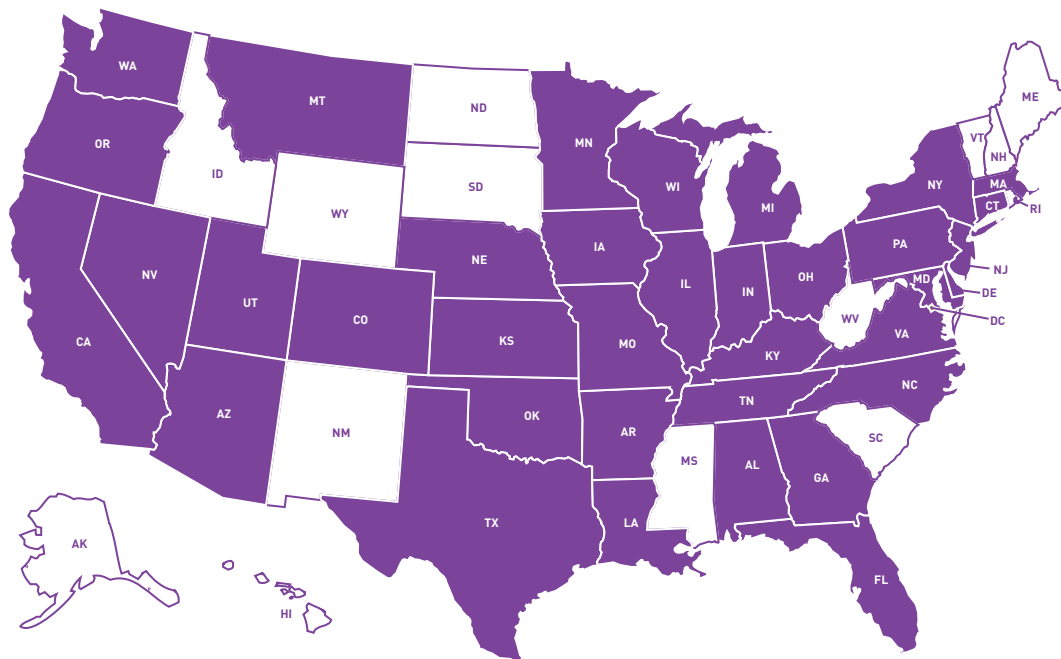
AScholar Rock, a biotechnology company based in Boston, has announced that they will be investing nearly \$50 million to bring SRK-105, a muscle drug for possible treatment of SMA, into human clinical trials. SRK-105 is Scholar Rock's lead clinical candidate. They expect to start clinical development in the first half of 2018, although timelines for SMA patient trials have not been announced yet.

Researchers believe that the most effective way to treat SMA will be a combination of drugs that address different aspects of the disease. Muscle drugs like SRK-105 could be used alone in certain patient populations or in combination with drugs like Spinraza or AVXS-101, which work to increase the amount of survival motor neuron (SMN) protein in the body. Due to the mutation in the SMN1 gene, individuals with SMA don't produce this protein at high enough levels.

In data presented at the 2017 Annual SMA Conference, researchers reported that, in a mouse model of SMA, SRK-105 resulted in a 60% increase in muscle force when given in combination with an SMN-enhancing therapy.

#### More About SRK-105

SRK-105 works by inhibiting myostatin. Myostatin is a protein that works with other proteins and hormones to help regulate muscle mass. In healthy individuals, myostatin limits muscle growth and differentiation, to prevent muscles from growing too large. For individuals affected by SMA, inhibiting this protein may combat the muscle weakness and atrophy that characterizes the disease.



## Spinraza Site List

Our goal at Cure SMA is to build this list to a few hundred active centers across the US, including multiple locations in each state, to meet the expected needs of our whole community.

This list is continually updated as we confirm more sites that are administering or preparing to administer Spinraza. If your local site is not listed, please email us, or ask the site coordinator to email us, at [patientcare@curesma.org](mailto:patientcare@curesma.org).

If your state does not yet have a site listed, check back frequently as we work toward at least one pediatric and one adult site in each state, then multiple sites in higher population states.

### An update on the status of Spinraza dosing across the US included the following information:

- As of December 2017, nearly 2,000 US patients had been dosed.
- 215 sites have dosed at least one patient, with an average of 9 dosed patients per site.
- 118 sites have been confirmed on Cure SMA's site list.
- 35 states plus DC have at least one site on the Cure SMA list.

For more information, visit <http://www.curesma.org/news/february-webinar-recording.html> to access the most recent webinar on treatment access and clinical trials.

To search for a treatment site in your state, visit [www.curesma.org/spinraza/sites](http://www.curesma.org/spinraza/sites)



## Cure SMA Receives Gift for Research

Cure SMA is extremely pleased to announce a generous \$620,000 gift has been made to the organization. The donation was made anonymously in honor of William N. Kanehann. Billy had SMA and died in 2013 at the age of 23. We are grateful for this amazing donation in memory of his life.

This gift will be dedicated to supporting new translational SMA research with the goal of identifying new drug targets which will lead to practical new drugs and combination therapies for SMA.

Funding for this research will help discover new systems, pathways and processes that are affected in SMA. Approaches that work on these new areas could then be used in combination with the current treatment approaches being tested in clinical trials and now approved that work on increasing SMN levels.

This important work will allow us to develop maximally effective treatments for all types, ages and stages of SMA.

As the SMA research landscape has developed and the drug pipeline has grown to include the first-ever FDA approved treatment, the needs for new translational SMA research have also developed. Cure SMA continues to invest in research by funding the areas of greatest need, and where we are best positioned to make a significant difference.



# I Have Watched a 'Miracle'

By Sarah Turnbull

*Sarah first told this story on stage at the Des Moines Storytellers Project "Everyday Miracles" event. An edited version of her story appears below, courtesy of The Des Moines Register.*

March 28, 2007. At 11:56 a.m., our second child entered the world. In my arms lay the most beautiful baby girl, with a full head of dark hair and bright beautiful eyes.

"Stella!" I said. "Her name is Stella." I could see the pride in my husband's eyes. Yep, he was smitten with our baby girl. In walked Stella's older brother. He was loving on her and kissing her feet, and in those first moments of Stella's life, everything was rainbows and unicorns. Perfect in every way. The nurse came and said: "Wow, you have a million dollar family." That's apparently the notion you have a perfect family if you have one boy and one girl. Yes, it was perfect. Then there was a knock on the door. Moments later everything that was normal would become a new journey, a new chapter in our lives. She was diagnosed with one condition and then another and then another. Each one seemingly more complex than the previous one. And then we were blindsided. She'd become a floppy baby so we were referred to a neurologist. As we sat in that room, rocking our baby girl, the neurologist looked at us for a long time, probably trying to figure out what she was going to say.

Then she said, as slowly and gently as possible: "Your child has SMA. Spinal Muscular Atrophy." Words we had never heard before. She told us not to Google it, but knowing we would, she cut to the chase. SMA is the leading genetic killer of children. It is the child form of ALS, Lou Gehrig's disease. And she most likely wouldn't see her first birthday. In Stella's case, she was the most severe this doctor had ever diagnosed. She gave us weeks or months. "What? She didn't look terribly sick. How could this be. She's got to be wrong!" My mind screamed, but for the first time in my life I couldn't say a word. She went on to tell us about the disease, that it was progressive, but her brain would remain unaffected. She smiled the most empathetic smile. "Take her home and love her. There's nothing we could do." How were we supposed to take home our child and let her go? We so desperately wanted hope, but there was none to give.

\*\*\*

When Stella was 5, I asked her kindergarten teacher: “Does she have friends?” Her kindergarten teacher laughed and said: “Are you kidding me? She’s the most popular kid in kindergarten.” At the end of the year, she wrote me a letter about how much Stella had impacted her classroom without ever having spoken a word. She talked about 20-plus different incidences in which Stella would be dressed up by other kids, or they would move her arms and legs to songs because she couldn’t dance herself. At the end she wrote: “Other students saw you as Stella, just another kindergartner. They didn’t see the things you couldn’t do, just the things you could. “I am so blessed to have you in my classroom and so grateful to have been your teacher.” I had no idea the impact my child was making on others. A couple years later, I was asked to speak at a parent’s information night. I was mainly there to talk to parents about my daughter’s condition, in case their children came home asking questions about her feeding tube or ventilator.

I was telling them how it would be great if they could leave their kids at home if they were sick, because a small illness for their child could mean a hospitalization for mine. I felt like I was burdening them with information. At the end, I asked if there were any questions. One mother said:

“Thank you, so much, for sending Stella to school. Because of your child, my child is learning to be caring, helpful and more accepting of others. “Because of Stella, I hope that all of our kids will become better people.” Other parents nodded and smiled. I’m not sure why it shocked me, but it did.

Sept. 21, 2016. It’s one of those days that impacts your life so much that you remember everything about the day: What you wore, who was there, every last particular. Stella had just had a surgery and she was recovering at home. She suddenly became unresponsive. Her ventilator was no longer supporting her, so we were bagging breaths into her tiny little chest. And calling 9-1-1. I can’t adequately tell you what it’s like to be a mother and see your child’s helicopter beeline across the sky — and you can’t get there fast enough. As we arrived at the hospital, lots of tests and procedures had been done. It was confirmed that Stella had surgery complications from the week prior.

Test after test came back, each one showing us that Stella’s body was failing. One last test came in, the doctor glanced at it and then looked at us and said: “There’s nothing we can do. You probably have about 20 minutes left with her.”

I glanced at every doctor in that room, looking for any glimpse of hope that perhaps what he was saying was wrong. But once again, I didn’t get any.

Our pastor stood behind us. We had seen the numbers. She was in kidney, liver and heart failure. And as he stood behind us, squeezing our shoulders, he asked the most difficult question we’ve ever been asked in our lives. “Are you ready to let her go?” Through tears I found myself saying, “The one thing I’ve asked for in on this entire journey is that I would not lose her in a crisis.” There was silence. Then a peace washed over me. An indescribable peace.

I smiled at my beautiful girl, and as I held her hand, I told her how proud I was of her for not ever giving up. I closed my eyes and held her hand.

Suddenly I felt her fingers moving. Not believing what I was feeling, I looked up and sure enough she was also opening her eyes. I looked at her monitors and her body was improving. The nurse who had been pushing fluids into my daughter’s veins for hours and hours smiled and said: “That my friends is a miracle. We didn’t do that.”

\*\*\*

Today, Stella is almost 11 years old. She is currently receiving the first-ever, FDA-approved treatment for her disease. We don’t know what our future holds, but what I can tell you is that I have had the privilege of watching a miracle right before my eyes. A child changing the lives of everyone she meets: doctors, students, teachers, parents, everyday human beings, without ever having spoken one word.





## Basic Research Funding

Cure SMA has a rich history of supporting research aimed at improving quality of life, expanding treatment options and advancing our understanding of SMA. This year, we are proud to announce that we have awarded 10 research grants, totaling over \$1.23 million – our largest contribution to date.

This year's several grants are aimed at exploring the pathology of SMA. These grants address unanswered questions in the field such as: how do low SMN protein level cause disease, what is the role of SMN in both central nervous systems and peripheral cells and tissues, and why do motor neurons die? Understanding the answers to these questions gives valuable insight into disease mechanisms and helps to inform the development of future therapeutics.

Another subset of this year's grants focus on therapeutic development. These grants explore the development of combination therapies designed to be used with a SMN-upregulating therapeutic such as Spinraza, possible biomarkers for SMA, and genetic modifiers of disease.

The final group of grants explores the unmet needs of SMA patients. These grants are aimed at understanding the clinical effect of Spinraza in adults, assessing needs not met by currently available therapeutics, and developing new outcome measures to assess clinical efficacy.

These basic research grants are the first step in our comprehensive research model. Funding basic research to investigate the biology and cause of SMA allows for identification of the most effective strategies for drug discovery.

**To read more about the latest basic research grants, visit [www.curesma.org/news](http://www.curesma.org/news)**

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



As the 2018 Annual SMA Conference quickly approaches, we want to hear from you!



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



Make today a breakthrough.

Stay in touch



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 Cure  
SMA

# Cure SMA Summit of Strength

As a national organization comprised of 34 chapters, we know it's important to leverage our collective strength and provide our community with personalized, local support.

Cure SMA is pleased to announce the Summit of Strength, a series of one-day local symposiums, beginning summer and continuing into fall 2018. These events will be held in 16 locations across 15 states across the US. Through the Summit of Strength, the SMA community will continue to share experiences, advocate for one another, and learn about the latest advances in treatment, care, and support.

## The Cure SMA Summit of Strength Program will be held in the following states:

- Alabama
- Arizona
- Arkansas
- Northern California
- Southern California
- Florida
- Illinois
- Maryland
- Massachusetts
- Missouri
- New York
- North Carolina
- Ohio
- Pennsylvania
- Texas
- Wisconsin

More information, including dates and specific locations, will be available in the coming months.



## SMA Treatment Site Grants

At the beginning of the year, Cure SMA announced the first grants from \$450,000 in funding to increase capacity at SMA treatment sites across the US.

In February, \$200,000 in additional funding was announced, bringing the combined total of grants to \$650,000. Thirteen grants will be used to help reduce practical barriers that create delays for our community in accessing treatments and care. These barriers include pre-authorization and insurance approvals, scheduling and clinic support. In addition, the grants will also help to increase the number of affected individuals that sites can follow, treat and evaluate.

