



**CUREGM1**  
FOUNDATION

# FUNDRAISING MANUAL



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# OVERVIEW

## HOW YOU ARE HELPING THE CURE GM1 FOUNDATION

We are grateful for your interest in hosting a fundraiser for Cure GM1. Your support will spread awareness for GM1 Gangliosidosis, as well as raise funds critical to the advancement of research toward treatments and a cure for GM1. Thank you!

## WAYS CURE GM1 USES THE DONATIONS WE RECEIVE

**Pre-clinical research studies** - Since Cure GM1's inception, we have funded GM1 Gangliosidosis research. We provide grants to scientists worldwide who specialize in fields relevant to GM1.

**Support Community** - Cure GM1 helps build community. Our online community offers information, guidance, and emotional support to families and individuals affected by GM1.

**Education** - We bring families, affected individuals, community members, scientists, and clinicians together during our annual conference to disseminate news, research, and ongoing endeavors to find treatments and a cure for GM1, as well as provide support for our community.

**Awareness** - We strive to raise awareness about GM1 so that we can raise money, educate, provide support to our community, and advocate for policies that positively impact those living with GM1. The latest news on GM1 is shared on our social media platforms and in our monthly newsletters. Our website is a resource for the newly diagnosed and our community.

## How will this manual help me?

This manual is meant as a guide. Choose the information which is most helpful to you to plan your event. If this is your first time fundraising, don't feel pressured to do something complicated. The simple easy route can be just as effective as the ambitious one. The aim of this manual is to help you effectively raise money and awareness for Cure GM1. We want your fundraiser to be a success!

# FUNDRAISER SUPPORT

*We are incredibly grateful to all those who commit to fundraising.*

## Support Cure GM1 can provide to you and your event:

- Consultation on fundraisers and events – we can help you brainstorm ideas and put you in touch with anyone who may have already organized an event like the one you're planning
- Approved use of our logo, when appropriate
- A letter of authorization to validate the authenticity of the event and its organizers
- Tax ID number for donation purposes only
- Help with written descriptions of GM1 gangliosidosis and our mission
- Your own personalized fundraising page on [curegm1.org](http://curegm1.org)
- Tax receipts for donors
- Support with respect to graphic design and marketing at our discretion

## Services we are unable to provide:

- Our sales tax exemption number
- Insurance or liability coverage
- Mailing list of donors and/or vendors
- Cure GM1 stationery
- Funding or reimbursement of your expenses
- Celebrities or professional athletes for your event
- Publicity (e.g. newspaper, radio, television)
- Guaranteed attendance of events by Cure GM1 board members or staff

We'd love to help you brainstorm and promote your event, so please email us the details of your fundraiser at [info@curegm1.org](mailto:info@curegm1.org).



# PLAN YOUR FUNDRAISER

**Committing to host a fundraiser for Cure GM1 Foundation instills hope and creates progress for our community. Thank you!**

**These 11 steps can help you plan your event:**

- 1. Recruit Volunteers.** Depending on the size of your event, it may benefit you to find like-minded, enthusiastic volunteers to help with the fundraiser before and during the event. Friends, family, and members of your community are great people to ask.
- 2. Brainstorm.** Gather together your volunteers as a committee to define your cause, set a fundraising goal, plan your outreach strategy, and brainstorm fundraiser event ideas.
- 3. Determine your audience.** Think about who will likely attend your event and use what you know about that demographic to help determine the event you choose and your marketing and outreach plans.
- 4. Choose the right event.** Account for the size of your fundraiser and the abilities, dedication, goals, and schedules of your volunteers to decide what type of event to put on. Choose one that fits your interests and community. For example, if you don't know anyone who golfs, don't choose a golf event.
- 5. Create a budget.** To keep your costs down, list anticipated expenses as well as possible sources of funds and support, like in-kind products and donated services.
- 6. Make a task list and timeline.** Apps like Notion and Trello are great free resources you can use to plan your event and make sure you have enough time and resources to get everything done.
- 7. Pick a date.** Find a date and time that will work best for everyone attending. It's helpful to cross-check potential dates against local community calendars to ensure there are no conflicting events.
- 8. Notify Cure GM1.** Tell us about your event! We can share your event on our social media accounts and in our newsletter.
- 9. Promote your event.** Create pages and accounts on social media, and contact local news stations, magazines, and newspapers to help promote your fundraiser.
- 10. Gather all donations.** Please forward the raised funds to the Cure GM1 Foundation within 30 days after the event. Address: PO Box 6890, Albany CA, 94706.
- 11. Show appreciation!** Remember to send thank you cards or make thank you calls to your volunteers and notable attendees and donors to show your gratitude and acknowledge their generosity in supporting Cure GM1.

