



Fundraising Made Simple Kit

**“Whatever you can do,
or dream you can do, begin it.”**

Johann Wolfgang Von Goethe

Friedreich's Ataxia Research Alliance

P.O. Box 1537

Springfield, VA 22151

Tel (484) 875-3015

Fax: (610) 363-1506

Email: info@cureFA.org

Web site: www.cureFA.org



~ THANK YOU ~ For Requesting this Information

We are so grateful that you are considering working to raise funds to accelerate research to find a treatment or a cure for Friedreich's Ataxia.

We hope this **FUNDRAISING MADE SIMPLE KIT** is helpful to you. It includes:

- ❖ a letter from FARA president, Ron Bartek
- ❖ inspirational letters from families who have raised money for research
- ❖ suggestions for types of fundraisers (just suggestions—plan whatever suits you)
- ❖ info on support FARA can offer you (let us know what you need)
- ❖ general suggestions for fundraisers
- ❖ FARA brochure that can be personalized for your event
- ❖ sample brochures from past events
- ❖ sample personal letter for letter writing campaign

We are here to help you and to help make your fundraiser a success. Feel free to contact us.

FARA's fundraising team

Sandy Lane
typesandy@aol.com

Marilyn Downing
mdown4@aol.com

Mary Caruso
meirbode@aol.com



Thanks also to Pamela Rasey and Vincent Guyaux of Embrase for their kindness and expert advice.



Dear FARA Friends,

Thank you for your interest in FARA – the Friedrich's Ataxia Research Alliance. FARA's mission is to slow, stop and reverse the damage done by Friedrich's ataxia -- a rare, hereditary, life-shortening, neurological disorder that is usually diagnosed in childhood and causes loss of coordination and strength in the arms and legs; impairment of vision, hearing and speech; scoliosis, diabetes; a life-threatening heart condition; full-time wheel-chair use by age twenty, and for which there is currently no treatment or cure.

FARA was founded in 1998 and, thanks to generous donors and the tireless fundraising efforts of Friedrich's ataxia families, FARA has raised and devoted more than seven million dollars to supporting the scientific research around the world that will lead to treatments and a cure. Thanks to that support and the growing number of gifted scientists applying their skills to this effort and working more and more closely together, exciting progress is being made at an ever-increasing rate. It is clear that, "in Friedrich's ataxia, we have entered the treatment era" and, in 2006 alone, at least four or five clinical trials of different drugs for Friedrich's ataxia will be conducted at key centers in the United States, Europe and Australia.

With your kind help, we are absolutely confident that we can push these clinical trials across the finish line to a successful conclusion – treatment and a cure. Your generosity will be certain to make a real difference – it will help provide hope and then health for Friedrich's ataxia families everywhere. Thank you very much.

Ron Bartek
FARA President

Friedreich's Ataxia Research Alliance
P.O. Box 1537
Springfield, VA 22151
Tel (484) 875-3015; Fax (610) 363-1506
Email: info@cureFA.org Web site: www.cureFA.org

~ TABLE OF CONTENTS ~

1.	Why Do Fundraising.....	5
1.1	Welcome to Holland	6
1.2	Importance of Continuous Funding	7
1.3	Getting Over the “Asking” Hurdle	8
1.4	What is a 501(c)(3) organization?.....	10
2.	Parent Experiences in Fundraising.....	11
2.1	Downing Letter	12
2.1	Lane Letter	13
2.2	Luebbe Letter	14
3.	Fundraising Ideas	16
3.1	General Suggestions for Successful Fundraising.....	17
3.2	Auctions	19
3.3	Bake Sale	20
3.4	Bingo.....	21
3.5	Bocce Ball.....	22
3.6	Bowlathons	23
3.7	Cake Walk.....	24
3.8	Charitable Performances.....	25
3.9	Fashion Show.....	26
3.10	Galas and Receptions.....	27
3.11	Garage Sales.....	28
3.12	Golf Tournament.....	29
3.13	Memorials or Tributes in Lieu of Gifts.....	30
3.14	Personal Letter-Writing Campaign.....	31
3.15	Progressive Auction	32
3.16	Restaurant Benefit Nights.....	33
3.17	Walkathons/Races.....	34
4.	Sample Documents	35
4.1.	FARA Brochure	36
4.2.	Campaign Letter.....	37
4.3.	5K Race Registration and Corporate Sponsor Form.....	39
4.4.	Wine Tasting Introduction Letter.....	43
4.5.	Profile Document to Include with Event	44
4.3	Quotes for Reference in Documents	45
4.4	Sample Timeline for Walk (May timeframe)	47
5.	FARA Support	49

1. Why Do Fundraising

1.1 Welcome to Holland

by Emily Perl Kingsley

I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this.....

When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guide books and make your wonderful plans. The Colosseum, Michelangelo's David, the gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around.... and you begin to notice that Holland has windmills....and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy... and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever, ever go away... because the loss of that dream is a very very significant loss.

But... if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things ... about Holland.

1.2 Importance of Continuous Funding

Limited Funding from National Organizations

Because Friedreich's Ataxia is such a rare, progressive, neuromuscular disease, the attention it gets from government health agencies to find a cure is limited. FARA board members seek support and funding from the NIH (National Institutes of Health) and other groups but we can not count solely on dedicated resources from others for cures.

There are other organizations that offer some financial support and clinical outreach to FA patients but they focus on a number of neurodegenerative diseases, of which FA is just one.

FARA Established to Focus on FA Cures

With the establishment of FARA, the organization has helped focus and coordinate worldwide research and knowledge of the disease while also offering a resource to parents and patients looking for answers and cure advancements. The organization has a truly vested interest in cures because it is led primarily by patient families.

To continue such focused research efforts, yearly funding is needed. FARA injects thousands and millions (when possible) into research grants and lab testing in support of finding treatments.

How You Can Make a Difference

- Start small with one-off type of events like bake sales, spaghetti dinners, pancake breakfasts, garage sales or a letter-writing campaign
- Or, plan annual fundraising events like a 5K race or wine tasting or carnival that continue to draw more and more people each year with awareness
- All FARA fundraising proceeds go directly to research!
- Starting is the hardest part – once you decide on planning an event, the rest falls in place

Money Raised = Research = A Cure = Longer, Happier Lives for FAers!

1.3 Getting Over the “Asking” Hurdle

Fundraising is a process - a journey. Like any journey, it begins with a plan.

1. Remember why you are considering fundraising

Either someone in your family or someone close to you has been diagnosed with Friedreich’s Ataxia. You are motivated to make a difference and do something to try and find a cure. You are not alone and the more people that join the battle, the faster a cure will come.

2. Set a goal

You’ll be surprised how much you can raise and how quickly you can do it when you put your mind to it. Part of what fundraising is about is doing something bold, something beyond the limits of everyday life. Think about what amount would be a big challenge for you. And once you reach that goal, set another one. As you talk to more and more people about Friedreich’s Ataxia, you are already accomplishing one important goal – educating people about FA. You are letting people know that it’s OK to talk about it.

3. List potential donors

Start simple. Write out a list of everyone you know: relatives, friends, neighbors, co-workers, classmates, your doctor, dry cleaner, babysitter, auto mechanic, boss, the guy behind the counter at your local coffee shop, the woman ringing up your groceries, the librarian checking out your books. Each contact you have during the course of the day is a potential conversation you can have about your fundraiser. Don’t be afraid to talk about it.

