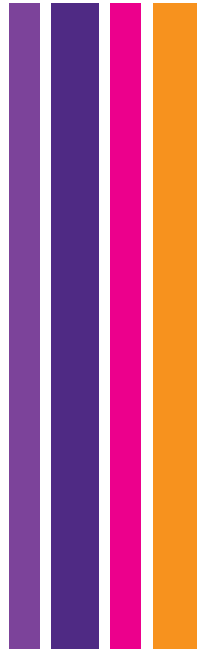


**cure
SMA**

DO IT YOUR WAY

FUNDRAISING



FUNDRAISING TOOLKIT

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Thank you for your interest in organizing a special event in support of Cure SMA! The information in this toolkit is intended to help make your fundraiser as successful as possible while staying within the Cure SMA guidelines. We appreciate your support!

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ABOUT

ABOUT CURE SMA

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



Learn more about Cure SMA and our programs at www.curesma.org

ABOUT DO IT YOURSELF FUNDRAISING

Cure SMA's Do It Yourself (DIY) Program empowers supporters like you to fundraise your way! These third-party events allow individuals, groups, and community organizations to host their own unique, special events with the purpose of raising funds and awareness for Cure SMA. With so many different ways to raise money, we want you to choose one that's meaningful to you. Let your creativity shine!



This toolkit was designed to make planning your community fundraiser for Cure SMA as easy as possible, while staying within our guidelines. From creating a timeline and a budget, to organizing and promoting your event, this guide will help you to become a successful fundraiser and make the most of your event.

For more information on Do It Yourself Fundraising, contact diy@curesma.org



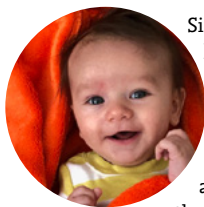
AT A GLANCE

Make today a breakthrough.



Spinal muscular atrophy (SMA) is a disease that robs people of physical strength by affecting the motor nerve cells in the spinal cord, taking away the ability to walk, eat, or breathe. **Historically, it has been the number one genetic cause of death for infants.** SMA affects approximately 1 in 11,000 babies, and about 1 in every 50 Americans is a genetic carrier. SMA can affect any race or gender. But there's great reason for hope. We now have multiple approved treatments that target the underlying genetics of SMA, with more treatments on the horizon. We know what we need to do to develop and deliver effective therapies. And we're on the verge of further breakthroughs that will continue to change the course of SMA for everyone—from infants to adults to families.

RESEARCH

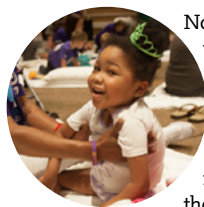


Since 1984, Cure SMA has led and invested in the research that has made today's breakthroughs possible. With deep connections and expertise in both the patient and research communities, we're uniquely positioned to direct funds to where they can make the greatest difference as quickly as possible.

We have invested more than \$82 million in research and have funded half of the new drug programs for SMA, including all FDA-approved treatments for the disease.

We now have multiple FDA-approved therapies for SMA, and many more research programs ongoing.

COMMUNITY SUPPORT AND CARE



No matter your connection, we're committed to being an irreplaceable resource for anyone facing an SMA diagnosis and we seek to improve the quality of life for everyone with SMA so they can live active, engaged, and hopeful lives.

Each year, we send out approx. 4,000 information packets, newly diagnosed and teen/adult care packages, and much-needed equipment. We also support medical professionals through CME and our Care Series Booklets.

Because of FDA-approved treatments and successful initiatives, such as the Cure SMA Care Center Network and SMA Clinical Data Registry, we have made significant progress enhancing the lives of people with SMA.

CONFERENCE AND COMMUNITY



Our Annual SMA Conference brings together researchers and healthcare professionals, as well as individuals with SMA and their families, to network, learn, and collaborate.

The conference is the largest in the world focused specifically on SMA, and it attracts the top scientists and companies in the field.

Today, we have more than 170,000 members and supporters, with 36 volunteer chapters throughout the country. We host over 300 fundraising and awareness events annually.

FUNDRAISING INCENTIVES

We want to reward you for the work you put into organizing a DIY fundraiser for Cure SMA!

When you register a fundraising page through Cure SMA's DIY website, you will automatically receive:

- Individualized fundraising support from Cure SMA staff to help you create your impact
- Opportunity to receive Cure SMA giveaways for your fundraiser, including bracelets, pens, and temporary tattoos



**WHEN YOUR FUNDRAISER RAISES \$100,
YOU WILL ALSO RECEIVE:**

An exclusive DIY t-shirt



**WHEN YOUR FUNDRAISER RAISES \$500,
YOU WILL ALSO RECEIVE:**

An exclusive DIY baseball hat



**WHEN YOUR FUNDRAISER RAISES \$1,000,
YOU WILL ALSO RECEIVE:**

**An exclusive DIY
waterproof duffel bag**

PLEASE NOTE:

Cure SMA event kits (including branded giveaways and materials) are sent out approximately 14 days pre-event. The total funds raised at the time of shipment will determine your eligibility. All other DIY incentives (including t-shirts, baseball hats, and duffel bags) are sent on a quarterly basis to all qualified third-party event organizers who have created a DIY fundraising page online.