The grants were awarded to sites through a competitive RFP process. Sites were assessed based on number of patients currently seen and treated, an evaluation of the current bottlenecks and barriers to access, and the number of additional patients that could be seen and treated if these barriers were eliminated.

### 2017-18 Treatment Access Grants

- Boston Children's Hospital
- Children's Hospital of Philadelphia
- Johns Hopkins School of Medicine
- The Ohio State University
- Washington University School of Medicine, St. Louis
- Stanford University School of Medicine, Pediatric Neuromuscular Clinic
- Nemours Children's Hospital
- Columbia University Medical Center
- University of California, Los Angeles
- University of Utah, Health Sciences Center
- Washington University in St. Louis School of Medicine
- University of Texas Southwestern Medical Center, Children's Medical Center
- Massachusetts General Hospital
- Gillette Children's Specialty Healthcare



## Newborn Screening Federal Update

On February 8th, the Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) recommended that newborn screening for spinal muscular atrophy be implemented nationwide.

This decision is an important step toward our goal of having every baby born in the United States screened for SMA. The recommendation now goes to Health and Human Services Secretary Alex Azar for final approval.

We are extremely grateful that, after a thorough review of the evidence, the committee confirmed that universal newborn screening and early treatment will change the lives of babies born with SMA. SMA is currently the leading genetic cause of death for infants under two years of age, but newborn screening presents an historic opportunity to change that. We look forward to Secretary Azar's speedy approval of this recommendation.

### What Led Up to This Decision

Early last year, following the approval of Spinraza, Cure SMA and the SMA Newborn Screening Coalition prepared and submitted a nomination of SMA to the ACHDNC. The nomination was accepted into evidence review in May 2017. That nine-month evidence review process culminated in February's vote. During the review process, Cure SMA and the coalition supported the nomination through public testimony given by Cure SMA staff and SMA families, and advocacy for adequate federal funding of newborn screening.

### What Happens Next

We will work alongside our advocates to push for a quick approval by HHS Secretary Azar. This includes working with our partners in the House of Representatives and Senate to encourage Secretary Azar to act. By law, the Secretary has 120 days to approve the recommendation.

It is also vital that we continue advocating in all 50 states, since the final decision on implementation rests with each state. Working together, we can save the lives of babies born with SMA.

### Thank You

We would specifically like to thank and acknowledge the families who testified in support of this nomination. Thank you to Kristen Lasko, Amy Medina, Beth Moore, Debra Schaefer, and Cheryl Yoder for sharing your stories. Thank you to Drs. Tom Crawford, Darryl DeVivo, and Kathy Swoboda, who also testified in support of the nomination.

*We thank the committee for their careful consideration of the SMA nomination. We also thank the working group who assembled the nomination packet.*

*We thank our partners in the SMA Newborn Screening Coalition—Biogen, AveXis, and Genentech/Roche—for their support of this important issue.*

# State Newborn Screening Update

**Though the federal process is critical to our case for SMA newborn screening, it is also vital that we continue advocating in all 50 states, since the final decision on implementation rests with each state. On average in the US, one baby each day is born with SMA. Each day represents the opportunity to save a life through newborn screening and early treatment.**

Four states—Missouri, Utah, Minnesota and Indiana—have adopted permanent screening and others are making progress.

## Utah

In February, the Utah Department of Public Health announced that, effective immediately, all newborns born in the state will be screened for spinal muscular atrophy. This announcement made Utah the first state to implement permanent SMA screening.

Late last year, the Utah Newborn Screening Advisory Committee recommended that SMA be added to the state screening panel. The Executive Director of the Department of Health approved the Advisory Committee recommendation, and the recommendation was followed by rulemaking to add SMA. The rules went into effect on January 29, 2018.

### Cure SMA Advocacy and Funding Leads to this Historic Moment

Cure SMA advocates led the efforts to support newborn screening for SMA, testifying before the legislature and the Advisory Committee.

In October 2017, Cure SMA hosted a luncheon for state legislators to educate them on the science of treating SMA and to discuss state implementation of and funding for newborn screening.

Cure SMA also supported newborn screening efforts in Utah by providing a grant to assist the state lab and the University of Utah in implementing SMA screening. The state legislature is in the process of passing a new budget that will include a nominal fee increase for screening kits to support the state's newborn screening program, including the addition of SMA. The grant from Cure SMA will cover the costs until this new budget is passed, so there is no delay in implementing screening.

## Minnesota

On December 27, the Minnesota Commissioner of Health accepted the recommendation of the state's Advisory Committee on Heritable and Congenital Disorders to add SMA to Minnesota's newborn screening panel. With this decision, Minnesota became the second state, after Missouri, to adopt permanent newborn screening for SMA.

In March, the Minnesota Department of Health announced the addition of SMA to the state's newborn screening panel via Facebook Livestream.

## Indiana

In March, Governor Eric Holcomb of Indiana signed HB 1017, adding spinal muscular atrophy (SMA) and severe combined immunodeficiency (SCID) to the state's newborn screening panel. The bill makes Indiana the fourth state in the country to adopt permanent SMA screening, following Missouri, Utah and Minnesota. The legislation was sponsored by Representative Doug Gutwein, and came about because of the tireless efforts of Adrienne Vollmer, an SMA community advocate.

The Indiana state lab will now initiate the start-up process for SMA screening, with screening expected to be fully implemented by summer 2018.

## Illinois and Wisconsin

In November, Erik Peterson and Jill Magsam Zmaczynski gave passionate testimony in support of legislation adding SMA to the newborn screening program in Illinois. In Wisconsin, Cure SMA committee member and SMA mom, Dany Sun testified before the Wisconsin Newborn Screening Advisory Committee. “I had to watch my children lose strength with no chance of changing that course. We have that opportunity right now. I am asking that you support the clear evidence that spinal muscular atrophy should be added to the newborn screening panel in Wisconsin to give children the opportunity to live a healthy, strong life,” Sun said.

## Pennsylvania

Families in Pennsylvania recently spent two days in Harrisburg educating state elected officials about SMA and newborn screening. Allyson Henkel and her son, Peter; Paula Saxon and her two children, Kate and Jake; Hillary Schmid; and Christie Barnard attended an SMA awareness ceremony on the floor of the Pennsylvania House of Representatives.

Comments were also shared with the Pennsylvania Newborn Screening Advisory committee by Peter and Jake. “Despite these challenges, it is possible to have a happy life with SMA. I have a great family, two brothers and a twin sister, lots of friends, and I play on a power wheelchair hockey team. I am here today to support screening babies born in Pennsylvania for SMA. Because of the new treatment for SMA, if babies are treated early they could be much stronger and likely even walk. This would help them avoid many of the challenges I have faced,” Peter said.

Jake talked about his experiences with SMA but he also spoke about his sister who is affected. “Kate is now six years old, but unlike me at this age, she does not require a wheelchair to get around. As a matter of fact she is running, jumping, riding bikes and climbing trees! Spinraza has shown incredible results when given prior to symptoms of SMA starting. My sister, Kate, is proof of this and why it is so important that SMA be added to the newborn screening panel,” Jake said.

## Ohio

Earlier this year, the Ohio Newborn Screening Advisory Committee recommended that SMA be added to their state’s newborn screening panel. The recommendation now goes to the Ohio Department of Health for a rulemaking process. Once these rules are developed and approved, SMA will be officially added to the state panel.

During this rulemaking process, SMA advocates will be able to voice their support for the proposal and for speedy adoption of the rules.

## Georgia

In February, Cure SMA prepared and submitted a recommendation for SMA to the Georgia Newborn Screening Advisory Committee. The recommendation was accepted into review the committee, with a decision to be announced at their next meeting in July.

Advocate Rachel Carrington gave compelling testimony at the meeting. In addition, the White, Merriken and Carrington families all worked to secure letters of support from their state legislators.

*Because of the dedicated advocacy of our community, Cure SMA has been at the forefront of federal and state-level work for newborn screening. We would like to sincerely thank all of the families and individuals who have testified in support of adding SMA to newborn screening panels in their respective states. Working together, we can save the lives of babies born with SMA.*

**If you have not already, please sign up to be an advocate.**  
**When you sign up, we’ll notify you of opportunities to advocate in your state or district.**  
[www.cureSMA.org/actioncenter](http://www.cureSMA.org/actioncenter)





## Miller McNeil Woodruff Foundation Gift

The Miller McNeil Woodruff Foundation recently awarded \$87,000 to Cure SMA, in order to further research that will lead to treatments for all ages, stages and types of SMA. Their gift will also help fund continued advocacy and awareness initiatives.

The generous donation is made each year by Patrick and Meredith Woodruff, in honor of their son, Miller, who passed away from SMA type I at 87 days old. In the last five years, the Woodruffs have raised \$446,937 for Cure SMA. We are especially honored to have once again been chosen as beneficiaries of a gift from this incredible family and foundation.

Since Miller's passing, the Woodruffs have been dedicated to spreading awareness and helping to fund crucial research. The support Cure SMA has received from the Woodruffs and their foundation has been vital to a range of projects that include providing critically needed medical equipment to SMA families.

On behalf of the entire SMA community, thank you to the Woodruff family and the Miller McNeil Woodruff Foundation.



# Weisman Family Foundation

The Weisman Family Foundations awarded \$65,800 to Cure SMA in order to further new scientific research and to help provide access to treatments, trials, and care.

A generous donation is made each year by the Weisman Family Foundations. The Weisman family has given over \$1.2 million to Cure SMA through contributions from their foundation and associated family foundations.

We are especially honored to have once again been chosen as beneficiaries of a gift from this incredible family and foundation.

On behalf of the entire SMA community, thank you to Loree, Ward, Lyza and Lena Weisman, The Weisman Family Foundation, The Toby & Nataly Ritter Family Foundation, The Louis A. Ritter Foundation, and The Irene Ritter Foundation for their generous contributions to Cure SMA.





Emma Schnyders



Evan Perez



Stuart Deshotels



Jaxson Payne



Lucas Braga



Karen Seeley



MaKenna Huber



Theo Scafuto



Max Peppers



Abigail Hammond



Adrian Soto



Aulden and Nolan Lange



Arwa Mouakkil



Delaney Womack



Ellie Carver



Mya Cala



Hunter Rhodes



Jeffrey and Austin Olander



Mohammad  
Mustafa Jawwad



# Eagle Scout Project

By Declan Murphy

Declan Murphy of Troop 192 in Norwell, MA has attended the New England Cure SMA Walk-n-Roll for all sixteen years of his life (He only missed the first one because he wasn't born yet!). The walk, organized by his mom Silvia Murphy, is held in memory of his brother Cianan and sister Cecilia who passed away from SMA.

Declan joined Cub Scouts in first grade and then moved up to Boy Scouts in fifth grade, when his troop began to volunteer at the Walk-n-Roll. It was no surprise that when the time came to work on an Eagle Project, he chose Cure SMA as the beneficiary. He decided to build sturdy, long-lasting carnival-style games for children to enjoy at this and other Cure SMA fundraisers throughout New England.

In the fall of 2016, the process began with a fundraising bake sale. He was able to raise enough money to purchase all the supplies needed to build and play the games -- and still had over \$100 remaining to donate to Cure SMA. Over the winter of 2016-2017, Declan, his father, and grandfather worked on detailed plans, studied video demonstrations of how to build games, purchased supplies, and cleared out a work area in the garage. The building, sanding, and painting of the games were done over the course of the summer of 2017, with the help of other scouts and his siblings Johanna and Cormac. Final touches and the project paperwork were completed in the fall of 2017.



Three of the games made their debut at the Rhode Island Walk-n-Roll in October, and of course they will be on proud display at the New England Walk-n-Roll on May 12th!

***Thank you so much to Declan for dedicating his time and Eagle Project to Cure SMA; these games are a huge hit at our events and everyone at Cure SMA appreciates all his hard work!***

*The names of the games are: frog flip, prize wheel, plinko, bean bag toss, ring toss, ricochet*



# Family Support



We received an amazing shipment of 45 maracas from the Renedez family on behalf of Jack Renedez. These were donated in honor of Jack's 2nd Birthday as they are his favorite toy!

Thank you so much to the Renedez family for this donation to our care packages and for thinking of Cure SMA as Jack celebrated his 2nd Birthday!



Many beautiful handmade blankets and burp cloths arrived at the Cure SMA National Office. These were all made with love in honor of Ellie Ann Stevenson and to be included in newly diagnosed care packages.

Thank you to the Stevenson family for your incredible support and generosity!



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



Special thanks to the Fighting for Kaiden Foundation for donating this wonderful assortment of toys to include in our newly diagnosed care packages!



In honor of Logan Sanders and Ava Adams, Cure SMA received an exciting donation of toys to be included in our care packages. The items were collected in honor of Logan's 1st birthday and the Infanto Touch Pads were collected in memory of Ava Adams. Her parents had also collected toys to donate in honor of her 1st birthday and Logan was fortunate to receive a touch pad in his care package on behalf of their donation. It quickly became one of his favorite toys. Thank you all for these wonderful donations!



We received a special delivery of toys from the Armstrong Family to include in our care packages in honor of their son Knox's birthday! Thank you to the Armstrong's for these wonderful items!



# Family Letters

## Dear Cure SMA Family Support:

On behalf of Abigail Hammond and Family, we would like to thank you so much for the Care Package and wagon. You have given us so much information and enabled us to share with our family and friends as well. Abby, and her big brother Quintin, are enjoying all the goodies included in our package, and the wagon is so helpful in giving Abby “legs to run with” so to speak. She loves to sit at the table playing with all her new toys.