4. Ask for your first donation today

You may be reluctant to talk about Friedreich’s ataxia or that it is now something you must deal with in life. That is part of what this journey is about - coming out of your comfort zone and sharing your story. Through your fundraising experience, you are letting people know that it’s OK to talk about your situation. Wearing a FARA T-shirt, hat or wristband can also help open the door to a conversation.

To jump-start your fundraising efforts ask for your first donation today. In person, over the phone, in an email, however you can - just take the leap and ask. The sooner you get started, the easier the fundraising process will be and the rewards and outpouring of support you will feel help drive you to ask for the next donation or sponsorship.

The golden rule of fundraising is: You raise money when you ask for it. You can’t raise money when you don’t ask for it. It sounds simple, but think about it. If you ask someone for \$50, you might get \$50, or you could get less. But if you ask someone for \$10, you might get \$10, but you probably won’t get any more than that. You don’t lose anything if someone says “no” to your request, or gives less than you ask for. But you are losing out on a potential donation if you don’t ask in the first place, or don’t ask for very much.

5. Ask a friend or family member

By forming a team with your friends and family, you will be creating an instant support group. You'll soon realize that by participating with the ones you love, fundraising becomes easier, and the experience on the event becomes even more meaningful.

6. Write a fundraising letter

Compose a letter that describes what you are doing and why (sample letter is in the binder). Remember to personalize it as much as you can. Address each donor by name, and start out conversationally, as if it were any other friendly letter. Then talk about event or request and mention your personal reasons for doing it. Don't make the letter too long, but just long enough to inspire your donors.

7. Expand your circle

Every time someone agrees to make a donation (or even if they tell you they cannot make a donation), ask them if they will take an extra donation form and pass it on to someone else. Or ask them to forward your email to a friend. You can also expand your donor circle via the media.

8. Corporate Sponsors

Start locally with the people you know and the businesses you frequent. Tell them about your event and give them a few options for support (e.g. levels of giving or in-kind donations). It will help to have a printed letter or brochure about the event and how they can help. (Samples are included.)

9. Explore matching-gift opportunities

You can potentially double your donations with matching gifts. Many corporations will match any donations their employees either raise or give. Ask your employer and your donors if they or their corporation participate in a matching-gift program.

10. Follow up

Remember that list of donors you created? Make sure that you follow-up with anyone who has not donated. Oftentimes, people might be intending to donate and just need a gentle reminder. Let them know that every dollar counts and that there is still time to donate. Send them a note to keep them updated on your progress as you fundraise.

11. Thank your donors

Once you have received a donation from someone, let them know that their contribution - whatever the amount - is important to you and that you appreciate it. Send them a thank you note or invite them to the next event. After the event, you may want to send out a newsletter or email with some photos and an additional "thank you" for your donors' support.

12. Other ideas

- Issue a Press Release or news clip to local newspapers and media groups (free press release submissions on www.prweb.com)
- Create a web site or page to promote your event
- Contact local TV or radio stations for free promotion
- Have your event posted on the FARA website

1.4 What is a 501(c)(3) organization?

FARA is a 501(c)(3) organization

When you start off fundraising, many people will ask if their donation is “tax deductible”. You don’t need to become a tax expert to answer the question but it is good to have basic knowledge.

1. What counts as a charitable organization?

A charitable organization is generally defined as any nonprofit organization that is incorporated and identified by the IRS as a 501(c)(3) organization. These organizations have been given tax-exempt status and can accept contributions.

2. What does it mean to be a 501(c)(3) organization?

For charities, this means that they can accept contributions and offer donors a tax deduction for their gifts. For donors, this means contributions are fully tax-deductible to the amount allowed by law.

3. Do I need a receipt for donations I make?

The IRS requires documentation such as cancelled checks, credit card receipts etc. for donations under \$250, so you should keep this information for your records. Contributions of \$250 and over require an acknowledgement from FARA.

4. Do I need any acknowledgement for donations under \$250?

Be sure to keep the canceled check, credit card statement, or email receipt from the organization to which you donate. Always note the donation amount, the date of the contribution, and the name of the charity. Cash contributions of any amount will be acknowledged from FARA, for your records.

5. Can I take a deduction for volunteering my time and services?

Volunteers cannot deduct the value of time or services to a charitable organization, but they can deduct any hard costs associated with that volunteering, such as the gas or bus fare it costs to get there. For example, if you volunteer in a charitable hospital and have to wear a uniform, you can deduct the cost of buying and cleaning the uniform. The IRS will let you deduct any out-of-pocket expenses you acquire in the course of volunteering.

2. Parent Experiences in Fundraising

2.1 Downing Letter



Friedreich's Ataxia Research Alliance
P.O. Box 1537
Springfield, VA 22151
Tel (484) 875-3015; Fax (610) 363 1506
Email: info@cureFA.org Web site: www.cureFA.org

Thank you for considering fundraising for Friedreich's ataxia research through the Friedreich's Ataxia Research Alliance. As parents of a child with Friedreich's, we are especially grateful to your family for offering your time and your expertise to help all those dealing with FA. Our daughter with FA, Bridget, who is in college at this point, has been an inspiration to us and her strength has pushed us forward to become pro-active.

Raising money for research was our family's panacea. It was the best thing we could actively do that would help us deal with our grief when we first heard the diagnosis. Our friends and family felt helpless also and were happy to be able to help in any way they could. We started with a letter to friends and family that we felt would want to help and over the next few years held five Walks. The work was therapy for all of us and the support we received was healing.

We are here to help you as needed with the details of your event. Feel free to call us with your ideas or your concerns.

Again, thank you for being motivated to raise money and awareness.

Gratefully,
Marilyn and Terry Downing (FARA Secretary and Treasurer)
Marilyn.downing@cureFA.org
tmdowning@roadrunner.com
716-626-0274

2.1 Lane Letter



Friedreich's Ataxia Research Alliance
P.O. Box 1537
Springfield, VA 22151
Tel (484) 875-3015; Fax (610) 363 1506
Email: info@cureFA.org Web site: www.cureFA.org

As a member of the FARA Board, I would first of all like to thank you for your decision in agreeing to participate in a fundraiser. As parents, we are a single link, but as a group of parents, we form a solid chain that can and will make a difference. Please know that you are making a difference in the lives of many individuals. For that, we all thank you.

There are many fundraisers that have been done in the quest for finding a cure. Some are a little more labor intensive than others. They all require time and dedication. You will find through your adventure that your work becomes its own reward, and becomes a joy. You will find great pleasure as the momentum amongst your family and friends picks up with the planning and preparations that are taking place. This is very satisfying knowing that there are others out there who want to help. There is nothing more gratifying in knowing that you, as well as those you love, are contributing in finding a cure for your child, as well as other children. You have chosen to step forward and make a difference.

On the flip side, I also ask that you not become discouraged in your quest. There may be friends or family who you thought would be there for you in your time of need, but for whatever reason, they have not come forward. While I understand how hurtful this can be, please try not to take it personal. Along those same lines, please try not to take it personally when some of your family and friends do not donate what you thought they would or should. Again, we all set goals in our minds of what we would like to achieve, and we don't attain those goals, it can be very hurtful. In your heart, know that you are truly doing the best you can, and you are definitely making a difference.

