

Fundraising Manual





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MESSAGE FROM CEO

Dear Friend,

Thank you for your interest in fundraising for the Friedreich's Ataxia Research Alliance (FARA). While many choose to participate in events like rideATAXIA, the FARA Energy Ball, or Team FARA, others find it especially meaningful and rewarding to plan and run their own events or campaigns on our behalf.

No matter how you choose to fundraise, your support is vital to ensuring that we have the resources to advance research towards treatments and cures for Friedreich's ataxia (FA) with urgency.

This Fundraising Manual is meant to provide some guidance on ways to get involved in fundraising and how FARA can support you in your endeavors. This is not an exhaustive guide, and we hope you will consult with our staff and the other fundraising materials available on our website. We are here to support you — please reach out at info@curefa.org with any questions. It takes all of us and it is truly a team effort to slow, stop, reverse, and cure FA.

With gratitude,



Jen Farmer
Chief Executive Officer

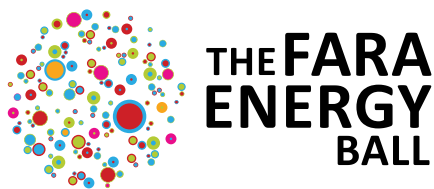
rideATAXIA & THE FARA ENERGY BALL



rideATAXIA

rideATAXIA is a program of the Friedreich's Ataxia Research Alliance (FARA), offering single-day family fun bike rides at locations across the USA. rideATAXIA has served as a unique destination event for families living with FA and other movement disorders to join with researchers, pharmaceutical representatives, and area cyclists in the ride to cure FA. From all corners of the country, people gather to rideATAXIA events for camaraderie and to celebrate their fundraising efforts. Learn more about how to get involved at rideataxia.org.

If you are unable to make it to one of our current locations, we invite you to join rideATAXIA Hometown. rideATAXIA Hometown offers teammates the opportunity to ride individually or host local trail rides in their community as part of the rideATAXIA Program Series.



The FARA Energy Ball

The FARA Energy Ball is a fun, high energy gala held each year in Tampa, Florida. The event features dinner, live music, a live and silent auction, as well as the "Fund A Cure" — a spirited give to support FA research.

Tickets and sponsorship opportunities are available for this event. More information can be found at curefa.org/energyball.

OTHER FUNDRAISING OPPORTUNITIES



Team FARA

Team FARA is made up of people around the globe who raise awareness for FA and fundraise for FARA. Whether someone is participating in an endurance event, celebrating a milestone achievement, or just looking for a way to be involved, Team FARA is for them.

With the FARA name in their fundraising materials, local press releases, or their race jerseys, Team FARA members are introducing the general public to this rare disease and the importance of supporting FA research. Join today at give.curefa.org/teamfara.

Virtual Campaigns

FARA also has virtual fundraising campaigns that you can take part in! Tune in to our social media and newsletter for more information on these campaigns.

- The Gift of Research is a platform for your loved ones to make donations in your honor in lieu of presents for birthdays, holidays, and other momentous occasions. The holiday campaign is kicked off on Giving Tuesday, a global movement held the Tuesday after Thanksgiving encouraging communities to include charitable giving in their holiday plans.
- The Pathway is a budget-friendly, monthly recurring gift program that provides year-round sustaining resources for our research initiatives.



Learn more at curefa.org/get-involved/ways-to-give.

HOSTING YOUR OWN GRASSROOTS FUNDRAISER

At FARA, we know our community is full of creative individuals who may wish to host their own fundraiser for FARA. The Grassroots Program is designated for volunteer-run fundraising endeavors such as this, and staff and resources are available to assist you with such efforts.

The first step is choosing the type of event that works for you and your community.

Once you have selected the type of fundraiser you wish to hold, please complete the fundraising interest form available at curefa.org/grassroots-interest.

Letter/Email Campaigns

Are you interested in fundraising for FARA through a letter writing or email campaign? Past letter writers have used these campaigns as an opportunity to educate family and friends about FA, their experience and why it is important to fund research. Such campaigns can be done with little time commitment and from the comfort of your home! A sample letter is available on page 10.

