

# DIRECTIONS

COMMUNITY NEWSLETTER | SPRING 2020





# UPDATE ON 2021 ANNUAL SMA CONFERENCE

**JOIN US IN AUSTIN, TEXAS!  
THURSDAY, JUNE 10 – SUNDAY, JUNE 13, 2021**

If the unexpected circumstances of 2020 have shown us anything, it is how impactful this one week of the year is for families, individuals, researchers, and medical professionals in the SMA community. We cannot wait to welcome you back as we gather next June in Texas. The JW Marriott Austin will host the 2021 Annual SMA Conference and SMA Research & Clinical Care Meeting. The hotel is centrally located in Austin's lively downtown neighborhood with a variety of restaurants, live music, and entertainment venues.

Cure SMA is excited to reunite the SMA community for the 2021 Annual SMA Conference in Austin, Texas from Thursday, June 10 – Sunday, June 13, 2021. Additional conference details will be announced in the upcoming months and registration will launch in the fall of 2020.

**If you have any questions, please contact [conference@curesma.org](mailto:conference@curesma.org).**

**WE LOOK FORWARD TO SEEING  
YOU IN AUSTIN NEXT JUNE!**

**STAY TUNED**

**to the Cure SMA website for more details  
on the 2021 Annual SMA Conference as they  
become available.**

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## LETTER FROM KENNETH

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As we entered 2020—ready to launch into a new year of Walk-n-Rolls, Summits of Strength, and the Annual SMA Conference back in Orlando—no one could have imagined what the world was about to face and how our lives would be changed. However, despite these rapid and unexpected changes, the SMA Community has once again demonstrated its strength.

In quick order, Cure SMA was able to: distribute thousands of COVID-19 Support Packages and Financial Support Gift Cards to homes across the U.S.; offer a constant stream of information, resources, and advocacy materials for the community to use when navigating the uncertain times; and pivot our many support and fundraising programs to be offered virtually.

While launching these new programs, Cure SMA has also kept our funding and continued our focus on SMA research and clinical care needs. In April, we announced \$1.1 million in research funding for seven (7) new research grants, and we now have 20 Cure SMA Care Centers contracted into our network.

Thank you for all of the support from the community and sponsors, as we would not be able to provide the resources and programs we are today without you or your continued commitment.



**Kenneth Hobby**  
President

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

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**“I’ll always remember the day when a one-time dose gave him a second chance at life.”**

**Natalie, mother of Eli**

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



Eli, treated at ~4 months and pictured at 5 years, has SMA Type 1.

To learn more, talk to your child’s doctor about **the one-time-only dose** and visit [ZOLGENSMA.com](http://ZOLGENSMA.com).

## Indication and Important Safety Information

### What is ZOLGENSMA?

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

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

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

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

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

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

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

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

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

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

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

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

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

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



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

### USE

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

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

### WARNINGS

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

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

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

### OTHER IMPORTANT INFORMATION

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

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

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

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

### COMMON SIDE EFFECTS

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

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

### QUESTIONS?

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

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Bannockburn, IL 60015

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# Letters from the Community



Thank you so much for the care package. Kailey, Type 3, was super excited! I am so happy I am not alone!  
~Gina Turner



We received the care package and Lily was super happy and excited. It also made our day when we saw the joy it brought her. She loves all the toys—especially her favorite, the play food items! Thank you for the support.  
~Daniel Park



A special thank you from my family for the care package we received in the mail! Everything in there was perfect for my son with SMA Type 1. I think his favorite things are the bright orange feather and the Baby Einstein musical fish tank. Thank you also for the loaned car bed. I am not sure how we would travel without it.  
~Chelsea Chan

[The care package] was so much more than expected and Tenley has loved playing with everything so far. She has especially loved the feather, frog balloon, pinwheel, and cat toys—the simple things! Oh, and the Cure SMA puppy! Thanks again so much for everything!  
~Katie Sherman



On behalf of Aaron, Celeste, Natalie Fleck and the Dobbin family, we just had to reach out to you to tell you what a comfort the Cure SMA chapter in Arizona has been. We appreciate and thank you all so much for the care package. So many wonderful and useful gifts! Thank you again for supporting my family. As you know, these are times of struggle, but it is good to know that so many other's like yourself and the chapter care.  
~The Fleck and Dobbin Families

I cannot stress enough how much we appreciate it. The info has really helped a lot, we have contacted other families in our area also. The kids loved everything! I am not going to lie, I cried when I saw what you all sent. This has been an emotional roller coaster and to see that there is an entire group of people willing to do everything you all have done to make this a little easier, is just amazing. Thank you so much!  
~Conchita Tucker

I cannot thank you enough for the information and the box of goodies for my son. The look of joy on his face brought tears to my eyes. Thank you so much for making this hard transition in our lives a little bit brighter.  
~Catie Brown

I just wanted to let you know that we received the care package today and it is WONDERFUL! Thank you so much for everything. We love it all. So very generous. We cannot wait to pull everything out and really look at it all. Thank you for all that you do to help ease the stress of this for families.  
~Debbie Sias



Thank you so much for your support! Betty is very excited about her new toys!  
~Sherena Finn

Thank you so much for the support package! I am currently typing this while my phone is in my new phone holder and I have a comfortable spry recovery pillow behind my scoliosis back for support. My reacher is beside me in case I drop anything, and I have an Echo to call for help if I need anything. I am also using the hot pack on my neck, which is relieving a lot of pain. Bottom line, Cure SMA has blessed me beyond measure. I cannot wait to receive the sheepskin blanket. Who knew there were so many great products for accessibility!  
~Crystal Anderson

Today was a hard day for me. I have cried most of the day just thinking about how I would take this for him in a heartbeat and how heartbreaking it is to watch your baby lose function so quickly. We came home to this gift. We wanted you to know just how much this meant to us. We are forever thankful and appreciative of such a gift. Thank you!  
~Katlyn Green



I received a packet of information from you last week and we just received a box full of toys and other items for our son, Jasper. You have showered us with information and support/love. I am overwhelmed—in a good way. Thank you for the investment you make in families when life feels like it is starting to cave in.

~Nicole Webb

We received the support package for our daughter, Kaitlyn, over the weekend. She really loves every item. Her favorite item is the Echo Plus. We are grateful for this package. All the items are very useful and practical. This is an early Christmas present for Kaitlyn.

Thanks again for supporting the SMA families.

~Jennifer, Jeffrey, and Kaitlyn Nguyen



We received your package. Thank you so much for your support. Kira enjoyed it very much. Thanks so much!

~Olga



Thank you so much for the package of gifts! That was so generous of you. We have been enjoying using some of the items with Maggie during play time and look forward to trying out the rest as she gets older. Thanks for all the fun toys we can use to practice!

~Derrick, Leah, and Maggie Anderson

I just wanted to say, THANK YOU! This support package was such a nice surprise. I really appreciate it and I am already finding many items very helpful! Cannot thank you enough for all you guys do; you are literally a life saver!

~Charlie Cerpa

I just wanted to say that my daughter received her care package today, and she was so happy. I cannot believe how excited she was over everything. Thank you so much. A few of the items we really needed, and a few of the others, like the Alexa, she just cannot get enough of. It is amazing. Thanks!  
~Shawn Humble



Thank you so much for the delightful care package! It certainly brightened our day. Kenzie has enjoyed her toy blocks and absolutely loves her O-Ball. We are so thankful for your support and the community you provide as we venture down this path with Kenzie.  
~Sydney, Kody, and Kenzie Graves



We have used so many of these things already and it's been such a big help. Thank you, guys, so much!  
~Jessica Low

I just wanted to say thank you for the support package for my daughter, Kylie. Her favorite things are the sheep skin and the Echo Plus. She's still working very hard to get the Echo to understand her enough and is a great way to get in some "speech therapy" without having to do speech therapy! I love it so much as well because Kylie loves to listen to music. Thank you so much for all you do for all our children.  
~Heidi Niedermier

# Congratulations

## Class of 2020

Despite the unexpected end to this academic year, the accomplishments of those in the SMA community who met an educational milestone should not be overlooked. We want to help you celebrate this important moment in life. Whether it is graduating from preschool, kindergarten, middle school, high school, college, or grad school – please share your photos with Cure SMA so we can applaud your efforts!



@curesmaorg



facebook.com/cureSMA



## Thank You

Cure SMA was excited to receive a generous donation to our newly diagnosed care packages!

These unicorn stuffed animals were donated in honor of Liv Harlow McDonald's third birthday from her grandparents, Debbie and Richard Butler!

Thank you to Debbie and Richard for this wonderful donation!



Annika Hendricksen



Aria Bashark



Bear Bonner



Brady & Lucas Chan



Betty Finn



David Hernandez



Kevin, Henry, and Jacob Meyer



Nicholas Wheatley



Aubree Kelly



Eliana Allemand



Ellison Currie



Ghalia Ali Aburowais



Elisa Macias Garza



Emiliano Giordano



Hanna Warfield and Max Lasko



Henry Farkas



Ely Franche



Mary Nelson



Jaclyn Greenwood



Jailah Guerrero



Kira Eliseeva



Kyle Kevin



Mila Thomas



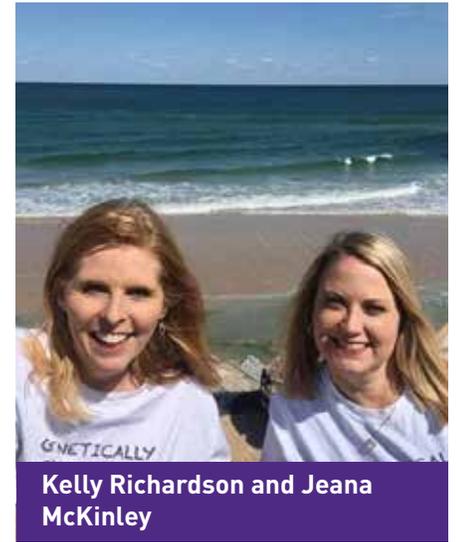
Maggie Anderson



Max Lasko



Seth Pina



Kelly Richardson and Jeana McKinley



Mya Cala



Otto Knutson



Penelope Brown



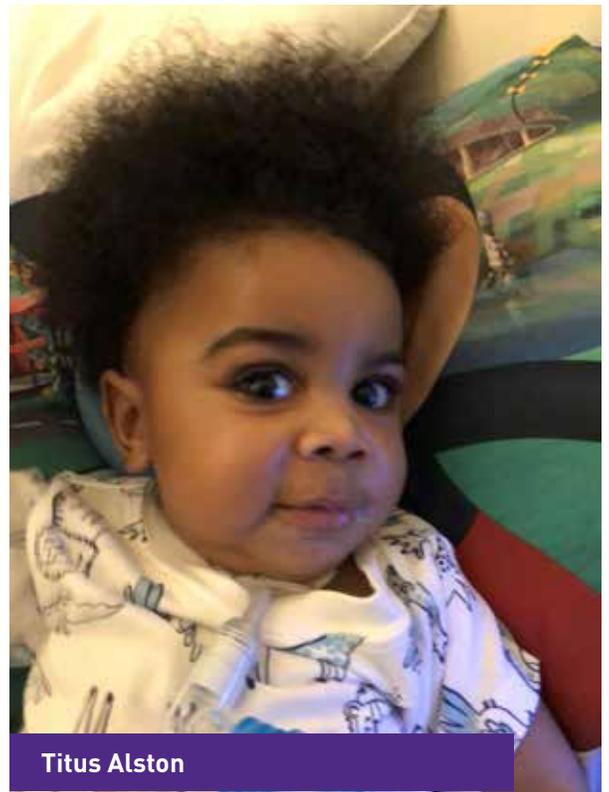
SBL 2019 Cure SMA Bingo



Tenley Sherman



Thea Starr



Titus Alston



Remi Catlett



Christabelle Amartey



Eleanor Lynn Butler Bente



Ellison Burns



# Adapting to a New Normal...Again

By Dr. Al Freedman Family Psychologist and SMA Dad

The world has been turned upside down by COVID-19. For families affected by SMA, this isn't the first time our world has been turned upside down. None of us ever forget the day of an SMA diagnosis. You may remember feeling shocked, disoriented, anxious, sad, scared, or some combination of these. You may remember waking up in the morning shortly after receiving the diagnosis and thinking, "Maybe this is all just a bad dream. Maybe this isn't really happening." As time passes, most of us find that we can come to terms with the diagnosis and adapt to what I've always called "our version of normal."

It is very common for us to experience strong feelings in response to drastic changes in our lives. Just as an SMA diagnosis elicits a wide range of strong feelings, so, too, has this worldwide pandemic. COVID-19 has understandably caused many in our community to be fearful—people affected by SMA are already very physically vulnerable, so it makes sense why we may feel that our sense of safety is threatened.

But in many ways, our SMA community is in a stronger position to understand and manage the feelings that come from this crisis because we have experience with abrupt change, living with uncertainty, and the need for isolation. As a community, we are well prepared to face this new challenge. We know how to adapt, we are resourceful and creative, we are resilient, and we are hopeful. These qualities will serve us well as we move through this complicated period.

Although we are well prepared to handle the unexpected, the feelings of anxiety and vulnerability we may feel during this pandemic are very common and need to be respected. There are many aspects of this pandemic that don't feel within our control. Uncertainty is unsettling for all of us. It's very difficult to be in a situation that doesn't feel in our control. But we do have the ability to focus on what is in our control.