# FUNDRAISER IDEAS

If you're planning on hosting a fundraiser for Cure GM1, you have a lot of great options. First, identify common activities or your favorite hobby. Be it exercising, baking, photography, or cars; you can easily add a fundraising component to it. Centering the event around something familiar will make it that much simpler and enjoyable.

## Online Fundraisers

Fundraisers can be simple and easy. If you feel overwhelmed by the notion of a big event, it's not necessary. A simple fundraiser that only requires a computer can also be effective. Examples:

- Birthday
- Letter
- Holiday
- Fundraiser in lieu of gift

## Simple Ideas

The following are some easy ways you can enlist your close friends and family to make an impact for those suffering from GM1:

- Bake Sale
- Movie Night
- Lemonade Stand
- Picture with Santa, Easter Bunny, movie character, etc.
- Craft Sale
- Wishing Well
- Trivia Night
- Car Wash
- Holiday Gatherings
- Pie Smash
- Potluck
- Game Night
- Cook Off
- Relay Race

## More Ambitious Options

Host a fundraiser that involves a larger part of your community, like your neighbors, co-workers, and other locals. Here are some ideas for a fun event that will carry a big impact:

- Variety Show
- Garage Sale
- Office Jeans Day
- Flea Market
- Fashion Show
- Talent Competition
- School Fundraiser
- Super Bowl Party
- Bike-A-Thon
- Sports Tournament
- Auction
- Music Concert
- Scavenger Hunt
- Car Show
- Luncheon
- Fun Run
- Read-A-Thon
- Boat Racing
- Church Fundraiser
- Golf Outing
- Walk-A-Thon
- Black Tie Event
- Dance-A-Thon

# SET UP YOUR CAMPAIGN

Cure GM1 has had a lot of success with family fundraising using videos and social media. It is not required to fundraise in this way, but your personal story is extremely important and powerful. Here are some ideas to consider on creating your own platform for fundraising.

- Choose a name for your campaign, e.g. Cure for Clara
- Ensure your fundraising page states that it benefits Cure GM1
- Create a Facebook page for your story
- Consider if you would like to maintain pages on other platforms, like TikTok, Instagram, or Twitter. Create accounts there, too.
- Create a *fundraising* webpage for your story. Cure GM1 can set up a personalized web page on [curegm1.org](http://curegm1.org) for your fundraiser, or you can use a third-party platform such as GoFundMe
- Have professional photography of your child and family taken and use them on your fundraising page. Also incorporate candid photographs. People love to see photos and are more likely to support your campaign if you include them.
- Request a logo for your campaign from Cure GM1, or have a friend with graphic design skills help you create one. This logo will be used to brand your campaign online and for merchandise, like t-shirts.
- Link your fundraiser page to the Facebook page and all pages where you are soliciting donations.
- Consider buying a domain name for your fundraiser such as [acureforclara.org](http://acureforclara.org)
- *Remember, if you are planning to raise money for your personal use, you must make a separate fundraiser which clearly cites the money is for personal use and not for Cure GM1. Consult a tax professional or an accountant to appropriately handle donations for your personal use.*





# CAPTIVATE WITH YOUR STORY

How you present your story can make a big difference in the success of your fundraiser. Remember, your story is competing against a lot of others for the attention of people bombarded with endless content. To make them care about your story, be honest and vulnerable. Tell a moving story.

