



Fundraising Guidelines

Families United for a Cure

Some families and friends run for a cure while other sell cookbooks, hold bake sales, golf tournaments, dinners or ski-a-thons. These events take place in rural communities and in large metropolitan centers. Some involve small numbers of people while others involve hundreds and maybe even thousands.

It all just proves that there are many ways to raise money for cystinosis research and join in the quest for a cure. The CRF is here to help you with the tools and assistance to organize your fundraising efforts.

If you decide to fundraise on behalf of CRF you will need to contact us as soon as possible so that we are aware of your efforts and can support your event. If you would like to use the CRF logo, please email Zoe Solsby at zsolsby@cystinosisresearch.org.

Please ask questions and remember we are here to assist and hopefully alleviate your concerns, we are united in our effort to find a cure!

As your partner, here is what CRF can provide, at no expense to you to help get you started:

- Cystinosis Research Foundation IRS 501(c)3 non-profit designation letter.
- Design a logo for your organization or event, and create an event flyer.
- Set up an online family and donation webpage with your logo and event information.
- Provide the CRF cystinosis brochure with you or your child's photo on the cover to distribute at your event.
- Provide a CRF partner support letter for your event and templates of thank you letters, solicitation and sponsor letters.
- Promote and advertise your event in our Cystinosis Magazine, our social media sites, and monthly Star Facts e-newsletter.
- Provide the most recent CRF video to show at your event.

And here is what you will need to be thinking about:

Fundraising Guidelines

Families United for a Cure (CONTINUED)

- Select a committee of family and friends to assist in your planning and organizing your event.
- Choose an event theme, time and venue. Because we are a non-profit some venues will provide a discount.
- Make every attempt to put together an event budget of estimated expenses and expected revenue. The goal is to keep expenses around 25% of your total revenue. Setting an event goal actually will help make it become a reality!
- Approach your neighborhood vendors, restaurants, beauty spas, tennis and golf clubs etc., to solicit gifts in kind and/or sponsors to help underwrite your event. People give to people so tell your story and the community will gather around you!
- Coordinate with individual vendors who might provide unique items for your silent or live auction.
- Send invitations, and then track the RSVP's. The CRF webpage can be set up to sell tickets online. We will provide a web link for your invitations and flyers. We recommend you provide name tags so people begin to know one another.

The CRF recognizes hosting an event incurs costs and because you are raising funds for cystinosis research, you shouldn't have to bear the burden of all those expenses. We will reimburse you for up to 25% of the funds raised. For instance, if your event raises \$10,000 and the expenses are \$2,500 (25%), the CRF will reimburse you for those receipted and documented expenses. One-hundred percent of the **gross** amount, \$10,000 will go directly to cystinosis research, as 100% of the CRF expenses are underwritten.

As the donations are received, we will maintain a detailed donor list with name, contact information and donation amount and provide a weekly update so that you may write your personal thank you letters.