DIY FUNDRAISING ROLES & RESPONSIBILITIES

Our DIY fundraisers range from birthday posts on Facebook to day-long lemonade stands to annual concert events! Whether you need a little help from us or a lot, we want to make sure you feel ready to tackle your fundraiser-- no matter the size!

ORGANIZER'S RESPONSIBILITIES

- Plan and execute a fundraiser with guidance from Cure SMA staff
- Create a fundraising page through [DonorDrive](#) with help from Cure SMA, if desired
- Recruit committee members or volunteers for event help, if needed
- Obtain necessary permits, insurance, licenses, and other safety measures as required by the venue and/or vendor(s) with guidance from Cure SMA staff
- Finance all associated event costs such as venue, food/beverage, and vendors
- Solicit in-kind and/or monetary gifts from donors and sponsors, if needed
- Promote the event online and/or in your local community
- Ensure event proceeds are submitted to Cure SMA within 45 days of the event

HOW CURE SMA CAN HELP

- Offer fundraising and event planning expertise, recommendations, and advice
- Assist with the creation and maintenance of a fundraising page through [DonorDrive](#)
- Review promotional materials that utilize the Cure SMA logo before use
- Help create marketing materials including flyers, save the dates, social media graphics, and QR codes
- Share event-related posts made by the organizer to Cure SMA's national social media when possible
- Offer branded swag (bracelets, pens, temporary tattoos) and/or event materials (tablecloths, banners, fact yard signs) based on availability
- Acknowledge donors' direct contributions to Cure SMA



DIY FUNDRAISING FAQs



CAN SOMEONE FROM CURE SMA HELP ME PLAN MY EVENT?

We are happy to provide fundraising guidance and event expertise for your event. However, we do not have the capacity to plan third-party events. We hope this toolkit will help make planning your event a little bit easier! Please reach out to diy@curesma.org with any questions or concerns.

CAN SOMEONE FROM CURE SMA ATTEND MY EVENT?

We do our best to attend events supporting Cure SMA, but we cannot guarantee attendance of staff at third-party events. If you are interested in having Cure SMA staff present at your event, please let us know well in advance and we will see if we are able to accommodate the request.

CAN I USE CURE SMA'S NAME AND/OR LOGO FOR MY EVENT?

We are happy to help create event flyers, social media graphics, and other promotional materials that are branded by Cure SMA! Otherwise, any use of Cure SMA's name or logo must be approved by Cure SMA. Events that do not donate 100% of proceeds to Cure SMA cannot use our name or logo for their event. Please refer to our [Logo Use Form](#) before using our logo.

CAN CURE SMA PROVIDE INSURANCE OR HELP ME GET A PERMIT FOR MY EVENT?

Since Cure SMA has no direct involvement with the planning and execution of third-party fundraisers, we cannot provide insurance or permitting for these events. The event organizer is responsible for obtaining any necessary insurance, permits, licenses, and safety measures (including law enforcement or medics) for their event.

CAN I USE CURE SMA'S TAX EXEMPTION NUMBER?

No, by law third-party events are not able to use Cure SMA's IRS 501(c)(3) charitable donation classification, federal tax ID number, or tax-exempt certificate. Please reach out if you need a tax-exempt letter from Cure SMA and we will do our best to accommodate.

WILL EACH OF MY DONORS GET A RECEIPT?

Cure SMA can offer charitable tax receipts to donations made directly to Cure SMA through your DIY fundraiser.

Checks can be made payable to Cure SMA with the fundraiser name in the memo line. Checks should be sent in their original form to:

Cure SMA
c/o DIY
925 Busse Road
Elk Grove Village, IL 60007

Please note: Donors can make a donation directly to Cure SMA through your DonorDrive event page. Please note: charitable tax receipts cannot be guaranteed for things like cash, in-kind gifts, sponsorship, or Facebook donations for third-party events.

CAN I PAY MYSELF BACK FOR EXPENSES I'VE INCURRED FOR THE EVENT?

We recognize that event hosts may need funds to run an event and pay expenses. However, Cure SMA cannot fund or financially support third-party fundraisers. Event hosts are responsible for covering all expenses and cannot be reimbursed by Cure SMA. As you begin to collect money you may want to keep some funds on hand to help pay your expenses. This amount should not exceed 30% of your gross revenue. In your planning process, make sure to develop a budget reflecting the type of event you are hosting and the costs associated with the event.