## How to tell a great story:

1. Select a target audience and hone your content to connect with them. Their age, religion, location, and values will impact the way you tell your story.
2. Introduce yourself and be relatable. Who are you? Where are you? What do you like? What are your hopes and goals? Keep your language brief and powerful. People's attention spans are not very long these days.
3. Define the problem and keep it simple. What is the villain? What is it trying to do? What will happen if it succeeds? Again, answer these questions with as brief, powerful language as you can.
4. Outline the solution. What will you do to combat the villain? Why do you want to do it? What do you need to be able to do it? Remember this: day in and day out we are presented with a stream of endless problems with complex or impossible solutions. It's difficult to see so much that's wrong while feeling helpless to fix it. Make sure you frame your solution in a way that will help people feel like they're making a difference.
5. Use a call to action. Ask people to donate, suggest how much. Don't be shy or afraid, be ambitious in your ask. Our cause is worthy. People who set larger goals get bigger donations. Even if you feel overwhelmed by an ambitious goal, set it anyway. The higher you go, the more funds you will receive. You'll be surprised by who donates, so stay positive.
6. Spread your story. Share your story online with your friends, family, and social network. Share multiple times. Don't be shy. Ask every person you know for media contacts in radio, newspapers, magazines, television, blogs, etc. You'd be surprised how few degrees separate you and those who can tell your story. Also reach out to other people and organizations that have gone through a similar journey and ask them for advice, information, and contacts. Build a list of people who might help spread your message. Shorten your story into an elevator pitch, and reach out to these contacts when you're ready to launch your campaign.



# FOLLOW A PUBLICITY TIMELINE

Maximize the publicity of your event at very little cost by applying some or all of the following tips, which may be more or less useful depending on your event.

## Start with a timeline

A timeline can help you organize and coordinate tasks in advance of your event. It's also very help when putting together a publicity plan.

## Time before event: 3-4 months

- Notify Cure GM1 about your fundraiser so they can create a page for your event on the Cure GM1 website.
- Develop a list of media outlets you'd like to notify, like local news stations, newspapers, magazines, and community calendars; as well as social media channels you'd like to promote on.
- Create social media pages for your event. On your page, tell your story and explain why you are hosting a fundraiser. Give specifics about your goal, event details, and the difference it makes for Cure GM1 and those living with GM1 Gangliosidosis. Be sure to include a link to your Cure GM1 fundraising page.
- Post consistently on social media leading up to your event. You can share info about the event, your cause, and your story. The number of times you post is less important than posting on a predictable schedule. This could be once a week, or once a day.

## \*Suggested language

The following is an easy to understand description of GM1 Gangliosidosis, which you are welcome to use in your copy and communications:

*"GM1 Gangliosidosis is a rare inherited disease that primarily affects children. It has many debilitating ramifications, some of which are developmental regression, seizures, visual impairment, and neurodegeneration. The thousands of diagnosed children and adults who suffer from GM1 Gangliosidosis face the progressive loss of skills and abilities until death. This is a fatal disease that currently has no cure or effective treatment."*





### **Time before event: 1-2 months**

- Distribute media materials to the entities on your media outlet list (e.g. posters in your neighborhood or community center, a press release to magazines, Facebook posts, emails etc.).
- Continue to post consistently on social media leading up to your event.
- Write out a photo wish list. Photos are a great way to share your event with family and friends, as well as to look back on yourself. And, if you plan on hosting a recurring fundraiser, they're great for future publicity. A list will ensure you get photos of everything and everyone you want.

### **Time before event: 2 weeks**

Follow up via phone and email with the media outlets to whom you distributed materials and remind them of the event.

- Continue to post consistently on social media leading up to your event.

### **Time before event: 1-2 days**

- Email a reminder with the basic information about your event (who, what, when, where, and why) to your local news stations and newspapers.

### **During your event**

- Take candid and close-up photos during your fundraiser. Keep in mind that photos featuring between 1-3 people are great for publicity. Be sure to always ask permission from a parent or guardian before photographing children or using photos of others.