It touched us deeply to realize all the donations that made her care package possible. Specifically, thank you for the following donated items: the red wagon in honor of Kennady Quinnell, the sheep skin blanket by The Jacob Isaac Rappoport Foundation, the blanket by GoodenTree in celebration of Nora’s Life, the Dory Book in honor of Hannah Costlow, the Crayola Twistables in honor of Rhys Santiago, the Frozen Magnetic Marker in honor of Kate Veit’s 3rd birthday, the plastic cooking utensils in memory of Blake Avery Reid, CureSMA.org, and all the other donors and volunteers who give so generously.

It was so scary to hear Abby’s diagnosis of SMA Type III, but with your help we are coming to terms with our new reality and we are hopeful for Abby’s future. God willing, a cure will eventually be found for her and all the other children with SMA.

**Sincerely,**

**Joanna Hammond (Abby’s Grandma)**

*on behalf of the Hammond Family: Abigail, Quintin,  
Kate and Travis (parents), and Mike (Grandpa)*





### Hi Cure SMA!

I sat him on the floor and he couldn't stop smiling and playing when his care package came. I would like to thank you very much. He was beyond happy and super excited to see everything in the box. He loves it all and I love to see him happy. You guys are extremely caring and I will forever be grateful.

Thanks again,  
Elizabeth Vega & Adrian Soto



### Dear Cure SMA,

Thank you so much for the wagon you sent to Claire. She just turned six and has been in strollers or her wheelchair her entire life. The wagon is something we have borrowed while in the hospital, but is new and exciting to have at home. The picture is Claire and her little brother, on their first ride in the wagon.

Thank you and bless you all for all you do.

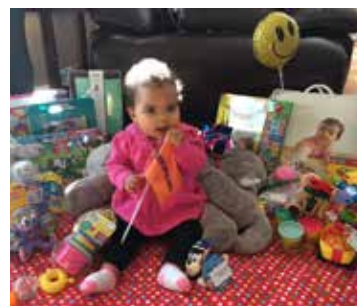
Tara Davenport



### To Cure SMA,

Thank you so much for my care package! It was such a thoughtful box full of wonderful goodies and I love it all! #CureSMA

Jurtiana Jeon



### To Cure SMA:

Thank you all so much! Miss Mila is loving all these goodies.

Holly Sontag



### Cure SMA,

Thank you so much from  
Ainarah and Caleb.  
She was so happy!

Michelle Rivera



**Hi Cure SMA,**

Thank you for the information and care package. We got it last week and we are just so amazed at the support and love we have from total strangers.

**Thank you for caring,  
Alecia Camp**



**Cure SMA,**

Our son, Dylan Hayes, received his care package yesterday. Thank you to everyone at Cure SMA. It does help us knowing there is such an amazing support system out there for us!

**Thank you,  
Christina Hayes**



**Cure SMA,**

Thank you so much for Emma's care package - she loves it!

**Erin Walsh**



**Cure SMA,**

Thank you so much for the amazing care package and wagon. Theo loved everything and we are so grateful to have this support. Attached are some photos of him enjoying the new toys!

**The Scafuto Family**

**Oh. My. Goodness.**

We just received the care package and are OVERWHELMED by the amazing generosity!!! We are too exhausted to do much more today, but we wanted to say thank you, and ask that you pass our heartfelt thanks on to all those who contributed items to the package. My wife was in tears looking through it, seeing the little precious faces taped on various things!

**Thank you, thank you, thank you!**

**-Adam and Rondi Kauffmann**



**Dear Cure SMA,**

Thank you so much for the package. It means so much to us. And Emma loves all the toys! We also received the car bed. Please send our sincerest gratitude to the Jacob Isaac Rappoport Foundation.

**Ryan and Michelle Schnyders**



**Hi Cure SMA,**

We received the care package and information and WOW! You all are awesome! There are so many neat things in that care package that he will be able to use. Thank you all so much for that! I have included a picture of Breckin with some items from his care package.

Thank you all again for the care package and information.

We really appreciate all the support already!

**Whitney Roberts**



**Cure SMA,**

I just wanted to thank you for the care package and information! I couldn't believe all the items in the box! We cannot wait to use them.

**Thank you so much,  
Jenni, Ryan & Blake Esselmann**



**Dear Cure SMA,**

Thanks so very, very much for the conference scholarships! My daughter and I are so very thankful from the bottom of our hearts! As I'm sure you can understand, Gabby is the most important priority in my life. I have put myself aside many times, because Gabby's health and well being are the most important parts of who I am. I've had to take off many days at work to be by her side when she is sick, because there is no other place in the world I'd rather be. When she is well I can work full time, and we have wonderful help from in home nurses. Financial times have been hard, but God gets us through it every time. Please pass on or share this email

to any and all who make these scholarships possible. They are such a wonderful blessing, and we send hugs your way!

**Thanks again,  
Maggie Weldon (Gabby Crawford's mom)**

**Cure SMA,**

I cannot tell you how utterly speechless I was. I cried at the pure kindness and compassion. I cannot tell you how appreciative we are. In such a tough time, watching my daughter smile and become fascinated with new things, was absolutely breathtaking.

**Thank you again,  
The Sattari Family**

**Good morning Cure SMA,**

I just wanted to thank you and the whole team for providing us with the wonderful care package, wagon, and booklets. We came home late last night to boxes delivered from Cure SMA. I fell asleep reading the overview of SMA and nutritional needs last night - it helped tremendously understanding what Scarlett has. Thanks to everyone again, Merry Christmas, and have a happy New year! We look forward to being a part of the community.

**- The Johnsons**

**Hi Cure SMA,**

Just received another package today from Cure SMA filled with toys, blankets etc. Thank you so much! Our daughter is having so much fun playing with all the new toys. And we are learning so much. Thank you again.

**Warm regards,  
Khalif & Aiyu**

A photograph showing two pairs of hands, one adult and one child, gently holding a small green seedling with two leaves as it is planted into dark brown soil. The background is a blurred field of similar seedlings.

# IMAGENE IF

GENE REPLACEMENT THERAPY COULD HELP CHANGE LIVES.



**GENE REPLACEMENT THERAPY** is changing the way we see genetic diseases. By targeting faulty or missing genes, this innovation is creating a new world of opportunities and potentially helping people living with genetic diseases.

---

Discover more about this scientific advancement at [ExploreGeneTherapy.com](https://www.ExploreGeneTherapy.com)



## Nathan Yates, Motivating Others

Growing up in Virginia, Nathan Yates always had a vision for his future. From an early age, he became interested in finance, and as a teenager managed his own small portfolio of stocks. Diagnosed in 1989, he also lives with spinal muscular atrophy type 2. To date, Nathan's diagnosis has never stopped him from holding onto his interests and working to achieve the goals he envisioned for his life.

After earning his Bachelor of Science in Economics & Finance, in addition to his Master of Science in Finance from Southern New Hampshire University, Nathan followed his passion and opened his own consulting business. Forward View Consulting was founded in 2014, and in 2016 won the "New Business of the Year" award from the Dickenson County Chamber of Commerce. Nathan is also an adjunct professor and faculty leader at Southern New Hampshire University.

With the success he's had, Nathan still seeks to inspire others and be an example to everyone. Most recently, he became actively involved with a Twitter finance group, FinTwit, in which he won the "Good Guy of Finance" award. As part of receiving the award, Nathan was also asked to nominate a charity for others in the group to donate to. He chose Cure SMA.

"My first goal was to raise \$500. They topped that mark in minutes," Nathan said.

As of today, 20 people have donated \$2,975 to Cure SMA in honor of Nathan.

Many of the gifts received came from first-time donors who many not have otherwise known about Cure SMA and our mission. Both Nathan and Cure SMA express our utmost appreciation to the members of FinTwit who donated to our cause. This incredible amount of support demonstrates the impact that Nathan has had on others.

"There's no level of involvement that won't make a difference," Nathan said.

Looking forward, an area of advancement in research that Nathan is particularly excited about is the SMA drug pipeline. The updated pipeline includes 16 active programs, including one approved therapy, and 6 programs in clinical trials.

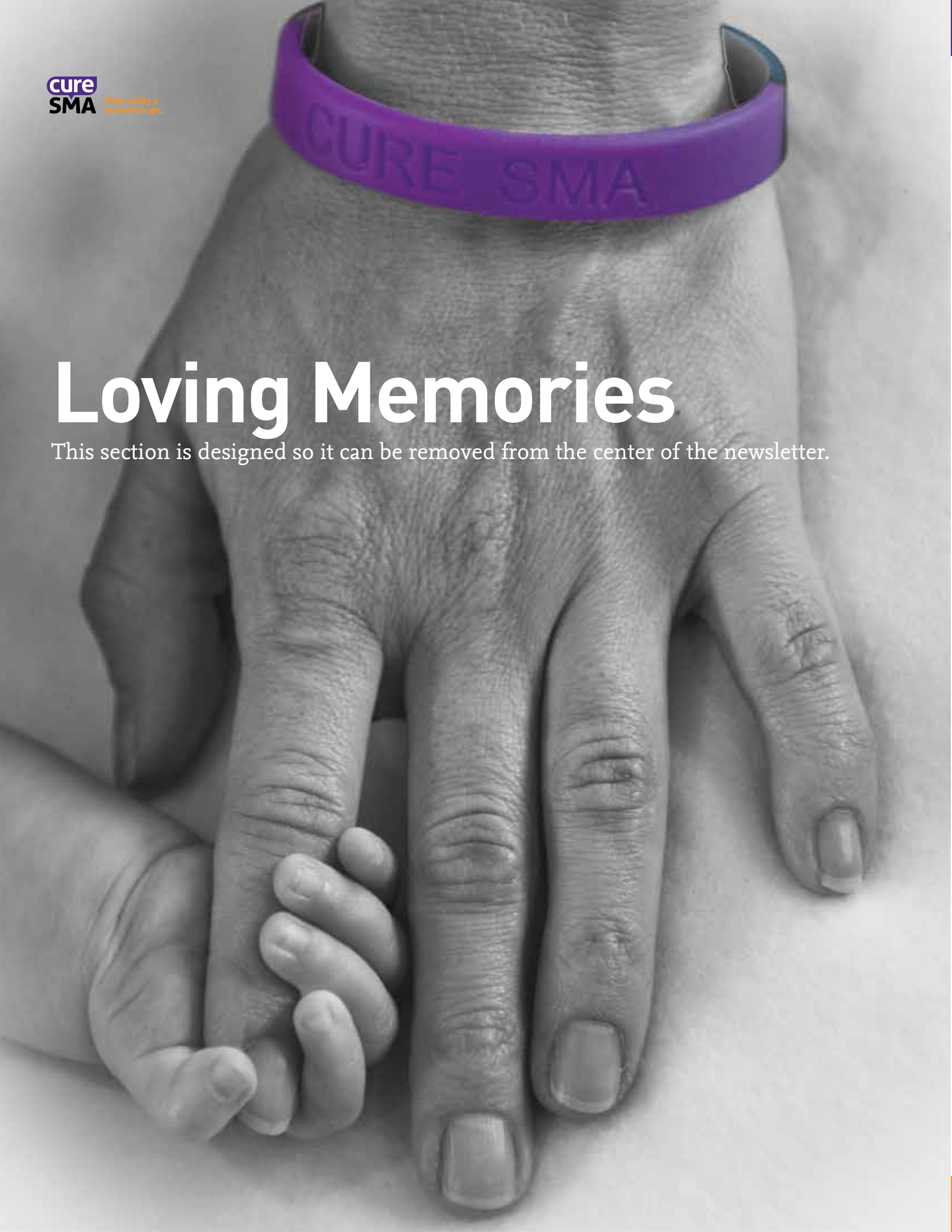
Without people like Nathan, people like you, this progress would not be possible. As a unified community, we can achieve anything if we have a vision and work together to change the future of all those affected by SMA.





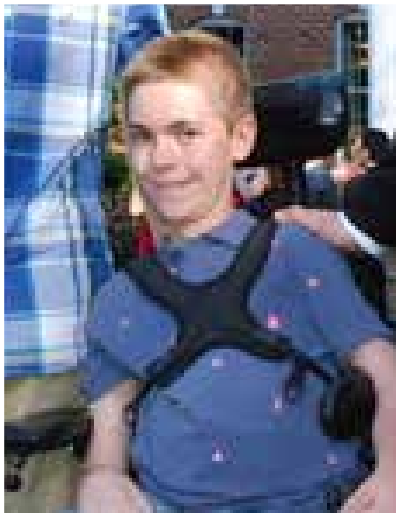
# Loving Memories

This section is designed so it can be removed from the center of the newsletter.



## In Memoriam

Zoya Jawwad | January 2011 - August 2011



## In Loving Memory

Peter Andrew Henkel | June 3, 2004 – January 3, 2018

### ON CHILDREN

By Kahil Gibron

Your children are not your children.  
They are the sons and daughters of Life's longing for  
itself. They come through you but not from you,  
And though they are with you yet they belong not  
to you. You may give them your love but not your  
thoughts, For they have their own thoughts.  
You may house their bodies but not their souls,  
For their souls dwell in the house of tomorrow,  
which you cannot visit, not even in your dreams.  
You may strive to be like them, but seek not to make  
them like you. For life goes not backward nor tarries  
with yesterday.

