

CureGRIN Foundation

Fundraising Toolkit






Your Support is Crucial!

Thank you for making the decision to help! Your help is crucial in accelerating research so treatments and cures for GRIN Disorder is found **sooner**.

Every dollar makes a difference in the fight to cure GRIN Disorder. No matter how you do it, your fundraising is vital and greatly appreciated. There is no right or wrong way to fundraise. Our GRIN Community has done some pretty amazing and creative things to raise money to cure GRIN Disorder. Big or small. In person or online. Every effort makes a difference.

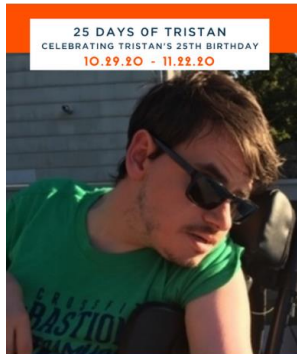
Fundraising is easy at 1-2-3

We are here to help you have a successful fundraiser. Here are the basic steps:

STEP 1	STEP 2	STEP 3
Make the decision to help	Create your fundraiser	Tell your friends and family
		
You've made a great decision! Now determine what kind of fundraiser suits your talents, interests, and personality. Will you do online or in person?	Setting up an online campaign only takes a few clicks. Creating an in-person fundraiser takes some organization and planning. Enlist your friends to help.	You are doing something amazing for our GRIN Community. Your friends and family will want to help you succeed. Make sure to ask them for their support.

Create Your Fundraiser

You can do anything to raise money. Here are some examples for inspiration. These are some campaigns and events that have helped make a difference. Each and every one is important and gives the parents of children with GRIN Disorder hope.



25 DAYS OF TRISTAN
CELEBRATING TRISTAN'S 25TH BIRTHDAY
10.29.20 - 11.22.20

Peer-to-Peer Event

The Mullen family created a P2P to celebrate Tristan's 25th birthday. They sent emails to family, friends, co-workers and alumni and shared on social media. Afterwards, they sent a thank you letter with the total amount raised along with personalized message.

Raised \$10,000



€ 3,00
Dimensioni 13x13cm

Facemasks Sales

Claudia Colombo and family sold face masks and donated the proceeds to CureGRIN. What a great way to help practice social distancing while raising money to support a cure for GRIN Disorder!

This GRIN family has raised \$11,000+ using a personalized fundraising P2P page for their daughter, Alice.

Raised \$2,300



Bracelets for Sale

Caroline Ambler, mom to Jon, sold bracelets. She posted "For GRIN Disorder Awareness Month, I have a limited amount of bracelets ... they are \$10 each... if you are interested, send me a message! Xo #GRINDisorderAwarenessMonth #CureGRIN

The Amblers have raised \$8,000+ through P2P and Facebook fundraisers.

Raised \$700



Bake Sale/Concert

Sue Banks, GRIN Grandmother, holds regular events where she sells home made marmalade and plants. She organizes a series of coffee mornings and afternoon teas featuring her home made cakes and harp concerts, all in her beautiful garden. A great example of combining personal interests and talents!

Raised \$TBD



CureGRIN Board Member, Paul Wasielewski (Austin's Dad), holds regular fundraising events. Formerly Austin's Purpose, now part of CureGRIN, Paul has raised \$100,000+ since 2015.

Motorcycle Run

A motorcycle enthusiast, Paul taps into his personal network and interests to plan an annual motorcycle run that raises funds and builds awareness.

Raised \$10,000



Tailgate Event

Attendees purchase tickets for \$20 and raffle tickets for \$10. Half of the (50/50) raffle total goes to CureGRIN and the winner keeps the other half.

Raised \$1,500



Steak and Cigars

Paul selected a venue and menu to determined overall costs. He charged each attendee \$50 over costs. Paul promotes this event as a networking opportunity for his guests.

Raised \$2,500



Fitness Class

Negotiating with his local fitness club, Paul arranged a spin and exercise class where attendees donated \$25 to attend. Instructors were volunteers. People often donated more money.