## Focus on What's in Your Control

**It will help us to shift the focus from the pandemic—something we can't control—to what we can control. Among the things we can control are:**

- How we take care of ourselves: Getting enough sleep, healthy eating/nutrition, spending some time outdoors.

- How we stay connected with others: Yes, we need to "physically" distance, but we also need to experience social connectedness. Technology allows us to stay socially connected in ways that are very healthy and helpful at this time.
- How we make choices about the use of our time: Because of SMA, many of us are already creatures of habit. It helps to follow familiar routines; watch only as much news about COVID-19 as you need to keep safe; read, watch movies, and enjoy time with your family. Relax and take a break from the difficulties happening in the world around us.
- How we plan and prepare: Preparing for the unexpected helps us to feel more in control and less anxious. For SMA families, it's always important to create and follow a health plan, to have needed medical supplies on hand, and to know how to reach our treatment providers should we need help. Accept help as you need to and take appropriate precautions with your caregivers. You will feel more in control if you are clear about what you expect of your caregivers and they will feel more in control if they feel protected, too.

All these strategies are well within our control. This virus is very contagious. That's why everyone is so concerned. But, as I have also learned from my many years as an SMA parent and as a professional, there are some other, more positive things in our lives that can be contagious...

A positive attitude is contagious.  
Resilience is contagious.  
Having hope is contagious.  
Gratitude is contagious.

From my many years as a member of our Cure SMA community, I feel very confident that our families are as prepared as anyone to face this challenge just as we've faced so many other challenges that have come before. We can adapt, once again, to a new normal, with grace and dignity—and move ourselves from feelings of fear to feelings of hope, gratitude for each and every day, and love.

If you have questions about this topic, please feel free to reach out to Al Freedman at [al@freedmancounseling.com](mailto:al@freedmancounseling.com).



# SHARE YOUR STORY

Each person in our community has a powerful story to tell about their journey with SMA. We want to share as many as we can, representing all ages and stages of SMA. Your story could inspire another member of the community or reassure someone just starting their journey.

**cure**  
**SMA**

Is there a moment, anecdote, or story that has stood out in memory for you and your family? Share your SMA experiences and photos with us by emailing [stories@curesma.org](mailto:stories@curesma.org)!



## The Power of the Spirit to Overcome

Cesar Rodrigues is a 32-year-old abstract painter from Worcester, Mass. His paintings have been showcased and sold in various galleries, and his first solo exhibition will be held May 2-June 27 at the Gallery Seven in Maynard, Mass. Cesar describes how his work “gives a feeling of freedom, but can evoke many different emotions depending on the viewer.” Cesar also lives with spinal muscular atrophy (SMA) Type 2.

“I feel my diagnosis is both a blessing and a curse,” Cesar shares. “It’s a curse because of the battles I face in having my disability. But it also built my patience and endurance, making me appreciate life more than the average person. SMA made me who I am today.”

Cesar was not even 4 years old when he was diagnosed with SMA. Back then, there was no treatment for SMA, and doctors gave Cesar only a few years to live. He defied those odds and did not allow his diagnosis to stop him from following his passion. Cesar began creating art using crayons while in the hospital, where he spent most of his time as a child.

Cesar was in his mid-twenties when he decided to take the next step and pursue a career in art. “People kept showing lots of interest in my artwork. I want people to feel happiness, hope, and encouragement when they look at my pieces. To do that was fulfilling,” said Cesar.

Cesar began painting people, landscapes, and animals with brushes and pencils. And despite the progression of his SMA, Cesar did not allow his physical setbacks to hinder his creation of art. He pivoted to abstract pieces and became

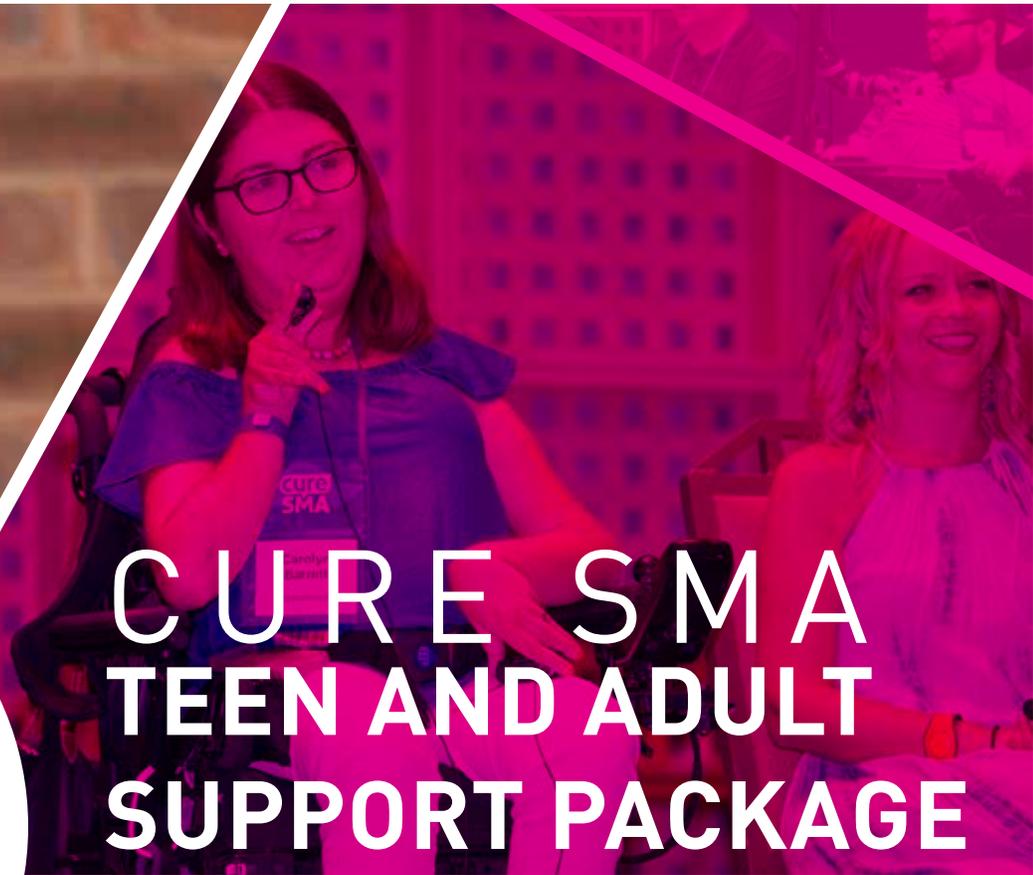
more resourceful. He changed his process by pouring paint, using gravity and tilting his canvas to spread the paint. And, when Cesar lost all hand strength, he created a 2-dimensional painting system using Bluetooth technology.

In using this system, Cesar directs his assistant where to pour the paint and how much to pour. “My goal is to paint independently. The issue I’m having with the current pouring system is it’s not as accurate as I’d like and it’s difficult moving it around the canvas in such a small space. In the future, when I’m financially able, I plan to advance this technology, making it smaller and more precise to allow for more independent work,” he said.

Cesar understands that pursuing a career in art is not easy. What is his advice to aspiring artists? “Enjoy and love to create, letting everything else happen naturally. Never chase the money and fame,” Cesar suggests.

Reflecting on his time as part of Cure SMA community, Cesar notes: “I was introduced to Cure SMA through the children’s hospital. It was a great experience and I gained so much knowledge about SMA. It felt like family,” he remembers. Cesar continues saying, “It’s a blessing to be a part of both communities—knowing there’s a powerful team behind you that’s fighting day and night to end the disease, while also supporting the lives of people like me.”

To see more of Cesar’s work visit his website:  
[www.cesarrodriguesfineart.com](http://www.cesarrodriguesfineart.com)



# CURE SMA TEEN AND ADULT SUPPORT PACKAGE



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

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

# SPOTLIGHT *on* The Forcier Family



Kara and Ryan Forcier, of Stillwater, Minn., were on a rollercoaster almost immediately after the birth of their son, Zachary. Zachary was born with skin lesions that turned into blood clots, which almost led to having his limbs and digits amputated. Thankfully this was not the case, and after the skin lesions healed, Kara and Ryan knew they had to help Zachary make up for some of the missed developmental milestones.

“Zachary’s skin lesions were on his arms so, of course, he didn’t want to push up or crawl. We accepted that he likely wouldn’t make any gross motor gains until he was fully healed,” Kara explained. “But after the lesions were gone, he was still regressing.”

The Forcier’s received a referral to see a neurologist, who screened Zachary for various diseases and disorders, including SMA. Initial tests indicated that things were not normal, but they could not pinpoint the root cause of Zachary’s delays. Initially, even SMA was ruled out. Kara—who at the time was 36 weeks pregnant with their daughter, Madilyn—said that the doctors described Zachary’s muscles as “looking like chicken when they should look like a steak.” Still unclear as to what was causing the problems, Zachary came home, and life went on.

It was not for a few more months that healthcare providers made an appointment to review the results of all the tests Zachary took. “This day was horrific,” remembers Kara. “First we were told that Zachary needed open-heart surgery to repair a common atrium. Then, in our third appointment, our lives were forever changed.” Kara and Ryan were told that Zachary had SMA Type 2.

At the time, there was no treatment and no cure, and it was difficult for them to comprehend that there was nothing that would help their son. “We were told we could expect Zachary to live into his late teens/early adulthood. It was devastating,” said Kara.

Today, the Forcier family enjoys the outdoors, fishing, and sports. Zachary’s diagnosis hasn’t stopped his passion for playing and watching sports—including the Minnesota Wild, Twins, and Vikings. This past summer, he started a program for shooting sports through 4-H, a youth organization hosted by the National Institute of Food and Agriculture, part of the U.S. Department of Agriculture. “He thoroughly enjoys it, and we hope to find him some adaptive equipment so he can participate competitively,” said Kara.

The family now considers SMA as part of their daily lives. “We are used to living in a world where we have to steer clear of illnesses, check for accessibility of new places we go, juggle insurance issues, and manage treatment and care. But some days, it just hits me how much I hate this awful disease. I hate how hard it makes everything. You get complacent and just go about your routine and life, and then something happens, said Kara. “But we are thankful for the online community of individuals affected by SMA, and other parents of children with SMA, who share their experiences so we can all learn more. We don’t face SMA alone. We have a community supporting us. And we do the same for those families. SMA is a community no one wants to join, but we are so thankful for the connections and friendships we have made.”

**Recognize the symptoms  
and save a life!**



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EARLY ACTION, EARLY TREATMENT, SAVES LIVES.

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



**[SMARTMoves.CureSMA.org](https://SMARTMoves.CureSMA.org)**



# Understanding the Benefits of Aqua Therapy

Each year at the Annual SMA Conference, the session on Aquatic Therapy is among the most popular for attendees of all ages. Jennifer Martyn, PT, is one of the leaders of this educational and fun session. Normally this time of year, Jennifer and her staff would begin ordering new gear for the pool, labeling items for time in the water, and deciding whose hotel room would be the laminating headquarters for exercise sheets. However, 2020 looks much different than she and her team anticipated.

“Although I wish the greater SMA community could come together and share this time in the water, I am encouraged that the water can still be a place of improved independence, active movement and, of course, much joy in your community and with your family,” says Martyn.

Should an opportunity arise for individuals and families affected by spinal muscular atrophy (SMA) to find a quiet community pool, a warm bay, or a family hot tub, Martyn encourages you to take it.

## Why Aqua Therapy?

Aquatic therapy is a valuable exercise for those with SMA. “Any exercise is more engaging when it is fun. And you are more likely to return to it, push yourself, and realize the benefits from being in the water,” says Martyn.

Water allows for ease of active movement, variations of stability levels, and the ability to support or challenge yourself on desired activity demand (Anderson, Aquatic Therapy). Additionally, aquatic therapy is an effective therapeutic tool for both physical and mental health.

“Being in the water is not only fun, social, and freeing from the nasty effects of gravity (not allowing movement) but it also has positive effects on your kidneys, mood, and digestive system. It also allows for stretching, pulmonary exercise, and trunk mobility that you cannot get while in your wheelchair,” shares Martyn.



As you plan for times in our “new normal” to get out and play, Martyn encourages you to think about a few things:

- **Always safety first.** If you use suction frequently, then have it pool side. Evaluate how you are going to get in/out safely. If you choose to get in the water with a trach, extreme care must be taken to ensure that no water gets in/near the stoma site.
- **Water temperature.** As you jump in the water for yourself or with your family member, think about the temperature. It does matter and it will impact how long you can stay in the water and how happy you will be there. 90-95 degrees Fahrenheit is considered therapeutic and ideal for most with SMA who are full-time chair users. If you have SMA and can walk/move vigorously, you may prefer a slightly cooler pool at 86-88 degrees Fahrenheit. This will allow you to move fast enough to keep up your body temperature.
- **What’s your goal?** Are you getting in for fun (time in the lazy river) or to work on more therapy related activities? Life jackets and head collars are great for the lazy river. You can be more hands-off but always eyes-on and within arms-reach. If you are more focused on exercise, pick the supports you need to maximize function and provide the needed support to maximize your ability to reach your goals and keep you safe. That could include a neck support, floats on your wrists or waist, or weights on your ankles for improved stability.

- **Mobility.** If you are a full-time chair user and want to work on standing/upright, try some light (1/2 pound to 1.5 pound) weights on your ankles. Folks with tight hips are generally unstable in upright but a light weight can provide the needed grounding to be stable and grounded in the water.
- **Toys.** Balls, floaty barbells, pool noodles, and wrist floats can be used for exercise and stability, and make your time in the water more engaging, stable, and fun.