Please know that as a member of the board, I am here to help. Accept this letter as a thank you, as well as encouragement in your new venture. Give yourself a pat on the back for agreeing to make a difference. We thank you for your time and dedication.

Sandy Lane
typesandy@aol.com

2.2 Luebbe Letter



Friedreich's Ataxia Research Alliance
P.O. Box 1537
Springfield, VA 22151
Tel (484) 875-3015; Fax (610) 363 1506
Email: info@cureFA.org Web site: www.cureFA.org

First and foremost, thank you for requesting the FARA fundraising packet! You have made a big step and we're behind you all the way for any questions, worries and best of all celebrations after you accomplish your goal!

When asked to write a bit about our fundraising experiences, I felt so honored to share some of the things I have learned. The first thing that sticks out in my mind is the true generosity of people who become aware of what Friedreich's ataxia is and why it's so important to help our kids. There are those who have never met our family, but have heard about Evan's diagnosis through a friend and have opened up their hearts to us with a donation. Education is critical since FA is so unknown. For me, the fundraising was something that I felt compelled to do for Evan. We literally jumped right in with both feet and held two fundraisers in the first year, including a 5k walk at his elementary school and a dinner/wine tasting event in the fall. Looking in from the outside, someone might have said we were a bit nuts, but we had terrific success with both events! The feeling you have after writing that check to FARA is unbelievable.

It's difficult to put into words my passion for the fundraising, but upon Evan's diagnosis, I knew that in my heart I needed to do something. The first time you go to a business, friend or family to ask for money is difficult, but it gets easier each time and the reward is so worth it. Evan said that he is a celebrity now because he was on the news and in the newspaper. It gave him a lot of confidence, which was terrific considering the diagnosis was so new at the time. I had no prior experience with fundraising, but I did have a great group of friends who offered to help me with the planning. My group changes from event to event and sometimes it's very small and other times I have a larger group, but there are a few that are always there for me. Ron Bartek came to our dinner and spoke about the research that is taking place and had everyone in tears! It's a night that we won't soon forget. Our walk this year is scheduled for May 20th and we know it will be a great day!

The fundraising has helped me keep my focus to find a cure for FA and it gives me the ability to mentally cope with the disease on a day to day basis. Something that was said at the NAF conference while talking with some of the parents was the fact that together we can make such a difference. The great thing is that everyone doesn't have to plan events that take months to plan,

but each event no matter how big or small, will go toward our attainable goal of finding a cure. FARA has so many great ideas for fundraising in your community. I am always on the lookout for new ideas to raise money for our kids. Together we'll find a cure for Friedreich's ataxia!

Tammy, Greg, Evan & Graham Luebbe

Please feel free to contact me at 513-755-6396 or e-mail at tammyluebbe@aol.com

(Evan is 9 years old and was diagnosed with FA on Oct. 7, 2004. Graham has not been tested.)

3. Fundraising Ideas

3.1 General Suggestions for Successful Fundraising

General Suggestions for Successful Fundraising

The most successful events are often organized around an extremely supportive institution that provides the foundation from which to build -- a school, church, extended family, business, etc. Also, the more you can attract from your local business community in way of donations of money, sponsorship, tee shirts/caps, items that can be auctioned or used as prizes, etc., the more successful you can be. Consider getting a local politician involved as official chairperson for the event. You may have better luck getting publicity!

1. Choose your event. Decide which type is best for you, based on your resources, time frame and fund-raising goals. Look through our suggestions offered here come up with an entirely new idea.
2. Set up a Committee to help you. Choose your committee members wisely. You may need:
 - Bookkeeper to document all checks, expenses, to be in regular contact with FARA, to send thank you notes as necessary. FARA will send tax letters to all those that donate \$250+
 - Volunteer chairperson to recruit and organize volunteers for the day of your event
 - Publicity chairperson who will contact radio and TV stations, newspapers and will be willing to hang signs and get brochures out to the public
 - Printing chairperson to have brochures, signs, T-shirts etc. printed
 - Sponsorship chairperson to recruit corporate sponsors, to get auction items donated, to follow up with confirmation letters etc. You need someone in this position who can network and who isn't afraid to ASK
3. Create a timeline. What needs to be done to make this happen? Set a date. You may need as long as 10-12 months to plan your event.
4. Reserve a location.
5. Recruit your sponsors (e.g. corporations, restaurants).
6. Enlist volunteers for the day of the event from local high schools, your neighborhood, area youth groups, churches, etc.
7. Bookkeeping notes:
 - Please do not open a FARA bank account. This gets unwieldy for FARA when tax time rolls around. All checks can be made out to FARA and sent the Philadelphia office.

Friedreich's Ataxia Research Alliance
102 Pickering Way, Suite 200
Exton, PA 19341

- FARA can help you with the expenses (e.g. T-shirt costs) but remember to keep costs as low as possible. Most feel that overhead costs should be less than 10% of your profits. Please check with us about your expenses, so that we can tell you what is and is not covered. Keep all receipts.
8. As a nice gesture, you may want to thank all of your donors, perhaps with a one-time mailing of postcards once the event has concluded.

3.2 Auctions

Cost of running event: Low to Medium

Degree of difficulty: Low to Medium

Keys to success:

- Many people combine an auction with a dance or dinner. However, having an auction on its own is fine. The core of the work lies in getting items donated. Your committee will need a good six months to do a thorough job canvassing for donations.
- You will want to find a good location that will hold the appropriate number of people you would like to attend. Local halls, church halls banquet facilities are great!
- Restaurants, weekends away and theater tickets are hot items.
- One person suggested starting by writing to as many inns/hotels in the area as you can.
- Basket theme ideas:
 - Wine
 - Date Basket (movie, dinner, rental gift certificates, etc.)
 - Kids (Barbie, sports, toys, etc.)
 - Scrap booking
 - Tool basket (don't forget the men!)
 - Chefs who come into your home!
 - Sports packages
 - Theater or symphony tickets
 - Photography
 - Golf
 - Music
 - Art (paintings, sculptures or others)
 - Tickets to sporting events (professional and/or college football, basketball, etc.)
 - Any celebrity items
 - Spa
 - Jewelry
- Use your imagination... one mother of a child with FA made apple pie that brought in \$200.00. This same mother also auctioned off a dinner date with one of her teenagers! The first year that brought in \$300.00 and last year it brought in \$400.00. People really have fun with these ideas.
- Be sure after soliciting that you follow up with phone calls and also send thank you notes following the event.

3.3 Bake Sale

Cost of running event: Low

Degree of difficulty: Low

Keys to success:

A bake sale can be held by itself or along with another event, such as an auction or a walk.
“Wherever there is food, there are happy people.”

- Arrange for volunteers to donate a variety of baked goods.
- Consider having a theme, especially if your bake sale is connected to an event days such as cookie day, cake day, brownie day etc.
- Advertise well in advance with posters, memos and emails.
- Sell baked goods in a busy location in your community or alongside a well attended community, church or school event.
- Consider selling recipes or a cookbook for a low price to raise additional funds.
- Recruit volunteers to help set up, sell and clean up afterwards.