You are the bows from which your  
children as living arrows are sent  
forth. The archer sees the mark upon  
the path of the infinite, and He bends  
you with His might that His arrows  
may go swift and far.

Let your bending in the archer's hand  
be for gladness; For even as He loves  
the arrow that flies, so He loves also  
the bow that is stable.

# In Memoriam

Merrick Akins | June 15, 2015 – June 22, 2017

Dear Family and Friends,

This season is really hard. We know it would be, but it's brutal. We strain to remember everything – our memories are it, now. We're forgetting though. It can't be helped. Tears are no fun and so exhausting, but they are what feel most real, closest to him. We lost him so horribly, so devastatingly. We knew his life was more fragile than most, but we certainly thought that we would have more time.

You must know how incredibly touched and thankful we are for the love and support we have received and continue to receive from each of you. Our Christmas card distribution list this year is at least three times that of previous years because we wanted to be sure to reach each caring individual that reached out to us in our grief. It brings some comfort knowing that we're not alone and that so many care about us and loved our little miracle man, Merrick Bradley Akins.

The burden is great. The need to somehow communicate to all of you the incredible, beautiful, crazy, brief, rollercoaster, phenomenal, heartbreaking, soul-fulfilling experience that was Merrick Bradley. I feel that this is my sole chance to attempt to make you see what he was and how incredibly much he meant to us in the few months that he was ours. Human communication, in all forms, falls catastrophically short.

Merrick loved Christmas. He loved Christmas lights. He loved all of the little Nativity scenes Mommy collected and loved playing the story with Mommy. He loved Elmo. He loved The Wonder Pets. He loved his buddy, Max. He loved his cousin, Leona. He loved his Grammy. He loved his Daddy (Daddy was his all-time favorite toy). He loved petting Sprocket with his hands and Tiger Lily with his feet. He loved when Kona licked him (Mommy didn't love this). He loved to wake up in the wee hours of the morning and call for Mom, just to play. He loved wiggling. He loved Turtle Invaders. He loved Little Einsteins. He loved playing with Mommy's phone. He loved to be held by Mommy. He loved school busses. He loved watching other children. He loved the book, Llama, Llama, Red Pajama. He loved to build block towers just to knock them down. He loved watching videos of hamsters on wheels. He loved bonking our noses. He loved his night-night fish tank. He loved chest P.T. and talking to his nurses and NOT talking to Mom. He loved watching the squirrels hang from the birdfeeder outside of his window. He loved Daniel Tiger. He loved balloons – all kinds. He loved to yell at the dog for barking. He loved finger plays like "Wheels on the Bus" and "Itsy Bitsy Spider." He loved when Mommy sang to him – sometimes.

Merrick hated baths and cough assist and being away from his parents. He hated doctors and needles and being hot and the Minions (Yes, he hated those little yellow guys). He hated bedtime and nail trims and having a wet diaper. He hated the bell ringing at Sabbath School. He hated to have his temperature taken (even though we always did it the underarm way).

Merrick was incredibly smart. While SMA severely limits most motor functions, cognition and intelligence are unaffected. He was a feisty, indulgent almost two year-old with remarkable manipulation skills. He was learning to use his eyes to communicate using pictures by looking at them, working towards utilization of digital eye gaze technology. With all of his physical limitations, he was great at vocalizing and using subtle eye and body language to communicate what he wanted. He was learning to control his stroller on a motorized platform – predecessor to driving a power chair.

His name meant "strong ruler of the sea." He never made it to the ocean while he was living, so we spread the majority of his ashes at our heart home: Kailua, Hawaii. We waited 9 long years to have a child. We were told we never would. He was our miracle and we are eternally grateful for every moment we had. Our faith is battered but still holding. We believe we will see him again, and he will be whole.

Please – Never hesitate to speak Merrick's name or ask us about him.

Michael and Brandi Akins

# In Memoriam

Takyla Lynch | July 20, 2015 – December 5, 2017

Takyla Lynch, an SMA angel was called home on Tuesday, December 5, 2017. Takyla was diagnosed with SMA type II in January 2017. We the parents of Takyla would like to thank you at Cure SMA for your support. Cure SMA was a blessing to us as Takyla was the first known case in our country.

I will not give up on raising awareness.

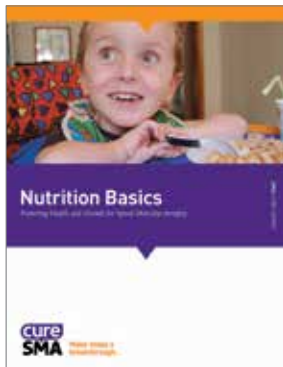
Thanks for all you have done.

Patricia Hunte and Anthony Lynch



# Publications From Cure SMA

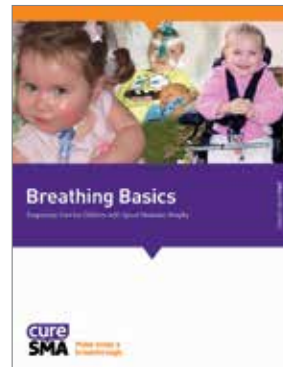
At Cure SMA, we're committed to making sure that families have the best, most accurate information about SMA and what it means for them, from day-to-day care to the changing landscape of research breakthroughs. Our care series booklets provide in-depth information on medical issues, genetics, and other topics of interest to both families and healthcare providers.



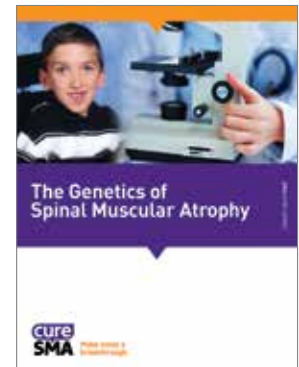
**Nutrition Basics**



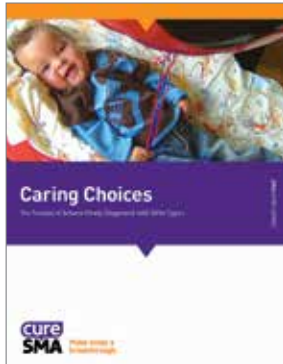
**Cure SMA Family Support and Patient Services**



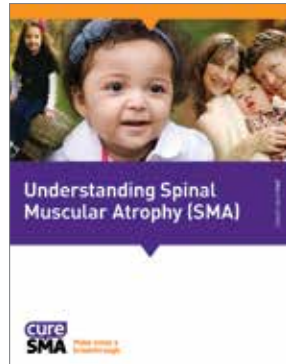
**Breathing Basics**



**The Genetics of Spinal Muscular Atrophy**



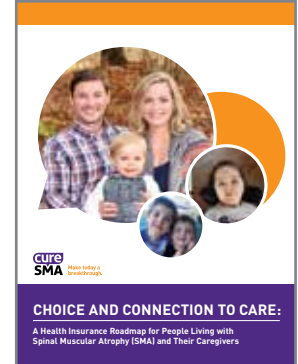
**Caring Choices**



**Understanding Spinal Muscular Atrophy (SMA)**



**Musculoskeletal System**



**Choice and Connection to Care: A Health Insurance Roadmap**

## For electronic copies:

Download this booklet from the Cure SMA web site at [www.cureSMA.org](http://www.cureSMA.org). Go to the support & care publications section on our website.

## For print copies:

Please contact the Cure SMA national office at [info@curesma.org](mailto:info@curesma.org).

**If you would like a hard copy mailed to you please email us at [info@curesma.org](mailto:info@curesma.org) or call 800.886.1762**

## Disclaimer:

*Cure SMA does not, as an organization, support or endorse any particular treatment or therapy. Information contained in this booklet is for informational and educational purposes only. All medical information presented should be discussed with a qualified physician.*



# cure SMA 2018

CURE SMA MERCHANDISE



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



**Cure SMA Adjustable**

**Baseball Hat | Cost: \$20**

This new Cure SMA hat comes in charcoal gray and has a low-profile unstructured fit. The front of the hat features the Cure SMA logo embroidered in the lower right corner and cureSMA.org embroidered on the back. The back of this baseball hat features an adjustable fabric strap with tri-glide buckle that allows you to customize your fit.



**Cure SMA Unisex Full**

**Zip Hoodie | Cost: \$49**

Style meets comfort with this popular new unisex full zip hooded sweatshirt! This trendy purple hoodie has a new Cure SMA circle design screen printed with white ink on the front left chest and enlarged on the back allowing you to spread SMA awareness everywhere you go! This design is printed on ringspun cotton and polyester which guarantees softness and comfort.



**Cure SMA Unisex and Youth**

**Baseball Tee | Cost: \$25**

Join the Cure SMA team with our new baseball tee! You and your little one will be ready for game day with this comfy athletic baseball tee available in heather gray featuring vintage purple 3/4 sleeves. This vintage jersey features a large number 50 on the back of the tee which represents the 1 in 50 people who carry the gene causing SMA. Available in both adult and youth sizes!



**Cure SMA Onesie | Cost: \$18**

Our Cure SMA Onesie lets our newest family members show their support for SMA! Made of 100% combed ring spun cotton for a natural softer feel. It's reinforced with three-snap closures to stay closed after hours of playtime.



**Cure SMA Vinyl Decal | Cost: \$5**

Make a statement and show your support by displaying the Cure SMA logo on any window or flat surface with this white vinyl decal. Made of vinyl and applied with transfer paper, this decal is easy to apply. There is no sticky background surface, just a 5"x3.7" white decal that you can apply anywhere. Easy to remove, this decal will not damage your paint like a sticker would.



**Cure SMA Popsocket | Cost: \$10**

The Cure SMA Popsocket can be used in a number of ways. It can be used as a collapsible grip which provides a secure way to hold your phone. It can also be used as a stand or to wrap up your headphone cords to store them neatly. The Cure SMA logo also allows you to spread awareness wherever you go!



**Cure SMA Unisex Orange**

**V-Neck Tee | Cost: \$24**

You won't want to take off this super soft and trendy new Cure SMA tee featuring a uniquely soft orange v-neck tri-blend fabrication and a modern fit for both men and women. The front of the shirt has our Cure SMA logo screen printed in bright white ink on the front left chest and the back features a unique new design highlighting our name "CURE" with SMA in small print repeating inside throughout the block lettering.



**Cure SMA Grey Crew**

**Neck Tee | Cost: \$24**

You won't want to take off this super soft and trendy new Cure SMA tee featuring a uniquely soft grey tri-blend fabrication available in both toddler, youth and adult sizes. The front of the shirt has our Cure SMA logo screen printed in bright white ink on the left chest and the back features a unique new design highlighting our name "CURE" with SMA in small print repeating inside throughout the block lettering.



**Cure SMA Fidget Spinner | Cost: \$6**

The Cure SMA Fidget Spinner is a fun new toy to add to your kid's collection! It is made of strong and durable plastic with steel ball bearings in the center for smooth spinning. Spinners can also be used to relieve stress, lower anxiety, eliminate boredom and increase focus. The Cure SMA logo also allows you to spread awareness wherever you go!



**Cure SMA Men's Performance**

**Half Zip | Cost: \$49**

Comfort and function describes our new Cure SMA performance half zip pullover! Made of moisture-wicking material, this performance shirt is designed to keep you dry and comfortable all day long! Reflective details on the right sleeve and lower back add to this unique style. Also available in both women's and men's sizes!



**Cure SMA Women's Performance**

**Half Zip | Cost: \$49**

Comfort and function describes our new Cure SMA performance half zip pullover! Made of moisture-wicking material, this performance shirt is designed to keep you dry and comfortable all day long! Reflective details on the right sleeve and lower back add to this unique style. Also available in both women's and men's sizes!

## Cure SMA Chapters

The mission of our Chapters is to support families and fundraise for SMA, giving hope to families in their community. Chapter fundraisers include Walk-n-Rolls, golf tournaments, gala events and more. Chapter support includes providing resources to families affected by SMA, linking families together for mutual support and providing public awareness in their communities for a wider awareness of SMA.

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## Chapter Highlights

### Arizona Chapter



## 12th Annual Arizona Walk-n-Roll

The 12th Annual Arizona Walk-n-Roll was held on November 4, 2017 at Papago 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 **\$20,000** in support of a cure for SMA. Participants enjoyed a delicious lunch provided by the Arizona Barbeque Association, various activities and games, and an amazing raffle.

*A special thank you to the volunteers that came out to the event, including the Occupational Therapy students from A.T. Still University. A huge thank you to Angel Wolff and her committee for another wonderful walk in Arizona!*



## Arizona Evening of Hope

The 2nd Annual Arizona Evening of Hope – Wine Tasting and Art Auction was held on October 7, 2017 at Su Vino Winery in Scottsdale, AZ. Attendees gathered together to enjoy an elegant evening out consisting of local wine from Su Vino Winery, delicious hors d'ourves, and live and silent auction items. This year's event raised over \$7,200 for SMA.