Be mindful of who you are getting in the water with and what level of respiratory protection everyone is most comfortable with.



## The Pool and Physical Distancing

While most, if not all, community aquatic facilities are closed during the COVID-19 pandemic, please monitor federal guidelines for reopening.

“If you have a small, apartment style pool, it will be worth paying attention to these guidelines to ensure the best practice for your smaller community,” says Martyn.

We hope you and your loved ones can spend time in the pool this summer while also practicing physical distancing, as your health and well-being are of utmost importance.

**Safety is Key! The American Physical Therapy Association does not recommend people with trachs use swimming pools.**



# What You Need to Know to Continue Protecting Yourself from COVID-19

Coronavirus (COVID-19) has impacted the SMA community—along with everyone else in the world. Cure SMA remains vigilant in monitoring and responding to the needs of the SMA community with accurate and timely information, as your health, safety, and well-being are our top priority.

Here are some good reminders on what to look for, including symptoms of COVID-19 and how to manage daily life with SMA in the pandemic world. And don't forget to keep an eye on the Cure SMA COVID-19 Information Center on our website ([www.curesma.org/covid19](http://www.curesma.org/covid19)) for the latest updates and resources for the SMA Community.

## What should I look for in identifying COVID-19?

Typical symptoms appear 2 to 14 days after and may appear as fever, cough, shortness of breath, chills, repeated shaking with chills, muscle pain, headache, sore throat, or sudden new loss of smell and taste. For people with SMA who develop symptoms suggestive of COVID-19, please contact your healthcare team to let them know. Please seek emergency healthcare if you experience trouble breathing and/or trouble speaking, persistent chest pain or pressure in the chest, new confusion or difficulty waking, or bluish lips/face or low oxygen saturations that do not improve with secretion removal and coughing or usual home breathing support if used. If you use at home breathing support and/or feeding support, please take your home equipment with you.

## How should I best prepare for the continued isolation periods?

Isolation protocols are normal in the SMA community during flu-season, and COVID-19 will mean a longer isolation period than the usual viral respiratory season. We recommend having at least an additional 2 weeks of medications and supplies on hand. This includes supplies for equipment, such as cough machines and other respiratory equipment, formula and feeding supplies, and any other regularly ordered supplies from durable medical equipment companies and suppliers. If you have state Medicaid insurance, some of the guidelines have been relaxed and you may be able to obtain additional supplies.

## Is it safe for me to continue going to clinic or doctor's visits?

People with SMA should continue their usual care routine, unless otherwise guided by your healthcare provider. The American Academy of Pediatrics recommends prioritization of in-person visits for newborn care, newborn well visits, and immunization of infants and young children through 24 months of age whenever possible. Other routine well-visits should be conducted by telehealth approaches or postponed whenever possible. For people of all ages, healthcare teams have been asked to think creatively—such as avoiding time in waiting rooms—to avoid unnecessary risk of exposure and pressure on their staff and healthcare facilities. Our recommendation is to always contact your healthcare provider first unless you are in an emergency.

## Should I continue to have in-home health nursing and other medical professionals in my home?

Safety and avoidance of exposure to infections is paramount. Healthcare professionals in the home are often providing critical services to maintain health, safety, and function. Each person and their family will need to decide whether to continue having these in-home services. We realize adults with SMA who rely solely on caregivers cannot opt to cancel; therefore, whenever healthcare providers are in the home, ensure they wash hands frequently and have ready access to hand sanitizer and face masks. In-home healthcare providers should be free of symptoms.

## I or my child is due to receive SMA treatment. What should I do?

SMA treatments are essential, not elective. We generally recommend that getting doses as close to schedule is important. A few weeks delay should not have a huge impact, as there may be specific personal health status issues or local COVID-19 issues that could influence your timing options. The best thing to do is contact your healthcare team to ensure you are waiting no more than a couple of weeks for treatment. And, when you do go in, call ahead to see if it is possible to wait in a private room instead of the waiting area.

## One person in the household goes to work outside the home, while others are at home. How do we control exposure?

It is recommended to create a “transition space” in your home, such as an entryway or mud room, that is used to take off clothes after returning from travel or work and to wash and/or shower before joining the rest of the family, as long as they are healthy. If the person who works outside the home has been exposed to someone with known COVID-19 or are a healthcare provider, they should self-quarantine, stay in a part of the home separate from others, frequently wash hands, and use separate drinking and eating utensils and dishes. Clothes should be washed and dried in the hottest temperature tolerable for the fabric. Do not shake out clothes, as this can put the infection into the air. If this person feels ill, they should wear a face mask and self-isolate from the rest of the family.

## 5 Tips for Family Emergency Readiness

*From Cure SMA and Dr. Robert Graham*

In general, preparation and contingencies should always be in place—not just during the Coronavirus (COVID-19) pandemic. Most families and individuals should have plans for school or work-related emergencies, like broken elevators, fires, etc. It is also important to have plans for any excursions outside the house if they are technology dependent, not just long travels.

- Adults and families should prepare for all emergencies—natural disasters and weather-related emergencies, like hurricanes, power outages, heatwaves, blizzards, etc.
- Ensure that you communicate about your individual SMA needs. Keep a thumb drive, note on your wheelchair or binder of relevant information, including the contact numbers for your primary medical team.
- Have a healthcare proxy identified and ready to help you advocate for your health needs when you are not able to. This person should know and understand your contingencies and care protocols.
- Do not delay your medical appointments. Telehealth appointments are a great alternative, so ensure that your healthcare team is open to this, when needed.
- In case of an emergency room visit, bring all the supplies you need, including breathing and/or feeding support. Hospitals may not have enough supplies. Make sure to label your supplies.

To keep up-to-date on SMA and COVID-19 news visit: [www.curesma.org/covid19](http://www.curesma.org/covid19)



This story is brought to you from

*The*  
**MIGHTY**

# 11 Tips to Become a Confident Wheelchair User

I recently got a new wheelchair, well I got it almost a year ago, but things take time to get used to. You may have heard my moans. It wasn't until I got my new wheels, a chair totally different than any I've had before, that I really considered the impact my wheelchair has on my life and what not having the right chair can mean to me. If you're new to being on wheels, or have a new set of wheels, here are some things to keep in mind.

## 1. Driving doesn't always come naturally.

If you see my PA or friend driving my wheelchair you'll realize it isn't as easy as it looks. It took practice to get this good. I've been driving since the age of 3. Can you imagine 3-year-old little me racing around? It's terrifying, isn't it. I have a 4-year-old niece and I wouldn't let her loose in an electric wheelchair. Yet it was just the next step (ha) for me, the thing to do, like walking is for most I guess. I can't really remember it much to be honest, I've been told I bashed into things and scratched door frames, which isn't much different to now really. I remember being at playgroup and all the kids wanted a ride; that was the coolest way to make friends.

Every chair is different — the pressure needed, maneuverability, turning circle, width, length. My new wheelchair is my first mid-wheel drive, which means it can almost turn on the spot. That's great for small spaces and tight corners, but not so great when I forget that the back of this chair turns with me.

Enjoy a bit of practice driving, get out in those open spaces. Do a wheelie if you can. Speed down a hill. There have got to be perks, right? One of my biggest irritants is people using the term "wheelchair-bound." I am not wheelchair-bound. That implies being tied down unable to escape. Contrary to popular belief, I do not sleep in my wheelchair, and sometimes I get out of it. Some wheelchair users can also walk. Shocker, right?

## 2. It is freedom.

Having a suitable wheelchair enables me to have independence and freedom. It is not a restriction. It's the difference between moving or not, leaving the house or not. Simple. The correct wheelchair for your needs is also crucial. I can't just use any chair. Durability and maneu-

verability are everything. Finding a wheelchair to suit your lifestyle, or the lifestyle you want, is as important as getting a wheelchair at all. For me anyway. There's no point me having wheels if I still don't have independence.

Be fussy when choosing a chair. Try several first. You need to find your best pal, someone to live with day in and day out. It may accompany you on the bus, in the car, on holiday, in the rain, in the snow, at the cinema, at a festival, doing the housework, going to work, in the pub, at the park.

## 3. Fit matters.

You'd think getting a new wheelchair would be exciting, a cause for celebration. It's not for many people. A millimeter change in position can make or break my independence. An armrest being slightly different can mean I can't lift my cup of tea or get a fork to my mouth. Blowing my nose is a struggle at the best of times, but it was impossible until I got my chair just right. The little tweaks are what makes a wheelchair mine.

When you're having a wheelchair fitting, you may not do daily life stuff. I didn't try drinking tea, crocheting or typing, I should have. Take your time in getting the little things right. Don't be afraid to ask multiple times for adjustments. A footplate two millimeters higher or a headrest a fraction to the left. Once you've got a chair you love, you may never want a new one.

#### 4. **Perseverance is key.**

Not only do you need to persevere with getting a chair that is right for you and your lifestyle, having that “keep calm and carry on” attitude can be key to getting around. It’s easy to get lost in the crowd or ignored when you’re half the height of the average Joe. Don’t be afraid to push in. Make yourself known. It wasn’t until I attended a few festivals that I got confident in crowds. If I didn’t stand my ground I’d literally get trampled on and tripped over. My method now is to just go, go, go. I’m very aware of the people around me. An ocean of legs and feet. But still I keep on plowing through, as I know if I stopped to let just one group push past it would be the end of me. My focus would be gone, pathway gone, flow non-existent. The same goes for automatic doors and getting in an elevator.

#### 5. **Don’t assume you can’t go in.**

The back entrance, a side door, a hidden alley shouldn’t be how we enter a building, but sometimes that’s the case. It’s not OK, but it’s better than not going in. Always ask for access if it isn’t obvious. Some places have hidden ramps and doors. If they don’t, tell them they should. Having a portable, fold-up ramp is great for visiting friends and family. When you use wheels and start getting invited to other people’s houses, you start to realize how inaccessible they actually are.

#### 6. **Expect to become a leaning post, but don’t accept it.**

You will undoubtedly get leaned on, sometimes multiple times a day. Many people don’t seem to understand that your wheelchair becomes a part of you, an extension of your body. You wouldn’t just lean on a random person’s shoulder without permission, but others will lean on your handlebars, slouch on your armrest, put their feet up on your footrests. My footrest, where my feet live. The best way to rid yourself of this irritant is short, sharp movements — not intended to hurt, just to wake the culprit into realizing you are a moving, living being.

#### 7. **Your wheelchair will become a part of you.**

You’ll become protective, attached (not just physically) and proud of your new wheelchair. Dare anyone to diss your wheels. My wheels are my life, my independence. They allow and enable me to explore the world. They are my friend and nobody should mess with them.

#### 8. **Buckle up, it’s an adventure out there.**

Having wheels opens up a whole world of possibilities and ground surfaces. Wheels have all the feels. Dropped curbs. Ha. I don’t know what the specifications of a dropped curb / curb cut are (you know, those places in the pavement where there’s no step), but I do know there’s no such thing as smooth ground. Wheels highlight every little bump and hole. You will learn to slalom like a pro. It will

become second nature on your well-used trails; you’ll find yourself automatically keeping to the left or right to avoid a drain cover or crater. Cobbles, shingles, grass and wonky pavements all become a challenge to be defeated.

#### 9. **People are often friendly.**

You might get a few stares and sideways glances. Some people haven’t yet realized wheelchairs are from the same planet as them. You may also get raised voices and spoken to in slow motion, but on the whole, people are good. Assumptions are irritating and people can be ignorant. It happens. Don’t take offense at the little old man or over-bearing granny when they ask “are you OK?” “Do you need help?” “Where’s your mum?” Take the higher ground and assure them you are in fact fine, just getting on with your day. If you do need help, ask.

#### 10. **Know your style.**

One of the biggest yet unexpected challenges of always sitting down is clothing. Things look very different when worn in a wheelchair, there’s no changing it. There are also very few wheelchair-using models, and rarely a fully accessible changing room. But that’s another rant. You’ll learn what looks good on you, what is comfortable, practical and what will fit. I wear trousers and shoes that are a size too big for me. But who knows, or cares. Own your style and don’t lose you.

#### 11. **Make things work for you.**

Being a wheelchair user can push you to become creative at adapting situations to work for you. Don’t be put off after a first try of something. Think of how it could work if the task was undertaken differently or the environment was arranged in another way. I always appear to be sitting at a table awkwardly, perched up the corner or parked at an angle, but it works for me. Whatever works for you is what you should do. I like to have multiple things within reach at a time. I have a desk set up (a friend calls it my “daily life” table), where all the things I may want in a day are within reach. Sometimes it feels good not having to ask for help. Think about your house set up, bedroom, kitchen. Make space and have things within reach.

This article was written by Gemma Orton, a disability and lifestyle blogger with SMA Type 2. You can read more about her “life on wheels” at [www.whelescapades.com](http://www.whelescapades.com).



# 7 CONTINENTS, 1 WHEELCHAIR: MY JOURNEY TO EVERY CONTINENT AS A WHEELCHAIR USER

This story is brought to you from



I was six years old, sitting in my first grade class, and listening to my teacher, Mrs. Russell, talk about different countries around the world. In the midst of my daydreaming, she mentioned that there are seven continents: North America, South America, Europe, Africa, Asia, Australia, and Antarctica. “But nobody goes to Antarctica. It’s just ice,” she said. It may be just ice, but as soon as those words came out of her mouth, it opened up a world of possibilities for me.