3.4 Bingo

Cost of running event: Low

Degree of difficulty: Low

Keys to success:

Bingo can be held alongside another event, such as a bake sale or auction. It may draw more people and really can be a lot of fun.

- Arrange for the rental of bingo supplies such as slide cards and electronic ball machine.
- Arrange for a location to hold the event and advertise.
- Ask local businesses to donate prizes.
- Arrange for volunteers to be card checkers, callers and to award prizes.
- Local movie theatres often give leftover popcorn for fundraising events – sell bags of popcorn at the event.
- Check local laws to be certain that bingo is allowed in your locale.

3.5 Bocce Ball

Cost of running event: Low

Degree of difficulty: Low

Keys to success:

- Arrange to borrow a set of bocce balls (or several).
- Arrange for a location to hold the event (large grassy area).
- Ensure each team has a copy of the rules of the game (or make up your own rules!).
- There are 4 people on a team, and different divisions participate against each other in the tournament (initial game, semi-finals and finals).
- Teams are charged an entry fee.
- Individuals sign up as ‘sponsors’ and pay a fee to sponsor their favorite team.
- Arrange for volunteer ‘officials’ to oversee the games.
- Ask a local celebrity to throw the first ball at the first game.
- Award prizes to the winning team (a trophy or medals are good prizes).

Note: A horseshoe tournament could be done in the same way.

3.6 Bowlathons

Cost of running event: Low

Degree of difficulty: Low

Keys to success:

- This event is lots of fun. Local bowling allies are very cooperative. They often provide a large number of lanes for your participants.
- The bowling alley can also provide special rooms where you can combine the bowling with other activities such as: awarding of prizes of all type, eating, a bake sale, conducting an auction or raffle (you can solicit prizes from local businesses and individuals).
- Try to get prizes or trophies donated.

3.7 Cake Walk

Cost of running event: Low

Degree of difficulty: Low

Keys to success:

This old fashioned event is fun and quite easy to do. This would typically be done in conjunction with another event, such as an auction. Children especially love cake walks. This is a good school event.

- Organize a volunteer group and find volunteers to bake cakes or ask a local bakery or grocer to assist with donations.
- Include the cake walk on your publicity for a larger event.
- Put a picture of a cake on paper and photocopy it as many times as you feel is appropriate (e.g. twenty).
- Number the copies 1-20 and tape the 'paper cakes' on the floor in a circle.
- Put slips with numbers 1-20 into a basket.
- Charge admission to enter the cake walk. Each 'paper cake' must have a person standing next to it before you begin.
- Play music while the people walk around the circle of 'paper cakes'. When you stop the music each person will be standing next to a numbered 'paper cake'. Draw a number from the basket and whoever is standing next to that number picks a cake from all those donated.
- Clear the entrants and begin again until all cakes are gone.

3.8 Charitable Performances

Cost of running event: Medium

Degree of difficulty: Very high

Keys to success:

- If you have a talented group, you may want to consider a concert, play or even a musical.
- A family in North Carolina has held musical productions with proceeds going to FARA over the past few years. They have been quite time consuming but have been *very* well supported.
- Location is important. It is critical to get a church or civic group behind you with production such as this and consider practice time.
- Including a local celebrity will help to draw an audience.

3.9 Fashion Show

Cost of running event: Low to Medium

Degree of difficulty: Low to High

Keys to success:

- If you have a willing boutique in your area, they can be a great help! Approach them and ask about doing a fashion show. It may be easier to work with one store whose owner may want to handle many of the specifics.
- You can go to one store or up to three stores. This helps determine the degree of difficulty and can vary the types of clothing seen at a show – permitted they all agree to work together cooperatively for the cause.
- Your committee may be handling the raffle, music, decorations, refreshments, emcee and ticket sales.
- Children's and/or women's clothing are typically the most popular.
- Best times of the year would be around holidays or spring season.
- Getting local people (e.g. politicians, school faculty members) to model clothes is a plus!
- Determine your location.
- Plan 3 months in advance.
- Ask for donations to do a raffle.

3.10 Galas and Receptions

Cost of running event: High

Degree of difficulty: High

Keys to success:

- A gala dinner, dinner/dance or a cocktail reception can raise a great deal of money for research at a single event.
- Recruiting and enlisting the help of local celebrities to host the event will draw new people to the cause of accelerating this research.
- There are two very ambitious groups that organize such an event each year, one in Connecticut and one in Northern California.
- Dinner/dances are work-intensive since they include feeding a large group of people, organizing the music and perhaps even an auction.
- It is important to consider the costs involved and to secure donors for as many of the costs as possible.
- Of course, you can combine other approaches, such as an auction, with a gala or reception.

3.11 Garage Sales

Cost of running event: Low

Degree of difficulty: Low

Keys to success:

- It's easy! Go through all of your stuff! Tag it and put it out! A bake sale works well with a garage sale.
- Enlist the help of family, friends, and neighbors; make it a team effort in which everyone plays a part and is invested in its success.
- Put an ad in your local papers requesting donations of items for the sale; make it clear that all proceeds go to charity and that all donations of sales items are tax deductible.
- Offer to pick up donated items; provide information about Friedreich's ataxia before and at the sale.
- Consider establishing your community yard sale as an annual event to which people will look forward. The more the merrier!
- Have your kids get involved by selling those old clothes or toys they no longer use. Ask if they want to have a lemonade or bake sale along with your tag sale.

An elementary-aged student from New Jersey with Friedreich's ataxia held a community yard sale. In addition to having fun, he raised money to support FARA research.

3.12 Golf Tournament

Cost of running event: High

Degree of difficulty: High

Keys to success:

- Golf tournaments are often well attended but are very work intensive.
- The cost for dinner and golf is usually quite high and so your profits often come from an auction that might accompany the tournament. It is rare to get a golf club to donate to a charity, as they are approached by a variety of charities and the cost to them is high.
- You will need people on your committee who know the game well.
- Try to get prizes and auction items donated.

3.13 Memorials or Tributes in Lieu of Gifts

Cost of running event: No cost

Degree of difficulty: Low

Keys to success:

- This type of contribution enables you to support research while remembering a special family member, friend, colleague, or special occasion such as a wedding, birthday, First Communion, graduation or holiday.
- Memorials can also be established in the event of a death. An acknowledgement card is sent from FARA to the person you are honoring or to the family of the deceased.
- One young girl in California, in lieu of accepting birthday gifts, asked for donations in honor of her friend who has Friedreich's ataxia.

3.14 Personal Letter-Writing Campaign

Cost of running event: low

Degree of difficulty: low

Keys to success:

- Time to draft a letter and make edits (sample campaign letter is included in Fundraising Binder).
- Paper
- Stamps (FARA can help with postage unless one of your donors offers to cover the expense.)
- Because FARA is a 501(c)3 organization, be sure to include that all donations are fully tax deductible.
- Thank you follow-up notes or postcards

This is the easiest way to raise funds and can be extremely successful. You may want to start with a letter writing campaign and then weigh the success of that venture before beginning a larger fundraising event. This enables you to inform people — family, friends, colleagues, etc. — of the disease, and helps you put into writing some of your feelings about it. You may want to include quotes from our researchers (included in the binder), so that your donors can appreciate how their hard earned money is to be used.

