

Third-Party Fundraising Events

A Guide to Hosting Your Own Event to Benefit UMSDF

Welcome

Thank you for your interest in supporting United MSD Foundation. We appreciate your support very much, as we depend on the generosity of people like you to continue funding MSD research, raising awareness, and supporting families around the world.

Founded in 2016, United MSD Foundation is a 501(c)(3) nonprofit organization serving an international community of Multiple Sulfatase Deficiency (MSD) families, researchers, and care providers. Since inception, our mission has been to cure MSD. To that end, we have funded a knock-out mouse model, an AAV9 gene therapy, subsequent toxicology study, and a Natural History Study. We run an MSD Biobank and Patient Registry to provide researchers with access to patient data and samples. Currently, we are supporting first-in-human gene therapy trials with our partners at the Children's Hospital of Philadelphia.

General Guidelines

If you are interested in hosting a fundraiser on behalf of the Foundation, please read through this guide and submit the application form. The application will provide us with a clear understanding of your plans and will allow us to verify the legitimacy of your fundraiser should we receive inquiries from the public.

United MSD Foundation is accountable for fundraising activities that use our name and visual identity and that reflect back on the Foundation. The application is not a guarantee of event approval. It must be submitted for review and be approved before any public event announcements are made. It is important that your event align fully with our mission, not conflict with other Foundation events, and not over ask our supporters or sponsors.

Until the application is approved, no announcements can be made and the fundraiser may not be promoted in any way using the UMSDF name and/or logo.

If expenses are greater than money raised by the event, the event organizer is responsible for those expenses. We ask for proceeds to be distributed to the Foundation within 30 days of the fundraising event.

Overview

What is third-party fundraising?

Third-party fundraising is any type of fundraising event or program conducted by an individual, group or organization where United MSD Foundation is the beneficiary. Fundraising can take many forms, including a special event or as proceeds of a sale.

Who can conduct a fundraiser on behalf of United MSD Foundation?

Individuals and organizations—including existing sponsors, MSD families or staff/board members—can fundraise independently in support of the Foundation. Anyone in the community can fundraise to support the areas of greatest need, a specific research project, or a family support program.

How will this guide help you?

We hope this guide will assist you as you plan to fundraise for the Foundation. Included are frequently asked questions, some tips on how to get started, and how to proceed during and after you have fundraised for us. Our goal is to provide you with the tools necessary to host a successful fundraiser for United MSD Foundation.

Where will your donation go?

All donations made to United MSD Foundation will go to our area with the most need unless you designate a specific Foundation project or program.

How can United MSD Foundation help you with your fundraiser?

- Provide a letter of authorization to validate the authenticity of the fundraiser
- Create and provide a custom fundraising webpage for information and donations, including periodic donor reports
- Offer feedback on your fundraiser and/or event
- Provide and approve use of our logo on materials related to your fundraiser
- Help you select a Foundation area for your donation to support
- Provide public thanks via social media, if desired

While we are here to support your fundraising effort, following are services we are **unable** to provide:

- Our tax exemption number
- Insurance or liability coverage
- Permits and/or licenses
- Mailing list of donors and/or vendors
- UMSDF letterhead
- Funding or reimbursement of your expenses
- Publicity (e.g. newspaper, radio, television)
- Guaranteed attendance of Foundation staff or other representative individuals



Frequently Asked Questions

Can I use the Foundation name and logo?

Once your fundraiser is approved, we will provide you with a .png file of the UMSDF logo for your marketing materials. We must review everything with our name and/or logo before it's printed or distributed. This includes the use of the UMSDF logo on your website or your company's or organization's website. All UMSDF logos added to websites must be removed no more than 30 days after the conclusion of your fundraiser.

How long does it take to get my event application approved?

Applications will be approved within 10 business days of submission.

Do I need to create a 501(c)(3) non-profit organization to host a fundraiser for United MSD Foundation?

No, anyone can host a fundraiser for the Foundation with our approval. Staff can provide an authorization letter confirming the organizer's intent to raise funds for the Foundation.

Can someone from United MSD Foundation help me plan my fundraiser, and attend and/or speak at my event?

We are happy to provide guidance and some support, but our limited staff capacity is unable to handle the organizational and administrative tasks associated with third-party fundraisers. We do our best to attend events supporting UMSDF that take place in the Gulf Coast region between New Orleans, Louisiana, and Biloxi/Ocean Springs, Mississippi; however, we cannot guarantee any attendance at your event.

Can United MSD Foundation help me get a permit and/or license for my fundraiser?

The organization and execution of the fundraiser is the responsibility of the organizer. The organizer must obtain any necessary permits or licenses.

Frequently Asked Questions (cont'd.)

Can United MSD Foundation provide insurance for my fundraiser?

Because the Foundation is the beneficiary and has no direct involvement with organizing or executing the fundraiser, we cannot provide insurance certificates. The event organizer is responsible for obtaining insurance, if necessary.

Can I use United MSD Foundation's Tax Exempt Number?

Because UMSTDF is not the host, it is considered a third-party fundraiser. For this reason, you will not be able to use our IRS 501(c)(3) charitable classification, federal tax ID number, or tax-exempt certificate.

Will each of my donors get a receipt?

