

FUNDRAISING TOOLKIT



A Practical Guide for Community-led Giving, Awareness, and Advocacy



Thank you for your interest in supporting Global DARE Foundation. This toolkit is designed to help community members, families, advocates, and volunteers launch successful fundraising efforts that build awareness, expand support, and advance the organization's mission. Whether you are creating a personal fundraiser, organizing a community event, or inviting others to give through your network, this guide will help you get started and share the mission clearly and confidently.

About Global DARE Foundation

Global DARE Foundation's mission is to promote worldwide awareness and a better quality of life for all who are diagnosed with Adult Refsum Disease. Founded in 2020, the organization serves as convener of a global community of patients, caregivers, healthcare professionals, and supporters dedicated to improving the lives of those affected by Adult Refsum Disease.

Our community supports research, education initiatives, awareness campaigns, and advocacy, with research at the center because we believe there is a cure for Adult Refsum Disease. Because many Adult Refsum patients face a lengthy diagnostic journey while losing quality of life, awareness and early diagnosis are especially important.

Before You Begin

Please contact Global DARE Foundation before publicly promoting any fundraiser that uses the organization's name, logo, or branded language. Approval helps protect the organization's brand, maintain message consistency, and confirm that fundraising activity aligns with the mission.

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Why Your Fundraising Matters

Fundraising for Global DARE Foundation does more than fund an important mission. It introduces new audiences to Adult Refsum Disease, encourages earlier recognition of symptoms, and supports research, education, awareness, and advocacy priorities.

This peer-to-peer toolkit links your personal fundraising to movement-building and provides simple ways to explain why gifts matter. That same principle fits Global DARE well: every fundraiser becomes both a revenue opportunity and an awareness tool for a rare disease that too often goes unrecognized.

Ways to Fundraise

There are many meaningful ways to support Global DARE Foundation through fundraising. Community-led efforts can take many forms, including events, online fundraising pages, milestone campaigns, and local partnerships.

- Online fundraising pages
- Birthday, anniversary, or milestone campaigns
- Community events

- Workplace giving efforts
- School or student-led campaigns
- Athletic challenges

- House parties or small gatherings
- Percent-of-sales partnerships with businesses

Spotlight: Michael Ogilvie's Oxford Half Marathon



"It made me quite upset to learn that my dad and uncle could have been diagnosed at 25 and 22, which is my age now, instead of 45 and 42 — [then] my uncle might not be blind," Michael says. "I think it's so important for people to get tested and follow the diet. It might mean giving up some of your favorite things, and it won't cure you, but the quality-of-life improvements can be massive."

-Michael Ogilvie

At just 23, Michael Ogilvie decided to turn his love of running into support for his dad and others living with Refsum Disease. He registered for the Oxford Half Marathon, dedicating his race to Global DARE Foundation.

Michael set up a fundraising page, shared his story, and invited friends, family, and colleagues to join him by giving, sharing his link, and cheering him on. Supporters responded enthusiastically, contributing gifts, sending messages of encouragement, and helping his campaign gain momentum.

By choosing a visible, community-based event and tying it to a clear personal "why," Michael showed how a single race can be a powerful platform for storytelling, solidarity, and impact.

Michael reminds us that anyone can take something they already enjoy—running, walking, cycling, swimming, or another physical challenge—and turn it into a "run for a cure" moment for Global DARE.



Peer-to-Peer Fundraising

Global DARE Foundation will create personalized online fundraising pages for supporters. Each page can feature the supporter's story, fundraising goal, progress updates, and a unique shareable link to help them invite their networks to give. Email us at info@globaldare.org or faith.mcgown@globaldare.org to get started.

Fundraiser Spotlight: Alan Gunzburg's Social Campaigns

Sample Outreach Messages

Email

Subject: I'm supporting
Global DARE Foundation
— will you join me?

Hi [Name],

I'm raising money for
Global DARE Foundation
because I care deeply
about improving
awareness and quality of
life for people diagnosed
with Adult Refsum
Disease. Global DARE
supports research,
education, awareness,
and advocacy, and I'm
hoping you'll help me
reach my goal of [\$___]
by [date]. Here is my
fundraising link: [insert
URL]

Thank you so much for
your support.