With a personal letter writing campaign, you will want to consider distribution to friends, family members, high school and college classmates and church, club and work associates. As the responses come in, it is so encouraging to see how many people are willing to help.

Potential profit varies but you can look for about a 30% response to your letters.

3.15 Progressive Auction

Cost of running event: Low

Degree of difficulty: Low

Keys to success:

- This is another really easy fundraiser. You are basically inviting people to come to an auction and ask them to bring along a new item to be auctioned off. Remember, you can solicit prizes from local businesses and individuals that may or may not be in attendance.
- You will need a space for the function (e.g. Church hall, local hall, school gym or cafeteria).
- You can keep this as casual or as formal as you would like. One FA family did their auction with homemade desserts. A few girlfriends got together and baked one night.
- You can get a professional auctioneer (hopefully one who would donate their time) or have a friend who is funny and loud!
- Each person comes and puts their item on a table for all to see. Then one by one you auction the items off.
- It really is a lot of fun!

3.16 Restaurant Benefit Nights

Cost of running event: Low

Degree of difficulty: Low to Medium

Keys to success:

- You might suggest one night a month on which a designated restaurant donates a small percentage (maybe 5%) of its sales to FARA. Or, try one night and see how it goes.
- If the managers agree, you would get to invite all your friends to join you that evening!
 - Reminder: Typically, the restaurant's donation is tax-deductible.
- If you invite enough friends, the restaurant can make more money than usual and in addition, collect more money for research. A true win-win.

3.17 Walkathons/Races

Cost of running event: Medium to High

Degree of difficulty: Medium to High

Keys to success:

- This type of event can be as involved or as basic as you like. Again, the creation of your committee may be the most important aspect of your planning.
- You may want to establish chair-people on your committee to handle various phases of the event, so that you are not doing all the work yourself. You need to talk to local police about your route, need to reserve a location, decide on prizes, solicit sponsors, establish contacts for publicity, find food donors, arrange for music or some type of entertainment, rent tables and chairs, design and print brochures etc.
- Adding a silent and/or live auction to your day or basket raffle makes it more interesting for your participants, who then feel they have a chance to take something home with them. It also keeps people in the vicinity after the actual Walk has ended and allows those not walking to have some level of participation.
- Adding other activities like magicians, carnival-type games, face painting, fire truck rides, concession stands, moon walk, bake sale, etc. can help attract not just walkers and runners but entire family – such an event becomes a “family fun day.”
- Including a local celebrity may help to increase the level of awareness in your community.
- Your event becomes more complex when you move from a simple Walk to planning a Race (ex. 5K or 10K race), as you are then incorporating your community’s streets as your path, rather than just using sidewalks. Typically, you will want to give race numbers and to keep the time of your runners. A race does, however, tend to draw more people who are running competitively and are not necessarily aware of your cause, so your attendance numbers may be greater.
- In addition to getting donations for food and other race-day items, be sure to approach any and all businesses for larger corporate sponsorships of the event. This money can help off-set some of the race preparation costs and provide a solid base of money from which to build the total fundraising amount. Makes a BIG difference.
- See the sample Timeline for Walk sheet for more planning structure.

4. Sample Documents

4.1. FARA Brochure

FARA Progress

Funding over \$10M in Scientific Research

- \$5M in Research Grants
- \$4.5M in Biotech Research and Drug Development
- \$500K in supporting network of clinics
- Three International Friedrich's Ataxia Scientific Conferences

Supporting Advances In Key Areas

- Friedrich's ataxia gene expression
- Frataxin protein production
- Improving mitochondrial function
- Iron regulation

Facilitating Clinical Trials

- Potential therapies are entering clinical trials.
- Research for FA will have an impact on many other neurodegenerative, neuromuscular and mitochondrial related diseases like ALS, Parkinson's, Huntington's, SMA, Alzheimer's, MELAS and many more.

FARA continues to need your help-
Acting alone there is little any of us can accomplish, whereas acting together there is little we can NOT accomplish.





Ways to Get Involved

FARA's research program would not be successful without the support of grassroots fundraising, individual and corporate donors and foundations.

As you look for ways to get involved, please consider FARA in your giving portfolio. With continued funding and support, we will find a cure!
www.cureFA.org

- Local Fundraisers
- Individual and Corporate Donations
- Stock Donations
- Planned Giving
- Corporate Matching Programs
- In-Kind Gifts
- Memorials
- And more...

For more information call
(484) 875-3015
 Email
info@cureFA.org



Friedrich's Ataxia Research Alliance

"Together, we will find a cure for Friedrich's ataxia."

Ron Bartek
 FARA President



FARA International Scientific Conference in 2006

Friedrich's Ataxia Research Alliance
 P.O. Box 1537
 Springfield, VA 22151
www.cureFA.org

Friedrich's Ataxia

Friedrich's ataxia (FA) is a debilitating, life-shortening, degenerative neuro-muscular disorder. About 1 in 50,000 people in the United States have Friedrich's ataxia. Onset of symptoms can vary from childhood to adulthood. Childhood onset of FA is usually between the ages of 5 and 15 and tends to be associated with a more rapid progression. Late onset FA (LOFA) can occur anytime during adulthood.



Sign and Symptoms

- Loss of coordination (ataxia) in the arms and legs
- Fatigue - energy deprivation and muscle loss
- Vision impairment, hearing loss, and slurred speech
- Aggressive scoliosis (curvature of the spine)
- Diabetes mellitus (insulin - dependent)
- Serious heart condition (enlarged heart - hypertrophic cardiomyopathy)

These symptoms are not present in all individuals with FA, for example diabetes occurs in about 10-20% of individuals with FA. The mental capabilities of people with Friedrich's ataxia remain completely intact. The progressive loss of coordination and muscle strength leads to motor incapacitation and the full-time use of a wheelchair. Most young people diagnosed with FA require mobility aids such as a cane, walker, or wheelchair by their teens or early 20s.

FARA's Mission

FARA, a 501(c)(3) organization, was founded in 1998 by a group of parents wanting to make a difference. FARA's mission is to marshal and focus the resources and relationships needed to cure FA by raising funds for research, promoting public awareness, and aligning scientists, patients, clinicians, government agencies, pharmaceutical companies and other organizations dedicated to curing FA and related diseases.

Drive Research Forward

- Promoting scientific biomedical research — basic, translational, and clinical — through research grants, workshops, and the collaborative exchange of information within the scientific community.

Educate and Increase Awareness

- Serving as a patient advocacy group to educate the public, elected representatives, and other government officials regarding Friedrich's ataxia and the importance of funding biomedical research.

Develop Partnerships for Success

- Working cooperatively with government entities, scientific investigators, healthcare providers and other advocacy groups worldwide that support scientific research aimed at treatments for this disorder.

Generate Funding to Accelerate Research

- Rallying patients, families, foundations, corporations and support groups together to raise funds for research to more rapidly reach our goal of a treatment or a cure for FA.

Making a Difference

- Learn more about Friedrich's ataxia and FARA www.cureFA.org and sign up for news email updates on our website.
- If you or your child is diagnosed with FA, go to www.cureFA.org/registry to enroll in the Patient Registry to qualify for upcoming clinical trials.
- Initiate and attend FARA fundraisers, cultivate corporate donors and encourage others to get involved.



