



CHOROIDEREMIA

RESEARCH FOUNDATION

FUNDRAISING TOOLKIT



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1. Overview

How am I helping the Choroideremia Research Foundation?

Thank you for your interest in raising funds to support the Choroideremia Research Foundation (CRF). Our success depends on the initiative of supporters like YOU. Each dollar that you raise will help CRF fund research of a possible treatment and restorative measures, as well as provide vital information to our members and families. We are here to help!

What does the CRF do with the donations?

Science & Research – Early and ongoing investments and efforts are moving us closer to effective treatments for Choroideremia (CHM). As of this writing, we have awarded over \$2.5 million to support research on causes and potential treatments. The CRF-funded biobank created from CHM patient samples is being used by researchers in the US, Europe, and Canada.

“CHM Family” Services – CRF’s caring community shares information and resources, personal stories, emotional support, adaptive tools, guided access to patient engagement, news of current research, and empowerment as a CHM and a rare disease community.

Clinical Trials – CRF works with companies to inform potential participants about their clinical trials; we play an essential role in recruiting study participants and study sites; and we actively provide family and patient support.

Partnering for Advocacy and Awareness – Our staff presents at conferences and panels across the U.S. and internationally, focusing on retinal research, strategies for identifying new patients, and rare disease support. We represent patient needs as we address regulatory challenges for ongoing disease research.

How will this toolkit help me?

Feel free to use a few of our ideas and suggestions or all of them – whatever works best for you and your event! You may want to start with something simple and easy-to-plan, but our hope is that this toolkit will help you, however ambitious you feel.

Whether you've hosted fundraising events in the past or are new to fundraising, the toolkit is designed to help you effectively raise money and awareness for CRF. Its aim is to make planning your fundraiser as easy as possible. From creating a timeline and a budget, to organizing and publicizing your event, it is a complete planning guide that will allow anyone to become a successful fundraiser for CRF.

2. Let's get started!

Thinking of hosting a fundraiser to raise money for the CRF? The possibilities are endless! Once you email us the details of your fundraiser, at info@curechm.org, CRF is here to help you.

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;
- CRF swag;
- A letter of authorization to validate the authenticity of the event and its organizers;
- Tax ID number for donation purposes only;
- Templates for letters, emails, press releases, and other promotional material;
- Setting you up with CRF's on-line giving platform, and a tutorial to keep your event on track and make reaching out to your contacts a snap.

Deciding to host a fundraiser for the CRF is a huge accomplishment in itself – thank you!

Here are 10 easy steps to help you get started:

1. **Form a planning committee.** Depending on the size of your event, bringing together a group of enthusiastic and dedicated people who share your passion and dedication to CRF fundraising will increase the probability of a successful event. This could just be you and a few friends or family members – get your kids involved – you will be amazed at the results.
2. **Brainstorm.** Gather members of your planning committee, or just family and friends, to brainstorm ideas for your fundraiser. Give free rein to your imagination – several heads are better than one! All you need is a pen and a white board!
3. **Choose the “right” event.** The type of event you choose should fit the size, interests, talents, goals, and time availability of everyone involved.
4. **Identify your audience.** Consider who is most likely to attend and support the type of event you have selected.
5. **Develop a budget.** Try to identify expenses and possible sources of funds, including securing in-kind products and services, corporate matches and the like. This will help keep your costs down, which is something everyone will appreciate.
6. **Develop an event timeline.** A timeline is important in planning for your event.
7. **Schedule the event.** Select a time that is appropriate and convenient for those who will be attending. Be sure to check local community calendars for conflicting events.
8. **Let CRF know.** Let us know about your event. We can then publish your event on our website and help you set up a Classy event page to share with your donors/attendees.
9. **Collect all funds.** We ask that all funds be forwarded to the Choroideremia Research Foundation within 30 days following the event. Address:

Choroideremia Research Foundation, Inc.
23 East Brundreth Street
Springfield, MA 01109

10. **Say thank you!** Sending thank you letters, notes, emails, or best of all, making a personal phone call, to everyone who participated in or supported your event shows your appreciation and reinforces their goodwill in supporting CRF. CRF will also send an acknowledgement letter to all donors.