I went home and immediately began questioning my mom about the seven continents. She dug out the encyclopedias and that was the day that my life changed forever. That afternoon, I learned that there were animals known as kangaroos in Australia, a huge landmark known as the Eiffel Tower in France, and Antarctica actually had more than just ice. It had a massive amount of whales and penguins also!

Before that day, I had no idea that there was even a world beyond my small hometown of LaFayette, Georgia. However, now that I knew, I needed to see it for myself. In that moment, I set a goal to visit all seven continents. As a six year old, I had no idea how it would realistically happen and as I got older, I really had no idea how it would happen as a wheelchair user.

I have always known that the road to all seven continents wouldn’t be an easy one, especially with a 350 pound wheelchair attached to my butt, but I maintained my determination. Has it been easy? Definitely not, but it has certainly been worth it.

Last week, I returned home from a 22 day cruise around South America and Antarctica, where I finally reached my seventh continent. It’s incredibly surreal to me that it finally happened and I’ve been reflecting a lot on how I got to this point and how I accomplished my goal of visiting all seven continents. That goal that I set at six years old was finally completed 23 years later.

As many of you know, if you’ve been following me for a while, my mom raised me as a single parent. She struggled to make ends meet as a paraprofessional in an elementary school from the time I was six until I graduated high school, making about \$800 per month. Needless to say, we didn’t have money to jet off to Europe in the summers, but we would always go on one or two trips per year. We’d make the nine-hour drive to Orlando and tour timeshares in order to get free tickets to Walt Disney World, we’d have yard sales all summer and go to the beach with the money we made, and we’d explore locally, venturing to nearby cities and attractions for a cheap weekend getaway. She was determined to show me as much as she could, and these experiences undoubtedly instilled the travel bug inside of me.

I didn’t set wheels on another continent until I was 18, but I fully believe that our many trips around the southeastern U.S. fed my wanderlust and kept the drive in me to continue exploring. At the age of 18, I was preparing to graduate high school. After taking German classes for all four years of high school, I had a strong desire to actually visit Germany. I sent graduation announcements to pretty much everyone that I’ve ever met and by some miracle, I received over \$2,000 from family and friends, along with many congratulatory cards. With the money, I booked a nine day trip to Germany and Austria as my high school graduation trip. While my fellow classmates were headed to Florida, I was flying to Europe for the first time and I couldn’t have been more excited.

On that trip, I learned about the hassles of traveling with a powered wheelchair. When my mom and I arrived at our hotel, there was a step to get in the lobby. I called and emailed before booking the hotel to check accessibility, but that apparently wasn't enough. With the help of the hotel staff, we managed to get me up and down the step every time we entered or left the hotel during that trip. And on our first night in that same hotel, my wheelchair charger blew up when we plugged it in (and yes, we had a converter and adapter). The next day, we had to find a wheelchair repair shop in Munich and purchase a new charger. Luckily, it all worked out, but that trip taught both my mom and I that patience and optimism are necessities when traveling as a wheelchair user. It was a valuable lesson and I'm grateful that I learned it early on. Now that I had two continents under my belt, I was unstoppable. Only five more to go!

Throughout college, I saved every dollar that I could. I worked as a telemarketer for a few months, interned at Disney World for a semester, and I, somewhat embarrassingly, even took out extra student loans so that I could travel. Was it a smart decision? Probably not the wisest, but I did what I had to do and for my college graduation trip, I went to continent number three – Australia!

Australia was everything that I wanted it to be and to this day, it remains one of my favorite places on the planet. It's also one of the most accessible in my opinion with wheelchair friendly taxis, buses, ferries, and more. Seriously, the rest of the world needs to look at Sydney to know how to truly be inclusive.

Not only did that trip to Australia give me the chance to finally see kangaroos in real-life, just like I had learned of 18 years earlier in the encyclopedia, but it also gave me the idea to start my blog. Prior to the trip, I was searching online for accessibility information on Australia and was struggling to find anything. Suddenly, I had an idea: What if I created a blog, where I could share my travels and accessibility that I've encountered along the way? With that thought, Curb Free with Cory Lee was born. I googled "how to start a travel blog" and followed the instructions step-by-step. Within a few days (on December 9th, 2013 to be exact), my blog was live.

When I started my blog, I gave myself one year to grow it. If I was making some money from it and it was doing well, I'd stick with the whole blogging thing. If it wasn't a success at the end of that first year, I'd look for a job in advertising or marketing, which is what my degree is in. It was a tough year. I wrote until my fingers couldn't write any more, I took online classes and studied the art of blogging nonstop, and I worked my butt off. I was determined to make the blog a success, so I put everything that I had into it.

Toward the end of that year when I was about to give up, I received an email inviting me to speak at the Abilities Expo in Los Angeles. The expo didn't pay a speaker's fee or cover flights, but something inside of me said that I needed to go. I booked flights and a hotel that same day and a couple months later, I was in Los Angeles giving a speech about traveling as a wheelchair user to a crowd of no more than thirty people.

When my presentation finished, a lady came up to me and introduced herself as the Travel Editor of the Los Angeles Times. I was shocked. An editor of the Los Angeles Times, one of the biggest newspapers in the country, was in my audience?! Not only did she introduce herself, but she asked if she could interview me for two upcoming articles about flying with a wheelchair in the Times. I said yes, of course, and a few weeks later, the first article came out. My blog was mentioned and I was quoted throughout the entire piece. It was the publicity that I needed to take my blog to the next level.

After both of the L.A. Times articles came out in early 2015, I began receiving emails from different companies that wanted to collaborate. Finally, after a year of hard work and devoting my entire being to my blog, I began making some money. I decided to keep blogging and trying to grow the Curb Free with Cory Lee brand.

What a wildly amazing five years it has been since the *Los Angeles Times* stories came out!

Since starting this blog, I have received invitations to visit remarkable places like South Africa, India, Finland, Morocco, Israel, Costa Rica, Spain, and most recently, I partnered up with Allianz Travel Insurance to visit my seventh continent, Antarctica! In my wildest dreams, I could have never imagined the places that this blog, along with the constant support of all of you reading this, would take me.

When I clicked the publish button on my first blog post in 2013, I had no idea that that decision would allow me to accomplish my life goal of visiting all seven continents. But sometimes, if you have enough determination, even your craziest dreams can come true.

As I sat in Antarctica, staring at giant icebergs and seeing more whales than you can possibly imagine, the power of that moment hit me. No matter what it is that you hope to achieve, whether you want to graduate college, or climb Mount Everest, or something totally different, you can do it if you stay motivated. Remind yourself daily that it's what you want, surround yourself with people that believe in you just as much as you believe in yourself, and be completely open to the process that the universe has in store for you. Eventually, when the time is right, you will reach your goal. It may even take 23 years, like my goal did, but enjoy every step of the process and it will make you who you are meant to be.

There's a saying that "Nothing worthwhile is easy," and I learned that firsthand. If it was easy, it wouldn't be nearly as special when it happens.

**So, what is your goal and what steps are you taking to achieve it?**

To read more about Cory Lee's adventures visit his website:  
[www.curbfreewithcorylee.com](http://www.curbfreewithcorylee.com)

# 2020 National Partners

Thank you to our National Partners for their continued support of Cure SMA!  
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# Cure SMA Merchandise

Check out our online store at [www.curesma.org/merchandise](http://www.curesma.org/merchandise) to support our mission and raise awareness by purchasing some Cure SMA merchandise.



Shop now through the end of June and receive 25% off your entire merchandise order with discount code "2020conference" at checkout. And share a photo in your Cure SMA gear with [familysupport@curesma.org](mailto:familysupport@curesma.org).

*Share a photo of you sporting your Cure SMA gear to [familysupport@curesma.org](mailto:familysupport@curesma.org) and you may see it in a future publication or our next issue of Directions.*

# Clinical Care Update



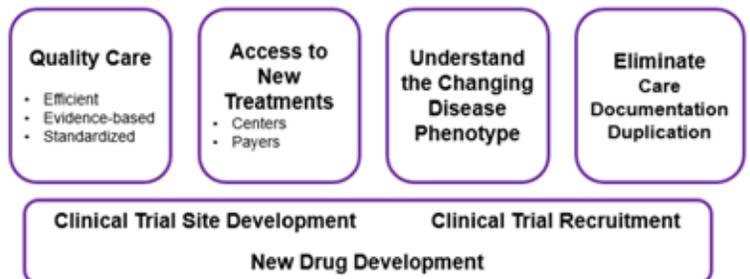
Duke University SMA Care Center Team: Stephanie Thera; Edward Smith, MD; Karen Cornett, BS MT, CRC; Tara McKellar, RN-BSN; and Richard Kravtiz, MD

Cure SMA partners with established neuromuscular care centers across the U.S. to establish best care and practices for all living with SMA. The core of the Cure SMA Care Center Network is the SMA Clinical Data Registry (the SMA Registry). The SMA Registry secures electronic medical record (EMR) information from people with SMA who receive care at Care Center Network sites.



A Care Center team documents each usual clinic visit in their EMR as part of usual care. Patients provide their consent and agree to have their care information transferred to the SMA Registry. The SMA Registry information is analyzed to identify best care practices for SMA and will be used to accredit Care Centers of Excellence for SMA. A unique feature of the SMA Registry is that patient information in the EMR is electronically transferred through a secure pathway to the SMA Registry. This information is available to the originating Care Center healthcare team for their review of the patient care data.

## Cure SMA Care Center Network and SMA Registry Goals





262  
Total Patients

11,571  
Encounters

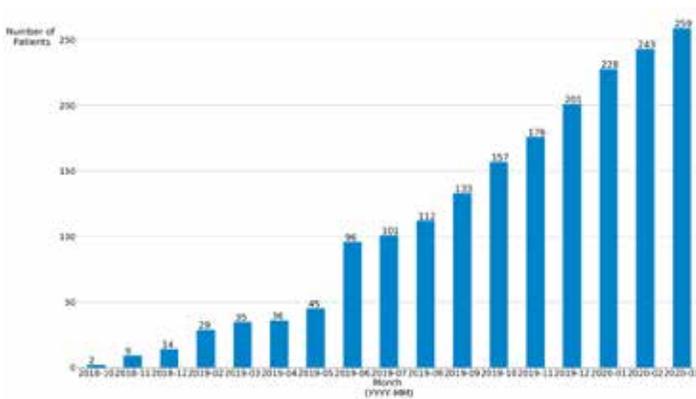
8,109  
Diagnoses

10,523  
Labs & Vital Signs

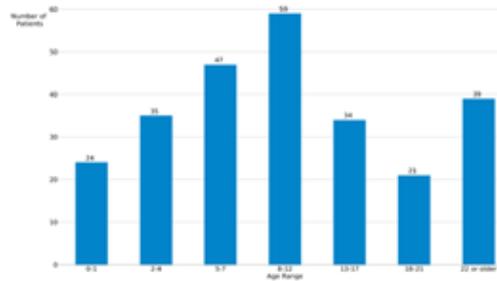
14,007  
Procedures

4,882  
Medications

## SMA Registry Demographics

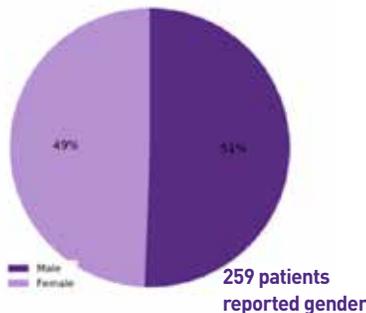


### Patient Age Range

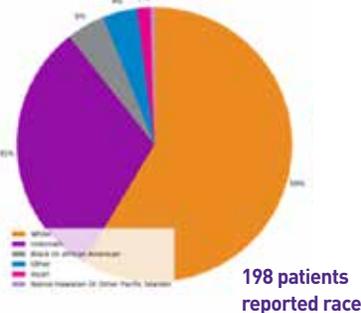


**Age Breakdown**  
2 months  
Youngest  
63 years  
Oldest  
9 years  
Median

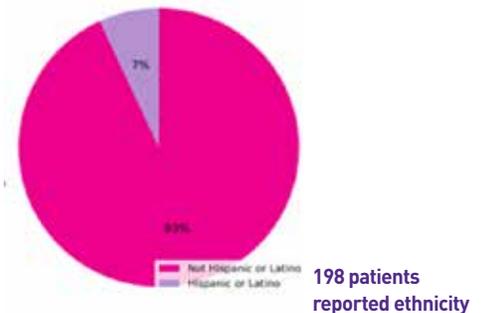
### Gender



### Race



### Ethnicity



## SMA Newborn Screening Registry

For children diagnosed with SMA through newborn screening, Cure SMA requests that families answer a 20-question survey. Families can also consent to have their healthcare provider answer questions on their behalf. The SMA Newborn Screening Registry (NBSR) is a secure, online registry. If you are a parent or caregiver of a child with SMA who was identified through newborn screening, we invite you to participate in our registry by visiting [www.curesma.org/NBSR](http://www.curesma.org/NBSR).

## Educational Materials

Cure SMA remains focused on providing the most up-to-date information about SMA to the entire SMA community. Our Care Series Booklets, including new booklets on newborn screening and clinical trials, are valuable publications that are continually updated and available in English and Spanish (where possible) at [www.curesma.org/care-series-booklets/](http://www.curesma.org/care-series-booklets/). If you would like paper copies of these materials, please contact [info@curesma.org](mailto:info@curesma.org).