Today there is no treatment or cure.



Friedrich's Ataxia Research Alliance

4.2. Campaign Letter



Friedreich's Ataxia Research Alliance
P.O. Box 1537
Springfield, VA 22151
Tel (484) 875-3015; Fax (703) 4134467
Email: info@cureFA.org Web site: www.cureFA.org

Date

Dear _____,

As you may already know, [our year-old son/daughter], was diagnosed with a rare neurodegenerative disorder named Friedreich's Ataxia (FRDA). FRDA is a life-shortening genetic disorder which afflicts about one in 40,000 people. Symptoms include impairment of vision, hearing and speech; scoliosis (curvature of the spine); diabetes; a serious heart condition; and loss of strength and coordination in the legs and arms. The onset of symptoms is usually in childhood.

Most patients need a wheelchair full-time by their 20s. This relentless disorder has already robbed [.....] of his ability to [ride a bike, rollerblade and write legibly]. Walking is becoming more and more difficult. Sadly, there are NO treatments or cures and average age at death is in early adulthood.

Words cannot describe the devastation we feel, but we are working hard to find solutions. The FRDA gene was found in 1996 by a team led by Dr. Massimo Pandolfo. That discovery has revolutionized the study of FRDA, leading to an extraordinarily rapid explosion of findings relevant to the disorder. There is real HOPE AND EXCITEMENT in the FRDA SCIENTIFIC COMMUNITY.

Redirecting our anguish towards efforts to accelerate research, we are raising funds for the Friedrich's Ataxia Research Alliance (FARA). The scientific projects FARA is nurturing right now, including clinical trials over the coming year, look so promising that there is a real possibility that the results will lead to treatments. Due to the relatively small population affected by this disease, however, funding through traditional sources has been limited. Because FARA is a 501(c)(3), tax-exempt organization, your contribution is fully tax-deductible.

We hope you will share our concern and will want to help. If you already support various charities, we ask that you consider adding one more to your list:

Friedreich's Ataxia Research Alliance (FARA), c/o your name, your street address, your city-state-zip

Part of our mission is to raise the level of awareness of Friedreich's ataxia, so please share this letter with those who might be sensitive to our plight. Although heartbroken by this disease, we are cautiously optimistic about the direction of research. With your help, we hope and pray that the research you support will hasten a breakthrough that will help [.....] and all patients and their families coping with this extremely rare, relentless disease.

Thank you for caring,

(Personally signed)

FARA is a 501(c)(3), tax-exempt organization and all contributions are fully tax-deductible. For further information about FARA, go to <http://www.FAResearchAlliance.org>

4.3. 5K Race Registration and Corporate Sponsor Form

Tri-Fold Race Registration Form (Front Side)

<div style="border: 1px solid black; padding: 5px; text-align: center; margin-bottom: 10px;">Registration Form</div> <p>Name _____</p> <p>Address _____</p> <p>City _____</p> <p>State _____ Zip _____</p> <p>Phone _____</p> <table style="width: 100%; border-collapse: collapse; margin-top: 10px;"> <tr> <td style="width: 30%;"></td> <td style="width: 35%; text-align: center;">Pre-Register by May 12, 2006</td> <td style="width: 35%; text-align: center;">Register Day of Walk</td> </tr> <tr> <td>Adult (14 & over)</td> <td style="text-align: center;">\$20</td> <td style="text-align: center;">\$25</td> </tr> <tr> <td>Child (13 & under)</td> <td style="text-align: center;">\$5</td> <td style="text-align: center;">\$5</td> </tr> </table> <p>Donations and pledges due day of walk, but can be sent with pre-registration. FARA accepts funds from corporate matching programs (check with your employer). 5.685% Federal Tax ID Number is 52-0122720. Registration fee is non-refundable.</p> <p>I am unable to attend the walk but please accept my donation of \$_____</p> <p>The first 300 pre-registered walkers will receive a T-shirt on the day of the walk. T-shirt sizes (check one):</p> <p>Child <input type="checkbox"/> M <input type="checkbox"/> L <input type="checkbox"/> XL Adult <input type="checkbox"/> M <input type="checkbox"/> L <input type="checkbox"/> XL</p> <p>Are you a Shawnee student? <input type="checkbox"/> Y <input type="checkbox"/> N Teacher's Name _____</p> <p>To pre-register, mail this form (or a photocopy) and make checks payable to FARA.</p> <p style="text-align: center;">FARA Race Friedrich's Ataxia Research Alliance Cincinnati Chapter 6457 Norroll Ct. Liberty Twp., OH 45044</p> <p>WAVIER: (MUST BE SIGNED) In consideration of being allowed to participate in the FARA Race for a Cure, I hereby personally assume all risks in connection with the Walk/Run for any harm, injury, or damage that may befall me while I am a participant in the Walk including all risks connected therewith, whether foreseeable or unforeseeable. I understand and agree that neither the Friedrich's Ataxia Research Alliance, their agents, nor any participating business, nor the municipalities through which the Walk may take place, and their directors, officers, agents, representatives, employees, predecessors, successors, and assigns (collectively "Released Parties") may be held liable or responsible in any way for an injury, death, or other damages to me or my family, heirs, or assigns that may occur as a result of the negligence of any party, including the Released Parties, whether passive or active. I HAVE FULLY INFORMED MYSELF OF THE CONTENTS OF THIS LIABILITY RELEASE AND EXPRESS ASSUMPTION OF RISK BY READING IT BEFORE I SIGNED IT ON BEHALF OF MYSELF AND MY HEIRS.</p> <p>Walker's signature _____</p> <p>Grandpa's Signature _____ (If participant under 18)</p>		Pre-Register by May 12, 2006	Register Day of Walk	Adult (14 & over)	\$20	\$25	Child (13 & under)	\$5	\$5	<div style="border: 1px solid black; padding: 5px; margin-bottom: 10px;">Family Fun Day</div>  <div style="border: 1px solid black; padding: 5px; margin-top: 10px;">Purchase FARA Bracelets</div> <p>A Reminder you Made a Difference FARA bracelets will be sold the day of the race for \$2.00 a piece. FARA has designed the bracelets as a reminder of the work that is being done to find a cure.</p> <p>Bracelets, hats and t-shirts will be sold at the FA information table during the event.</p> <p>Don't miss out!</p>  <p style="color: red; text-align: center;">See you at the Race!</p> <p>For Information Call: Tammy Luebke 513-755-6396</p>	 <p>Cincinnati's Race for a Cure for Friedrich's Ataxia 2nd Annual 5K Walk / Run & Family Carnival</p> <p style="color: red; font-weight: bold; font-size: 1.2em;">May 20, 2006</p> <p>Corporate Sponsors:</p> <div style="display: flex; flex-wrap: wrap; justify-content: space-around; text-align: center;"> <div style="width: 30%;">  </div> <div style="width: 30%;">  </div> <div style="width: 30%;">  </div> <div style="width: 30%;">  </div> <div style="width: 30%;">  </div> <div style="width: 30%;">  </div> <div style="width: 30%;">  </div> <div style="width: 30%;">  </div> <div style="width: 30%;">  </div> </div>
	Pre-Register by May 12, 2006	Register Day of Walk									
Adult (14 & over)	\$20	\$25									
Child (13 & under)	\$5	\$5									

Corporate Sponsor Document

2006 Race for a Cure
 Friedrich's Ataxia Fundraiser
 First Annual 5K Family Walk/Run



Goal:	Raise Awareness and Research Funds for Friedrich's Ataxia
Date:	May 20, 2006
Location:	Shawnee Elementary, 9394 Sterling Drive, Cincinnati, Ohio
Activities:	Walk/Run, Silent Sale Raffle, Refreshments, Entertainment

Request Your Support

We are requesting your sponsorship for this event, which will bring together participants of all ages from throughout the community to promote the adoption and fitness, while raising funds and awareness for Friedrich's Ataxia. Walkers and runners can raise money by asking friends, family, business associates and co-workers to sponsor them. Funds will also be raised through company sponsorship and corporate donations.