DIY FUNDRAISING IDEAS



CREATE A DIY FUNDRAISER

Host an event and ask attendees to donate in exchange for participating.

- BBQ Cookout
- Field Day
- Carnival
- Paint & Sips
- Benefit Concert
- Outdoor Film Showing
- Art Show
- Dessert Auction
- Food Truck Festival

Ask for donations in exchange for goods or services.

- Car Wash
- Community Yard Sale
- Craft Fair

Create some competition with a group activity. Participants can either donate to register or raise funds to play.

- Cornhole Tournament
- Bingo Night
- Scavenger Hunt
- Pet Photo Contest
- Trivia Night



STREAM AWAY SMA

Calling all content creators! Set up a charity stream and ask for donations from your IRL and virtual supporters.

- Video Gaming on Twitch
- Virtual Concert on YouTube
- Pet Cam on Facebook



HOST AN ATHLETIC EVENT

Train for something tough and ask your community to support you with a donation.

- Marathon or 5K
- Tough Mudder
- Spin or Cycle
- Triathlon
- Hike or Climb

Create your own physical challenge.

- Outdoor Yoga Class
- Pledge Laps (Swimming or Walking)



DONATE A SPECIAL OCCASION

Dedicate a special day and ask your loved ones to donate in honor of you!

- Birthday
- Wedding
- Anniversary
- Graduation



ORGANIZE A YOUTH EVENT

Fundraising isn't just for the adults. Get your kids involved in all sorts of events!

- Bake Sale
- Lemonade Stand
- Handmade Holiday Card Sale
- Read-a-thon
- Talent Show



START A MEMORIAL OR TRIBUTE PAGE

Celebrate a special person by asking people to donate in their honor or memory.

- Memorial
- Tribute

FUNDRAISING 101

It's time to get started! Every dollar you raise is directed toward research, care, advocacy or support programs that benefit our entire community. Here are the first steps to success!



SET YOUR GOAL

Decide what kind of impact you'd like to make through your fundraiser. Check out the [Dollars at Work](#) infographic for inspiration.



TELL YOUR STORY

Your personal story inspires others to donate. Share why you are participating in DIY and be sure to include a photo or a video of who you are participating for.



LEAD BY EXAMPLE

Make a meaningful personal donation to kick off your fundraising efforts to show your family, friends, and colleagues how important Cure SMA's mission is to you!



CREATE A FACEBOOK FUNDRAISER

Facebook's fundraising feature is an amazing tool that helps you easily collect donations in real-time from your Facebook friends. Connect your Facebook Fundraiser from your Participant Center or check out our [Facebook Fundraiser How-To-Guide](#) to get started.



SHARE VIA E-MAIL AND ON SOCIAL MEDIA

People are often willing to make a donation, they just need to be asked. Once you customize your fundraising page, share your link on Facebook, Instagram, or the social network of choice to spread the word. Your Participant Center also has pre-written e-mails for you to send out.



LOOK INTO MATCHING GIFTS PROGRAMS

Ask your donors and event attendees if their company has a matching gifts program. This is an easy way to quickly multiply the impact of your fundraising!



LOOKING FOR MORE FUNDRAISING TIPS?

Check out our [Steps To Planning Your Fundraiser](#) infographic.

ADDITIONAL RESOURCES

We hope you've found the information in this toolkit helpful in jumpstarting your DIY Fundraiser! If you're interested in additional resources that can help you to plan and execute your event, visit the [Resources Page](#) on Cure SMA's DIY website. Whether you're looking for materials to help ensure Cure SMA's mission is central to your event, or you need some creative inspiration on how to customize your event collateral, we've got you covered!

Here's a preview of some of the information you'll find linked on our Resources Page:

- [Dollars at Work Infographic](#)
- [SMA Newborn Screening Flyer](#)
- [Care Center Network Information](#)
- [Know Your Network Worksheet](#)
- [Planning Your Fundraiser](#)
- [Editable DIY Event Plan](#)
- [DonorDrive Participant Portal Guide](#)
- [Facebook Fundraiser Guide](#)
- [Matching Donation Search Link](#)

Need more help?

Cure SMA staff are available to offer guidance and expertise for your DIY event! You can reach out to diy@curesma.org with any questions that come up along the way. We're happy to help!





DO IT YOUR WAY

FUNDRAISING



facebook.com/cureSMA



linkedin.com/company/families-of-sma



@curesmaorg



twitter.com/cureSMA



tiktok.com/@curesmaorg



youtube.com/user/FamiliesofSMA1



For more information on Do It Yourself (DIY) Fundraising, please reach out to:

Audra Gordon

audra.gordon@curesma.org

847.264.1161