Restaurant/Store Give Back Nights

Many restaurants and stores hold Give Back events, where they donate a percentage of sales to a specified charity. These are generally easy to arrange and do not require a huge time commitment on your part. Typically, patrons are asked to bring in a flyer for the event to have a percentage of their bill credited to the fundraiser.



IDEAS FOR HOSTING YOUR OWN GRASSROOTS FUNDRAISER

Movie Screenings

Movie nights are fun, inclusive and effective ways of fundraising. Follow-up your film with a Q&A, Trivia, or a small reception! You can even use a screening as an opportunity to educate your community on FA by showing *The Ataxian*. This documentary film features FARA Spokesperson and rideATAXIA director, Kyle Bryant, and three of his friends, Sean — who also has FA, John, and Mike, as they embark on the “toughest bike race in the world,” the Race Across America (RAAM).



GO VIRTUAL: The *Ataxian* can be viewed by your supporters on YouTube, and FARA staff can help facilitate a virtual Q&A with the stars.

Game Night

Board Games, Trivia, Baggo, and more! Everyone loves a little friendly competition. Play for prizes or just bragging rights.



GO VIRTUAL: With a little ingenuity many games can be played virtually! Mail out cards in advance or find online versions of your favorite games.



IDEAS FOR HOSTING YOUR OWN GRASSROOTS FUNDRAISER

Cocktail/Dinner Party OR Back-Yard Party

Everyone loves a party, and you can host an event as high or low key as you would like! Whether it be a glamorous cocktail party filled with food and dancing, or a casual barbeque in the backyard, these ideas are all fun in support of a good cause! In addition to raising funds through ticket sales, donations, and sponsorships, these parties are also great opportunities to raise extra funds through silent auctions and games.



GO VIRTUAL: Instead of hosting in-person, you can host a virtual party! Design a fun program for your supporters to view from the comfort of their own homes.

Walk/Run Event

Holding a walk or run for FARA is a great way to bring people together and fundraise. While these events generally require a significant time commitment from a planning committee, they are effective in engaging the local community and enable all of your participants to fundraise within their larger networks, maximizing your impact.



GO VIRTUAL: You can invite your community to participate from their own neighborhoods! Track miles through fitness apps or just ask everyone to get out and be active in their own way.



HOW FARA CAN SUPPORT GRASSROOTS FUNDRAISING EFFORTS

Planning Support by FARA Staff

The FARA Staff is experienced in event planning and fundraising. The team is happy to support you in planning your event — helping to evaluate venues and vendors, linking you with a mentor, and more.

Promoting Your Event

- ▶ **Online Calendar:** FARA publishes all fundraising events on our website's Events Calendar (curefa.org/events).
- ▶ **FARA Newsletter:** FARA includes a list of upcoming events in our monthly newsletter.
- ▶ **Social Media:** FARA posts a monthly list of upcoming events on social media with the event name, date, location and a note to visit curefa.org/events for more information. Due to the number of grassroots events, we are unable to share customized posts for grassroots events. We encourage organizers to host their own social media pages to engage with your event supporters and create excitement around the event.
- ▶ **Press Releases:** FARA Staff can work with you to write a press release for your event and help share it with your local media.

Branding & Branded Materials

We encourage the use of the FARA logo as a beneficiary of the event in accordance with the Style Guide available at curefa.org/media.

FARA can provide branded materials for your event. Please request event materials from curefa.org/materials-request at least 3 weeks in advance to allow for shipping. FARA offers the following branded materials free of charge.

- ▶ Informational postcards
- ▶ Pens
- ▶ Bumper stickers
- ▶ Banners on loan
- ▶ Wristbands

If you are interested in ordering branded apparel in a bulk quantity for your event, we recommend working with local vendors. FARA can provide advice on quoted items to help you choose your vendor.

