



Fanconi Anemia
RESEARCH FUND, INC.

FUNDRAISING

FOR

FA RESEARCH

Reach for a cure...



Fanconi Anemia

RESEARCH FUND, INC.

Thank you so much for raising funds for research into Fanconi anemia! Since the Fanconi Anemia Research Fund's inception in 1989, donations have funded research into this deadly disease that has brought rapid progress including the discovery of almost all of the FA genes, and the development of new or improved treatments that now buy precious time for FA patients as we search for a cure. Your help is truly making a difference!

The following guidelines should be helpful to you in your fundraising efforts:

Notify the Fund: Please contact us well in advance of your fundraising event or letter to let us know and/or to solicit our help with it. We can list your event on our website's Calendar of Fundraising Events. You can call the Fund toll-free at 1-888-FANCONI.

IRS Status of the Fanconi Anemia Research Fund: The Fund is a 501(c)(3) not-for-profit organization. Donations to the Fund are tax deductible.

Stewardship of the Fund: The Fund strives to keep its fundraising and administrative costs low. Our independent audit for 2008 documents that our combined fundraising and administrative expense was **6.91%**.

Use of the Fund's logo: Please use our logo only after you have contacted the Fund for approval.

Receiving checks: Donation checks should be written to the Fanconi Anemia Research Fund. In order for a donor to receive a tax deduction, the check must be written to the Fund or endorsed over to the Fund. Please send donation checks to the Fund as soon as possible.

Receiving cash: If a donor gives you cash, please use the attached form to note the donor's name, address, and the amount of the donation. Please send the cash with the completed donation form to the Fund as soon as possible.

Thank you and tax receipt letter: When a donation is received, we will send a letter of thanks from the Fund that may be used as a tax receipt. We will notify you of donations made in your name on a weekly basis.

Fundraising Letter

Write a letter to your family, friends, and acquaintances asking for a donation to the Fanconi Anemia Research Fund. Many letter writers have increased their fundraising dramatically by asking their recipients to forward or write their own solicitation letter to *their* friends. Consider also printing extra letters to carry with you to hand out to new acquaintances or those not on your mailing list.

We have samples of letters that we would be happy to share with you.

The Fund can help with a fundraising letter by:

- editing your fundraising letter
- inserting a photo of your child or family in the letter
- photocopying it
- providing the postage
- mailing it from our office, using your mailing list
- sending a thank you and tax receipt letter to all who donated through your letter
- notifying you of the donors who donated to the Fund

You might consider sending your letter by email. You can personalize your email letter with photos, and creative fonts and borders. In addition to saving the costs of printing and postage, a benefit of an emailed fundraising letter is the ability to link to the Fund's "Donate" webpage, making it easy for your donors to donate online. Some FA families have found that their email letters are forwarded by their contacts, thereby expanding the scope of your message and increasing your fundraising ability.

Fundraising Event

Fundraising events include car washes, dinners, auctions, walk/runs: the list is endless!

The Fund can help with a fundraising event by:

- editing your invitation to the event
- photocopying
- providing postage
- mailing it from our office, using your mailing list
- printing FA brochures personalized with a photo of your child or family
- providing a tabletop display board about FA
- sending a thank you and tax receipt letter to the donors
- notifying you of those who donated via your event

The following steps will assist your event planning:

Attendee List: If you charge admission for the event, please provide a written list of the attendees. According to the IRS, donors can receive a tax deduction only on the portion of their donation for which they did not receive something in return. For example, if the admission is \$50, and they receive a dinner valued at \$10, their tax receipt will be for \$40.

Insurance: The Fund asks those who hold events to make certain that the event is covered by liability insurance. Insurance for a one-time event is often available through a family's homeowner's insurance provider as relatively inexpensive "special event" insurance. Please contact the Fund if you need assistance obtaining or paying for this required insurance.

Reimbursement of Expenses: The Fund is happy to reimburse an FA family for an expenditure associated with holding an event. In general, our policy is to keep expenses below 10% of the anticipated proceeds of the event. If you need reimbursement for expenses, please contact us as soon as possible for approval of the expenditure. A receipt is required for reimbursement.

Fundraising Committees: A fundraising committee or helpers will often assist with an event. While these folks may not donate directly to the Fund, we realize they are indispensable to fundraising success. If you supply us with their names and addresses, we are happy to send a letter of thanks.

In-kind or Auction Item Donation Form: A donation of an item or service is considered an "in-kind" donation. So we may thank donors for in-kind donations, please contact our office.