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

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

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



# Advocacy Update

Left: Dr. Francis Collins with Derek, Tina and Julian Lewis; Middle: Rep. Cathy McMorris Rodgers; Right: Rep. Greg Walden

## SMA Treatment Discoveries Inspire Attendees of 9th Annual *Hope on the Hill* Event

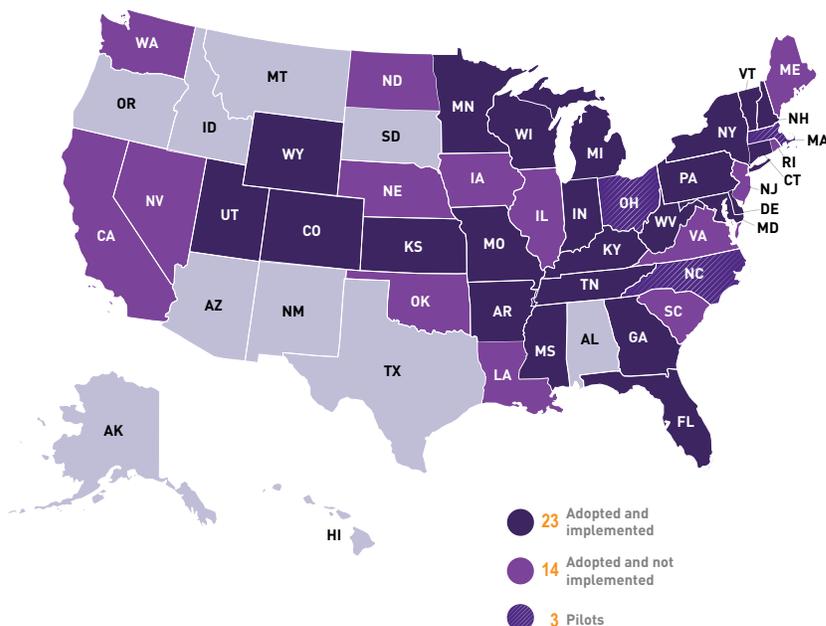
More than 180 people from the SMA community—including families, government officials, and industry partners—attended the 9th Annual Hope on the Hill Congressional Dinner on December 3, 2019, at The Willard Hotel in Washington, D.C. The event, which raised \$195,000 to fund advocacy efforts, research, and family support services, featured a keynote address by National Institutes of Health (NIH) Director, Dr. Francis Collins, and remarks from several Members of Congress.

Dr. Collins described the amazing progress in SMA research and how the entire research community has been inspired by the dramatic discoveries and successes in SMA research and development. “When [others] see what you all have been able to accomplish in SMA, they are inspired, they are uplifted, and encouraged. And you can see how academic researchers and industry have gathered now to see rare disease as an opportunity for advancement,” said Dr. Collins, who oversees a \$39 billion NIH medical research budget. He concluded his remarks by telling *Hope on the Hill* attendees that the NIH remains a committed SMA partner, noting that, “We want to continue this fight until there is an answer for every person who has every form of this condition.”

The evening also featured remarks by four Members of Congress. Rep. Greg Walden (Oregon), Rep. Fred Upton (Michigan), Rep. Cathy McMorris Rodgers (Washington), and Rep. Michael Burgess (Texas) each spoke about the importance of the bipartisan 21st Century Cures Act, signed into law in 2016, and its role in accelerating research for treatments and cures for rare diseases, such as SMA.

They also discussed their commitment to SMA and the rare disease community, and plans to expand patients’ access to new treatments and health technology through legislation they are calling Cures 2.0. Guests also heard from event co-chairs, Greg and Shannon Zerzan, Walter Robb, a parent of children with SMA, and Cure SMA President, Kenneth Hobby.

*Hope on the Hill*, which began in 2011 as a small dinner, has grown into a major Washington, D.C. event that has raised more than \$1.4 million for Cure SMA. The 10th Annual *Hope on the Hill Congressional Dinner* is scheduled for Wednesday, December 2, 2020 at The Willard Hotel in Washington, D.C.



## Newborn Screening of SMA Reaches Screening Milestone

More than half of all U.S. states now screen newborns for SMA, less than 2 years following the federal recommendation that states screen newborns for SMA. As of May 30, 26 states are screening newborns for SMA—23 through permanent SMA screening programs and 3 through pilot programs.

While more than half of states screen for SMA, just under 50% of all newborns in the U.S. are being screened for SMA, based on the birth estimates of the 26 screening states. However, the percentage of newborns screened for SMA is expected to increase to more than 70% by the end of 2020, based on Cure SMA projections, as several large states—including California and Illinois—implement permanent programs during Summer and Fall 2020.

Cure SMA now focuses its advocacy and support on non-screening states to accelerate its goal of universal screening by July 2023, which would mark the 5-year anniversary of when the U.S. Health and Human Services Secretary approved the Advisory Committee on Heritable Disorders in Newborns and Children recommendation to add SMA to the Recommended Uniform Screening Panel (RUSP).

Early diagnosis of SMA through newborn screening is critically important now that we have multiple effective SMA treatments. “This early success reflects the great advocacy collaboration among Cure SMA supporters, families, healthcare providers, and industry partners. Our work and partnership will continue until all babies born in this country are screened for SMA,” said Kenneth Hobby, President of Cure SMA.

## Cure SMA Advocates for SMA Community During COVID-19 Outbreak

From the start of the COVID-19 public health emergency, Cure SMA was actively educating policymakers at the federal and state level about the needs, concerns, and impacts of the COVID-19 outbreak on the SMA community. Our advocacy efforts, which have been informed by direct conversations and survey responses from the SMA community, have included:

- Cure SMA letters to Congress, Governors, and key state health care officials on the unique care, treatment, equipment, and other needs of children and adults with SMA and their families;
- Letter downloads for the SMA community to use to send directly to their state officials on their specific COVID-19 related needs; and
- Grassroots action alert to Congress to ensure safe and ongoing access to community services, including in-home care and personal care attendants.

In addition, Cure SMA has joined other national healthcare, rare disease, and disability organizations in letters urging federal and state officials to stop the discrimination of individuals with underlying health conditions, such as SMA, in accessing healthcare and equipment (e.g., ventilators) during the public health emergency. Separately, Cure SMA wrote to all 50 state Governors demanding that they rescind any discriminatory rationing of care policies. This collective effort has resulted in policy reversals and gubernatorial statements supportive of equal access to care and equipment during this crisis.

### GOT A NEWBORN SCREENING TIP OR UPDATE?

Want advocacy help to support your local efforts related to COVID-19 or other issues?

Contact the Cure SMA Advocacy Team at (202) 871-8004 or at [advocacy@curesma.org](mailto:advocacy@curesma.org).



# Fundraising Update

## How Your Help Impacts Our Community

Despite these unexpected times we are facing, Cure SMA's mission continues by creating hope for the SMA community through action in our fundraising. And every little action helps move us one step closer to our goal of a world without SMA. If you can, please consider supporting Cure SMA through one of these easy ways.

- 1. Participate in a Virtual Event**  
Grab your friends and walk, roll, or dance in a virtual Cure SMA event!
- 2. Set Up a Facebook Fundraiser**  
In lieu of gifts for a birthday or special event, consider setting up a Facebook Fundraiser for Cure SMA!
- 3. Get Involved**  
Connect with your local chapter to find out how you can get involved as a volunteer on a committee. Check out our website for contact information.
- 4. Become a Monthly Donor**  
Set up a recurring monthly gift that can fit into any size budget. Every dollar matters!
- 5. Share Our Mission with a Friend**  
Take a minute and share with your network on social media why supporting Cure SMA is important to you.
- 6. Shop Through Amazon Smile**  
Visit [www.smile.amazon.com](http://www.smile.amazon.com) and select Cure SMA as your charity. After that, 0.5% of every purchase you make goes directly to our mission!
- 7. Get a Company Match**  
Check to see if you or your partner's employer will match your donation. You can double the size of your gift—and double your impact for the SMA community.
- 8. Seek Out a Company Sponsor**  
Companies like to support what is important to their customers. Make your voice heard and ask them to join in supporting our mission!
- 9. Follow and Share Us on Social Media**  
Spread the word and stay up to date on all that is happening by following all our social media platforms. We are on Facebook, Instagram, Twitter, and LinkedIn.
- 10. Join Virtual Team Cure SMA**  
Participate in virtual race training and fun fitness challenges from the convenience of home!

For more, visit our website at [www.curesma.org/ways-to-give/](http://www.curesma.org/ways-to-give/).

# IMPACT REPORT

July 1, 2019 – May 1, 2020



Cure SMA wants to thank our donors, event organizers, and volunteers who support our mission every day. We continue to invest in comprehensive research to create new breakthroughs in treatment and care, while providing the local and national programs that the SMA community depends on today. In fact, 83 cents of every dollar raised is funding research, patient services, family support, and awareness programs.



## Donor Spotlight Michael Galas

Monthly donations are a vital gift option that fuels Cure SMA's success. We would like to thank Michael Galas, a monthly Cure SMA donor from Florida, for his dedication and support! Michael is grandfather to 2-year-old Tilly, who was diagnosed at 6 months of ages with SMA Type 3. Tilly was able to receive Cure SMA's newly diagnosed support package and equipment from our equipment pool. "I give to Cure SMA monthly because it is important that others get the same support that my granddaughter did, and that she continues to receive today," said Michael. Michael's wife and her sewing guild also show their support by sewing more than 60 quilts and 100 pillowcases to be included in some of the support packages. Monthly donors choose what they can give each month in support of our mission's critical SMA research and family support programs. If you'd like to support Cure SMA on a monthly basis, please contact [fundraising@curesma.org](mailto:fundraising@curesma.org).

# Research Update

A clinical trial, also called an interventional study, tests new drugs and treatments. It can also test new applications for approved drugs or treatments (e.g., using drugs in different combinations or for different diseases). A drug must pass each individual phase of a clinical trial before advancing.



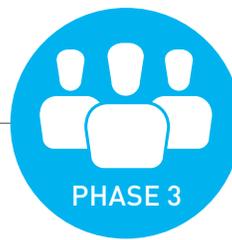
PHASE 1

Tests safety and dosage levels, usually on 10-20 individuals. Sometimes, these volunteers are healthy individuals. However, for an orphan disease like SMA, some or all may be patients with the condition being studied.



PHASE 2

Tests a slightly larger group, usually 20-40 individuals, all of whom have the condition being studied.



PHASE 3

Increases the number of people tested—up to 100-200 including the control or placebo group. A drug that passes these three phases can be approved and marketed to the general public.



PHASE 4

Primarily involves ongoing evaluation and monitoring, even after a drug is approved for the general public.

## Recruiting and Ongoing Clinical Trials for SMA

**Genentech**, a member of the Roche group, is assessing the safety and efficacy of risdiplam in its clinical trials RAIN-BOWFISH (currently recruiting), JEWELFISH, SUNFISH, and FIREFISH (ongoing). Risdiplam is an investigational, oral medicine that is systemically distributed and designed to increase SMN protein levels in the central nervous system (CNS) and throughout the body. It is designed to help the SMN2 gene produce more functional SMN protein that better supports motor neurons and muscle function. In November 2019, the U.S. Food and Drug Administration (FDA) granted Priority Review for risdiplam with a decision for approval expected by May 24, 2020. As requested by the FDA in February of this year, additional data from the pivotal SUNFISH Part 2 study was

submitted, and due to the volume of data submitted by the company, the FDA extended its New Drug Application (NDA) review to August 24, 2020. The FDA confirmed the extension is not related to any current efficacy or safety concerns of Risdiplam or to the COVID-19 pandemic.

**AveXis** is conducting a long-term, safety follow up study of patients in the AVXS-101-CL-10 (START) gene replacement therapy clinical trial for SMA Type 1, delivering **onasemnogene abeparvovec-xioi**. Patients will roll over from the parent study into this long-term study for continuous safety monitoring for up to 15 years. This study is expected to be completed in late 2033.



**Biogen** recently announced the start of recruitment for its global **nusinersen** clinical study, DEVOTE. The study is designed to evaluate the safety, tolerability, and potential for greater efficacy of nusinersen when administered at a higher dose than currently approved for the treatment of SMA. The Phase 2/3 randomized, controlled, dose-escalating study will be conducted at approximately 50 sites around the world and aims to enroll individuals of all ages with SMA.

**Scholar Rock** is currently conducting the TOPAZ study to assess the safety and efficacy of **SRK-015** in later-onset SMA (Type 2 and Type 3) in pediatric and adult patients. SRK-015 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. TOPAZ is a Phase 2 study made up of three cohorts: ambulatory Type 3 SMA; Type 2 and non-ambulatory Type 3 SMA; and Type 2 SMA and enrolled patients ages 2 to 21 years. Preliminary results released in November 2019 show that the drug works to increase myostatin and reported clinically significant safety findings. Trial enrollment is now complete, and the trial is currently ongoing with topline results for the 12-month treatment period expected in Q4 2020 and early 2021.

**Novartis** is conducting an open-label, multi-part, first-in-human study of oral **branaplam** in infants with Type 1 SMA. The purpose of this study is to evaluate the safety and tolerability of the drug, as well as determine appropriate dosing. Branaplam works by increasing the amount of functional SMN protein made by the SMN2 gene. The study is no longer recruiting but is ongoing with an estimated completion in Summer 2020.