# MAXIMIZE DONATIONS

Sometimes, people may want to donate in ways that don't involve direct payments, or can leverage their donation to generate more funds for Cure GM1. If you offer alternative donation methods in your fundraisers, you'll get more than by suggesting monetary donations alone.

Alternative donation ideas include:

- **Stocks.** For some, stocks are a particularly advantageous way to donate due to the tax deduction. If your network includes people who would make use of this option, Cure GM1 can help facilitate this donation. If you know someone in your network who would like to use this option, let them know about it.
- **Used Vehicles.** Encourage your network to donate their used vehicles. If they have an old car they could stand to get rid of, donating it to us is a fantastic way to do so. It doesn't need to be operational, either!
- **A workout routine.** Raise funds by using the Charity Miles app. In this app, you can request donations from friends and your network and earn donations from sponsors of the Cure GM1 program. The sponsorships are subject to availability, but anyone using the app can donate and ask others to do so.
- **Corporate matching.** Many companies have donation matching programs for their employees. Some companies, like Apple and Exxon, even triple donations. If you have a professional network you can tap into, suggest to your donors that they take advantage of their corporate match to double or triple what Cure GM1 receives.



# AFTER YOUR FUNDRAISER

The money you raise during your fundraiser will further research toward treatments and a cure for GM1 Gangliosidosis, and will give the GM1 community hope. We are so grateful for your efforts.

Once your fundraiser is over, there's not much left to do:

## Share your Photos

- Post photos from your fundraiser on your social media pages and tag @curegm1foundation. Use hashtag #curegm1.
- Please also email your favorite 3-5 images from the event to us at info@curegm1.org, and include the names of photo subjects.

## Send in your proceeds

- Checks should be made out to Cure GM1 Foundation. Please mail them to: Cure GM1 Foundation, PO Box 6890 Albany, CA 94706. Please also include a short note with your fundraiser name and info.
- Please do not mail cash. Your local bank can convert the cash into a check, made out to Cure GM1 Foundation, which you can mail to the address above.

## Email Cure GM1 a few things

- We need to send the donors individual receipt letters for tax purposes and to thank them for their donations. We'd also love to keep them updated about Cure GM1 progress and initiatives. Please email the donor list to info@curegm1.org.
- We would also love to have official permission to use some of the photos from your event for our media and communications. If that's okay, please send your favorite 3-5 photos from the event to info@curegm1.org.

## Thank your donors and participants

- An easy way to thank participants is to tag them in photos from the event and thank them for coming online.
- For those volunteers and donors who went above and beyond, a thank you card, email, or phone call is a wonderful way to show your appreciation for their support.

## Think ahead to your next event

- While your fundraiser is fresh in your mind, assess what went well and what could improve. Take notes to make your next fundraiser even easier and more successful.

# FUNDRAISER DOS & DON'TS

A “Third-Party Event” is defined as follows: a fundraising activity organized by a group or individual that is not employed by Cure GM1, where Cure GM1 has no financial responsibility and little or no involvement in its execution. The following policies relate to all events or activities benefiting Cure GM1, which a third party organizes and conducts.