Credit Card/Cash Donation Form: If a donor uses a credit card or cash, please contact our office for the appropriate form on which to record the donation. Note that we only accept VISA and MasterCard.

Overcoming Fundraising Doubts

During a recent fundraising session at the annual FA Family Meeting at Camp Sunshine, Lynn and Dave Frohnmayer, founders of the Fanconi Anemia Research Fund, addressed the following common anxieties about fundraising.

I am a private person. I don't want the whole community to know we have this devastating illness in our family. I don't want others to feel sorry for us.

- Others may already sense or know something is wrong; they just don't know what it is!
- You receive emotional and social support from others that will surprise and hearten you when you engage in fundraising efforts.
- You don't want to realize some day that you haven't done everything you could to make a difference. Research funding might make that difference.
- FA is an extremely rare disease. If those most affected don't lead the effort, who will?

Having this illness is already hard enough on my child. I don't want people to treat him or her differently.

- Ask your child's permission, telling him or her why you would like to fundraise. With your child's consent, proceed with your fundraising in an upbeat, encouraged manner.
- Your child may already feel different. Fundraising can be a way to give him or her a sense of power and control. Your family, including your FA child, will feel part of the solution.
- Don't underestimate the reservoir of support that comes when people understand what affects your child.

Like many people, I am proud or shy and don't like to ask for help.

- That is probably true of most of us, but do these emotions outweigh the good we can do?
- Consider that you may be depriving people—including family and friends—who want to help of the opportunity.
- Some of our Fund's largest and most loyal contributors are people we didn't even originally know, showing us that there are many people who genuinely want to help others.
- It really does get easier to ask with experience, and the outcome justifies the exertion.

I'm not a born fundraiser, and I don't know how to raise money.

- A letter writing campaign is often an easy way to start fundraising. The Fund can provide sample letters that have proven appeal. All you need are names and addresses of friends and relatives from your holiday mailing list, and any clubs, groups, religious organizations or other support sources you may have. The Fund can help edit and personalize your letter, add a photo if you wish, and mail the letter using your mailing list. After donations are received in response to your letter, the Fund mails a thank you letter and tax receipt to your donors, and provides you with a list of your donors.
- When you do write for help, don't bury it in a holiday letter full of other news. Make it clear what you are asking people to do.
- Your friends, local social and community groups, even your child's school are always eager to help and often have wonderful inventive ideas.
- Believe that people are flattered to be asked to help. It's true.

I don't know any wealthy people, I can't raise as much as some people, so I won't do it.

- This is just wrong. Foundations we ask to help us very often look to the breadth and depth of our donor base. The larger the number of donors—of any amount—the better we look when we ask.
- People who are billionaires and celebrities already contribute to the Fund. They want to know what we are doing for ourselves.
- It's simply true that every dollar counts! And the Fund spends our dollars wisely.
- No matter how much, or little, you raise, fundraising for FA research allows you to be part of the solution. You are rewarded with the knowledge that you did as much as you could.

I'm feeling tired and overwhelmed. I just don't have the energy to do more.

- Anyone dealing with FA feels this way, at least at times. But working to combat this disease gives a sense of rejuvenation. We feel less the victim if we are fighting back. Fundraising can actually alleviate depression, and gives us more energy to cope with our lives.

I'm secretly afraid of personal rejection. What if I ask and no one gives?

- It's true that even some close friends and relatives may not always be generous, but don't take this personally. Some people are simply more altruistic than others. Complete strangers may leap at the chance to help.
- Don't be disheartened if there's a less than hoped-for initial response. Donors may want to give on their own philanthropic cycle; or they may need to consider the request for a long period. We have received very large donations from donors who didn't respond initially for two or three years.

I'm not sure the funds I raise will make a difference.

- Family fundraising has already made a huge difference. Complementation studies which have led directly to discovery of almost all of the FA genes were funded by FA families. Thirteen FA genes have been cloned, and each single discovery was funded in part by FARF.
- Research concerning the use of Fludarabine in FA transplants, which has dramatically improved transplant outcomes, was funded by FARF.
- The new edition of *Fanconi Anemia: Guidelines for Diagnosis and Management* was funded by FARF, as are our FA Family Newsletter and other publications, the annual FA Family Meetings, regional meetings, and the annual Scientific Symposia.
- Because of the Fund's education and outreach efforts, more physicians are aware of this disease. This should result in earlier diagnosis and better treatment of patients.
- Scientific discoveries, including the relationship between breast cancer genes and FA, have brought our rare orphan disease into the mainstream of modern scientific investigation. **Every dollar has counted!**