For more information about these and other SMA clinical trials, please visit [www.curesma.org](http://www.curesma.org) and [www.clinicaltrials.gov](http://www.clinicaltrials.gov).



# Family Support Update

## Cure SMA Helps Over 2,200 Individuals and Families with COVID-19 Support Programs

Despite the new reality of quarantines, remote working, and social distancing, Cure SMA made sure our work for the SMA community continued. Despite the rapid and unexpected changes, Cure SMA remained vigilant in monitoring and responding to the needs of the SMA community by launching new support programs to help individuals and families affected by SMA during the COVID-19 pandemic.

From the beginning, Cure SMA was proactive in its response to the COVID-19 pandemic. Our COVID-19 Information Center provided the most up-to-date information and resources in support of the health and advocacy needs of the entire SMA community. From communications about the latest preventative recommendations to template documents for doctors, employers, and schools to letters for state and federal lawmakers protecting the rights of those with SMA, Cure SMA offered unwavering support for the entire SMA community.

Then, just weeks into the nation's quarantine, the COVID-19 Support Package was created to help members of the SMA community obtain essential items that were difficult to locate, such as hand sanitizer and antibacterial wipes.

The packages also included fun items to help keep everyone entertained and engaged as people were asked to isolate at home.

In addition to the Support Package, Cure SMA also launched the COVID-19 Assistance Program, designed to help alleviate some of the financial burden for those in the SMA community who may be experiencing hardships due to the COVID-19 pandemic. This Assistance Program offered individuals and families a \$50 gift card to help with purchasing items such as meals, groceries, or other essential supplies during these difficult times.

As of May 1, Cure SMA is pleased to have shipped more than 1,420 support packages and provided 820 gift cards to individuals and families affected by SMA to support the SMA community during these unexpected times. At the end of the day, the health, safety, and well-being of the community is always our top priority.

Cure SMA thanks our generous donors and sponsors, whose contributions made this effort possible. A special thanks to AveXis, Biogen, Genentech, and Ionis for their additional support of Cure SMA's new COVID-19 Support Programs.



## Cure SMA Launches Summit of Strength Virtual Webinar Series

For the past 2 years, Cure SMA's Summit of Strength program has brought together thousands of SMA community members for the opportunity to network and learn about the latest advances in treatment, care, advocacy, and support. Considering event cancellations across the country due to the ongoing pandemic, Cure SMA launched the Summit of Strength Virtual Webinar Series.

These virtual webinars started in May and will run through the summer, bringing experts into your home to speak on a variety of educational topics tailored to help individuals and families with SMA during this life in quarantine. Presentations will include family support and patient care topics like those that may have been shared at our in-person Summits, while also touching on new and beneficial topics that arise as time goes on. Also, during each webinar, attendees will hear a brief presentation from one of our Summit of Strength presenting sponsors: AveXis, Biogen, or Genentech.

While we look forward to returning to in-person Summit of Strength events when we are able, we hope you will consider joining us virtually. If you have any questions, please contact [familysupport@curesma.org](mailto:familysupport@curesma.org).

*Thank you to the National Presenting Sponsors for the 2020 Summit of Strength Programs: AveXis, Biogen, and Genentech. We would also like to recognize Platinum Sponsor, Scholar Rock, for its support.*



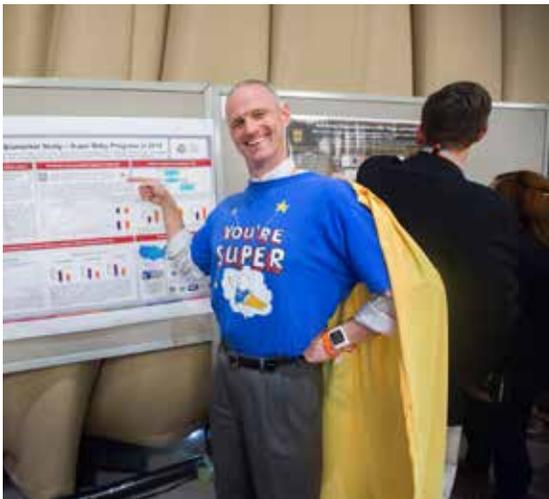
# THE ANNUAL SMA CONFERENCE: 36 YEARS STRONG

Every year, Cure SMA hosts the Annual SMA Conference and SMA Research & Clinical Care Meeting to bring together researchers, healthcare professionals, affected individuals, and families to network, learn, and collaborate. We have been hosting the Annual SMA Conference since 1988, offering the SMA community a wide variety of workshops, keynote sessions with leading researchers, a family-friendly poster session, and memorable age-specific programming that strengthen our community's connections.

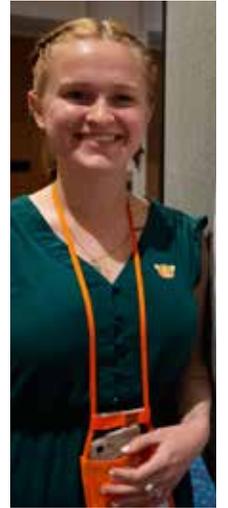
The cancellation of the 2020 Annual SMA Conference due to the worldwide COVID-19 pandemic was a disappointment to all involved. To ensure we give proper recognition to just how special this annual event is, we are looking back at photos from previous Annual SMA Conferences—we hope you enjoy.

We look forward to reuniting as a community at the 2021 Annual SMA Conference and SMA Research & Clinical Care Meeting. More details to come!









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

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



Cure SMA is committed to providing the entire community with the information they need to make decisions about treatment and care.

Check out the updated Cure SMA Care Series Booklets.



Find them online: [www.curesma.org/care-series-booklets/](http://www.curesma.org/care-series-booklets/)



# GET INVOLVED WITH YOUR LOCAL CHAPTER

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

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



**VOLUNTEER OPPORTUNITIES ARE AVAILABLE NATIONALLY**

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

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



# Family Socials

**Thanks to generous support from AveXis, Cure SMA hosted 16 Family Socials across the country in 2019.**

These fun, family-friendly events brought hundreds of affected individuals and families together to network and socialize. Events were held everywhere from local museums to zoos to clubhouses.

*Thank you, again, to AveXis for giving us the opportunity to bring together our community! Socials were held in Arizona, Arkansas, California, Colorado, Florida, Illinois, Indiana, Massachusetts, Minnesota, New York, Ohio, Oklahoma, Texas, and Wisconsin.*



## Alabama Chapter

### Mississippi

#### 2020 St. Vincent De Paul Catholic Church

Students and staff came together to help fundraise and support Cure SMA. Their efforts were done in honor of Blakeley Quinn Hammons and Henry Northcutt III. Thank you to the students and staff who participated and raised **\$805** for Cure SMA.

## Arizona Chapter



### Arizona

#### 2019 Arizona Walk-n-Roll

The 14th Annual Arizona Walk-n-Roll was held on November 9, 2019, at Steele Indian School Park in Phoenix, AZ. Teams of families, friends, sponsors, and vendors, came out to make the day another huge success by raising more than **\$22,000** in support of a cure for SMA. Participants enjoyed various activities, games, and an amazing raffle. Thank you to Angel Wolff, her committee, and all the supportive volunteers for another wonderful walk in Arizona.



#### 2019 Cure SMA Wannabe Cup

The Wannabe Cup kicked off on October 3, 2019, at the Talking Stick Resort & Casino in Scottsdale, AZ. Each year this incredible group of friends come together to fundraise for Cure SMA in celebration of Skylar Bahrenburg. The 2019 event resulted in nearly **\$13,000** in donations for Cure SMA. This traveling golf event has taken place for more than 20 years. A special thank you to Joe and Andy Belcher for their dedication to Cure SMA and the Bahrenburg Family for their support!

## Northern California Chapter

#### 2019 Our Lovely Angels Crab Feed

On March 6, 2019, Our Lovely Angels hosted their 2nd Annual Crab Feed in Stockton, CA. This sold out event raised more than **\$3,000** for Cure SMA and was held in memory of Jessica and Jaylin Gayle. A huge thank you to Gloria Lopez and Priscilla Gutierrez for organizing this excellent fundraiser!

## Southern California Chapter



#### 2019 Cure SMA Reach4Sky Goes Bi-Coastal

In September 2019, Reach4Sky went bi-coastal to celebrate what would have been Skylar Bahrenburg's 18th birthday. "In honor of this important milestone, we felt compelled to reach for the sky in our fundraising efforts," said Jim Bahrenburg, Skylar's dad. For more than 17 years, Team Reach4Sky's dedicated swimmers have come together in California for a one-mile open water swim to raise funds and awareness for Cure SMA. To include more east coast family and friends, the Bahrenburg's organized two events by participating in the Annual Labor Day Oceanside Pier Swim in sunny California on September 2, 2019, followed by the Annual Boston Sharkfest Swim in chilly Massachusetts on September 21, 2019. Both events were a huge success with more than 35 swimmers, 150 beach supporters, and raised over **\$43,000**. A huge thank you and congratulations to the Bahrenburgs on the success of their events!

*Note: The amounts raised and shown are totals as of April 30, 2020 and may differ from current fundraising totals by the time you get this newsletter.*

## Leaf Invitational Benefiting Cure SMA

On September 11, 2019, Leaf Communications held the Leaf Invitational at the Monarch Beach Golf Links in Dana Point, CA. This year, Cure SMA was selected as the charity beneficiary of the tournament, which raised **\$40,000**. Special thanks to Dan Leaf and the Leaf Communications Team, Abbe Pell, and Nikki and Tony McIntosh for making this event a tremendous success.



## Honoring Alexandra Nina Meigs' 12th Birthday

Each year, Andrea and John Meigs from Los Angeles, CA, honor the life of their beautiful daughter, Alexandra, by raising money for Cure SMA to commemorate her birthday. This year, in celebration of Alexandra's 12th birthday, the Meigs Family raised **\$22,000** – bringing their total contribution since 2008 to more than \$166,700. John and Andrea are determined to continue fundraising to support medical research and support services for families facing SMA. The Meigs' Family wants to say thank you from the bottom of their hearts for remembering Alexandra's birthday and to please continue to support Cure SMA's mission in her honor.

## Ruby's Diner

Thank you to Lynn De Blasio, for hosting another successful Dine and Donate event at Ruby's Diner, in memory of Jaimie Ramsey, on November 13, 2019. This partnership raised more than **\$1,290** for Cure SMA.

## 2019 San Diego Walk-n-Roll

The 2nd Annual San Diego Walk-n-Roll took place on November 3, 2019, at Liberty Station NTC Park in San Diego, CA. More than 140 participants and 11 teams gathered to raise over **\$15,000!** The day included arts and crafts, lawn games, a petting zoo, photo booth, ice cream truck, and a two-mile walk around beautiful NTC Park. A big thank you to our event organizers, Brittany Sattari, Tara Hahn, and Autumn and Rickk Montoya, for all the hard work to make this event a success!

## Capital Region Chapter



## 2019 Cure SMA 5K & Walk-n-Roll in Memory of Trooper Cunniff

On September 28, 2019, more than 215 participants came out to Colonie Mohawk River Park, in Colonie, NY, to support Cure SMA. With help from the generous sponsors and donors, the event raised nearly **\$46,000!** Congratulations to the top five fundraising teams for helping exceed the goal: Caleb's Dream Team, Team Greyson, Team Chloe, Brooks Wolfe Pack, and Team Whalen Chevrolet. Thank you to event organizers, Amy Cuniff-Bleau and Allie Wolfe, for their leadership and dedication!

*Note: The amounts raised and shown are totals as of April 30, 2020 and may differ from current fundraising totals by the time you get this newsletter.*



## 7th Annual David Cunniff Glen Lake Ice Fish Tournament

The 7th Annual David Cunniff Fishing Tournament was held on January 25, 2020, at the Dockside Restaurant in Lake George, NY. The day was a great success and nearly **\$2,400** in proceeds were donated to Cure SMA. The NYS Signal 30 Fund is an organization that supports members of the New York State Troopers who have been killed in the line of duty, like Trooper Cunniff. Thank you to the Cunniff family for their hard work and efforts to start, promote, and run this ice fishing tournament.



## South Carolina

### 2020 Hayes' Heroes Presents a Cure SMA Evening of Hope

The 5th Annual Hayes' Heroes Evening of Hope was held on February 22, 2020, at the Country Club of Lexington, in Lexington, SC. The event was hosted by award winning journalist, Brand Taylor, and guests enjoyed the fun evening full of great food, a silent and live auction, wine pull, and live music by Jumpstart Band. This year, the event raised **\$36,747** – an all-time high! Special thanks to the amazing planning committee: Keri Johnson, Kathy Cooper, Kari Taylor, Jamie Wingard, Dawn Hyatt, and Joyce Sireno. This event would not be possible without their hard work and dedication every year.

## Carolinas Chapter



## North Carolina

### 2019 Raleigh Walk-n-Roll

The 7th Annual Raleigh Walk-n-Roll was held on September 28, 2019, at the beautiful North Cary Park in Raleigh, NC. This event raised **\$27,278** for Cure SMA! It was a great day for friends and families to come together to celebrate the SMA community. There was a catered lunch from PDQ, a DJ, games, and a walk around the park. Thank you to the hard-working planning committee: Jennifer Lee, Marla Kasper, Amy Hoke, Carrie Ann Boles, and Remona Sandridge. A special thank you to AveXis and Biogen for their incredible fundraising efforts! Thank you to all the amazing families and friends that came out to support!