3. It All Starts With YOU!

What activities do you enjoy? Whether it's cooking, crafting, or exercising, simply add a fundraising component to it. It's the perfect way to give back to a great cause while doing something you love.

Ideas to get you started

- Jeans Day
- Guest Bartender
- Trivia Night
- Bake/Tag Sale
- Silent Auction
- Collect Change
- Wine Tasting
- 5K
- Lemonade Stand

4. Fundraising Ideas – If you're feeling a bit more ambitious

Why not open up your fundraising efforts to a larger crowd? Organize a fun event with a truly meaningful mission. Here are some great ways to engage friends, neighborhood residents, co-workers, and more:

- Dinner in the Dark
- Sunday Brunch
- Garage Sale (could involve a neighborhood, community or church)
- Fun Run
- Bike/Car/Motorcycle Ride
- Charity Concert
- Golf Outing
- OktoberFest
- Cinco de Mayo
- Halloween Spooktakular
- Birthday-drives
- Possibilities are endless....

5. Marketing and Organizing –

These tips and tools will help maximize publicity of your event at very little cost. Apply some, or all of them, depending on the size of your event.

Create a timeline to maximize publicity

A timeline is important in planning a publicity strategy for your event. Keep this timeline in mind as you put together a publicity plan:

3-4 months before the event

Identify your target audience based on age-group, interests, and location, develop a targeted media list. Let CRF know about your fundraiser. Set up your Classy personalized event page.

4-6 weeks before the event

Distribute media materials (i.e. posters in your neighborhood, a media alert, Facebook posts, emails etc.).

2 weeks before the event

Make follow-up calls and send emails to media who received the information from you.

1-2 days before the event

Email and/or fax a media alert with the basic information about your event (who, what, when, where, and why) to the TV news assignment desks and daily newspapers.

6. Make it Personal – Make it Visual

Your first outreach to your community announcing your event is critical. Try to capture their attention and use language and imagery that is personal and will leave a lasting impression. Because Choroideremia is a rare disease – you will likely have to educate folks not only on what the condition is but the practical impact CHM has on the patients and their families.

Suggested language:

The following is a simple description of Choroideremia, which you can use in your communications:

Choroideremia (CHM) is a rare inherited disorder that causes progressive vision loss, ultimately leading to complete blindness. Currently, there is no cure.

The first symptom is generally night-blindness, followed by vision loss in the mid-periphery. These “blind spots” appear in an irregular ring, only leaving patches of peripheral vision, while central vision is still maintained. Over time the peripheral vision loss extends in both directions leading to “tunnel vision” and eventually complete loss of sight. The disease affects the retina, which is the area at the back of the eye. CHM is considered a rare disease because it only affects an estimated 1 in 50,000 individuals. The disease is caused by a genetic defect of the X-Chromosome, and thus typically only males suffer the full effects of complete blindness, while females are carriers of the disease. CHM has a 50% chance of passing onto the children of an affected parent, although – due to the defect’s presence on the X-Chromosome affected males cannot pass the disease on to their sons.

Social Media

Whether you're promoting your event or celebrating its success, social media can play an important role in your fundraising. Remember these tips when spreading the word through your social media accounts.

- Tell your friends and followers why you have created this event. Be specific about event details, your goal, and the difference it makes for CRF.
- Be sure to include a link to your fundraising page, if applicable.
- Post consistently! Share updates before, during, and after your event.
- Tag us in your photos on Facebook (Cure CHM) & Twitter (@CureCHM) & Instagram (Cure CHM)

Create Lasting Memories

Photos are a great way to document your event, whether for publicity or simply to share with family and friends. Here are some tips on capturing special moments at your fundraiser:

- Write out a photo wish list in advance to make sure you get photos of everything and everyone you want.
- Take candid and close-up shots that capture the different aspects of your fundraiser.
- Include kids in the photos, if applicable. It's essential to always ask permission from a parent or guardian first.
- Take pictures of your corporate sponsors, if applicable.
- Photos with 1-3 people only are the best for publicity.
- Post the photos to your social media accounts that are the most appropriate for the event.
- Use these photos when you thank your supporters.
- After the event, please email the best 3-5 photos to info@curechm.org, with the names of the people featured, and we may share it on our social media!