In addition, we are also seeking donations of goods to supplement to costs such as paper goods (napkins, plates, cups), water bottles, printing and signage, food, advertising in papers, on radio and television.

Anything you can do to help this worthy event would be greatly appreciated. We thank you in advance for your support. If you wish to mail in a donation or gift certificate, please send to the address listed below. Checks should be made to FARA. Should you have any questions, please contact Tammy Liebke at 513-755-6396 or e-mail at tammyliebke@aol.com.

Best Regards,

Tammy Liebke
 6457 Norfolk Ct.
 Liberty Twp., OH 45044

4 Levels of Corporate Sponsorship

<p>LEVEL 1 - Miracle Sponsors (\$2,500+) (Include 3 companies who donate gift certificates or items for the silent sale that equal this amount)</p> <ul style="list-style-type: none"> Company Logo on T-shirt Banners or signage may be displayed at the Fundraising event Corporate sponsors will be listed on the www.fara.com site Business cards and flyers are welcome for display Special recognition the day of the event Mention in all press and media releases 	<p>LEVEL 3 - Silver Sponsors (\$300 - \$1,000)</p> <ul style="list-style-type: none"> Banners or signage may be displayed at the Fundraising event Corporate sponsors will be listed on the www.fara.com site Business cards and flyers are welcome for display
<p>LEVEL 2 - Gold Sponsors (\$1,000 - \$2,500)</p> <ul style="list-style-type: none"> Banners or signage may be displayed at the Fundraising event Corporate sponsors will be listed on the www.fara.com site Business cards and flyers are welcome for display Mention in all press and media releases 	<p>LEVEL 4 - Bronze Sponsors (\$250 - under)</p> <ul style="list-style-type: none"> Business cards and flyers are welcome for display Recognition on the www.fara.com site

Tax Information

FARA (Friedrich's Ataxia Research Alliance) is a 501(c)(3) tax-exempt non-profit organization. 100% of FARA donations are dedicated to supporting research. FARA is recognized by the Internal Revenue Service (IRS) under US law as a non-profit, tax-exempt organization, dedicated to the pursuit of educational, scientific and research activities. FARA's IRS identification number is 52-2122720. A copy of FARA's letter from the IRS recognizing FARA's tax-exempt status will be provided upon request. You can read more about FARA at www.fara.com.

Corporate Sponsor Sample Letter

Date

Dear Business Owner:

We are preparing to kick off the _____ for Friedreich's Ataxia (FA). The event will take place on _____ at _____. We are the proud parents of _____ (age), who was diagnosed with Friedreich's Ataxia on _____. With the help of our wonderful friends and family, we hope to raise funds for critical research and foster awareness about this disease.

Friedreich's ataxia is a life-shortening, debilitating and rare genetic neurodegenerative disorder. Onset of symptoms usually occurs between the ages of 5 and 15. Symptoms include muscle weakness and loss of coordination in the arms and legs; impairment of vision, hearing and speech; aggressive scoliosis (curvature of the spine); diabetes, and a serious heart condition. Most patients need a wheelchair full-time by their late teens or early twenties. There is currently no treatment and no cure.

The Friedreich's Ataxia Research Alliance (FARA) was established in 1998 by a group of patient families and leading FA scientists. FARA is supporting research that will improve the quality and length of life for those diagnosed with Friedreich's ataxia and will lead to treatments that eliminate its symptoms. In 2007, FARA approved funding for over \$1 million for 17 grants, and our partner organizations funded an additional \$500,000 for these meritorious projects. The biggest challenge **facing our organization and our Friedreich's ataxia community is translating basic science discovery** into effective therapies in the most expedited and appropriate way possible. Your support can give us the resources to meet this challenge. Please see www.curefa.org for more information on FARA.

[Insert information re: fundraiser]

We are also seeking Corporate donations. **Checks can be made to:**
Friedreich's Ataxia Research Alliance or (FARA)
Mail to:

FARA is a 501 (c)(3) tax-exempt non-profit organization. **FARA's tax ID number is 52-2122720.** Donations are tax deductible.

You can contact me at _____ or by cell phone at _____. E-mail _____
Any donations are greatly appreciated and will help to find a cure for Friedreich's Ataxia! Thank you for your generous support!

Sincerely,

4.4. Wine Tasting Introduction Letter



Friedreich's Ataxia Fundraiser

EVENT: Wine Tasting, Silent Auction and Dinner
LOCATION: Beckett Ridge Country Club
DATE: October 14, 2005
TIME: 6:00 – 11:00 p.m.

Join Us in Finding a Cure

What is Friedreich's Ataxia?
 Friedreich's Ataxia is a rare, genetic, neurodegenerative, mid-sytem, life-shortening disorder with no known treatment or cure. In the United States, approximately one in 50,000 people have Friedreich's Ataxia and one in 100 are carriers. Onset of symptoms is usually occurs between the ages of five and fifteen.

What are the Symptoms?

- Muscle weakness and loss of coordination (ataxia) in the arms and legs
- Vision impairment, hearing loss and slurred speech
- Aggressive scoliosis (curvature of the spine)
- Diabetes, mellitus or carbohydrate intolerance
- Enlarged heart (hypertrophic cardiomyopathy), arrhythmias, heart condition

For most, progressive loss of muscle strength and control leads to motor incapacity and the use of a wheelchair. The mental capabilities of people coping with Friedreich's Ataxia, however, remain completely intact.

Who is FARA?
 Friedreich's Ataxia Research Alliance (FARA) is a national 501(c)(3), non-profit, charitable organization dedicated to accelerating the research leading to the therapeutic cure and elimination of Friedreich's Ataxia and related sporadic ataxias.
www.faresearchalliance.org

There is no known treatment or cure for this life-threatening disease.

Event Highlights

\$ 60.00 per person
 \$120.00 per couple




5595 Beckett Ridge Blvd
 West Chester, Ohio 45069

Wine Tasting and Silent Auction

- Wine tasting hosted by Tramonté & Sons
- Purchase your favorites that night
- Light appetizers served with tasting

Full Course Dinner at Beckett Ridge Country Club

- Catered by Absolutely 4 Food
- Chocolate dessert fountain
- Additional desserts available

KeyNote Speaker
 Ronald J. Bartek, FARA President, Co-Founder



Ron will speak about FA and how it affects those who are coping with this disease, the research being done around the world to find a cure and his own personal experience with FA in his family. A Q&A session will follow.

