THE FARA ENERGY BALL
SUPPORT OPPORTUNITIES
NOVEMBER 7, 2020

TO BENEFIT:
FARA
USF Ataxia Research Center
USF HEALTH
August 20, 2020

Dear friends,

At this time of great global health and economic concern, we hope this note finds you, your loved ones, and your livelihood well. On behalf of the Friedreich’s Ataxia Research Alliance (FARA) and all people living with Friedreich’s Ataxia (FA), thank you for your past contributions to the FARA Energy Ball. Your support has enabled great progress in our understanding of FA and the development of therapeutic approaches for the condition.

As we are all striving to keep our loved ones safe, we can all feel the importance of keeping an urgent pace for research. FA research continues because time is critical when trying to outpace the loss of a progressive disease. FARA is committed to counter this loss by advancing research towards meaningful treatments to slow, stop, and ultimately cure FA. To support this ongoing effort, the 12th FARA Energy Ball will take place as a virtual event on Saturday, November 7, 2020. The program will be live streamed, and we hope you will tune in from home, perhaps even with a small viewing party of your own.

In this Supporter Packet, we’ve outlined the types of research and the impact that is possible at different contribution levels. As you know, our FA patient community is very engaged in clinical research so we may all learn more about the condition and how best to approach treatments. One of FARA’s key roles is to enable the research that advances the entire field. As we continue to advance research and connect our families to this important work, we humbly and respectfully request your support at a level comfortable for you.

FARA is a 501(c)3 nonprofit organization (EIN 52-2122720), with a 4-Star rating from Charity Navigator for the past 10 years.

For more information on FARA and the Energy Ball, visit cureFA.org/energyball.

Thank you again for your support and generosity.

Sincerely,

Ron Bartek
President

Jennifer Farmer
Chief Executive Officer
FARA Energy Ball 2020

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$50,000  BREAKTHROUGH SUPPORTER  
Supports an Investigator at the  
FA Research Lab Bench for a Year

Since FARA’s founding, one of the key priorities has been to grow the research field with smart, passionate, and innovative scientists. FARA’s first scientific conference consisted of ~65 researchers.

Last November, FARA co-hosted ~400 scientists for a multi-day ataxia research conference, demonstrating significant growth in the field. FARA grants include salary support for researchers such as lab technicians, graduate students, PhD candidates and post-doctoral fellows for their time at the lab bench carrying out experiments to answer key questions about FA and approaches to treatment. This work leads to enhanced understanding and meaningful breakthroughs for FA.

$25,000  CAPACITY BUILDER
Develops New Research Resources to Support Patient Care  
and Trial Recruitment  (examples: Clinical Management Guidelines,  
FA Global Patient Registry, Integrated Database).

FARA has identified the need for tools and resources that support patient care and build research capacity. One project is an update of the Clinical Management Guidelines in FA. These guidelines include best practice clinical management of the disease and are assembled by experts in the field.

This resource will help ensure people with FA get care based on current information about the disease.

The FA Global Patient Registry is another resource benefiting both the patient and research communities. It is the primary tool used to notify people with FA about clinical trial opportunities - reducing the time to recruit patients for clinical trials.

It’s very important to me to be involved in FA research because it helps our doctors learn about this disease so that they can help us quicker in the future.  
The patient registry helps me find out what research I can be involved in!   - Isabel
**The FARA ENERGY BALL VIRTUAL EXPERIENCE**

**Support Opportunities**

**$15,000 TECHNOLOGY INNOVATOR**

Funds Biomarker Study Visits for 10 patients

FARA is funding several different types of biomarker studies which provide a window inside the activity of tissue and cells in FA. Biomarker studies include brain and spinal cord imaging, cardiac assessment, blood based biomarker and wearable devices. These are innovative ways to measure changes in the disease with cutting edge technology. They not only provide insight into the disease process but may also allow for shorter clinical trial duration.

_I participate in biomarker studies for myself and others; for the people that want to but can't._

_Information is power - power to find a cure._ - Christian

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**$10,000 GROUNDBREAKER**

Launches a New Clinical Research Site

One of FARA's priorities is to increase the number of Clinical Research Network (CCRN) sites for FA to make clinical care and research more accessible to people with FA. Travel to sites can be a significant burden on FA families. FARA added 3 CCRN sites (Colorado, New Zealand and Canada) in the last 18 months, and plans to add additional sites in California, Colorado and Tennessee in the upcoming year. For new CCRN sites, FARA funds site training, staff time devoted to FA clinical research as well as equipment.