## As the event organizer:

### Do

- Capture donor name, address, email, and donation amount during the event so Cure GM1 can send tax receipts and thank you letters.
- When selling goods to raise money as part of a fundraising event, clearly communicate what percentage of the sale benefits Cure GM1 to the event participants.
- Independently obtain all applicable permits or licenses, including, but not limited to: alcohol, solicitation, and sales tax licenses.
- Make clear in publicity and communications that Cure GM1 is the beneficiary, rather than the host or organizer of the fundraiser.
- Clearly state in promotional materials that the event is raising funds to benefit Cure GM1 (e.g. “donations benefit Cure GM1 Foundation”).
- Gain review and approval of all event materials that include Cure GM1’s logo prior to distribution. These materials may include but are not limited to: advertising, press releases, posters, flyers, t-shirts, and public service announcements.
- Accept responsibility for all expenses related to the event. Cure GM1 is not responsible for any expenses incurred for a third-party fundraiser and will not provide funds or reimburse expenses without prior approval from our Board of Directors. To mitigate cost, we recommend soliciting event sponsors or charging a registration fee. You may not make purchases under Cure GM1’s name, and you cannot extend Cure GM1’s sales tax-exemption (on purchase) to any third-party fundraising event.
- Assume sole responsibility for the planning and execution of the event, including safety compliance and adherence to relevant laws. As the beneficiary of a fundraising event, Cure GM1 does not accept or assume any liability pertaining to the event. This may include but is not limited to any injuries sustained by event volunteers or participants during the event. The event organizer will indemnify, defend, and hold harmless Cure GM1, its directors, officers, and employees from any and all claims that may arise out of or relate to such an event.
- Inform donors that they can only receive tax deductions from the amount of their donation that is over the value of the goods and/or services received in exchange for the donation. For example, if a donor gives \$300 to attend a gala, and the cover cost of the gala is \$75, the donation amount would be \$225. If a donor were only to pay the \$75 cover fee, then they could not receive a tax deduction.

### Do Not

- Do not use the name of Cure GM1 in the name of the event, for example: “The Cure GM1 Luncheon.” You may include Cure GM1’s name in a second clause that describes the relationship of the event to the Foundation, such as “Smith Family Luncheon, to benefit Cure GM1.”
- Do not keep any portion of the proceeds (beyond actual expenses) as profit or compensation.
- Do not set up a temporary bank account in Cure GM1’s name. This is illegal.
- Do not neglect to collect or forward donation records and donor contact information along with donations. Cure GM1 needs this information to send tax receipts.
- Do not lump donations into one donation under the organizer’s name in order to receive a tax benefit. Each individual donor shall have the sole ability to claim their donation for a tax deduction.

*If you fundraise for personal reasons such as paying medical expenses etc., you must make a separate fundraiser for yourself that is not linked to Cure GM1 in any way. These donations are not tax-deductible and it is your responsibility to manage the tax implications, etc. It is illegal to claim personal donations are for a nonprofit charity.*



# FAQS

## **Is Cure GM1 Foundation's tax exemption number available to me?**

No. Because you are conducting your event independently of Cure GM1, it is considered a third-party event. This means you cannot use the Foundation's IRS 501(c)(3) charitable classification or tax-exempt certificate. You may use the federal tax ID number, but only for donation purposes. Please email us at [info@curegm1.org](mailto:info@curegm1.org) for details.

## **If I need a permit for my event, will Cure GM1 help?**

No. Every component of the event planning and execution is the responsibility of its event organizer. You must secure all necessary permits or licenses independently.

## **How will my event be properly insured?**

If it's needed, insurance must be procured by the event organizer. Insurance for third party events is not something Cure GM1 Foundation can provide.

## **Is there tax-related documentation I can give donors upon receipt of a donation?**

Cure GM1 Foundation does not provide our tax exemption status in conjunction with any third party event. What we can provide is an authorization letter confirming that the organizer is raising funds for Cure GM1. Cure GM1 will also send acknowledgement letters to each individual donor, provided the organizer sends a list of donors, their contributions, and the donor's email or physical address.

## **Am I responsible for giving donors receipts?**

No. The Cure GM1 Foundation will issue thank you letters, which will serve as receipts, to each donor, provided we have their name, contribution amount, and email or physical address.

## **How can I track the donations I solicit?**

This will depend on which platform you use to run your fundraiser. GoFundMe and JustGiving both offer detailed donation tracking, and Facebook shows donations, too. If you're receiving cash donations, using accounting software is recommended.

## **Can a Cure GM1 Foundation staff member attend or help me plan my event?**

Due to the large number of events and the small number of staff, Cure GM1 staff and board members are by and large unable to attend and plan third-party events. Cure GM1 is also unable to provide supplies for the fundraiser or software to help plan or put on the fundraiser. We are happy to provide guidance, but unfortunately we do not have the staff or resources to handle the organizational and administrative tasks associated with third-party events.