## 8th Annual Mistletoe Jam

Friends and families came together on December 12, 2019, for the 8th Annual Mistletoe Jam at the Southside Smokehouse and Grille in Landrum, SC. The event raised **\$7,000**. As always, it was a night filled with live music by local bands, all while raising money for Cure SMA in honor of Alexandra Genovese. Thank you to Chris Genovese and Don McInerney for hosting another successful event!

## Chesapeake Chapter

## Delaware

### Steamboat Landing Bingo Fundraiser

Thank you to the Steamboat Landing Campground in Milton, DE, for hosting its successful 2019 bingo fundraiser. Cure SMA is grateful to the owners of Steamboat Landing, Rusty and Linda Pride, and the Calvert family for organizing this event and raising **\$1,500** in honor of Olivia Calvert.

*Note: The amounts raised and shown are totals as of April 30, 2020 and may differ from current fundraising totals by the time you get this newsletter.*

## Connecticut Chapter

### West Rocks Middle School Fundraiser

Thank you to West Rocks Middle School for hosting a successful fundraiser and raising **\$1,500** to support Cure SMA's mission.

## Greater Florida Chapter



### 2019 Greater Florida Walk-n-Roll

The 11th Annual Greater Florida Walk-n-Roll was held on October 5, 2019, at Philippe Park in Safety Harbor, FL, and was a huge success! More than 152 participants and 17 teams joined this year for family-friendly activities, fundraising for a cure, and to celebrate the SMA community. Together they raised more than **\$29,700** for Cure SMA! A special thank you goes to the Outback Bowl who returned as the Presenting Sponsor. Thank you to the event committee members for their hard work and dedication: Audra Butler, Amanda Camp, Jimmy Geueke, Katie Kerns, Asia Nowotny, Michelle Schnyders, and Jennifer Smith. Thank you to all the outstanding teams for fundraising this year!



### 19th Annual Costume Crusade

On October 25, 2019, more than 175 families and 40 local businesses participated in the 19th Annual Costume Crusade hosted by the Village Early Learning Center in Brandon, FL. Costume Crusade began with a gift basket fundraiser that ran for about two weeks. Costume Crusade culminates in a wheelchair race, costume parade, carnival style games, and silent auction. The event raised **\$4,250** for Cure SMA. Thank you to Susan and Joe Miller for continuing to host this great event.

## North Florida Chapter



### 2020 St. Augustine Walk-n-Roll

The 2nd Annual St. Augustine Walk-n-Roll took place at the Riverview Club in St. Augustine, FL, on February 29, 2020. More than 200 people joined the North Florida Chapter in its second successful walk! Participants enjoyed a beautiful walk through Canopy Shores Park and family-friendly activities. Friends and family came together to exceed the goal by raising nearly **\$30,000**. A big shout-out to Kevin Campbell, Corinne Romano, Coral Friend, Maureen Ford, Jeana Kinley, and Kim Storms, for all their help planning this successful event!

## South Florida Chapter



### 2020 Miami Walk-n-Roll

On March 3, 2020, more than 150 participants came together to help the South Florida Chapter host their 2nd Annual Miami Walk-n-Roll at Amelia Earhart Park in Hialeah, FL. Participants enjoyed a beautiful walk through the park, and family-friendly activities like yard games and crafts. The event committee was instrumental in exceeding the goal by raising **\$22,000**, along with the help of nine teams. A big shout-out goes to Allie Royal, Idalmis Del Toro, Maylan Chavez, and Ellie Villaescusa for their help in planning this successful event!

*Note: The amounts raised and shown are totals as of April 30, 2020 and may differ from current fundraising totals by the time you get this newsletter.*

## Georgia Chapter



### 2019 Atlanta Walk-n-Roll

The 2nd Annual Atlanta Walk-n-Roll was held on September 21, 2019, at Etowah River Park in Canton, GA, and was a huge success! More than 85 participants and nine teams joined this year for fundraising, family-friendly activities like decorating mini pumpkins, face painting, and great door prizes, all to support the SMA community. Together they raised **\$15,948** for Cure SMA! A special thank you to event organizers, Tara Ragan and Valerie White, for their continued dedication to making this an awesome event in this area. Thank you to all the amazing teams for being part of this great event!

## Greater New York Chapter



### 2019 Greater New York Walk-n-Roll

On September 22, 2019, 150 people came out to Eisenhower Park in East Meadow, NY, to celebrate the event's 15th anniversary! Thanks to the incredible fundraising efforts of the 10 teams, the event was able to raise **\$21,500**. Congratulations to the top fundraising teams: Friends of Julia, Team Bear, Team Fab Five, and Team Ross. A special thank you the event's new co-chairs, Erin and Kevin Bonner, for their dedication to Cure SMA.

15 Years

### Marta Cyhan Bowels' Individual Fundraiser

Thank you to Marta Cyhan Bowels of Brooklyn, NY, for donating her birthday to Cure SMA. She raised **\$900** in honor of her niece, Alexandra Ellis.

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## Illinois Chapter



### 2019 Evening of Hope in Honor of Cameron Lily Shish

The Evening of Hope in Honor of Cameron Lily Shish took place on October 18, 2019, at the Wilder Mansion in Elmhurst, IL. More than 80 guests enjoyed cocktails, hors d'oeuvres, music, a wine raffle, and a silent auction. The successful event raised **\$20,000** to support Cure SMA's mission. A huge thank you to Jamie Shish and her dedicated committee for their work putting this event together and fundraising for Cure SMA.

### Mikaela Rose Dinner of Hope

Thank you to John Szajna, the entire Szajna family, and John's local Knights of Columbus Chapter in Ingleside, IL, for hosting the Mikaela Rose Dinner of Hope in October 2019. The special evening included a silent auction, 50/50 raffle, and a tasty dinner, all of which raised **\$6,000** for Cure SMA in honor of John's youngest granddaughter, Mikaela Rose. Additional thanks to the local Women's Club and the Parent's Association for donating food, flowers, and auction items. The dinner was one of the biggest events hosted by St. Bede's Church.

### Deer Path Middle School Fundraiser

The SLS Club at Deer Path Middle School in Lake Forest, IL, hosted an after-school event on January 31, 2020, to raise funds and awareness about Cure SMA's mission. Students had a fun afternoon playing different games against their teachers and raised **\$713**! Thank you to all the students, teachers, and administrators at Deer Path Middle School who participated in this event. Also, special thanks to teachers Ken Smith, Shawn Weber, and Katlyn O'Brien, for planning this event to support Cure SMA.

### Davenport School Benefit for Annalise Wettstein

During the first 2 weeks of December, Davenport Elementary School in Eureka, IL, hosted a fundraiser in honor of Annalise Wettstein. Instead of having a holiday gift exchange, the students were encouraged to bring a donation to support Cure SMA's mission. The school raised **\$613** for Cure SMA!



## 5th Annual Chicago Gala of Hope

On February 21, 2020, more than 200 guests gathered at the Ivy Room in Chicago, IL, for the 5th Annual Cure SMA Gala of Hope. This incredible evening raised more than **\$120,000** in support of Cure SMA. This fun event brought together families, researchers, doctors, business leaders, and generous supporters to raise funds to find treatments and a cure for SMA. The evening featured cocktails, hors d'oeuvres, a silent auction, live auction, and live entertainment. Comedian, Brett Walkow, was the MC and a live performance from the band, Shout Out, kept everyone on the dance floor all night! A special thank you to the title sponsor, AveXis, for their generous support, as well as to the other sponsors who generously supported this event: Biogen, Genentech, Alight, Ivy Room, and Atlas Forms & Graphics Inc. Thank you to all the committee members and volunteers for their hard work, dedication, and commitment to the success of this event, especially Maria Marusich and the O'Brien family and their friends.



## Chapter Update

During her years of service as the Illinois Chapter President, Janet Schoenborn, welcomed and supported newly diagnosed families, connected patients with resources, and helped create a community for local Illinois SMA families. Janet also served as a leader on the Libertyville Walk-n-Roll committee and tirelessly fundraised in honor of her son, Samuel.

**Thank you to Janet for all her hard work and dedication.**

*Note: The amounts raised and shown are totals as of April 30, 2020 and may differ from current fundraising totals by the time you get this newsletter.*

## Iowa Chapter



### 23rd Annual Beaverdale Beaverdash

The 23rd Annual Beaverdale Beaverdash took place on September 21, 2019, in Des Moines, IA. Six teams and more than 150 participants took place in the timed 5K, untimed one-mile frolic, and Beaver Trot Kids Fun Run—raising over **\$8,000** for Cure SMA. Thank you to the Mercy Medical Center volunteers for their help and a special thank you to Chris Burch, Julie Greenwood, Shauna, DeeDee and Tricia Wright for organizing this year's event.

## Kansas City Chapter



### Kansas

#### 2019 Kansas City Walk-n-Roll

The 2019 Kansas City Walk-n-Roll was held on September 14, 2019, at Sar-Ko-Park Trails Park in Lenexa, KS. It was another fun event for more than 130 family and friends of the Kansas City Chapter, who worked together to raise more than **\$16,000** for Cure SMA. Special thanks to Leslie and Krys Hart for all their hard work to make this event a success!

### Missouri

#### 4th Annual Forest Hills Charity Gala

The 4th Annual Forest Hills Country Club Charitable Foundation Gala took place on January 25, 2020, in Chesterfield, MO. Items auctioned on behalf of Cure SMA raised **\$9,140!** Thank you to Valerie and Lawrence Giglio for choosing Cure SMA as their charity of choice for this event in honor of their grandson, Luke, and the Luke 18:1 Foundation.

## 2019 Bommarito Z Car Show

The 16th Annual Bommarito Z Club Car Show took place on September 1, 2019, at Bommarito Nissan in Hazelwood, MO. The day included a DJ, door prizes, raffle, food, and a variety of cool cars. This event was in honor of Brittany Carpenter and in memory of Madeline Schmidt, Michael Goodyear, and Brian Goodyear—raising more than **\$23,096!** A huge thank you to Janet Hutchinson, all the members of the Gateway Z Club, and the Bommarito Automotive Group for their continued support of Cure SMA.

## 2019 Turkey Trot

The 2019 Turkey Trot celebrated its 6th year in Farmington, MO. The fun day included the chance to win prizes from the help of the community, raising **\$1,842** in memory of Cason William Bauss. A huge thank you to Lisa May for your continued support to Cure SMA.

## Westbury Manor Haunted Forest “Scare Away SMA”

The 2019 Scare Away SMA took place in October 2019 in Chesterfield, MO. This event raised **\$1,270** in honor of Matilda (Tilly) McRoberts. Thank you to Leslie Derrington for her continued support of Cure SMA.

## Michigan Chapter

### Vincent Family Fundraiser

Josh and Jamie Vincent hosted a can donation fundraiser at their B’Naj Mitzvah in memory of their sister, Jessica Vincent. Together, they raised **\$150** for Cure SMA. Thank you to the Vincent family for their continued dedication to Cure SMA and the Michigan Chapter.

### Detroit Pistons Awareness Game

On March 7, 2020, the Detroit Pistons played the Utah Jazz at the Little Caesars Arena in Detroit, MI. Michigan families and supporters enjoyed a fun evening and an exciting game. The attendees enjoyed a post-game court shot and a special promotional item!

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## Minnesota Chapter



### 2019 Minnesota Walk-n-Roll

The 2019 Minnesota Walk-n-Roll took place on September 7, 2019, at Central Park in Eagan, MN. The day included family games and activities, raffle, silent auction, and food sale. With 16 teams and more than 140 participants, the event was a huge success, raising **\$22,657** for Cure SMA! A special thank you to Kara and Ryan Forcier, Matt and Laura Czech, Kayla and Rich Yaeger, and Jon Schwerr for helping organize this event. Thank you to the sponsors, team captains, participants, volunteers, and donors for making this day such a success.



### 2019 Boston Evening of Hope

The inaugural Boston Evening of Hope took place on September 14, 2019, at the Miel Restaurant in Boston, MA. More than 50 people came together to help fund a cure for SMA by raising more than **\$19,000**. Guests enjoyed a memorable evening at Miel Boston's first Provence-themed brasserie, along with cocktails, fabulous food, silent auction, and more. A big shout-out goes to Sam and Teresa Norton for making this first-time event a true success.

## New England Chapter



### Massachusetts

### 3rd Annual Evening of Hope in Honor of Natalia

The 3rd Annual Evening of Hope in Honor of Natalia was a great success! On November 11, 2019, more than 220 guests gathered at the Knights of Columbus in North Easton, MA, to celebrate Cure SMA. Everyone, including the guest of honor, Natalia Boidi, had an amazing time and helped raise over **\$49,000** for Cure SMA. Thank you to Marissa Boidi and the entire Boidi family for their support!



### Rhode Island

### 2019 Cure SMA Eggs with Evan

The 2019 Cure SMA Eggs with Evans was held on September 28, 2019, at the Kirkbrae Country Club in Lincoln, RI. Guests enjoyed a brunch, which included a breakfast buffet, omelet station, games, silent auction, and a raffle. Thanks to the hard work on behalf of the Vaudry family and the support of their community, Eggs with Evan raised **\$22,295** for Cure SMA!