Raised \$1,000

More Fundraiser Ideas

Hosting a fundraiser is a great way to support CureGRIN's mission to find treatments and cures for GRIN Disorder. Here are some more fundraising ideas:

- ✓ **Jeans Day at Work** – coordinate with your employer and other businesses to offer a jeans day at work. Each person must donate a specific amount of money in order to wear jeans to work.
- ✓ **Bake Sales**
- ✓ **BINGO Night!**
- ✓ **Restaurant Night** - approaching a local restaurant to host a dinner on a non-busy weeknight benefits both the restaurant and our foundation.
- ✓ **Golf outings** - approaching a golf course on a weekday that might not be so busy for them and offering to get people to sign up to play with a percentage of the fees donated to CureGRIN.
- ✓ Doing a **virtual fund-raising event online** - a 24 hour or 48 hour event online that parents can invite their Facebook friends to. Throughout the event with permission, you can post pictures of our GRIN kids and a little bit about them, what CureGRIN is all about, what we are trying to accomplish excreta. Every donation gets an entry to win a donated prize.
- ✓ **Silent Auctions or Tricky Trays** - getting local businesses or friends and family to donate items and this can even be done virtually to get more people involved.
- ✓ **Local businesses and grocery stores donate** and sponsor local teams for recreational sports all the time. It is a tax write off and if most of the parents can do this it will all add up.
- ✓ **Sell raffle tickets to offer an experience.** Hot air balloon ride, a weekend away some place, horseback riding, race car driving experience - etc. Sell tickets at a higher rate depending on the experience we are offering. These experiences would be donated by the companies involved.
- ✓ Have a **giant yard sale** event - people get rid of all the stuff in their house all the profits go towards CureGRIN research. For people who come but don't want to buy anything – set out a jar with a sign and information about CureGRIN.

How to Write a Fundraiser Letter/Email

Now that you've set up your fundraiser, it's time to start fundraising! Using social media to promote your fundraiser is the easiest way to get donations. But many people may miss your posts and it's easy to scroll past them. There is still power in the written word, so here are a few hints in writing letters/emails to help get started.

1. **Create a list of EVERYONE you know using our Who Do You Know list.** Don't say "no" for anyone by assuming that they can't or won't support. Send them the letter or email and let them decide. Do not hesitate to include casual acquaintances, as they will understand that you are seeking donations for a worthy cause.
2. **Ask. Include a call to action.** Don't just tell them what you're doing, ask for their help. Include your personal fundraising goal in the content and suggest giving levels. Do not diminish your request by being apologetic or by saying something like "I hope you can donate something."
3. **Make it personal.** If mailing, hand address the outside envelope and hand sign each letter. For emails, don't send a mass email with everyone's address showing. Sending individual emails will make potential donors feel special. Write a short personal note to those you don't see regularly, i.e., "Mary, I hope this finds you doing well!"
4. **Put your HEART into it.** Let them know why you're fundraising. This cause is important to you: share why. Don't include too many facts and figures; instead include your personal story of why you have taken on this task. Someone will donate to you because they know you and want to support your efforts.
5. **Make it easy to donate.** Include your personal fundraising page link and encourage online donations. If mailing, include a return envelope for them to send their donation to you. Label the envelopes with your address. It's also nice to include a stamp on the return envelope. If you are organizing an in-person activity, instruct them to bring a check payable to CureGRIN Foundation.
6. **Set a deadline.** People are always motivated by deadlines. We recommend that you set a deadline earlier than the end July. This way you can assess your fundraising and revise your plan if needed before the actual deadline.
7. **Send a reminder.** Keep a list of those who send in donations. Send a reminder to those that have not yet donated. Include fundraising updates in your reminder. Let them know that fundraising is going well, but you still have a bit farther to go. Sometimes, reminder letters are more successful than original letters for bringing in the money.
8. **Thank your supporters.** You can update the story on your page, send emails out to your donors, tweet a thank you, update your Facebook status or send a hand-written note. Let people know how your fundraising went, just what their support has meant to you and what a difference it will make to CureGRIN.

Pro Tip: If you are doing an online peer-to-peer event, put your fundraiser page link in your email signatures for a quick and easy win. It only takes doing it once and then every email that you send out will be raising more awareness of your fundraiser. Example:

I'm participating [insert event name] Visit [my page](#) to learn more and support my efforts to fund research for a cure for GRIN Disorder.