[Your Name]



Alan Gunzburg is a longtime advocate, community leader, and Global DARE Foundation Country Ambassador who shows how sustained, relationship-based fundraising can grow out of everyday networks and service. Diagnosed with Adult Refsum Disease after years of unexplained

Text

Hi [Name] — I'm fundraising for Global DARE Foundation and working to reach my goal of [\$___]. This mission matters to me because [short personal reason]. Would you consider making a gift? Here's my link: [URL]

Social post

I'm proud to support Global DARE Foundation and help raise awareness of Adult Refsum Disease. If you're able, please consider making a gift to help me reach my goal of [\$___] by [date]. Every contribution helps strengthen awareness, advocacy, education, and research support.

vision and hearing loss, Alan has turned his personal journey into a platform for awareness, accessibility, and rare disease research.

Alan uses multiple channels to support Global DARE Foundation. On social media and through birthday and anniversary campaigns, he shares his story, invites friends and colleagues to give, and ties his personal milestones to the broader goal of accelerating research and improving quality of life for people with Adult Refsum Disease. These smaller, recurring fundraisers don't just raise dollars; they keep the cause visible and remind people that our quest for treatments, and eventually a cure, is ongoing.

In addition to individual and online giving, Alan has helped connect Global DARE Foundation to his service community through his local Lions Club. As an active member and past president of the Greenwich Lions Club, he has used his leadership roles to highlight accessibility, vision loss, and rare disease needs. Lions Clubs International has a long history of supporting vision-related causes, and Alan's personal story, combined with his club's commitment to service, creates a natural bridge for awareness and philanthropic support.

Alan's example underscores that **you don't have to organize a single large event to make a meaningful impact**. By pairing milestone dates and social media fundraisers with the support of a community service organization like Lions, he has created multiple touchpoints—online, in person, and through local media—to educate others about Adult Refsum Disease and invite them into the Global DARE mission.

Tell Your Story

People are often most inspired to give when they understand why a cause matters to someone they know and care about. Sharing your personal connection will help others see why Global DARE Foundation's work in awareness, research, education, and advocacy is important.

Helpful prompts:

- Why does this issue matter to me?
- Why am I supporting Global DARE Foundation?
- What do I want others to understand about Adult Refsum Disease?
- What change do I hope this campaign will help create?

It can also be helpful to make the first gift to your own fundraiser to build momentum and encourage others to join you.

How to Spread the Word

A strong fundraising campaign usually starts with personal outreach and then expands outward. Email and text can be especially effective for early asks, followed by social media posts and progress updates.

Suggested outreach sequence:

1. Make your own first gift.
 2. Reach out personally to close friends, family, and key supporters.
 3. Post on social media.
 4. Share progress updates as you approach milestones.
 5. Send a final reminder as your campaign deadline approaches.
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Fundraising Events

Spotlight: John DeMarco's Rare Character Barrel Pick

"Turning my hobby into a fundraiser for Global DARE was more fun—and honestly a lot easier—than I expected," John says. "Once we had the idea, people in our bourbon group and our partners at Rare Character didn't hesitate; they were excited to jump in, support a great cause, and make the barrel pick something truly special. It showed me how ready people are to say yes when you give them a meaningful reason to be part of the story."

-John DeMarco

Looking at his bourbon community, John DeMarco saw more than a hobby. He saw a network of people who care about quality, discovery, and showing up for one another. Working through an established enthusiast group and legally compliant distribution process, he turned a special barrel pick into a fundraiser for Global DARE Foundation.

John's effort combined product sales, raffles, and community giving, with proceeds benefitting Global DARE Foundation. Just as importantly, it introduced new people to Global DARE Foundation and demonstrated how a passion-based community can rally around a rare disease mission in a creative and authentic way.

Like John's example, successful fundraising begins with what people already love. Whether the setting is a bourbon group, local brewery, winery, restaurant, coffee shop, or another enthusiast community, a shared interest can become the foundation for generosity, awareness, and connection.