United MSD Foundation cannot issue charitable tax receipts for donors or sponsors who make payments directly to your third-party fundraiser. If your donor wants a receipt, please be sure the check is made payable to *United MSD Foundation* and leave the check in its original form before sending it to the Foundation.

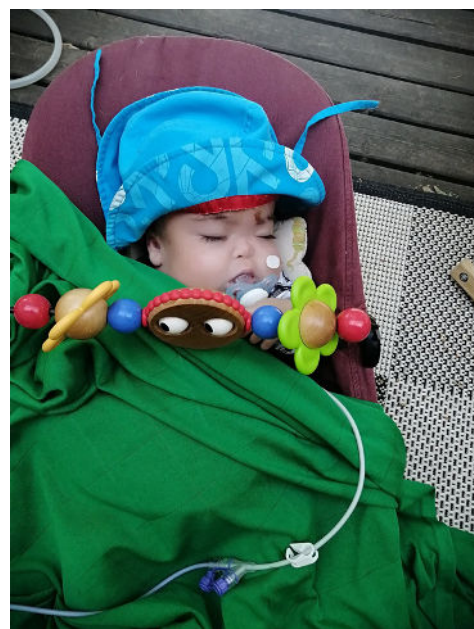
Please note that there are complex regulations around the distribution of charitable tax receipts. This includes donations of money, in-kind items, and services. Issuing an inappropriate receipt can put our charitable tax status in jeopardy. Please do not promise any kind of receipt. For more information about charitable tax receipts, please contact the UMSTDF Executive Director, Sarah Cortell Vandersypen.

Can I pay myself back for expenses I've incurred?

United MSD Foundation cannot fund or financially support community fundraisers. Coordinators are responsible for covering all expenses and cannot be reimbursed by UMSTDF. For these reasons, as you start to collect money you may want to keep some funds on hand to help pay your expenses or procure in-kind donations for event needs.

Should I send a personal thank you letter or card to my donors?

Of course! It is important to thank everyone who was involved with your fundraiser!



Getting Started

You may know you want to fundraise for United MSD Foundation, but you're unsure where to start. This list is designed to help you narrow your focus and be more successful!

1. **Form a committee and brainstorm.** Bring together a group of enthusiastic people willing to be part of a planning committee and brainstorm ideas for your fundraiser.
2. **Decide on your fundraiser.** Whether you choose to host an event or raise money through a business, make sure it's something you and the committee can handle.
3. **Create a budget.** You may find this to be a difficult part of the planning process, but it is vital. Try to identify all the expenses involved with your fundraiser (invitations, postage, rental space, signage, food and catering, promotional materials, website, advertising, permits etc.). Next, think about the streams of revenue (ticket sales, items sold, etc.). You should also think about your ability to get items or services donated (food, equipment, printing, etc.) to reduce your costs. This step may make or break your idea so be as thorough as possible. We encourage you to keep your expenses to a minimum and try to estimate the value of your time to determine the "net profit" goal of your event.
4. **Tentatively schedule the fundraiser.** Select a date and time that is appropriate and convenient for those who will be attending your event. If you are fundraising over a period of time, choose a time of the year you think is best for your potential supporters.
5. **Once you have a plan, apply for approval of your event.** Fill out the UMSPDF third-party fundraising event application and submit it for approval. We will get back to you within 10 business days of receiving the application.
6. **Create and maintain a timeline.** An event timeline is important in planning a complete strategy for your fundraiser, including publicity and communications. Create goals and set target dates to meet those goals.
7. **Tackle the logistics.** Whether you're hosting an event or fundraising in another way, start planning the details of your fundraiser.
8. **Money management.** You may find that you will need to establish a bank account to accommodate incoming revenue and expenses.
9. **Send in the donation.** We ask that all event proceeds designated for United MSD Foundation be submitted within 30 days following the conclusion of your fundraiser.
10. **Say thank you.** Sending thank you letters, notes or e-mails to everyone who participated in your fundraiser is a must.



Don't Forget

Before Your Fundraiser

Get approval! All fundraisers on behalf of United MSD Foundation need Foundation approval before our name or logo can be used. This will allow us to keep track of all fundraising done in the community and help us inform the public about legitimate fundraising efforts.

Have all materials with the Foundation logo approved before distribution. The Foundation must review and approve all uses of our logo before they become public. Any use of the UMSDF name or logo without approval is prohibited.

At Your Fundraiser

Thank everyone for their support! Every dollar makes a huge difference so please be sure to thank everyone for attending your event or supporting your fundraiser.

Take Lots of Photos! Photos and videos are a great way to document your fundraiser. If you have sponsors, be sure you take photos with their signage and send to them. Don't forget about us! Be sure to capture a couple of pictures for the Foundation to possibly use on social media or in our e-newsletter.

After Your Fundraiser

Send in Your Donation!

Mail a check to:

United MSD Foundation
P.O. Box 806
Biloxi, MS 39533

- Checks should be made payable to *United MSD Foundation*
- Include a short note explaining how you raised the funds
- Once we receive your donation, an acknowledgement letter will be sent to you

Send us Photos!

E-mail the best 3-5 photos from your fundraiser to: info@unitedmsdfoundation.org



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