If you are interested in general FARA-branded apparel, visit FARA's Bonfire store at www.bonfire.com/store/curefa. A portion of each sale goes back to FARA.

WEBSITE PLATFORM OPTIONS

FARA utilizes the Classy fundraising platform to create event websites, and to collect donations and registration fees. FARA Staff will work with those hosting grassroots events or campaigns to decide which website option is appropriate and design the website using your desired event branding.

Note: if you are participating in rideATAXIA or Team FARA, these websites will be set up for each campaign – you just need to register and customize your team and personal fundraising pages.



Donation Page

A donation page is a checkout form where supporters can submit donations. You can create a standalone donation page to use as your main donation form. Then, you can link to the page from a donation button on a separate website, social media, or email to gather gifts.



Crowdfunding

Crowdfunding campaigns allow your supporters to make a donation. But before they reach the donation form, they see a landing page where you can share photos, video, more information about your story, the cause, or even a fundraising thermometer.



Ticketed Event

Ticketed Events allow you to sell tickets and sponsorship to fundraising events. No matter what type of event you host, you control the number and types of tickets you offer. These pages also allow for those who cannot attend to contribute.



Peer-to-Peer

Peer-to-peer campaigns allow supporters to fundraise on behalf of your event. On your campaign page, supporters can set up personal or team fundraising pages. Then, they can ask family and friends for donations that go to FARA.



Registration with Fundraising Event

Registration with Fundraising campaigns combine Peer-to-Peer campaigns and Ticketed Events. Supporters register for the event and also set up personal or team fundraising pages. This allows supporters to ask family and friends for donations before or during your event. This platform works well with events such as runs, walks, or dance-a-thons.

HOW YOUR COMMUNITY CAN SUPPORT YOUR EFFORTS

Organizing a Committee

Planning a fundraiser includes many details and tasks. For one person, planning an event can be overwhelming. Forming a committee of dedicated volunteers who meet regularly is key to having a successful event. A committee allows you to delegate the responsibilities, which can include finding a venue, obtaining event sponsorship, soliciting auction items, promoting the event, and recruiting volunteers.

Asking for Support

Making the ask for sponsorship and donations, whether they be monetary or in-kind, requires thoughtful planning and time. Start with people you know such as friends, colleagues, and local businesses you frequent. We recommend starting asks by email or mail and following up with a phone call to see if they have questions. You will be surprised at your community's generosity — all you have to do is ask! See pages 10–12 for sample letters for requesting sponsorships and in-kind donations.

Note on medical and pharmaceutical industry sponsorship: FARA makes one annual ask to each of our industry partners for all events. If you would like to request support from a specific pharma partner, please reach out to FARA Staff to be included in this ask.

Involving Your Lawmakers

We strongly encourage our grassroots fundraisers to invite their representatives to their events, as this provides a perfect opportunity to raise awareness and foster government relations. This way, when FARA goes to them for legislative action, our community already has a relationship in place and the lawmaker will have a better understanding of our requests. Visit congress.gov/members/find-your-member to find your federal and state representatives.



DONATION CAMPAIGN LETTER TEMPLATE

[Date]

Dear [Name of Family or Friend],

As you know, our son, Sam, was diagnosed with Friedreich's ataxia (FA) in August 2018. FA is a genetic, progressive neuromuscular disease. People with FA experience issues with balance and coordination of movement that lead to life-altering loss of mobility. Other common symptoms can include fatigue, serious heart conditions, scoliosis, and diabetes. FA is life-shortening and affects an estimated 5,000 individuals in the United States and 15,000 worldwide.

Sam has not let having FA define him. At 14 years old, Sam began a daily regimen of exercising and eating healthy. As his FA progressed it became more and more difficult for him to exercise on his own. Even though he was reluctant to accept help from others, his determination has not let him quit. Like Sam, we will not quit in raising awareness and much needed funds to continue research to find treatments and a cure for FA.