Adapt John's fundraiser into your own by partnering with a brewery, winery, restaurant, coffee shop, tasting club, collector group, or other enthusiast community to build a fundraiser around a product, limited release, tasting event, raffle, or hosted gathering—always making sure plans follow applicable laws, licensing rules, and Global DARE's approval process.



Start with your community.

Think about the places, hobbies, and groups that bring people together. A limited release, tasting, menu special, raffle, workshop, or hosted event can become a meaningful way to support Global DARE Foundation and invite new people into the mission.



Event Planning Basics

If you are organizing an event, start with a clear and realistic plan. Careful planning can help you manage costs, stay organized, and create a positive experience for supporters.

Checklist:

- ☐ Form a small planning team.
- ☐ Choose a fundraiser that matches your capacity.
- ☐ Draft a budget and estimate net proceeds.
- ☐ Set a date and create a planning timeline.
- ☐ Confirm venue, permits, vendors, and volunteer roles, if applicable.

Gift Handling and Compliance

Please keep the following in mind:

- Do not use Global DARE Foundation's tax ID or tax-exempt status unless explicitly authorized in writing.
- Do not promise charitable tax receipts for gifts made to a third-party event organizer.
- Whenever possible, direct donors to give through the approved Global

- ☐ Plan communications and promotion.
 - ☐ Track gifts and expenses carefully.
 - ☐ Submit proceeds promptly after the fundraiser ends.
- DARE giving channel.
- Fundraiser expenses will not be reimbursed.

After Your Fundraiser: Thanking Donors and Following Up

Thanking donors is an important part of any successful fundraiser. Prompt and sincere follow-up helps supporters feel appreciated and keeps them connected to the mission.

Sample thank-you language:

Thank you so much for supporting my fundraiser for Global DARE Foundation. Your generosity is helping raise awareness and support a mission dedicated to improving quality of life and advancing research, education, awareness, and advocacy for people affected by Adult Refsum Disease.

Suggested follow-up actions:

- Thank each donor promptly.
- Share a progress update during the campaign.
- Report back after the campaign with final results.
- Invite supporters to stay connected to Global DARE Foundation's work.

How Global DARE Foundation Can Support Your Efforts

Global DARE Foundation is grateful for community-led fundraising and may be able to support approved efforts in several ways.

Global DARE Foundation can provide

- A letter of authorization for prospective sponsors and partners

Global DARE Foundation typically cannot provide

- Event insurance or liability coverage

- Fundraising page set up and messaging guidance
- Feedback on event or campaign messaging
- An approved donation link or fundraising page guidance
- Public acknowledgement on social media, when appropriate

- Permits or licenses
- Reimbursement for expenses
- Direct event planning or day-of event management
- Donor, sponsor, or mailing lists
- Guaranteed media coverage or staff attendance

Approved Logos



Frequently Asked Questions

- Can I use the Global DARE Foundation name and logo?

Yes, please use the logos within this toolkit and feel free to reach out for assistance.

- Can Global DARE Foundation help me plan my fundraiser?

We are always available to support you, answer questions and share resources.

- Will someone from Global DARE Foundation attend or speak at my event?
- Will donors receive charitable tax receipts?

All donors who contribute through our donation page will receive tax receipts

and acknowledgement of their support. Additionally, if you provide names, contact information and the amount donated when you turn in your dollars raised via other channels, we will send a receipt and gift acknowledgement.

- Can I be reimbursed for expenses?

Although we are not able to reimburse for expenses, if you send us receipts we can issue you an in-kind donation receipt for tax purposes.

- When should funds be submitted?

Best practice is to submit expenses immediately after your event.

Thank you

Thank you for being part of the Global DARE Foundation community. Your leadership in raising both awareness and dollars for people living with Adult Refsum Disease makes a real difference in what we can do together.

As you plan, launch, and grow your fundraiser, please know that you are not alone—we are here to help at every step, from shaping your idea to sharing your success story. Your efforts fuel our mission, strengthen our community, and bring us closer to a future where every person affected by Adult Refsum Disease is seen, supported, and informed.

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