100% to Research!

FARA is a non-profit organization. 100% of proceeds go towards finding a cure. FARA's Federal Tax ID Number is 52-2122720.


Event Contact:
 Tammy Luebbe
 8915 Rambling Ridge Drive
 West Chester, Ohio 45069

Phone: 513-755-6396
Cell: 513-304-2137
Email: tammyluebbe@aol.com

*All donations are due by October 1, 2005.

4.5. Profile Document to Include with Event


2006 Race for a Cure Friedreich's Ataxia Fundraiser



Goal: Raise Awareness and Research Funds for Friedreich's Ataxia
Date: May 20, 2006 **Time:** 9:30 a.m.
Location: Shawnee Elementary, 9394 Sterling Drive, Cincinnati, Ohio
Activities: 5K Family Fun Walk/Run, Silent Sale Raffle, Refreshments

Cincy Families Fight FA

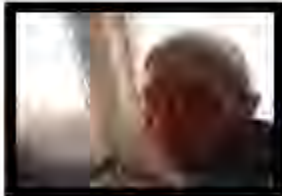
Evan Luebbe



Age: 9
School: Shawnee Elementary
Residence: Liberty Twp., OH
Parents: Greg & Tammy Luebbe
Siblings: Graham (6)

Biography: In October 2004, Evan was diagnosed with FA. He loves sports, especially playing basketball and golf and watching football. Evan is a Game Cube "master," loves reading books and learning new things like geography, poetry and any kind of trivia.


Jessica Jones



Age: 12
School: Pleasant Run Elementary
Residence: Cincinnati, OH
Parents: Michael & Michelle Jones
Siblings: Andrew (13), Sarah (9), Holly (7), Matthew (3)

Biography: In September 2004, Jessica was diagnosed with FA. Always happy and smiling, Jessica is active in her church, enjoys swimming and reading and her latest passion is attending MDA and Heart camps.

Brandon Emerson



Age: 13
School: Pleasant Run Middle School
Residence: Cincinnati, OH
Parents: Richard & Judy Emerson
Siblings: Bryan (10), Samantha (5)

Biography: In July 2000, Brandon was diagnosed with FA. He enjoys swimming, playing video games and hanging out with friends. He has a cat named Bandit and dog named Ritchie.

FARA (Friedreich's Ataxia Research Alliance) is a tax-exempt non-profit organization. 100% of FARA donations are dedicated to supporting research leading to a treatment or cure for this relentless and devastating disease. FARA was founded in September 1998 by parents of children diagnosed with Friedreich's Ataxia. With the generosity of donors, the tireless commitment of people conducting fundraisers, co-funding Seek-A-Miracle/MDA, FARA has been able to award research grants to the doctors who are working so hard to find a cure! With your help, we CAN make a difference for these children! www.faraonline.com/

4.3 Quotes for Reference in Documents

Quotes from our Researchers

Can be included in letters to your donors or on your fundraising materials.

"The funding from FARA has been vital for my research into establishing a model of Friedreich's ataxia for therapeutic studies. I am truly indebted to the many dedicated fundraisers"
Dr. Mark Pook, Ph.D., Dept. of Medical Genetics, Imperial College London

"The support of FARA has been essential in developing clinical measures to follow Friedreich's Ataxia. The insight of the board members into the need for specific programs to move the field forward has been very impressive. Among all of the funding agencies I have been associated with, this group sets the standard for the facilitation of getting the most important done."
David Lynch, M.D., Ph.D., University of Pennsylvania, Department of Neurology

"Support from FARA is greatly appreciated and gives one the tangible sense of being part of a wonderful team of people striving to achieve something tremendously worthwhile."
Dr. Ian Alexander and Dr Jane Fleming, Neurology, Children's Hospital at Westmead, Australia

"...looking back at our progress over the last three years, I see so many of our more immediate dreams turned into reality that I am now more confident than ever that the dream of a safe and effective therapy for Friedreich's ataxia is now no longer a dream, but an achievable target! With this in mind, we will adopt the phrase 'KNOWLEDGE TURNS DREAMS INTO REALITY' as the motto of our group from now on."

The late Panos Ioannou, Ph.D., The Murdoch Children's Research Institute, Royal Children's Hospital, Melbourne, Australia

Inspirational Quotes

You may want to include items like this that have meaning for you.

“Unless someone like you cares a whole awful lot, nothing is going to get better. It's not.”

The Once-ler in “The Lorax” by Dr. Seuss

“I have found in life that if you want a miracle you first need to do whatever it is you can do - if that's to plant, then plant; if it is to read, then read; if it is to change, then change; if it is to study, then study; if it is to work, then work; whatever you have to do. And then you will be well on your way of doing the labor that works miracles.”

Jim Rohn

“Out of difficulties grow miracles.”

Jean De La Bruyere

“It is my joy in life to find
At every turning of the road
The strong arm of a comrade kind
To help me onward with my load.”

F.D. Sherman

4.4 Sample Timeline for Walk (May timeframe)

From September to January

Set up the committee

Decide on date

Reserve location

Obtain prices for T-shirts, hats, etc.

Solicit food donations

Mail letters to potential sponsors

January

- Solicit event sponsors—follow up phone calls from December mailing
- Establish incentives and prize levels
- Complete Logo—decide on colors
- Fee paid to village for use of park (was reserved months ago)
- Music arrangements confirmed
- Approach TV, radio stations and newspapers to promote event

February

- Continue soliciting event sponsors
- Design brochures, posters
- Send out teaser postcards
- Secure food donations
- Table and chair rentals arranged
- Secure clowns and mascots

March

- Print brochures and posters
- Place T-shirt and hat order
- Begin securing auction items
- Contact volunteers

- Secure Public Service Announcements (PSA's) with TV stations

April

- Recruit Walkers—send out brochures and hang posters around town
- Prepare press releases for newspapers
- Print signs
- Begin PSA's

5. FARA Support



Friedreich's Ataxia Research Alliance
P.O. Box 1537
Springfield, VA 22151
Tel (484) 875-3015; Fax (703) 4134467
Email: info@cureFA.org Web site: www.cureFA.org

FARA's Fundraising Team

Sandy Lane (typesandy@aol.com)
Marilyn Downing (mdown4@aol.com)
Mary Caruso (meirbode@aol.com)

How can FARA help?

- We want to stay in contact with you for support throughout planning, as needed. Feel free to call or email us at any point with questions you may have.
- We can hopefully connect you with an FA family that has done a similar event to yours so that you can get specific advice and see the publicity materials they utilized (i.e. Walk brochures).
- We can also personalize the FARA brochure enclosed in the packet for your event.
- We will post info about your event on the FARA website and also on FAPG (Friedreich's Ataxia Parents Group) website.
- FARA handles all of your checks, keeps a database of donors and sends out thank you/tax letters to \$250.00+ donors.
- Depending on your location and the scale of your event, a FARA representative or one of our scientists **may** be able to attend.
- Upon request, we can send a large FARA banner to be displayed at your event.
- We can let you know which research project(s) your donations are supporting so that you can notify and educate your donors.
- FARA can send press releases about your event to local papers, TV and radio stations.