



**THE FARA
ENERGY
BALL**

*Together we
will cure FA!*

SEPTEMBER 25th, 2021

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SATURDAY

SEPTEMBER 25, 2021



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 St.
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:
Blonde Ambition

 @FARAEnergyBall

 @curefa_org

 @CureFA_org



*FARA received a 4 star rating
for the 11th consecutive year!
(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. Your support has enabled great progress in our understanding of this progressive neuromuscular condition and the development of therapeutic approaches.

Over the past twelve years, FARA Energy Ball supporters have:

- Funded >\$15Million in Drug Discovery and Development and Clinical Research; including research leading to >8 potential therapies being tested in clinical trials
- Expanded the research capacity of the Collaborative Clinical Research Network (CCRN) in FA:
 - >1,200 individuals with FA enrolled in clinical research, including those seen at USF
 - Biobank with DNA, RNA, serum, and plasma samples available for collaborative research with pharmaceutical companies
- Raised unparalleled awareness of FA within the Tampa Bay community and beyond

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. One of FARA's key roles is to support the research that advances the entire field. As we continue to advance research and connect our 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 for the past 11 years. For more information on FARA and the Energy Ball, visit cureFA.org/energyball.

Thank you again for your support and generosity.

Sincerely,

Jennifer Farmer
Chief Executive Officer
FARA

Ronald Bartek
President
FARA

USF Health Ataxia Research Center

The USF Health Ataxia Research Center is one of the Nation's leading clinical research centers evaluating effective treatments for inherited ataxia disorders. Ataxias cause an inability to coordinate voluntary muscular movements and can lead to progressive disability. The Center combines the cutting edge research of a team of international neuroscientists with state-of-the-art clinical practice by physicians who focus on the development and delivery of effective therapies for those affected by Friedreich's and Spinocerebellar Ataxia. In addition to conducting major trials of new pharmaceutical agents to treat inherited ataxias, they are working on better methods of early diagnosis and a more comprehensive understanding of these diseases.

As USF pursues a cure for these diseases, we need your help! We are very proud of the relationship between FARA and the USF Health Ataxia Research Center and pleased to see that our common goal is being pursued with energy, efficiency, and creativity. 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

*Senior Vice President, USF Health
Dean, 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 34 grants, and 13 of these were to first time grantees, demonstrating important 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.

This Level Includes:

- Priority seating for ten guests at the Energy Ball (One reserved table)
- Eight 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. 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.

This Level Includes:

- Priority seating for ten guests at the Energy Ball (One reserved table)
- Six 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 ten 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

Launches a New Clinical Research Site

One of FARA's priorities is to increase the number of Collaborative 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.

This Level Includes:

- Table for ten 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, 1,200 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.

This Level Includes:

- Table for ten 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

SEPTEMBER 24 & 25, 2021

FRIDAY, SEPTEMBER 24

Understanding Energy for a Cure Symposium hosted by the USF Health Ataxia Research Center

Center for Advanced Medical Learning & Simulation

124 South Franklin Street, Tampa, Florida 33602

6:00pm Welcome/ Food & Drinks

6:45pm Science Symposium

Sponsors and guests are welcome to attend this informative event to learn how their support has helped advance research in finding treatments for Friedreich's ataxia.

For the evening's agenda and list of speakers, visit: curefa.org/energyball

SATURDAY, SEPTEMBER 25

The FARA Energy Ball

Tampa Marriott Water Street

505 Water Street

Tampa, Florida 33602

5:00pm Patron Party*

6:00pm Cocktail Reception & Silent Auction

7:30pm Seated Dinner & Live Auction

9:45pm Live Entertainment by Blonde Ambition

****The Patron Party welcomes Groundbreaker Sponsors and above.***

To register for the symposium, visit: <http://usf.edu/ua/RSVP>

R.S.V.P.

The FARA Energy Ball 2021 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

\$ _____

- Make checks payable to: **FARA**
- Charge: Visa Master Card American Express

Sponsor Name as it should be acknowledged on materials: _____

Account #: _____ Security Code _____

Exp. Date: _____

I would like to contribute the credit card 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 otherwise specified by the donor.

If not making payment online at: **curefa.org/energyball**
please either mail, fax or email this to:

The FARA Energy Ball
P.O. Box 26454
Tampa, FL 33623-6454

Ava Forney: (813)-600-8179
Fax: (813)-321-7783
ava.faraenergyball@curefa.org

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THE FARA ENERGY BALL 2021

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



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