*A special thank you to Bo Buchanan and his committee for spearheading this event!*

*Note: The amounts raised and shown are totals as of February 11, 2018 and may differ from current fundraising totals by the time you get this newsletter.*

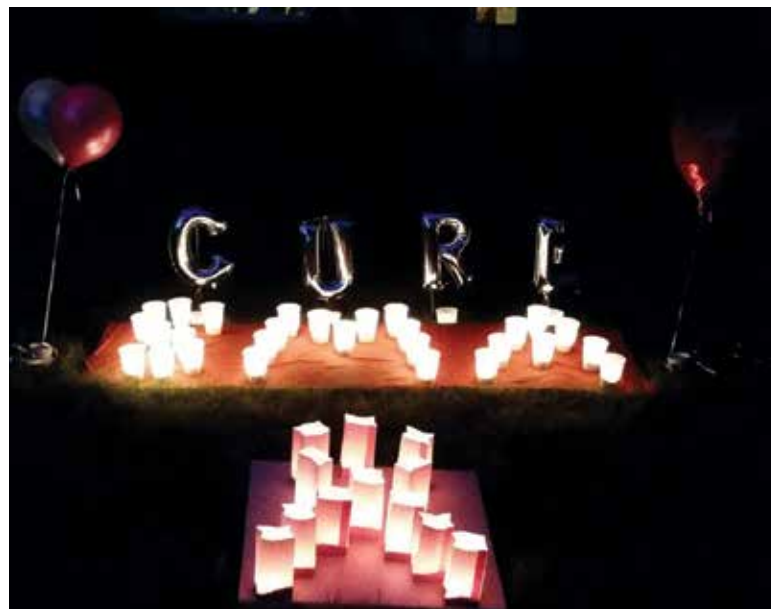
## Arizona Chapter *Continued*



### AZ BBQ Showdown

Cure SMA was once again the benefitting nonprofit for the Arizona Barbeque Association BBQ Showdown! The Arizona Chapter volunteers sold sample tickets for the showdown that took place on January 27, 2018 at Pleasant Harbor in Peoria, AZ. The event was a huge success, raising over \$4,300 for Cure SMA.

*A special thank you to the AZ BBQ Association for choosing Cure SMA as the benefitting nonprofit and to all the volunteers that came out in support of the event.*



### SMA Day with the Arizona Diamondbacks

In honor of SMA Awareness Month, the Arizona Chapter came together at Chase Field on August 27, 2017 for SMA Day with the Diamondbacks! After a decisive victory over the San Francisco Giants, kids got to run the bases on the field, and the Diamondbacks donated a portion of tickets sales to Cure SMA! This event not only helped spread awareness, but also raised \$74 to fund a Cure for SMA.

*Thanks to everyone who came out for a day of SMA and baseball!*

# 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

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

Note: The amounts raised and shown are totals as of February 11, 2018 and may differ from current fundraising totals by the time you get this newsletter.

## Carolinas Chapter



## Raleigh Walk-n-Roll

North Carolina

The 5th Annual Raleigh Walk-n-Roll took place on September 30, 2017 at Anderson Point Park in Raleigh, NC. For the last five years this event has been run by exceptional committee members and dedicated volunteers who always make sure the day runs smoothly and that everyone is having a great time. It was a beautiful day for everyone to enjoy walking together for a cause dear to their hearts. While the families all mingled with one another, kids played fun games like corn hole and giant Jenga, waited in line to get their faces painted and were entertained by a magician.

This year we are very pleased to say the walk surpassed its original goal of \$10,000 and raised a total of **\$31,261!**

*A huge thank you to Jennifer Lee, Remona Sandridge, Marla Kasper, Carrie Ann Boles, Bekka Mastin and all their family and friends for all the planning and time they put into this event. We could not have done it without you! Thank you to all the volunteers who came out to help. You all contributed to making this event the success it was.*

*Note: The amounts raised and shown are totals as of February 11, 2018 and may differ from current fundraising totals by the time you get this newsletter.*

**Carolinas Chapter** *Continued*



## Little Man Memorial Golf

On June 16 and 17, 2017 the 10th Annual Little Man Memorial Golf Tournament and Banquet took place at Warren County Armory. This wonderful day was filled with hope and celebration.

Teams had fun competing in the golf tournament and other attendees got to bid on auction items and enter to win raffle prizes. This year's event raised a total of **\$10,000** for Cure SMA!

The Little Man Foundation was founded in 2009 and created in memory of Joseph Blaine Reese with proceeds raised going to benefit Duke Children's Hospital in North Carolina and Cure SMA. The Little Man Foundation has been hosting this amazing event every year for the past 10 years and we truly appreciate their continued and generous support of Cure SMA.

*A special thank you to Joanne and Blaine Reese for all the work they put into this event every year.*



## Mistletoe Jam

South Carolina

This year's Mistletoe Jam took place on Friday, December 8, 2017 at the Southside Smokehouse and Grille. Everyone who attended enjoyed live music and good times all while raising \$3,145 in honor of Alexandra Genovese.

*A big thank you to Chris Genovese and Don McInerney for hosting this event each year.*



*Note: The amounts raised and shown are totals as of February 11, 2018 and may differ from current fundraising totals by the time you get this newsletter.*

## Northern California Chapter



## 15th Annual Northern California Walk-n-Roll

The 15th Annual Walk-n-Roll was held on August 20, 2017 at Golden Gate Park in San Francisco. Dr. John Day from Stanford University Medical Center updated us on the latest SMA research, and Cure SMA President, Kenneth Hobby, thanked event organizers for their dedication and support to Cure SMA for the past 15 years! Thanks again to Linda Shively, Marge Shively, David Sereni, and Dick and Patricia Wolff, we appreciate everything you have done!

The morning started off with energetic warm up exercises and stretches before heading out on the two-mile walk. We paused at the Conservatory of Flowers for our traditional photo before proceeding to Rainbow Waterfall and back to Peacock Meadow. The fun continued in the green space area with face painting, games, lunch, and a lively raffle and juice kindly donated by Barsotti Juice Company. This year, the event raised a record **\$98,000** for Cure SMA which included over 39 teams and 400 participants!

*Thank you to our families and friends for their generous donations and to our sponsors: Biogen, Avexis, Bayada, Cytokinetics, Sutter Health Palo Alto Medical Foundation, Live Rhystrong Foundation, Echos, and Make-a-Wish Greater Bay Area! Can't wait to see you again next year at our next location!*



*Note: The amounts raised and shown are totals as of February 11, 2018 and may differ from current fundraising totals by the time you get this newsletter.*

## Southern California Chapter



## 2017 Reach4Sky Swimfest

On October 8, 2017, Team Reach4Sky participated in their 7th bi-annual fundraiser as part of the San Diego Sharkfest Swim to honor the memory of Skylar Bahrenburg and raise funds for Cure SMA. Over 20 swimmers (ages 13-82) completed a 1-mile open water swim from San Diego to Coronado Beach and were joyfully greeted by over 75 supporters. Team Reach4Sky was honored to include 15 remote swimmers from the UK to Vermont and Hawaii.

“Our purpose was to have fun, finish safely, and raise money and that’s where you came in.” While planning the swim, the Bahrenburg family set a goal of 250 donations. This goal was surpassed with 279 donations and **\$38,650** raised!

“In his short life, Skylar had profound impact on those who knew and loved him. We are grateful for your part in allowing us to honor his memory in such a meaningful way. Wow what a race, what a weekend, what a wonderful way to celebrate the life of Skylar Bahrenburg!”

-Jim and Liz Bahrenburg

*Cure SMA would like to congratulate and thank the Bahrenburg, Matthews, Amlicke, and Quade families for their hard work and dedication in planning the weekend full of fun events. The funds and awareness that were raised are inspiring and we hope one day we will find a cure for spinal muscular atrophy.*

## Remembering Alexandra Nina Meigs' 10th Birthday



Every October 24th, we remember Alexandra Nina Meigs and celebrate her birthday. She would be 10 years old this year. We miss her so much but we continue to remember her by contributing to Cure SMA—determined to help find a cure for this terrible disease that took her life too soon.

Since Alexandra passed on New Year's Day in 2008, our family and friends have come together to raise over \$104,000 for Cure SMA. John and I truly appreciate our family, friends, and community who have supported this cause that is most personal and so dear to our hearts.

As we celebrated Alexandra's 10th birthday, we also wanted to celebrate the great news announced at the end of the year when the FDA approved Spinraza -- the first-ever approved therapy for SMA. Your contributions over the years have gotten us to this point and we're beyond appreciative. From the combined celebration of her 10th birthday and the Spinraza announcement after her passing, our family and friends raised another **\$31,000** this year alone.

John and I, along with Avery, Isabella and Calla, can't help but imagine how different our lives would be if Alexandra had the opportunity to access Spinraza. We wonder...would Alexandra lived to be with us today? Either way this progress is a dream come true.

As such, we wanted to say thank you as we celebrated this historic year for Cure SMA on Alexandra's birthday. We thank our family and friends for their generosity, friendship, and helping make Alexandra's life count for something great. Thank you for helping to keep her memory alive while helping us find a cure.

- Andrea and John Meigs

## Letter Writing Campaign in Memory of Ryann Stoll

*Thank you to Will Stoll and family for dedicating their time for a letter writing campaign in memory of Ryann Stoll in October. With their efforts, \$2,895 was donated to Cure SMA!*

*Note: The amounts raised and shown are totals as of February 11, 2018 and may differ from current fundraising totals by the time you get this newsletter.*

## Dinner and Donate at Ruby's – In memory of Jaimie Ramsey

On November 8, 2017, Ruby's Diner of Tustin, CA, held a dine and donate night to bring community awareness to SMA. Lynn and Ade DeBlaiso hosted the event at Ruby's where they welcomed and educated the dinner guests about SMA. Overall, the event raised over \$300 for Cure SMA in memory of Jaimie Ramsey, granddaughter of Lynn and Ade. *Thank you for your continued support!*

## San Diego Padres SMA Awareness Day

The 4th Annual San Diego Padres SMA Awareness Day took place on August 19, 2017 in San Diego, CA. The day brought together friends and family members for a fun afternoon at Petco Park.

*A huge thank you to Ionis Pharmaceuticals for sponsoring the families to attend this game!*

With the tremendous support we received at last year's UPB vs SMA fundraiser along with other fundraisers throughout the country over the years, the first drug, Spinraza, was approved by the FDA in December 2016. Thankfully our son has already received his fifth treatment in September 2017.

This drug has been life changing for those with SMA, however, this is not a cure and there is still work to be done! Researchers are working to find more treatment options and eventually, a cure. Thank you to everyone at UPB for making the event a great success. It was a day full of food, games, a bounce house, face painting, crafts and much more! Because of your support, the UPB Walk-n-Roll raised \$6,590!

*- Matt and Christine Bickel*

*Cure SMA would like to thank Matt and Christine Bickel for all their hard work and dedication to helping the SMA community find a cure for SMA.*

## Our Little Jewels Golf Tournament

On September 22, 2017, Our Little Jewels held its 9th Annual Benefit Golf Outing. The event was held at The Links at Challedon in Mt. Airy, MD. Our Little Jewels donated \$5,000 to help fund the research efforts of Cure SMA.

*Thank you to Jimmy Lewis and Our Little Jewels for their continued support of Cure SMA and the Chesapeake Chapter!*

### Chesapeake Chapter



## UPB Walk-n-Roll to Cure SMA

Maryland

On September 30, 2017, the United Parish of Bowie held a Walk-n-Roll to raise money to find a cure for SMA. Our son, Kyle, is 13 years old and affected by SMA.

*Note: The amounts raised and shown are totals as of February 11, 2018 and may differ from current fundraising totals by the time you get this newsletter.*

## 1st Annual Kaiden's Cup

On October 16, 2017, 60 golfers teed off at Ron Jaworski's Ramblewood Country Club in Mt. Laurel, NJ, to support the SMA community. Although it was a little cold and windy that didn't stop everyone from having a good time. The event raised \$4,660, all which was donated to Cure SMA. Our sponsors were a great help in kicking off the first year: Action Mailers, Helios Data, Annie Mac, Farmers Insurance Thomas Wittman Agency, Renegade Communications, Holman Industries, MCS Inc., Think Ink, MCS Services, along with over 40 hole sponsors.

The 2017 event was such a great success and we are excited for the 2nd Annual Kaiden Cup, scheduled for October 8, 2018. We hope to see you there and remember to register early at [www.thekaidencup.org](http://www.thekaidencup.org) to secure your foursomes in this fun event.

*Cure SMA would like to thank the DeFazio Family and Fighting for Kaiden Foundation for your continued support of Cure SMA and congratulate them on this new event!*



## Show Max Strength for SMA

In August 2017, Max's birthday month, the Lasko Family decided to celebrate his 4th birthday with an online fundraiser to reach a goal of \$4,444. With the support from donors throughout the US, the Laskos raised over \$4,000 in honor of Max!

*The Laskos wish to thank all the amazing friends and family who donated to Cure SMA in honor of Max's birthday.*



## 2nd Annual SMA Awareness Party

The 2nd Annual SMA Awareness Party in loving memory of Owen Jonas Close was held in August 2017. The night included a hay ride, piñata for the kids, and a candle lighting ceremony in memory of Owen and all of those affected by SMA. The Close Family is grateful to all their friends and family who helped make this night a success.

*Thank you to the Close Family for hosting the SMA Awareness Party in Accident, MD, and raising \$1,125 for critical SMA research and family support programs.*



## 21st Annual Arnold Family Golf Outing

West Virginia

In 2017, the Arnold Family Golf Outing reached its 21st year! This longstanding event was held on October 9, 2017 at Berry Hills Country Club in Charleston, WV.