Sample Fundraising Letter

Dear Friends and Family,

As many of you already know, our [son/daughter] [child's name] was diagnosed with GRIN Disorder.

We are participating in CureGRIN Foundation's 2021 Get Moving for GRIN event, during the month of July, to raise funds for research towards treatments and cures for GRIN Disorder.

GRIN Disorder is a rare genetic condition caused by a change in one of seven GRIN genes including GRIN1, GRIN2A, GRIN2B, and GRIN2D. These genes contain the code to create NMDA receptors, which are essential for learning and memory. **Many GRIN patients are non-verbal, unable to walk, and many cannot feed or toilet themselves. They often suffer severe and frequent seizures that are not responsive to medical therapies.**

There's no cure, yet. Fortunately, there is hope and my family is committed to improving the lives of those with GRIN Disorder.

Researchers agree that *a cure is possible*. Some of the world's best scientists and researchers are working specifically on treatments and a cure for GRIN Disorder and many of them are CureGRIN's Scientific Advisory Board members.

Please help support CureGRIN Foundation and those affected by GRIN Disorder by donating to my fundraising page and/or joining Team [INSERT YOUR TEAM NAME] and helping us to raise funds at [INSERT YOUR FUNDRAISING PAGE LINK HERE].

Thank you for your generosity and help. We truly appreciate it!

Learn more about GRIN Disorder and follow our efforts at www.curegrin.org.

[YOUR NAME]

Who Do You Know?

The most successful fundraisers are those who aren't afraid to ask their friends and family for support – they will want to help you because they care about you and your special GRIN! Filling out this worksheet will help jog your memory.

Make a Phone Call to:

Parents	Aunts/Uncles	Grandparents
Sisters/Sisters-in-law	Cousins	
Brothers/Brothers-in-law	Children	
	Nieces/Nephews	

Send an Email to:

Accountant	Chiropractor	Real Estate Agent
Attorney	Financial Planner	Physical Therapist
Dentist	Landlord/Manager	Physician

Drop Off a Letter to:

Bank/Credit Union	Esthetician	Nail Salon
Bar/Restaurant	Florist	School/Teachers
Owner/Manager	Golf or Tennis Club	Supermarket
Childcare	Gym/Yoga	Pet Groomer/Vet
Coffee shops	Studio/Trainer	Pharmacist
Drycleaner	Hair Salon/Spa	

Others You Might Call or Email:

College Friends	Children's Friends	Parents' Friends
Fraternity Friends	Children's Teachers	Former Co-workers
High School Friends	Neighbors	Coaches

Maybe You Know People From:

Work	Professional	Small business
Social Organizations	Organizations	owners Religious
Civic Organizations	Educational	Organizations
Volunteer Groups	Organizations/Alumni	Hobbies

How CureGRIN Can Help With Your Event

Here's what we can provide to help make your fundraiser a success:

- 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
- Tax ID number for donation purposes only
- Help with writing letters, emails, press releases, and other promotional material
- Displaying your event on our website: CureGRIN.org/news-events

Services We Are Unable to Provide:

- Our sales tax exemption number
- Insurance or liability coverage
- Mailing list of donors and/or vendors
- Funding or reimbursement of your expenses
- Celebrities or professional athletes for your event
- Publicity (e.g. newspaper, radio, television)

Your Event Was a Success! Now What?

After your fundraiser, all you need to do is send in your donations/proceeds. Checks should be made out to CureGRIN, and mailed to:

CureGRIN
5732 Regal Oak Lane
Parker, CO 80134

Please do not mail cash. Instead, keep the cash and mail a personal check made out for the same amount to CureGRIN and mail it to the address above. Include a short note explaining your fundraiser. If possible, send a list of those who donated with contact information (name, mailing address and email address). We would love to thank your donors ourselves and keep them in the loop about all the work their donation will support.

Please be sure to send some photos from the event. Email the best 3-5 photos from your event to info@curegrin.org. Say thank you! Sending thank you letters, notes, emails, or make a phone call, to everyone who participated in or supported your event shows your appreciation and reinforces their goodwill in supporting CureGRIN.