We are asking you to support our efforts by making a donation to the Friedreich's Ataxia Research Alliance (FARA). FARA is a non-profit organization dedicated to the pursuit of scientific research leading to treatments and a cure for FA. FARA's efforts have led to major breakthroughs in the fight against FA, bringing hope and confidence to families living with FA. Supporting FARA not only advances FA research but may also provide insights for other conditions both rare and common.

Thank you in advance for your thoughtful consideration. For further information about FARA, please visit cureFA.org or contact the office at 484-879-6160 or info@cureFA.org.

Sincerely,

[Your Name]

[Your Phone Number]

[Your Email]

[Family Pictures]

Editable Word Document Template available at curefa.org/tools.

SPONSORSHIP REQUEST LETTER TEMPLATE

[Date]

Dear [Business Owner/Corporate Donations Dept]:

Strolling for Sam will take place on February 28, 2025, in support of the Friedreich's Ataxia Research Alliance (FARA). This fun, family walk along Sampletown's Main Street is being held in honor of our son, Sam, who was diagnosed with Friedreich's ataxia (FA) in August 2018.

FA is a genetic, progressive neuromuscular disease. People with FA experience issues with balance and coordination of movement that lead to life-altering loss of mobility. Other common symptoms can include fatigue, serious heart conditions, scoliosis, and diabetes. FA is life-shortening and affects an estimated 5,000 individuals in the United States and 15,000 worldwide.

Sam has not let having FA define him. At 14 years old, Sam began a daily regimen of exercising and eating healthy. As his FA progressed it became more and more difficult for him to exercise on his own. Even though he was reluctant to accept help from others, his determination has not let him quit.

Like Sam, FARA will not quit in raising awareness and much needed funds to continue research to find treatments and a cure for FA by supporting FARA. FARA's efforts have led to major breakthroughs in the fight against FA, bringing hope and confidence to families living with FA. Supporting FARA not only advances FA research but may also provide insights for other conditions both rare and common.

We would like to invite you to help us in our endeavor by sponsoring this exciting event. Sponsor levels offer recognition of your support to be viewed by the anticipated 300+ participants and their donors. We are offering the following donation packages:

Gold Sponsor (\$2,500)

Company Logo on T-Shirt
Free exhibit space at the event
7 Registrations
7 T-Shirts

Silver Sponsor (\$1,000)

Company Name on T-Shirt
5 Registrations
5 T-Shirts

Bronze Sponsor (\$500)

Company sign or poster at halfway mark
3 Registrations
3 T-Shirts

Thank you in advance for your thoughtful consideration. Please contact me at the phone number below if you are interested in sponsoring this awesome event. For further information about FARA, please visit cureFA.org or contact the office at 484-879-6160 or info@cureFA.org.

Sincerely,

[Your Name]

[Your Phone Number]

[Your Email]

IN-KIND DONATION REQUEST LETTER TEMPLATE

[Date]

Dear [Business Owner/Corporate Donations Dept.]:

We are pleased to announce that the Sample Family Benefit Dinner for FARA will take place January 30, 2025 at the Sampletown School in Sampletown, MD. All proceeds from this event will go to the Friedreich's Ataxia Research Alliance (FARA), a non-profit organization dedicated to the pursuit of scientific research leading to treatments and a cure for Friedreich's ataxia (FA).

FA is a genetic, progressive neuromuscular disease. People with FA experience issues with balance and coordination of movement that lead to life-altering loss of mobility. Other common symptoms can include fatigue, serious heart conditions, scoliosis, and diabetes. FA is life-shortening and affects an estimated 5,000 individuals in the United States and 15,000 worldwide.

FARA's efforts have led to major breakthroughs in the fight against FA, bringing hope and confidence to families living with FA. Supporting FARA not only advances FA research but may also provide insights for other conditions both rare and common.

We hope that you will consider supporting us in this great cause. We are asking for in-kind donations to be used as auction items at the event. In exchange for your generosity, your company will be listed on our auction display and in our program seen by our anticipated 300+ attendees.