*Thank you to Linda, Kevin, and Eric for donating \$7,000 to Cure SMA and their unwavering support that has led to incredible treatments like Spinraza.*

*Note: The amounts raised and shown are totals as of February 11, 2018 and may differ from current fundraising totals by the time you get this newsletter.*

## Connecticut Chapter

### SMA Awareness Day with the Hartford Yard Goats

The families in Connecticut had a great day cheering on the Hartford Yard Goats on Sunday, August 20, 2017 as they took on the Reading Fightin Phils at Dunkin' Donuts Park and celebrating SMA Awareness month! It was great to have both long-time families as well as new ones gather for some fun and awareness-raising.

*Thank you to everyone who made this event a success and a big thank you to Macie Tozzoli for her help in organizing this outing!*



### 2018 Goin' for Koen Island Style

On January 13, 2018 the Savannah Parrothead Club hosted its second annual Goin' for Koen Poker Stroll event on beautiful Tybee Island, GA, to support SMA. Sixty-five fun seekers strolled along the beach and strand to five participating establishments where they drew a poker card hoping for either the best or worst hand. The Club also sold tickets for chances to win some awesome raffle baskets and prizes donated by local merchants. Awards were presented at the closing party where everybody had fun singing Karaoke. After the event ended a party ensued and everybody made return trips to the fun restaurants and bars that participated in the event. Participation from the 30 Chicagoland participants was unprecedented and they all had a great time on Tybee as they partied for a great purpose. Koen could not have been happier.

*The Savannah Parrothead Club is already planning for next year. Save the Date: January 19, 2019.*

## Georgia Chapter

### Rock 'n' Roll Savannah Marathon and Half Marathon



*Thank you to our amazing Team Cure SMA runner, Anami Lehmann, who participated in the Rock 'n' Roll Savannah Marathon and Half Marathon in November 2017! Anami ran in memory of her daughter, Louisa Lehmann. She raised an incredible \$2,635 for Cure SMA!*

## 2017 Summer Cool Down in Georgia

*Thank you to Patricia Parajon for organizing Prosecco and a Pop - Sunday Funday for Cure SMA! Patricia partnered with King of Pops to raise funds and awareness for SMA. On August 27, 2017 supporters gathered at the King of Pops location in Atlanta, GA for a fun afternoon including a raffle and plenty of prosecco and pops for everyone! Patricia raised an incredible \$595 for Cure SMA.*

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## Greater Florida Chapter



## 2017 Greater Florida Chapter Walk-n-Roll

The 9th Annual Greater Florida Chapter Walk-n-Roll was held on November 4, 2017 at Lake Parker Park in Lakeland, FL and it was a huge success! Over 150 participants and 17 teams joined us this year. Together we raised more than **\$26,000** for Cure SMA! Our “When You Wish Upon a Cure,” theme enchanted and entertained all our participants and special guests!

A special thank you to our event organizers Audra Butler, Laurie Sore, Asia Nowotny and Katie Kearns for all their hard work and dedication.

*Thank you to all our hardworking teams for all their fundraising this year: Team 2 Angels, Allison Wonderland, Arms for Asher, Andy’s Army, Team BAYADA, Brooks Wolfe Pack, Chris’ Charisma, Ember’s Fire, Home Team for Ezra, House of K, Jaceys Journey, Team Lucas, Mama Needs a Miracle, Positive Vibration, Rhydian’s Rockers & Rollers, and Tianna’s Troops.*

## Illinois Chapter



## 2017 Chicago Half Marathon & 5K

Members of Team Cure SMA ran the Chicago Half Marathon & 5K on September 24, 2017, in Chicago, IL.

This is the seventh year that Cure SMA participated in the run as an official charity partner and it was another special year as Koen Guest was able to be a part of the race as his mom, Noel, pushed him in a special stroller all 13.1 miles for a second year in a row!

Together, the runners raised over **\$13,000** to help Cure SMA!

Cure SMA would like to thank all our runners; Noel Guest, Koen Guest, Mary Beth O’Donnell, Vanessa Stokes, John Spina, Genevieve Spina, Kim Phillips, Sharon Stokes, Jake Stokes, Michelle Yohler, Alyssa Gravitt, Donnie Gravitt, Sierra Gravitt, Ron Gravitt, Jack Gonciarczyk, and Raelee Gravitt for their hard work in training to run this race as well as all their fundraising efforts!



## CorePower Yoga Donation Classes

A little over a year ago I became personally connected to building awareness for this disease as my childhood friend Adrianna and her husband Scott’s 6-month-old daughter Alexandria was diagnosed. Within minutes their world was turned upside down. Since then they have become advocates for developing awareness about SMA and helping fundraise for the Cure SMA organization. I always wonder what I can do and decided that this year I would start pulling together as many yoga studios as I could to host a donation-based class. This year my company InnerJasmine is collaborating with CorePower Chicago Suburban Studios and Revival Yoga Studio in Palos Heights to build awareness and help Cure SMA find a cure.

Thank you,

Katya Sidelnik

*Cure SMA would like to thank Katya Sidelnik for organizing over 21 donation-based classes throughout SMA Awareness Month in August which helped raise a ton of awareness and over \$1,700 for Cure SMA.*

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## Poetry Reading Event

In honor of our relative, Katie, and the SMA community, Joris Soeding and family decided to donate 100% of proceeds from his recent poetry book at an author reading at the Niles- Maine District Library, in Niles, IL. The book release reading took place on Sunday, April 2, 2017. The reading also coincided with National Poetry Month and was a huge success! Many family members and library patrons attended to support Kate, Cure SMA, and poetry. \$247 was raised for Cure SMA. Thank you very much for your vital efforts. Our families in Chicago and Dallas are so appreciative for your ongoing research, resources, and success stories. We wish you a wonderful and remarkable start to 2018.

Sincerely,

Joris and Family



## 2017 Illinois Chapter Holiday Party

The Illinois Chapter hosted a holiday party on Saturday, December 16, 2017 at Lurie Children's Hospital in Chicago. 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 arts and crafts 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 Jenny Kean and Anna Goldberger from Lurie Children's for their help in organizing this fun family event!*

## Iowa Chapter



## 21st Annual Beaverville Beaverdash

The 21st Annual Beaverville Beaverdash took place on September 16, 2017 in Des Moines, IA. With 7 teams and over 165 participants the event was once again a success! This year's Beaverdash raised over **\$14,000** for Cure SMA. We can't wait to see you again this September.

*Thank you to the volunteers, teams, and everyone who participated! A special thanks to Julie Greenwood for organizing another successful event.*

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## Kansas City Chapter



## 2017 Kansas City Walk-n-Roll

Kansas

The 2017 Kansas City Walk-n-Roll took place on August 26, 2017 in Roeland Park, KS. SMA families gathered together to support the event and enjoyed food, music, and a 5K walk. 14 teams were formed to help reach our fundraising goal to help fund a cure for SMA.

The event was a great success, raising over **\$34,000!** Thank you to everyone who supported and attended the Kansas City Walk-n-Roll.

*Thank you to Kim Sykora and Kristal Wilson for helping organize this walk!*

## 14th Annual Bommarito Car Show

Missouri

The 14th Annual Bommarito Z Club Car Show took place on September 3, 2017. The event honoring Brittany Carpenter, and in memory of Madeline Schmidt and Michael and Brian Goodyear, raised **\$23,337** to benefit Cure SMA.

*Thank you to Janet Hutchinson and all members of the Z Club for your continued support!*

## 2017 St. Louis Marathon

Team Cure SMA participated in the 2017 Michelob Ultra Rock 'N' Roll St. Louis Half Marathon held on October 15, 2017 in St. Louis, MO. Everyone teamed up to run the half marathon to raise money and awareness for Team Cure SMA. In total, our runners raised \$3,058.

*Thank you to our runners, Callie Bushmeyer, Melanie Guthrie, Brittany Meyer, Stephanie Rennecker, and Jenna Yelliott!*

## 2nd Annual Forest Hills Golf Charitable Foundation Gala

The 2nd Annual Forest Hills Charitable Foundation Gala took place on January 20, 2018 in Chesterfield, MO. Cure SMA was represented by two tables at the event and raised \$3,050.

*Thank you to Valerie Giglio for choosing Cure SMA as her charity of choice for this event in honor of her grandson, Luke.*

## 2017 Phi Tau Omega Trivia Night

The Annual Phi Tau Omega Trivia Night took place November 4, 2017 in St Louis, MO.

*Thank you to Kathy Goodyear and the Delta Phi Chapter of Phi Tau Omega for helping raise \$2,220 in honor of Brittany Carpenter and in memory of Michael and Brian Goodyear.*

## 2017 Kansas City Scare Away SMA

The 2017 Kansas City Scare Away SMA took place on October 29, 2017 in St. Louis, MO. Over \$1,000 was raised in honor of Matilda (Tilly) McRoberts. *Thank you to Leslie Derrington for organizing such a great event!*



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## New England Chapter



## Cure SMA Day at Mast Landing Brewing Company

Maine

The Cure SMA Day at Mast Landing Brewing Company took place on October 28, 2017 at the brewery in Westbrook, ME. A big thank you to Mast Landing Brewing Co. for partnering with Cure SMA to make this event such a success; they donated their venue for the day along with the proceeds from all beer sold at the event. Activities included a cornhole tournament, a Halloween costume contest, and a 50/50 raffle.

This event was started by Joel and Jenny Arnold in honor of their daughter, Jordan, who has SMA. Their family, friends, and community rallied around them to make this event such a success.

*A huge thank you to Joel and Jenny, and their whole Westbrook community, for their tireless work to put this event together and raise over **\$11,000** for Cure SMA!*



## 1st Annual Evening of Hope in Honor of Natalia

Massachusetts

The 1st Annual Evening of Hope in Honor of Natalia took place on October 21, 2017 at the Knights of Columbus in North Easton, MA. Guests enjoyed cocktails, hors d'oeuvres, music and dancing, and a silent auction that included a signed Kenny Chesney Guitar and a New England Patriots helmet signed by Rob Gronkowski.

This event was started by Marisa Boidi in honor of her daughter, Natalia, who was diagnosed with SMA at eight weeks old. Marisa started this event in hopes that she could raise \$20,000 for Cure SMA, but she tripled her goal and raised over **\$62,000!** Marisa's family, friends, and community gathered around her to make this event such a success.

*A huge thank you goes out to Marisa for her tireless work to put this event together, secure 22 sponsors, and overall raise so much for Cure SMA. We hope to see everyone again at the 2nd annual event in the fall!*

*Note: The amounts raised and shown are totals as of February 11, 2018 and may differ from current fundraising totals by the time you get this newsletter.*



## New Balance Falmouth Road Race

For the 3rd year in a row, Team Cure SMA joined thousands of runners to enjoy the famous New Balance Falmouth Road Race in Woods Hole, MA. We ran along the hilly, scenic seven-mile course in bright orange shirts, proudly raising awareness for Cure SMA.

*Thanks to our team's generous donors, our 15 runners raised over \$17,000 for Cure SMA!*

Plans are already underway for this year's race on Sunday, August 19, 2018. If you'd like to join us in one of the country's most popular and beautiful race courses, please reach out to Hannah at [Hannah@curesma.org](mailto:Hannah@curesma.org). We look forward to running in support of a cure!

*-Lin Lavalle, Milton, MA*



## 4th Annual Wakefield 5K

On August 26, 2017, 218 participants came out in support of the 4th Annual Wakefield 5K at Lake Quannapowitt in Wakefield, MA. It was a beautiful and sunny summer morning, and the race field was full of runners, walkers, and rollers who enjoyed a picturesque trip around the lake. Participants received an awesome race t-shirt and were automatically entered into some raffles! The course was chip timed by Race Wire and everyone enjoyed music and snacks after the race. Over **\$16,000** was raised for Cure SMA, and we are so grateful to all who ran, walked, rolled, strolled, supported, volunteered, and donated! There was a huge list of raffle prizes for which all registered participants were entered, including a variety of gift certificates, prizes and baskets.

*A huge thank you goes out to Kristen Farrell, the Wakefield 5K Race Director, for all her tireless hard work to make this event such a success year after year.*

We are looking forward to the 5th Annual Wakefield 5K in August of 2018 and will be excited to have even more participants and more fun this year!

## 4th Annual Medfield Pub Crawl for Cure SMA



Thanks to Joe and Renee Romanowski and the Crawl Committee, the 4th Annual Medfield Pub Crawl in honor of William Johnson was a huge success; they raised over

**\$11,000** for Cure SMA! On Saturday, November 4, 2017, 150 registered crawlers grouped in teams of ten strolled the streets of Medfield, MA, as they hit eight different local bars throughout the afternoon. William was even able to kick off the event at the first stop where all teams gathered around the huge bar as he helped pull raffle winners and could send the teams out on their various routes for the day. We hope to see you at our 5th Annual Crawl this fall!

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## 11th Annual Ride for Alex

*Thanks to Tammy Foisy and everyone who helped make the 11th Annual Ride for Alex such a success!*

*The funds raised at this annual event in Freetown, MA, are split between Alex's family and Cure SMA, and this year they generously donated over \$1,500 to Cure SMA! The event was so successful that Alex's family was able to buy him a new and bigger van, so he can continue to go out and about with his family! Thanks again to everyone who helped make this event a success!*



## 1st Annual Cure SMA Hike for a Cure

New Hampshire

Thanks to Natalia and Jason Wylie and Gunstock Mountain Resort of Gilford, New Hampshire for teaming up for the 1st Annual Cure SMA Hike for a Cure event in honor of Sofia Wylie. Thanks to their hard work it was a huge success; they raised over **\$15,000** for Cure SMA! On September 9, 2017 more than 140 eager runners, hikers, walkers, and rollers enjoyed a day of fun for a great cause. The sun was shining, and the surroundings couldn't have been more picture-perfect that day. 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 that took a mile-long stroll through the Gunstock Campground.