7. Gratitude! It's a Wrap!

The proceeds from your fundraiser will have a tremendous impact for CRF. Thank you for your support! After your fundraiser, all you need to do is:

Send in your donation/proceeds

- Checks should be made out to Choroideremia Research Foundation, and mailed to:

Choroideremia Research Foundation, Inc.
23 East Brundreth Street
Springfield, MA 01109
- Please do not mail cash. Instead, get your local bank to convert the cash into a check, made out to Choroideremia Research Foundation, and mail it to the address above, or charge your total donation on our website at <https://www.curechm.org/give/>
- Include a short note explaining your fundraiser.

Send a list of those who donated

- We would love to thank your donors ourselves and keep them in the loop about all the work their donation will support.
- Email the list, with names, addresses, and email addresses if available, to info@curechm.org.

Send some photos from the event

- Email the best 3-5 photos from your event to info@curechm.org.

Say thank you!

- Sending thank you letters, notes, emails, or making a phone call, to everyone who participated in or supported your event shows your appreciation and reinforces their goodwill in supporting CRF.

Start thinking of your next fundraiser

- The best time to think of a new idea is right after the event or fundraiser.

8. Frequently Asked Questions –

Can I use the Choroideremia Research Foundation's tax exemption number?

Because the Choroideremia Research Foundation is not hosting your event, it is considered a third-party event. For this reason, you will not be able to use the Foundation's IRS 501(c)(3) charitable classification, federal tax ID number or tax-exempt certificate. However, you may use the tax ID number for donation purposes only. Please email info@curechm.org.

Can you help me get a permit for my event?

The organization and execution of the event is the responsibility of its event organizer. You must obtain all necessary permits, insurance and licenses. Please note, if your event involves the serving or sales of alcohol, gambling, or a prize raffle, a special license may be required.

Who will provide insurance for my event?

CRF cannot provide insurance for third-party events. The event organizer is responsible for obtaining insurance for the event, if needed. Many insurance companies offer event-specific coverage. For example, check out www.theeventhelper.com

What can I give people who made donations for tax purposes?

If you provide the name and address, or email address, for donors or sponsors, the Choroideremia Research Foundation will send them a personal thank you from the Foundation, which will serve as a receipt for their donation.

Can someone from CRF attend or help me plan our event?

We are happy to provide guidance for your event, and depending on the location, our members will be there to support!

9. Fundraising Guidelines – and “To NOT-Do list” –

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

Organizer Responsibilities

- All expenses are the responsibility of the event organizer. CRF is not responsible for any expenses incurred for a third-party fundraising activity and will not advance funds or reimburse expenses. We recommend finding event sponsors or charging a registration fee to help cover expenses. Please contact Kathi Wagner, Executive Director, at 800-210-0233 or kathiwagner@curechm.org for tips and ideas on charging a registration fee to support your event. You may not purchase goods or services under CRF’s name, and CRF’s sales tax-exemption (on purchase) 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, CRF 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 CRF, its directors, officers, and employees from any and all claims that may arise out of or relate to such event.
- The event organizer is responsible for obtaining all applicable permits or licenses, including, but not limited to, alcohol, gambling, raffles, solicitation, and sales tax licenses.

Promotion and Publicity

- All third-party events must be publicized and conducted in a manner that makes it clear that CRF 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 CRF (e.g. “proceeds benefit Choroideremia Research Foundation”)
- All event materials that include CRF’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.

Financial Policies

- The event organizer may not keep any portion of the proceeds (beyond real expenses) as profit or compensation.
- The event organizer may not set up a temporary bank account in CRF’s name, as this is illegal.
- 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 CRF.

MOST IMPORTANTLY – THANK YOU!

HAVE FUN WITH THIS!

WE ARE HERE TO HELP!