_I participate in FA research because it is the only way a cure will be found. Even though traveling to a clinical site like USF is difficult because of many things, it is important because I know I am being seen by FA experts. I will continue to participate in research until a cure is found for others._ - Madelyn
The FARA ENERGY BALL VIRTUAL EXPERIENCE
Support Opportunities

$5,000  STUDY SUSTAINER

Funds the full cost of Annual Natural History Clinical Research Visits for 5 patients

Currently, 1,200 children and adults living with FA participate in an annual natural history and outcome measure study for FA. This study tracks and helps us understand the natural progression of the disease. Due to ongoing support from Energy Ball donors and participation from the patient community, we now have over 15 years worth of data - making this the most valuable resource in planning and implementing clinical trials across all programs.

FARA aims to grow the natural history study to 2,000 participants and sustain the engagement of existing patients. This funding supports the testing and assessment costs at clinical network sites, as well as patient travel expenses to those sites.

I started participating in the natural history study about 12 years ago.
I do it to help further research and understanding about FA. - Carly

$3,500  RESOURCE CONTRIBUTOR

Establishes a New Research Cell Line from Patient Donated samples.

People with FA often donate samples of their blood, skin or muscle to help further research into the condition. These patient derived samples are used to create a cell line in a FARA funded biorepository. These cell lines are shared widely with academic labs and industry to test new therapeutics approaches to FA.

I try to do everything in my power to help move research along. Even something as invasive as a muscle biopsy is worth it to me because it’s going to researchers who can do important work with my sample. - Shandra
$50,000  **BREAKTHROUGH SUPPORTER**
- Verbal and logo recognition as a Breakthrough Supporter during the Energy Ball broadcast
- Logo displayed on mobile bidding screens during the Energy Ball Auction
- Logo on event website cureFA.org/energyball, and the invitation*

$25,000  **CAPACITY BUILDER**
- Verbal and logo recognition as a Capacity Builder during the Energy Ball broadcast
- Logo on event website cureFA.org/energyball, and the invitation*

$15,000  **TECHNOLOGY INNOVATOR**
- Verbal and logo recognition as a Technology Innovator during the Energy Ball broadcast
- Logo on event website cureFA.org/energyball, and the invitation*

$10,000  **GROUNDBREAKER**
- Verbal and logo recognition as a Groundbreaker during the Energy Ball broadcast
- Logo on event website cureFA.org/energyball, and the invitation*

$5,000  **STUDY SUSTAINER**
- Name recognition as a Study Sustainer during the Energy Ball broadcast and on the event website cureFA.org/energyball

$3,500  **RESOURCE CONTRIBUTOR**
- Name recognition as a Resource Contributor during the Energy Ball broadcast and on the event website cureFA.org/energyball

**SUPPORTER**
- Name recognition as a Supporter during the Energy Ball broadcast

* Invitation print deadline for name and/or logo: September 14, 2020
The FARA ENERGY BALL VIRTUAL EXPERIENCE
YES, I want to be a supporter!

Please PRINT name exactly as you would like it to appear in any recognition.

eMail:  

Phone:  _______________________________   Cell: _________________________________  

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City:  __________________________________________ State:  _________  Zip: __________  

SUPPORT OPPORTUNITY LEVELS (Select One)  
☐ $50,000 *  
☐ $25,000 *  
☐ $15,000 *  
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☐ $ 5,000  
☐ $ 3,500  
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* INVITATION PRINT DEADLINE  
for NAME and/or LOGO:  
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CONTRIBUTIONS ARE UNRESTRICTED UNLESS OTHERWISE SPECIFIED BY THE DONOR.  

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☐ Please charge  $ __________________ to my Credit Card  (Check One)  
☐ American Express  ☐ MasterCard  ☐ VISA  

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Name As It Appears On Card:  _____________________________________________________  

Card Number:  _________________________________ Expiration:  ____ /___ CV2 Number:  ____  

Billing Address  

__________________________________________________________________________________  

Donor Signature  

__________________________________________________________________________________  

☐ Enclosed Is my check for:  $ ________________ payable to: The FARA ENERGY BALL  

FOR INFORMATION PLEASE CONTACT:  Ava Forney  ava.faraenergyball@cureFA.org or (813) 600-8179  

PLEASE COMPLETE and E-MAIL TO:  ava.faraenergyball@cureFA.org  FAX TO: (813) 321-7783.  

MAIL TO:  The FARA ENERGY BALL, P.O. Box 26454, Tampa, FL  33623  

The Friedreich’s Ataxia Research Alliance (FARA) is a 501(c)3 non-profit organization. FARA’s tax ID number is 52-2122720.  


REGISTRATION DOES NOT IMPLY ENDORSEMENT OF RECOMMENDATION BY THE STATE. OUR STATE OF FLORIDA REGISTRATION NUMBER IS CH25873.