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## New Mexico Chapter

### 2019 Bugaboo WOD

On November 16, 2019, dozens of CrossFit enthusiasts came out to CrossFit Albuquerque in Albuquerque, NM, to work out for Cure SMA. Participants completed a fun workout of the day and helped raise more than **\$10,500** for Cure SMA! A special thank you to Joe Vigil and Ben Abruzzo for all their hard work organizing this event.

## North Jersey Chapter



### Inaugural Tee It Up to Cure SMA Golf Outing Honoring Ava Finelli

Congratulations to the Finelli Family for raising nearly **\$97,000** for Cure SMA! The Inaugural Tee It Up Golf Outing Honoring Ava Finelli was a huge success! More than 120 golfers came out to the Forest Hill Field Club in Bloomfield, NJ, on September 12, 2019. Despite the gloomy weather, golfers still enjoyed a fun day on the green. After a full day of golf, 60 additional guests joined for a dinner and an evening of fun, which included a silent auction. Ava's father, Dan Finelli, gave a heart-felt speech and guest of honor, Ava, delighted everyone with her up-beat spirit and excitement about the birth of her little sister, Haley, who arrived just days before the outing. A special thank you to Dan and Laura Finelli, and Bill and Lorraine Finelli for their incredible leadership and support of Cure SMA!

## Pacific Northwest Chapter



## Washington

### 2019 Pacific Northwest Walk-n-Roll

On September 14, 2019, the 12th Annual Pacific Northwest Walk-n-Roll brought more than 100 attendees for a day of family fun games, entertainment, and SMA awareness. This event took place at Game Farm Park in Auburn, WA, and raised over **\$16,000!** A huge thank you to Kelly Hargrave, Jennifer Jeffries, Rozie McClay, Jodi Pretz, Erin Contreau, as well as volunteers, families, and friends for another successful Walk-n-Roll!

### 2019 Wreaths of Hope Fundraiser

On November 23, 2019, communities, families, and friends came together to celebrate the season at the 14th Annual Wreaths of Hope in Centralia, WA. Attendees enjoyed shopping for pre-made wreaths and were encouraged to make their own all while supporting the mission of Cure SMA, raising nearly **\$4,000**. Cure SMA thanks Sybil Kuhn, event creator and coordinator, for hosting this special event!

### 2019 Charity Rope Halter Program

Thank you to Sunset Halters for including Cure SMA as a beneficiary for their Hope Rope Halter Program. Through this program of selling select halters, Sunset Halters was able to donate **\$60** to Cure SMA.

### 2019 SMA Awareness Day with the Seattle Mariners

Families from the Pacific Northwest Chapter came together in September for SMA Awareness Day at T-Mobile Park in Seattle, WA. Everyone enjoyed a day out at the ballpark and helped spread awareness about SMA and Cure SMA. Thank you to Jennifer Stack for her help in organizing this event and to everyone who came out for this SMA Awareness day at the ballpark!

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## Pennsylvania Chapter



### 2019 Zane's Run

This year marked another successful Zane's Run in Malvern, PA! On September 29, 2019, more than 320 people came out to support Cure SMA and raised more than **\$43,000!** Proceeds from Zane's Run support Cure SMA's equipment pool, including purchases of car beds and Panthera pediatric wheelchairs. Thank you to Hillary and Keith Schmid for their dedication and support!



### 2019 Lukie's Fall Festival

Thank you to Lukie's Crew for hosting another Lukie's Fall Festival! On October 12, 2019, hundreds of people gathered in Weona Park in Pen Argyl, PA, to support Cure SMA and raise more than **\$14,000!** Everyone enjoyed the carousel, food, fund games, and pumpkin patch! A special thank you to Tara and Joe Maida for their continued dedication to Cure SMA's mission and Lukie's Fall Festival.

### 2019 Ultimate Granite Golf

Thank you to Ultimate Granite Surfaces for once again hosting a golf outing to support Cure SMA! The outing was held on September 6, 2019, in Butler, PA. With the support of generous golfers and donors, the outing raised **\$10,000** in memory of Benjamin Piper!

## 16th Annual Lily Kennedy Golf Outing

Thank you to Dr. Mark Lynch, Heather Kennedy, and all the dedicated volunteers who made the 2019 Lily Kennedy Golf Outing successful! Each year, students from Saint Francis University's Social Work Department and Social Work Club fundraise in memory of Lily Kennedy. This year's tournament was held on September 29, 2019, in Roaring Springs, PA, and raised **\$6,250** for Cure SMA!

### Casual Day at Bushkill Elementary Fundraiser

Bushkill Elementary of Dingmans Ferry, PA, held a fundraiser on September 20, 2019, as a part of their "Casual for a Cause," program. On Friday's teachers and staff could wear jeans in exchange for a donation to Cure SMA.

## Rocky Mountain Chapter

### Montana

### Veronica St. Onge's 15th Birthday

Each year on her birthday, Veronica St. Onge asked for donations in lieu of gifts to give back to Cure SMA. This year she celebrated her 15th birthday and received more than **\$1,100!** Thank you for your support and dedication, Veronica, and happy birthday!

## Texas Chapter



### 2019 Dallas Evening of Hope

The Dallas Evening of Hope took place on November 14, 2019, at the Dallas Country Club in Dallas, TX. Nearly 200 guests enjoyed cocktails, hors d'oeuvres, dinner, music, a silent and live auction, and a program hosted by Katy Blakey from local NBC5. In its first year, the event raised more than **\$140,000** for Cure SMA – an amazing result! A huge thank you to the host committee: Tiffany Armstrong, Allison Curran, Tiffani Mendez, Beth Moore, Kate Nelson, Jenny Pope, Kristen Resendez, Julia Schwarz, Nicole Stickane, Courtney Swinton, Daniella Giglio, and Hayley Troxell.

*Note: The amounts raised and shown are totals as of April 30, 2020 and may differ from current fundraising totals by the time you get this newsletter.*

## Tennessee Chapter



### 2019 Nashville Walk-n-Roll

The 5th Annual Nashville Walk-n-Roll took place on October 20, 2019, at the Centennial Park in Nashville, TN. The event once again brought together many local families and friends that were connected through the SMA community. The walk included fun for everyone with a DJ, games, and pumpkin painting. The event raised **\$19,711!** A special thank you to Kayla and Gary Harbin and their family and friends for helping make this event possible!

5 Years

### 2nd Annual Tennessee Newborn Screening Chili Cookoff

Thank you to Hilary Fryman and the Newborn Screening Coalition for their hard work at the 2nd Annual Tennessee Newborn Screening Chili Cookoff. The event was held on September 11, 2019 and raised **\$355** for Cure SMA.

## Chapter Update

Thank you to Jim Ferry for his involvement with the Virginia Chapter over the past few years. Jim played a helpful role in getting the Virginia Chapter started to connect and support other SMA families in Virginia and was inspired to be a part of the leadership team by his granddaughter, Addison Kuester.

**Best wishes to Jim and his family as he retires from his role with the chapter.**

## Virginia Chapter



### 2019 Virginia Chapter Walk-n-Roll

The 2019 Virginia Chapter Walk-n-Roll was held on October 19, 2019, at Gar-Field High School in Woodbridge, VA. More than 150 participants came together to raise over **\$18,000!** It was a fun-filled day with an incredible raffle organized by Debbi Schaefer, face painting, outdoor games, and a DJ. Thank you to the incredible sponsors and teams for their continued support! A special thank you to our Virginia Chapter Leaders for helping make this event success: Kyle Derkowski, Laura Derkowski, and Debra Schafer.

5 Years

### Tina Lane Events LLC

Tina Lane Events located in Lynchburg, VA, donated a portion of their profits, totaling **\$1,200**, to Cure SMA. Thank you to Tina Lane Events for their support in continuing Cure SMA's mission.

### 2019 Virtual Jogging for Joshua

The 2019 Cure SMA Jogging for Joshua participated in a letter writing campaign this year. The event was a success, raising more than **\$3,000** for Cure SMA. Thank you to Bayley and Nathan for their hard work and dedication in bringing the Hampton Roads community together for this event in memory of their son, Joshua. Thank you, Bayley and Nathan, for rallying together friends and family, and to everyone for your support and generosity in memory of Joshua!

*Note: The amounts raised and shown are totals as of April 30, 2020 and may differ from current fundraising totals by the time you get this newsletter.*



## Washington Nationals Awareness Game

Thank you to all the Cure SMA supporters and families for coming out to celebrate Cure SMA and spread awareness at Nationals Park in Washington, DC, on September 15, 2020!

### Western New York Chapter

## Schenectady PBA Black & Blue Golf Tournament

Thank you to everyone at the Schenectady PBA for making Cure SMA their charity of choice. On September 16, 2019, golfers gathered at the Van Patten Golf Club in Clifton Park, NJ, for a day of golf. Half of all the net proceeds were donated to Cure SMA, totaling **\$2,000!** Thank you to Kyle Derkowski for inspiring this partnership.

### Wisconsin Chapter



## 2019 Madison Walk-n-Roll

On September 22, 2019, families from the Madison area and beyond, came together for the inaugural Madison Walk-n-Roll. Even the gray and rainy weather could not keep more than 100 participants from raising over **\$14,000**. The morning started with a walk around the beautiful Brittingham Park in Madison, WI, and wrapped up with games and activities, a raffle, and a tasty pizza lunch. Thank you to Kristen Bausch, Christina Hayes, Nicole Fritts, and Melinda Heathcoat, for their hard work in getting this event off the ground and running, it was a very successful first year!



## 9th Annual Kennedy's Dream Cure SMA Walk-n-Roll

On September 25, 2019, families from all over Wisconsin gathered for the 9th Annual Kennedy's Dream Walk-n-Roll, which is held each year at Fox Brook Park in Brookfield, WI, in memory of Kennedy Quinnell. Despite the rain and clouds, all guests still enjoyed the walk around the park, a delicious lunch, and a great raffle filled with some fun prizes. With help and lots of love from friends, family, and supporters, the event raised more than **\$24,000!** These funds will go towards providing wagons to other SMA families, as well as research and education to continue working toward finding a cure for SMA. Thank you to all the teams that came out to help raise funds and a huge thank you to Corey, Erin, and Charlotte Quinnell for all their hard work this year in planning another great event.

## Chapter Update



Thank you to Amy Medina for her years of dedicated service to Cure SMA's Wisconsin Chapter! Amy became involved with the Chapter when her son, Mateo, was diagnosed with SMA. As a leader in the SMA community for many years, Amy dedicated countless hours to helping newly diagnosed families, parents, and adults with SMA, connect with each other and local resources. She also shared her family's story many times to help elevate SMA's platform and spread awareness to get SMA added to the recommended newborn screening list.

**Amy will continue to be a proud community member by serving on the National Cure SMA Board.**



# Join Our New Virtual Team Cure SMA Program!

Virtual Team Cure SMA is a new endurance program that offers runners and cyclists—both currently supporting Team Cure SMA or just thinking about it—a way to participate in races virtually while sharing their results and accomplishments with their communities. We want you to achieve your personal fitness goals, whatever they may be, and are here to support your fitness journey by providing race training plans that anyone can take advantage of from the convenience of home.

There is no fundraising requirement to participate, but athletes can earn awesome Team Cure SMA endurance gear if they choose to fundraise and reach milestones. Team Cure SMA is a group dedicated to taking on fun fitness challenges and we are here for you every step of the way, even virtually!

TEAM CURE SMA  
VIRTUAL PROGRAM



If you have questions about how to fundraise and train for an endurance event contact Alyssa Zavislak at [alyssa.zavislak@curesma.org](mailto:alyssa.zavislak@curesma.org).

# Events

## Recent Events

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### 2019 Allstate Hot Chocolate 15k/5k Chicago Race

Thank you to the eight incredible Team Cure SMA participants that ran in the cold and fundraised for the 2019 Allstate Hot Chocolate 15k/5k Chicago Race in early November. Together, the runners successfully raised \$3,000 for Cure SMA. We appreciate the team's hard work and dedication.

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### 2019 Philadelphia Marathon

Congratulations to the 10 amazing Team Cure SMA participants that ran in and fundraised for the 2019 Philadelphia Marathon in November. Together, the runners successfully raised more than \$12,000 for Cure SMA. Thank you to all the runners for their hard work and support!

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### 2019 Humana Rock n' Roll San Antonio Marathon and Half Marathon

Virtual high fives to the three amazing runners who took part in the 2019 Humana Rock n' Roll San Antonio Marathon and Half Marathon. Great job Cheryl Buntley, James Dick, and Jennifer Fuller. We applaud your efforts!

### 2020 Little Rock Half Marathon

Special shout out to the four amazing runners who took part in the 2020 Little Rock Half Marathon. Thank you to Kara Christensen, Bella Luper, Dana Luper, and Ashley Sparks! We appreciate your support!

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### 2020 Napa Valley Marathon

Congratulations to the four amazing runners that took part in the 2020 Napa Valley Marathon. Your support for Cure SMA means so much!



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### 2020 Portland Shamrock Run

Thank you Cheryl and Wren Grabham for participating virtually in the 2020 Portland Shamrock Run! We know it was not easy, but we applaud your dedication.

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### 2020 United Airlines New York City Half Marathon

A special congratulations to our 10 Team Cure SMA runners who virtually completed the 2020 United Airlines New York City Half Marathon on Sunday, March 15. Together, the runners successfully raised more than \$20,000 for Cure SMA—the most in the race's history for Cure SMA.

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



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



## 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.



Make today a breakthrough.

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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*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