Legal Information

A “Third-Party Event” is defined as any fundraising activity conducted by a group or individual that is not employed by CureGRIN, where CureGRIN has no fiduciary responsibility and little or no staff involvement in its execution. These policies pertain to all events or activities benefiting CureGRIN that are organized and executed by third parties.

All expenses are the responsibility of the event organizer. CureGRIN is not responsible for any expenses incurred for a third-party fundraising activity and will not advance funds or reimburse expenses **unless approved in advance by the Board of Directors.** We recommend finding event sponsors or charging a registration fee to help cover expenses. You may not purchase goods or services under CureGRIN’s name, and CureGRIN’s sales tax-exemption (on purchases) cannot be extended to any third-party event or fundraising effort.

The event organizer is responsible for the planning and execution of the event including safety precautions and adherence to applicable laws. As the beneficiary of a fundraising event, CureGRIN does not accept or assume any liability associated with the event, including, but not limited to, any injuries sustained by event volunteers or participants during the event. The event organizer will indemnify, defend, and hold harmless CureGRIN, its directors, officers, and employees from any and all claims that may arise out of or relate to such event.

Organizer Responsibilities

- The event organizer is responsible for obtaining all applicable permits or licenses, including, but not limited to, alcohol, solicitation, and sales tax licenses.
- All third-party events must be publicized and conducted in a manner that makes it clear that CureGRIN is the beneficiary, not the sponsor or host of the event.
- Promotional materials must clearly state that the event is raising funds that will benefit CureGRIN (e.g. “proceeds benefit CureGRIN Foundation”)
- Event names may not incorporate the name of CureGRIN, as in “The CureGRIN Walk-a-thon.” CureGRIN’s name may be used in a second clause identifying the relationship of the event with the Foundation, such as “John Doe Walk-a-thon, benefitting CureGRIN.”
- All event materials that include CureGRIN’s logo, including, but not limited to, advertising, press releases, posters, flyers, t-shirts, and public service announcements, must be reviewed and approved prior to distribution.
- The event organizer may not keep any portion of the proceeds (beyond real expenses) as profit or compensation.
- Donors must be informed that the tax-deductible amount of a donation is only the amount that is over and above the value of any goods or services received in exchange for the donation. For example, if a participant pays \$200 to participate in a golf outing, and the value of the outing is \$50, the donation amount is \$150. If a donor pays less than the value of an item, then they will not receive a tax deduction.

- If goods are sold to raise money as part of a fundraising event, it must be made clear to the event participants what percentage of the sale price benefits CureGRIN.

CureGRIN FAQs

ABOUT CUREGRIN

Our goal is simple and bold: To **find therapies and cures for people living with GRIN Disorder** caused by variants in the GRIN1, GRIN2A, GRIN2B, GRIN2C, and GRIN2D genes.

CureGRIN is a parent-run foundation committed to improving the lives of people living with GRIN Disorder. We work closely with scientists and the medical community to drive research that will lead to therapies and a cure.

WHAT IS GRIN DISORDER?

GRIN Disorder is **rare genetic conditions with severe life-limiting consequences**. Many GRIN patients are non-verbal, unable to walk, and many cannot feed or toilet themselves. They often suffer severe and frequent seizures that are not responsive to medical therapies.

GRIN Disorder is caused by a change in one of seven GRIN genes including GRIN1, GRIN2A, GRIN2B, GRIN2C and GRIN2D. These genes contain the code to create NMDA receptors, which are essential for learning and memory. Most cases are de novo (not inherited from the parent) missense mutations where a single letter is “misspelled” among the 3.2-billion letters of human DNA.

There is currently no cure for GRIN Disorder.

Fortunately, there is hope.

Scientists working at hospitals, universities, and pharmaceutical / biotechnology companies around the world are studying NMDA receptors and the GRIN genes that code them. Some believe a cure (or multiple cures) will be discovered for GRIN Disorder in the next ten to twenty years. Preliminary research suggests that if a malfunctioning GRIN gene is “mended,” brain function could improve dramatically, even in adults who have lived with GRIN1, GRIN2A, GRIN2B, or other GRIN Disorder for decades.