The hikers and runners were treated to a chairlift ride back down the mountain if they wished and the rest of the registrants were given the opportunity to ride the chairlift round-trip for a scenic ride. After the hike and walk, everyone was invited back to the lodge for a cookout BBQ and the adults were treated with a complimentary beer thanks to the generous donation from Woodstock Brewery. They finished the day off with drawings for more than 40 raffle items and several silent auction items. It was a fun day! Come join us this September at the 2nd Annual Hike for a Cure; we can't wait to see you!

## SMA Awareness Day with the New Hampshire Fisher Cats

The families in New Hampshire had a great day cheering on the Fisher Cats on Sunday, August 27, 2017 as they took on the Hartford Yard Goats at Northeast Delta Dental Stadium and celebrated SMA Awareness month! It was great to have both long-time families as well as new ones gather for some fun and awareness-raising.

*Thank you to everyone who made this annual event a success! We are looking forward to doing it again this year and hope you can join us!*



## 3rd Annual Rhode Island Walk-n-Roll

Rhode Island

The 3rd Annual Rhode Island Walk-n-Roll took place on Saturday, October 14, 2017 at Colt State Park in Bristol, RI. A record breaking 12 teams participated and there were over 140 people in attendance. Our walkers and rollers met at Colt State Park that morning for the 1.5-mile picturesque walk that ended along Narragansett Bay. Snacks and a raffle followed, along with some carnival games for the kids that were handmade by Declan Murphy, and everyone was able to take home a pumpkin! *Thank you to organizer Lynne Vaudy and her family and friends who made this event possible and helped raise over **\$21,000** for Cure SMA! We hope to see you at our 4th annual event this fall!*

*Note: The amounts raised and shown are totals as of February 11, 2018 and may differ from current fundraising totals by the time you get this newsletter.*



## 8th Annual Working on Walking Fundraiser for SMA

On a beautiful night in August of 2017, Working on Walking held its 8th Annual Fundraiser for SMA in Providence, RI. Overlooking the picturesque city skyline, hundreds of people gathered to celebrate a night in the city and an incredible milestone reached: the first drug treatment approved by the FDA. Filled with love, hope, and some killer dance moves, this evening raised thousands of dollars to support SMA research through the kindness and generosity from so many remarkable people that evening. Rhode Island congressmen and members from Biogen were also in attendance. Working on Walking would like to express the utmost gratitude to those near and far who make each year a success.

*Thank you so much to Alissa Silva, the founder of Working on Walking, who donates a portion of the total raised each year to Cure SMA. This year, Working on Walking contributed \$10,000! Thank you again to everyone who made this event possible!*



## 2018 SMASH SMA

Vermont

In October of 2012, during my senior year of college, my family faced a devastating diagnosis. It was discovered that my dad's cousin's daughter, Emma, was diagnosed with a rare genetic disorder: SMA. Only ten days later, their newborn baby Ruby was also diagnosed with SMA.

When I began teaching three years ago, I made it my mission to teach my students how to be good people. Outside of reading and writing, I want my ultimate goal to be to inspire my teens to want to do good in the world, and to help those who are less fortunate than themselves. There is always somebody who needs just a little bit more love, just a little bit more support, and just a little bit more opportunity/encouragement. One of my first stories I told them revolved around SMA and my continued fight to spread awareness of this disease as well as raise support and funds to help doctors continue to find a cure.

In the fall of 2015, I asked my soccer team to SMASH pumpkins with me in support of a disease that only a few of them had ever heard of. I decided to hold an event this past fall to take our pumpkin SMASHing to the next level- we added a two-hour soccer clinic to our program, and we went from three pumpkins in our first year to 30-40 pumpkins in our second year. We went from just our team to a whole crowd of community members there to support our efforts. We had Cure SMA tattoos, Cure SMA bracelets, and a new commitment and understanding of our unified fight to Cure SMA. Every effort counts, no matter how small in the large scheme of things. Emma and Ruby may be small beings in our large world, but they are stronger and more powerful than anybody else I know. Every effort they make each day shatters the odds that they were given!

-Casey McGill

*Thanks to Casey's efforts, they raised over \$100 in 2017!*

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## Michigan Chapter



## 2017 Michigan Chapter Golf Outing

We had a beautiful day for the first ever Michigan Chapter Golf Outing at the Grand Haven Golf Club.

*Thank you to all the golfers, donors, sponsors and volunteers who helped make this event a fun-filled day and a great way to spread awareness in the Michigan community. With everyone's help we raised \$5,000 to go towards funding research and programs at Cure SMA. Look for more information as we plan to host the 2nd Annual Michigan Chapter Golf Outing in the fall!*

## 2017 Detroit Marathon, Half, & 5K

On October 15, 2017, Team Cure SMA ran as an official charity partner in the Detroit Free Press Chemical Bank Marathon and raised \$1,219 to help find a cure for SMA.

*Thank you to our runners, Soo Jeong Hong and Kawangjin Lee, for all the hard work you put in to raise funds for Cure SMA!*

We would love to have you be a part of Team Cure SMA in 2018 as we partner again with the Detroit Free Press Marathon on October 20 and 21, 2018.

## 2017 Cure SMA Day with the Detroit Tigers

*Thank you to all the families that came out to the 2017 Cure SMA Day with the Detroit Tigers on September 17, 2017, to help raise awareness for SMA. Thank you to the Detroit Tigers Foundation for donating to tickets to all our families, it was a great day at the ballpark!*

## Minnesota Chapter



## 2017 Minnesota Chapter Walk-n-Roll

On September 9, 2017, the Minnesota Chapter held its 17th Annual Walk-n-Roll at Central Park in Roseville, MN. The day included a raffle, silent auction, and food sale for everyone to enjoy. With 14 teams and 236 people in attendance we raised over **\$19,000!**

Thank you to Kara Forcier, Jamie Mevissen, Matt Czech and Jon Schwerr for helping organize the event. We also want to thank our amazing teams, volunteers and donors. We look forward to our next walk in September!

*A special thank you to the teams that participated this year: Incredible Dash, Sweet Baby James, Team Xavier, Team Andrew, Team Antonio, Team Bayada, Team Britta, Team Brody, Team Gulden, Team Holly Cory and Kate, Team Jessica, Team Jordan, Team Madisyn, and Team Z!*

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## New Mexico Chapter

### 2018 Bugaboo WOD

On September 30, 2017, the New Mexico Chapter along with CrossFit Albuquerque and lululemon athletica hosted the annual Bugaboo Workout of the Day (WOD) at lululemon athletica in Albuquerque Uptown. The event raised over **\$10,000** for Cure SMA in memory of Benjamin "Bugaboo" Abruzzo III.

*A big thank you to lululemon athletica, Joe Vigil at CrossFit Albuquerque, and Natasha and Ben Abruzzo for organizing this event!*

## Greater New York Chapter



### 2017 TCS NYC Marathon

On Sunday, November 5, 2017, Team Cure SMA had six incredible runners from across the USA and Germany run in the 2017 TCS New York City Marathon. Each runner has a special and unique connection to SMA. Jenny Bruner and Melissa Feighery ran in honor of Ashley Bruner, Jenny's 18-year-old daughter. This was Kresh Lozina's second NYC Marathon in which he ran in memory of his daughter, Emily. Josephine Weise ran in memory of her son, Lucas, who passed away at 3 1/2 months old. Lastly, Sarah Bromley and Laura Fletcher dedicated this race to the researchers, patients and families affected by SMA due to their personal connection through Ionis

Pharmaceuticals and Biogen. We are grateful that this group of parents, cousins, and friends came together to help fight for a cure. The runners trained hard in the 6 months leading up to the race and fundraised over **\$22,000!**

*A very special thanks to our official Team Cure SMA runners: Sarah Bromley, Jenny Bruner, Melissa Feighery, Laura Fletcher, Kresh Lozina, and Josephine Weise.*



### 2017 Greater NY Chapter Walk-n-Roll

Thank you to everyone who donated and participated in the 13th Annual Greater New York Walk-n-Roll on October 15, 2017. Despite some morning showers, it cleared up in time for the teams to enjoy a walk around Hofstra University's beautiful campus. The day included a 50/50 raffle, bracelet and pumpkin sale, and raffle items to enjoy! This year's event was a great success due to each family who fundraised and participated with a total of **\$18,210** being raised for critical SMA research and family support programs.

An extra special thanks to each team: Fab Five, Fight for Owen, Florida Skylanders, Friends of Julia, Just for a Cure, Sweet Baby Jack, Team Bear, Team Carissa, Team Farmingdale, Team Juliana, Team Ross, and The Philly Cheesesteaks. And lastly, thank you to all the volunteers, especially Debbie Cuevas and her entire family for organizing this amazing event!

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## Tough Mudder - Emma's Warriors

On October 8, 2017, Philip Halpert participated in the Tough Mudder Tri-State area in Englishtown, NJ. Emma Zelmanovich was the inspiration to train and fundraise for this event.

*Thank you to Philip, his son Joshua and nephew Ethan for your hard work and raising \$5,738 to support Emma's fight against SMA!*



## NY Mets Awareness Game

Friends and families affected by SMA had a wonderful day cheering on the NY Mets at Citi Field on September 24, 2017 in Flushing, NY. Not only was it a day of fun at the ballpark, but the Greater NY Chapter raised awareness by accepting the Spirit Award on the field before the game. Following the game, 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



## 2017 Capital Region 5K / Walk-n-Roll

On September 23, 2017, the Greater NY Capital Region chapter held its 6th Annual 5K / Walk-n-Roll in Colonie, NY at Colonie Mohawk River Park. This year's event honored the memory of Greyson Kelly who lost his battle with SMA in 2016. The Capital Region Satellite chapter raised **\$29,861** and had so much fun in the process! Thank you to our sponsors, Hannaford and Whalen Chevrolet, for the part they played in making this event a success. We also want to thank the Kelly family for letting us publicly honor Greyson's memory.

*Thank you to the Cunniff and Bleau families for their continued support of the Cure SMA families in this chapter, without their support, this day would not be possible.*

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## Capital Region Satellite Chapter *Continued*



## 5th Annual David Cunniff Ice Fishing Tournament

The 5th Annual David Cunniff Fishing Tournament was headquartered at the Dockside Restaurant in Lake George, NY on Glen Lake. The day started at 5:00 am and was a great success with many local vendors who donated prizes, t-shirts, and gift certificates, and thank you to the generous 50/50 raffle winner who donated the \$589 back towards the tournament funds! The ice fishing tournament raised a total of \$2,466 for Cure SMA and is possible through partnering with the NYS Signal 30 Fund, 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, the owner of Dockside Restaurant, for their hard work and efforts to start and promote this tournament. A special thanks to Dan Ladd from the Chronicle newspaper and Channel 6 for attending and raising awareness for SMA.*





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## North Jersey Chapter

### North Jersey Awareness BBQ and Candle Lighting

In honor of SMA Awareness Month, the North Jersey Chapter hosted their first awareness event on August 26, 2017, at Donaldson Park in Highland Park, NJ. Attendees helped spread awareness, but also got to connect with local families and chapters members, enjoy a barbeque and honor their loved ones with a candle lighting ceremony at the end of the evening. We are looking forward to this year's event in August at Donaldson Park!

*Thank you to Kristen Smith and Anna Pham for spearheading this event!*

## OKI Chapter

### 2017 Marion Walk-n-Roll

Indiana

For the past three years we have had nothing short of beautiful weather and wonderful support at the Marion, IN Walk-n-Roll. A huge thank you to the amazing teams who showed up ready for a great day! We have been fortunate with such a thoughtful community who helps tremendously, thank you to the donors for the food, the fun raffle items, and our awesome DJ!

*Finally, this walk would not have been possible with out all of our great participants and donors who all helped contribute funds to Cure SMA's mission. Jessica, Brian, Stacie, Chloe, Leesa, Mike and everyone in between, we truly appreciate all you are doing and continue to do for so many families! With everyones amazing help, we raised just under \$5,000!*

See you all July 28, 2018 the for the 4th Annual Marion, IN Walk-n-Roll this summer!



### Jonah Smiles Refreshment Stand

Kentucky

On August 5, 2017, in Bowling Green, KY, Jonah Smiles hosted a refreshment stand to raise money for Cure SMA. Over \$1,200 was raised in just two hours! Jonah Smiles was founded in memory of Jonah Mckinley Setser who lost his battle to SMA when he was just 11 months old. Friends and family of Jonah will continue to honor his memory and all those who have lost their lives to SMA and those who continue to fight, with a fundraiser every August in celebration of SMA Awareness Month.

*We would like to extend a very special thank you to Breanna and Ashley Sona, two dedicated team members of Jonah Smiles for their wonderful idea to host the refreshment stand!*

*Note: The amounts raised and shown are totals as of February 11, 2018 and may differ from current fundraising totals by the time you get this newsletter.*



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breakthrough.**

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## Apollo High School Homecoming Court Fundraiser

This October Apollo High School in Owensboro, KY allowed students who were a part of this year's Homecoming Court to choose a charity they would raise funds for.

*Thank you to Dalton Curtis, who chose to fundraise for Cure SMA and raised a total of \$315!*

## Birthday Benefit in Memory of Mario Thompson Jr.

Ohio

The Thompson family hosted a benefit in memory of Mario Thompson Jr. on September 17, 2017 in Brunswick, OH. Attendees enjoyed the evening of fun, all while remembering baby Mario and raised a total of \$318.

