

Together we will Cure FA!

OCTOBER 14, 2023

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SATURDAY OCTOBER 14

2023



THE FARA ENERGY BALL

YOU ARE CORDIALLY INVITED TO THE FARA ENERGY BALL

Benefitting the Friedreich's Ataxia Research Alliance and USF Health Ataxia Research Center

Tampa Marriott Water Street 505 Water Street Tampa, FL 33602

Emcee for the Evening: Wendy Ryan, ABC Action News

Cocktail Attire, RSVP Required, Complimentary Valet Parking Available Cocktail Reception & Silent Auction 6:00pm

Seated Dinner & Live Auction 7:30pm

Live Entertainment by: ICON



@curefa_org

@CureFA_org



FARA has received a 4-star rating since 2010! (4 out of 4 stars)

THE RESEARCH



Dear Friends,

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. Through this event, you have provided significant funding for FA research and have been instrumental in our progress. This past February, the FA community reached a significant milestone with the approval of the first treatment for FA by the U.S. Food & Drug Administration. Reata Pharmaceutical's SKYCLARYS® demonstrated a slowing of FA disease progression in the clinical trials. Thanks to the donors who supported early discovery research with funding, we have arrived at this breakthrough for the FA community. As we celebrate this progress, we recognize there's still more work to do. We remain committed to bringing additional therapies forward to slow, stop, reverse and ultimately CURE FA.

One of FARA's key roles is to support the research that advances the entire field. On the following pages, we have 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, enabling us to learn more about the condition and how best to approach treatments. As we continue to connect FA families to this important work, we respectfully request your support at a level comfortable to you.

FARA is a 501(c)3 nonprofit organization (EIN 52-2122720), with a 4-Star rating from Charity Navigator since 2010. For more information on FARA and the Energy Ball, visit cureFA.org/energyball.

Sincerely,

Jennifer Farmer

Chief Executive Officer

FARA

Ronald Bartek

President FARA

USFHealth

Ataxia Research Center

The USF Health Ataxia Research Center provides nation-leading clinical care and clinical research for patients with ataxia. The ataxias (which include Friedreich's ataxia (FA) and the Spinocerebellar ataxias) are a group of genetic diseases causing progressive loss of the coordination in the arms and legs, as well as deterioration in walking, speech and other critical functions, often along with other neurological and cardiac problems. Many of these diseases cause severe disability, and some are fatal.

The USF Health Ataxia Research Center is dedicated to finding effective treatments and cures for these debilitating diseases through its cutting edge clinical research programs, while also providing state-of-the-art clinical care by international authorities and researchers in the field. In addition to an intensive focus on translational and therapeutic research, the center also is developing more sensitive methods for diagnosis and a more comprehensive understanding of these diseases.

We are very proud of the relationship between FARA and the USF Health Ataxia Center in our relentless pursuit of effective treatment and cures for FA. Thank you for your support, together we are making a difference and providing hope for those afflicted with these disorders. With your help, we will find a cure.

Charles J. Lockwood

MD, MHCM Executive Vice President, USF Health Dean, USF Health Morsani College of Medicine

SPONSORSHIP OPPORTUNITIES

\$50,000 BREAKTHROUGH SPONSOR

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. This past year, FARA funded 32 grants and 12 of these grants were new research projects. Nine of those newly awarded grants were to investigators who had not previously received FARA funding. 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.

This Level Includes:

- Priority seating for 10 guests at the Energy Ball (One reserved table)
- 10 guest invitations to the Patron Party
- Verbal and logo recognition as a Breakthrough Sponsor during the Energy Ball
- Logo displayed on mobile bidding screens during the Energy Ball Auction
- Logo on event website cureFA.org/energyball and the program booklet

\$25,000 CAPACITY BUILDER

Develops New Research Resources to Support Patient Care and Trial Recruitment

FARA has identified the need for tools and resources that support patient care and build research capacity. An example of one such project was 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 helps ensure people with FA get care based on current information about the condition. 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.

