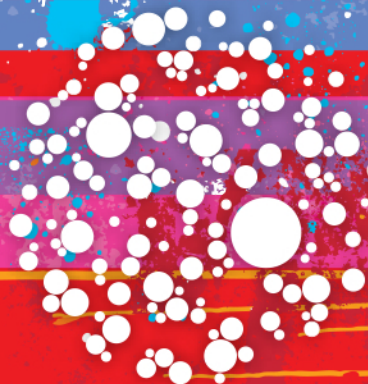


TOGETHER WE WILL CURE FA!

NEW DATE: DECEMBER 6, 2024



THE FARA ENERGY BALL

BENEFITING:

FARA | Friedrich's
Ataxia
Research
Alliance

USF Health
Ataxia Research Center

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Avery Lowry Zaritsky

Theresa Zesiewicz, MD FAAN

**FRIDAY
DECEMBER
6TH
2024**



**THE FARA
ENERGY
BALL**

**WE WOULD LOVE FOR YOU TO JOIN US
AT THE FARA ENERGY BALL**

*Benefiting the Friedreich's Ataxia Research Alliance
and USF Health Ataxia Research Center*

JW Marriott Tampa Water Street
510 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
7:00pm

Live Entertainment by:
Blonde Ambition

**The Patron Party welcomes Groundbreaker
Sponsors and above at 5pm.*

 @FARAEnergyBall

 @curefa_org

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. Because of your support, there have been great strides forward in the drug development pipeline for FA. As you know, the first treatment for FA was approved by the US Food and Drug Administration for people 16 years and older last year. The generosity of FARA Energy Ball donors played a major role in this achievement by helping to fund an FA natural history study, whose data supported this first approval.

Seeing firsthand the value of this clinical research, FARA has increased the number of clinical consortium sites from 15 to 33 sites throughout the world including locations in the United States, Canada, Europe, Brazil, India, New Zealand and Australia. We are excited about this global effort, research momentum, and the progress of the programs in the pipeline aimed at the underlying causes of FA. 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,

A handwritten signature in black ink that reads "Jennifer Farmer".

Jennifer Farmer
Chief Executive Officer
FARA

A handwritten signature in black ink that reads "Ronald Bartek".

Ronald Bartek
President
FARA

The logo for USF Health Ataxia Research Center. It features the text "USF Health" in a large, bold, green sans-serif font, with "Ataxia Research Center" in a smaller, green sans-serif font directly below it. The background of the top of the page is a vibrant red with abstract, splattered patterns in shades of orange and yellow.

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 37 grants and 22 of these grants were new research projects. 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

(FMV: \$3,750)

\$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)
- Eight 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

(FMV: \$3,600)

\$15,000 TECHNOLOGY INNOVATOR

Supports 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
(FMV: \$3,300)

\$10,000 GROUNDBREAKER

Helps to launch a New Clinical Research Site

Over the past 15 years, your support has helped FARA establish clinical research sites across the US, Australia, Canada, and India. Because of the proven value and impact of natural history study data and our clinical research infrastructure, FARA has made the commitment to further grow this network of research sites. In 2023, FARA launched the Friedreich's Ataxia Global Clinical Consortium (FA GCC), which expanded the number of clinical research sites from the existing 15 to 33 sites across 18 countries. The structure will become a key resource in planning and implementing clinical trials across all programs, across the globe. Every data point and biological sample collected moves research forward.

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
(FMV: \$3,150)

SPONSORSHIP OPPORTUNITIES

\$5,000 STUDY SUSTAINER

Supports the Cost of Annual Natural History Study Clinical Research Visits for 5 Patients

Due to the ongoing support from Energy Ball donors and participation from the patient community, FARA will be increasing its investment in the natural history study this year to gather an even more diverse set of data, foster collaboration across this global research network, and advance additional treatments. The FA GCC developed a global natural history study protocol called the UNIFAI study, which will collect natural history data and improve the panel of outcome measures that can be used in FA clinical trials. Participation in this study allow researchers to collect and share valuable data that accelerates the development of treatments for FA.

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

(FMV: \$3,000)

FA RESEARCH RECEPTION BRUNCH

DECEMBER

6

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

**LEARN ABOUT YOUR IMPACT ON
FA RESEARCH**

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

The FARA Energy Ball 2024 Sponsorship Commitment

- \$50,000 Breakthrough Sponsor
- \$25,000 Capacity Builder
- \$15,000 Technology Innovator
- \$10,000 Groundbreaker
- \$5,000 Study Sustainer

Admission to FARA Energy Ball

\$500 Per Person* _____ = \$ _____

Support - Other Amount

\$ _____

Sponsor Name as it should be acknowledged on materials:

Contact & Title (if a corporation): _____

Mailing Address: _____

City: _____ State: _____ Zip: _____

Phone: (_____) _____ Cell: (_____) _____

Email Address: _____

Web Address: _____

Contributions are unrestricted unless otherwise specified by the donor.

**For questions about the event, please contact Ava Forney: (813) 600 8179;
ava.faraenergyball@curefa.org**

If paying by check, make payable to FARA and mail to:

THE FARA ENERGY BALL, 533 W Uwchlan Ave, Downingtown, PA 19335

Pay online at:

give.curefa.org/energyball

If paying by credit card:

Call FARA at 484-879-6160

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

SPONSORS

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SULLIVAN

DR. THERESA ZESIEWICZ
& DR. JOSEPH STAFFETTI



THE FARA ENERGY BALL

On behalf of the Friedrich's Ataxia Research Alliance and families affected by FA, thank you for your continued generous support of FA research. Together, we will slow, stop, reverse, and ultimately CURE FA!



@FARAEnergyBall



@curefa_org



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