*Thank you to Mario and Melaina Thompson for your support of Cure SMA!*

### Pacific Northwest Chapter

## 4th Annual Flamingo Fun Run

Idaho

The 4th Annual Flamingo Fun Run, in honor of Oakley Smith, took place on September 30, 2017 in Grangeville, ID, during the local Oktoberfest festivities. With incredible community support, and a lot of donated help from friends and family, the 5K raised over \$6,500 toward finding a cure for SMA. Participants enjoyed Oktoberfest fun, food, and prizes.

*Thank you to the Smith family for organizing this amazing event for Cure SMA and the Grangeville community.*

*Note: The amounts raised and shown are totals as of February 11, 2018 and may differ from current fundraising totals by the time you get this newsletter.*



## Pacific Northwest Walk-n-Roll

Washington

On August 20, 2017 the 10th Annual Pacific Northwest Walk-n-Roll took place at Game Farm Park in Auburn, WA. The day was perfect – the sun was shining, and the temperature was flawless and brought out over 100 people for a morning and afternoon of family fun and awareness. The Game Farm Park in Auburn, WA was a great venue with lots of space, playground, paved walking paths around the park, and a picnic shelter.

In addition to the wonderful day, there were plenty of family fun activities including games, a balloon artist, a

fantastic raffle, a DJ, silent auction, vendors, and a food truck! Thank you to all the sponsors, donors, in-kind donors and volunteers. The walk raised over **\$10,500** for Cure SMA.

*Thank you to Russ and Kelly Hargrave for spearheading this event, as well as Jodi Pretz and Rozie McClay for all their help..*

We are excited for the 11th Annual Walk on August 19, 2018!

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## Microsoft Fundraising Night

Cure SMA was the benefitting nonprofit for a Microsoft Poker Fundraising Night in October 2017. The night was a success with spreading SMA awareness within the Microsoft Campus in Redmond, WA. The night raised \$2,900 for Cure SMA! Thank you to Microsoft for hosting the event and selecting Cure SMA as the 2017 benefactor.

*A special thank you to Teri Mackay and Laurie Pederson at Microsoft for nominating Cure SMA to be the benefactor for the 2017 fundraiser, honoring Teri's niece, Audrey, who was diagnosed with SMA.*

## Wreaths of Hope

The 12th Annual Wreaths of Hope took place in November 2017 in Washington. Guests enjoyed making holiday greens, caroling, baked goods and hot cocoa. The event was hosted by Sybil Kuhn and raised over \$500.

*Thank you to Sybil Kuhn for spearheading this event year after year!*

### Pennsylvania Chapter



## 2017 Zane's Run

2017 marked the 9th annual event for Zane's Run! Over 380 runners laced up their shoes and ran at Great Valley Middle School in Malvern, PA on September 24, 2017. With the support of our 11 fundraising teams and generous sponsors, over **\$35,000** was raised!

Sweet Baby Zane funds many Cure SMA programs including car beds, EZ-On Vests, and research.

*Thank you to the Schmid Family for their incredible support of Cure SMA. A special thank you to the entire event planning committee who make this event such a success each year!*

## 2017 Lukie's Fall Festival

The 2017 Lukie's Fall Festival was one of the best yet! Hundreds gathered in Pen Argyl, PA, on October 11, 2017 for a day of family fun! Everyone enjoyed games, raffles, live music, entertainment, pie eating contest, kid's costume parade, face painting, hay rides, clowns, balloons, mini golf, historic carousel, pumpkins, bake sale, and sand art.

*A special thank you to Tara and Joe Maida along with, "Lukie's Crew," for their incredible dedication to Cure SMA and tireless work on the event each year in memory of Lukie Maida.*



## Ultimate Granite Surface Golf Outing

The 5th Annual Ultimate Granite Surface Golf Outing held on September 30, 2017 in Butler, PA was successful again this year! Employees, vendors, and friends of Ultimate Granite Surface gathered for a fun day on the green and raised \$8,000 for Cure SMA in memory of Benjamin Piper!

*Thank you to Janet Bartley and everyone at Ultimate Granite for their incredible support.*

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## 2017 Lily Kennedy Golf Outing

Thank you to Dr. Mark Lynch, Heather Kennedy, and all the dedicated volunteers who planned the 2017 Lily Kennedy Golf Outing in honor of Lily Kennedy. The event was held on October 1, 2017 at the Iron Masters Country Club in Roaring Springs, PA. Thanks to the generosity of all the golfers, \$6,500 was donated to Cure SMA in honor of Lily Kennedy and all those affected by SMA!

## 8th Annual Dance Away SMA

On September 30, 2017 the Lyla Mertz Foundation hosted the 8th annual Dance Away SMA event in Schnecksville, PA. Thanks to the dedication of Steve and Jennifer Mertz along with their incredible committee of volunteers, \$5,202 was donated to Cure SMA in memory of Lyla!



## 2017 Philadelphia Marathon

Team William participated in the 2017 Philadelphia Marathon in Philadelphia, PA on November 18, 2017. Thank you to Jamie Forseth, Shannon Hostetter, Chris and Nick Jankowski for running the 8K in memory of William Jankowski. The team did an amazing job and raised \$4,400 for Cure SMA!

## Swing for a Cure Golf Tournament

On August 13, 2017 the Lyla Mertz Foundation hosted the 7th Annual Swing for a Cure Golf Tournament in Kunkletown, PA. The event raised \$3,460 in support of Cure SMA!

*Thank you to Steve and Jennifer Mertz along with all the foundation's generous supporters for fundraising in memory of Lyla!*

### Rocky Mountain Chapter



## Colorado Walk-n-Roll

Colorado

Over 400 people participated in the 11th Annual Colorado Walk-n-Roll held on August 26, 2017 at Clement Park in Littleton, CO. Participants enjoyed face painting, temporary tattoos, lunch, and entertainment! Thank you to everyone who volunteered, participated, sponsored and donated to the Walk. Together we raised over **\$53,000!**

*A special thank you to Michelle Pritekel for spearheading this event and thank you to the entire Walk-n-Roll Committee for your hard work and dedication year after year in planning and supporting the Colorado Walk-n-Roll.*

*Note: The amounts raised and shown are totals as of February 11, 2018 and may differ from current fundraising totals by the time you get this newsletter.*

## South Florida Chapter



## 2017 South Florida Gala of Hope

On November 16, 2017 Jennifer Miller Smith and Fiorenna Fuentes-Israel, two mothers of children with SMA, hosted an incredible evening to raise funds for Cure SMA. The gala is held each year in honor of their daughters, Madison Smith and Mia Israel.

The seventh annual event raised over **\$144,000** in 2017. Cumulatively the event has raised more than \$1.1 million in its seven-year history.

This year's event was held at the stunning W Hotel in Fort Lauderdale, FL. Guests enjoyed a deluxe open bar, live and silent auctions, and incredible entertainment provided by Galaxy Productions. The night ended with an incredible live action painting performance by painter Tim Decker.

Our sincerest thank you to Jennifer and Fiorenna, along with their husbands Aaron and Aldo, for their dedication to Cure SMA's mission and the incredible work they put into making this year's South Florida Gala of Hope a success.

*Thank you to the event's Diamond sponsors for their generous support: Accent Tradeshow & Event Furnishings, Davie Glass, Expo Convention Contractors, Galaxy Productions, The Pontes Group, and Prestige Construction.*

*Note: The amounts raised and shown are totals as of February 11, 2018 and may differ from current fundraising totals by the time you get this newsletter.*

## South Jersey/Delaware Chapter

### 2018 Cure SMA Camden Wyoming, DE 5K Walk/Run Pajama Rama

Delaware

On January 13, 2018 in Camden Wyoming, DE participants got dressed up in their cutest, comfiest, or warmest pajamas and came out to support Cure SMA. Participants enjoyed a silent auction, food and beverages, fun and entertainment! The run started and ended at Wild Quail County Club and raised over **\$18,000** for a cure for SMA.

*Thank you to all our sponsors and in-kind donors; without your support this event wouldn't have been such a huge success. A special thank you to Jessica Moyer for spearheading this event!*

## Tennessee Chapter



### Nashville Walk-n-Roll

The 3rd Annual Nashville Walk-n-Roll was held on Sunday, October 15, 2017 at Centennial Park in Nashville, TN. The sun made its way through the morning rain just enough for everyone to have a wonderful time walking and rolling to raise money for Cure SMA. This year's walk surpassed its goal raising **\$10,364!**

*A special thank you to Kayla Harbin and her family and friends for making this event such a huge success this year and every year.*

## Texas Chapter



### SMASH Dash

*Thank you to Jessica Hastings for hosting the 2nd Annual SMASH Dash on August 12, 2017 in Fair Oaks Ranch, TX. The event had 244 participants and raised \$5,000 for Cure SMA!*

### Kendra Gives Back Party

On October 13, 2017, Kendra Scott and Cure SMA hosted an evening of shopping, refreshments and awareness at Kendra Scott stores in Austin and Houston. During each event Kendra Scott donated 20% of sales, raising over \$1,900 for Cure SMA.

*Thank you to Kendra Scott for partnering with Cure SMA for this event, as well as volunteer Kirstyn Speich for all her help on event day!*



### Talbots Make a Difference Day

On October 20, 2017, Cure SMA and Talbots partnered to host Shop & Donate events at a store located in Houston. Customers were invited to shop, enjoy refreshments, and make a difference! During the event the store graciously donated 10% of all sales to Cure SMA, raising a total of \$100.

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A special thank you goes out to Talbots Town & Country Village manager Chieuanh Nguyen and Chapter Leader Kelly Coggin for organizing this opportunity to spread SMA awareness and raise funds for a cure.

### Virginia Chapter



## 2017 Virginia Chapter Walk-n-Roll

The 3rd Annual Cure SMA Virginia Chapter Walk-n-Roll was held on October 14, 2017, at Gar-Field High School in Woodbridge, VA. More than 150 participants and 11 teams from across the region were in attendance, raising over **\$18,000!** The autumn-themed event featured pumpkin painting, face painting, outdoor games, and a silent auction. For some great pictures of the event, check out our chapter Facebook page [www.facebook.com/cureSMAVirginia](http://www.facebook.com/cureSMAVirginia).

*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.*

### Western New York Chapter

## 2018 Cookie & 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 \$500 from her cookie and cake pop fundraiser for Saydee's 2nd birthday on January 6, 2018. Cure SMA is grateful to Dawn and her community for donating these funds to our care package program.*

### Wisconsin Chapter



## 7th Annual Kennady's Dream Walk-n-Roll

On October 8, 2017, families from all over Wisconsin gathered on a gorgeous morning for the 7th 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 **\$17,950!** 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 this year in planning this great event. We hope to see everyone next year on September 23, 2018!*



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## 13th Annual Grant Sheppard Memorial Scramble for SMA

On Friday, August 11, 2017 the 13th Annual Grant Sheppard Memorial Scramble for SMA was held at Hickory Hills Country Club in Chilton, WI. A total of \$7,200 was raised during this golf outing in memory of Grant. Cure SMA would like to send a special thanks to Scott and Lisa Sheppard for all their hard work in planning this amazing event year after year and for their continuous support!

## Iceman Darts Tournament

The Iceman Dart Tournament took place August 11-13th in Waukesha, WI., raised over \$6,000 for Cure SMA. So much fun was had by all attendees who competed in some exciting dart tournaments, and other fun activities such as the raffle!

*A big thank you to Tim McCarthy for nominating Cure SMA to be the recipients of this year's tournaments donations, and a huge thank you to Russ Nelson who works hard to put together this event each year in memory of his wife.*

## 2017 Round for a Cure

This August, 100 golfers came together in Wisconsin and raised \$5,000 at the 2017 Round for a Cure in honor of Ben Nelson. Although the weather was a bit chilly for an August day, a huge amount of fun was had by all!

*A big thank you to the Nelson and Marcou families for all their hard work on organizing this great event every year. Also, a special thank you to Ben's younger cousin, nine-year-old Cate Nelson, for raising \$52 all on her own!*

## Hoffman Family Block Party

Thank you to our friends in Milwaukee who raised \$302 for Cure SMA in honor of Jackie Hoffman at their annual block party. Thank you specifically to Laura Ewig for organizing this each year!



**cure SMA 2018**

CURE SMA MERCHANDISE



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

# Congratulations



Mary Nelson won first place in Showmanship at the Chisholm Challenge Horse Show in Fort Worth, TX!



Congratulations to the Reese family on the birth of their new daughter, Kharli Jae Reese, born November 15, 2017!



Congratulations to the Murray family on the birth of their new addition, Yasmeen!



**Make today a breakthrough.**

## **CURE SMA RELIES ON YOUR HELP AND SUPPORT**

- To fund basic research to investigate the causes and biology of SMA to find more effective ways of making SMA drugs.
- To meet the needs of the SMA community and accelerate our next phase of research and care. This includes launching a network of Cure SMA care centers to improve patient care and quality of life.
- To provide information packets, newly diagnosed care packages, equipment, Cure SMA Summit of Strength Program, and the Annual SMA Conference to nearly 4,000 families annually.

**Make a donation to Cure SMA and join thousands of others who are choosing to change the future of SMA. With your support Cure SMA will continue leading the way to a world without spinal muscular atrophy.**



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# 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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