This Level Includes:

- Priority seating for 10 guests at the Energy Ball (One reserved table)
- 10 guest invitations to the Patron Party
- Verbal and logo recognition as a Capacity Builder during the Energy Ball
- Logo on event website cureFA.org/energyball and the program booklet

SPONSORSHIP 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 biomarkers 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.

This Level Includes:

- Table for 10 guests at the Energy Ball (One reserved table)
- Four guest invitations to the Patron Party
- Logo recognition as a Technology Innovator during the Energy Ball
- Logo on event website cureFA.org/energyball and the program booklet

\$10.000 GROUNDBREAKER

Helps to launch a New Clinical Research Site

One of FARA's priorities is to increase the number of clinical research 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. Currently, there are nine clinical research sites throughout the US, two in Canada, one in Australia, one in New Zealand and one in India. Over the last year, FARA collaborated with investigators at these existing clinical research sites as well as those throughout Europe to launch the FA Global Clinical Consortium. For these clinical research sites, FARA funds staff time devoted to FA clinical research as well as equipment.

This Level Includes:

- Table for 10 guests at the Energy Ball (One reserved table)
- Two guest invitations to the Patron Party
- Logo recognition as a Groundbreaker during the Energy Ball
- Logo on event website cureFA.org/energyball and the program booklet

SPONSORSHIP OPPORTUNITIES

\$5,000 STUDY SUSTAINER

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

Currently, 1,500 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 while sustaining 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.

This Level Includes:

- Table for 10 guests at the Energy Ball (One reserved table)
- Name recognition as a Study Sustainer during the Energy Ball
- Name on event website cureFA.org/energyball and the program booklet

THE ENERGY EXPERIENCE

OCTOBER 14, 2023

FA Research Reception Brunch

USF Health, CAMLS

Center for Advanced Medical Learning & Simulation 124 S Franklin St, Tampa, FL 33602 10am-12:30pm

Learn about your impact on FA research

To RSVP for the symposium and access the agenda, visit: curefa.org/energyball

The FARA Energy Ball

Tampa Marriott Water Street 505 Water Street, Tampa, FL 33602

5:00pm Patron Party*

6:00pm Cocktail Reception & Silent Auction

7:30pm Seated Dinner & Live Auction9:45pm Live Entertainment by ICON

5.40pm Elve Entertainment by 100N

*The Patron Party welcomes Groundbreaker Sponsors and above.

R.S.V.P.

Downingtown, PA 19335

The FARA Energy Ball 20)23 Sponsorship Commitment
\$50,000 Breakthrough Sponsor	Admission to FARA Energy Ball
\$25,000 Capacity Builder	\$500 Per Person*=\$
\$15,000 Technology Innovator	Support - Other Amount
\$10,000 Groundbreaker	\$
\$5,000 Study Sustainer	O \$
Credit Card Authorization Form	
○ Visa ○ Master Card ○ Amer	ican Express
Sponsor Name as it should be acknowle	edged on materials:
Credit Card #:	Security Code
Exp. Date:	
I would like to contribute the credit ca	rd processing fee (2.6%) YES NO (please circle one)
Name on Card:	
Signature:	
Contact & Title (if a corporation):	
Mailing Address:	
City:	State: Zip:
Phone: ()	Cell: ()
Email Address:	Web Address:
Contributions are unrestricted unless o	therwise specified by the donor.
For check/charge, please mail or ema	ail this form to:
FARA 533 W. Uwchlan Ave	Ava Forney: (813)-600-8179 ava.faraenergyball@curefa.org

Sponsorship commitments, ticket purchases, and donations can also be made online at curefa.org/energyball. Fees will apply for tickets and sponsorships purchased online.

A COPY OF THE OFFICIAL REGISTRATION AND FINANCIAL INFORMATION MAY BE OBTAINED FROM THE DIVISION OF CONSUMER SERVICES BY CALLING TOLL-FREE WITHIN FLORIDA 1-800-435-7352. REGISTRATION DOES NOT IMPLY ENDORSEMENT OF RECOMMENDATION BY THE STATE. OUR STATE OF FLORIDA REGISTRATION NUMBER IS CH25873.

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The Friedreich's Ataxia Research Alliance gratefully acknowledges the generous supporters who help advance FA research.



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