Thank you in advance for your thoughtful consideration. For further information about FARA, please visit cureFA.org or contact the office at 484-879-6160 or info@cureFA.org.

Sincerely,

[Your Name]

[Your Phone Number]

[Your Email]

Editable Word Document Template available at curefa.org/tools.

All fundraising events carried out under the Friedreich's Ataxia Research Alliance (FARA) name and logo must adhere to Generally Accepted Accounting Procedures (GAAP) for non-profits. FARA has a responsibility to accurately report its income using GAAP for non-profits. Please follow the guidelines listed below to help us keep track of proceeds from your event.

Checks

Please ensure that all checks and donations are made out to the Friedreich's Ataxia Research Alliance or FARA. You or your supporters should mail checks directly to the FARA Office (533 W. Uwchlan Ave, Downingtown, PA 19335) within one week of event. Please clearly mark checks with the event name and what the payment is for (i.e. donation, registration fee, tickets, etc). This helps the FARA Staff to appropriately credit your event for the funds and receipt donors.

Credit Cards

During the event: FARA uses Square to take credit card payments at events. Contact FARA Staff to receive a card reader for your event and further instruction.

Cash

Please bring cash to a bank to have a bank check or money order made out to FARA for the total cash amount. Do not deposit cash into your own bank account, as this could have tax implications for you.

A Note on Bank Accounts

All fundraisers are prohibited from opening an account in FARA's name. You should not open a bank account for the purposes of your event nor deposit into FARA's existing account yourself. Please encourage all donors who write checks to make them payable to FARA. If your donors make a check payable to anyone but FARA, we will be unable to provide a tax receipt acknowledging their gift.

Fair Market Value

The fair market value of goods and services that a supporter receives is not tax-deductible. Anywhere the cost of admission or sponsorship is listed should disclose the fair market value of goods and services received to comply with IRS guidelines. Please speak with FARA staff to estimate appropriate fair market values.

Expenses

For Grassroots Events, FARA is typically able to cover expenses for approximately 10% of the income projected by the FARA staff for your event. All expenses must be pre-approved by FARA before any payment or vendor contracts are signed. Please submit contracts to FARA for review and signatures. FARA cannot guarantee reimbursement or payment for expenses not submitted and approved in advance. Please submit vendor invoices for FARA to pay invoices directly. For small, incidental event needs, please submit receipts to FARA for reimbursement within one month of purchase.

GIFT ACKNOWLEDGEMENT PRACTICE & PRIVACY POLICY

Monetary Donations

FARA acknowledges donations according to IRS Guidelines. All donations of \$25 and above received through fundraising events will be acknowledged with a tax receipt/thank you letter signed by the CEO. (Volunteer fundraisers are strongly encouraged to thank all of their donors.) FARA will strive to acknowledge these donations within three weeks of receipt of donations and event accounting details from the organizers. Credit Card transactions made through Classy and Square are automatically receipted by the respective software.

Donations Made In-kind

FARA can provide letters documenting goods or services provided as in-kind donation for the purpose of your event. Please provide FARA with a listing of donations made in-kind. FARA will document the item donated in kind on their receipt. Donors should consult their tax advisor regarding these in-kind contributions.

Donor Privacy Policy

FARA's policies and disclosures serve to present FARA's best practices in our relationships with key stakeholders including donors and the community we serve. Please visit www.curefa.org/privacy-policy/ for our most updated Privacy Policy.



Accessing Donor Information for your Event

FARA understands that volunteers hosting an event need detailed contact information for those supporting them, as well as sponsorship, ticket, and donation amounts.

If you need access to donor information for an event you are holding, contact the FARA Staff. To receive information on amounts, all volunteers are required to sign a Non-Disclosure Agreement with FARA. FARA reserves the right to determine if you are eligible to receive this access.

Thank you for your interest in hosting an event in support of FARA's mission. Please contact us at info@curefa.org if you have any questions. We look forward to working with you!

 facebook.com/CureFA

 linkedin.com/company/fara

 instagram.com/curefa_org