



**THE FARA  
ENERGY  
BALL**

**TOGETHER WE WILL  
CURE FA!**

# THE COMMITTEE

## HONORARY CHAIR COUNCIL

Suzanne & Paul Avery, Chairman, FARA Board of Directors  
Ron Bartek, President, FARA  
Charles J. Lockwood, M.D., M.H.C.M., Senior Vice President, USF Health

## HONORARY CHAIRS

Janell & Steve Griggs, CEO, Tampa Bay Lightning

## HONORARY COMMITTEE MEMBERS

Anna & Frank Alfano  
Dorothy Alfonso  
Alison Avery  
Laurel Avery  
Michael Barbaro  
Lori & Anthony Barkett  
Debbie & Bob Basham  
Steve Blair  
Tom Bradley  
James Buell  
Sandy & Bob Callaghan  
Sofia Parker Chang  
Lauren Cooper  
Trudy & John Cooper  
Janey DePew

Tanya & Herman Fernandez  
Sarah & Jason Foglia  
Lori & Matt Hill  
Lexi Hoffman  
Amy & Kurt Hull  
Mary & Paul Jacobs  
Pamela & Chris Kelsch  
Lisa & Vic Lafita  
Dawn & Kevin Lambert  
Susan McLaughlin  
Pastor Jane McDonnough  
Kaye & Jim Pollard  
Nancy & Brad Rex  
Mary Ridgeway  
Julie Robertson

Kathy & Doug Rothschild  
Wendy Ryan  
Susie Snowden  
Sandi & Chris Sullivan  
Georgette & Chris Tsavoussis  
Kelly & Lou Varsames  
Bridget & Richard Verrecchia  
Heidi & Bill Wright  
Avery Lowry Zaritsky  
Theresa Zesiewicz, MD FAAN

## FARA STAFF

Jennifer Farmer  
Ruth Acton  
Kyle Bryant  
Jamie Dean

Felicia DeRosa  
Erin Goerss  
Megan Malloy  
Ann Musheno

Elisabetta Soragni, PhD  
Barbara Tate, PhD  
Susan Walther

SATURDAY

NOVEMBER 7, 2020



# THE FARA ENERGY BALL

**YOU ARE CORDIALLY INVITED TO THE  
VIRTUAL FARA ENERGY BALL**

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

*Broadcast right to your home at 7:00pm*

 @FARAEnergyBall

 @curefa\_org

 @CureFA\_org



*FARA received a 4 star rating  
for the 10th consecutive year!  
(4 out of 4 stars)*



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](http://cureFA.org/energyball).

Thank you again for your support and generosity.

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 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

# SUPPORT OPPORTUNITIES

## **\$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.

### **This Level Includes:**

- Verbal and logo recognition as a Breakthrough Supporter during the Energy Ball broadcast
- Logo displayed on mobile bidding screens during the Energy Ball Auction and on event website [cureFA.org/energyball](http://cureFA.org/energyball)

## **\$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.

### **This Level Includes:**

- Verbal and logo recognition as a Capacity Builder during the Energy Ball broadcast
- Logo on event website [cureFA.org/energyball](http://cureFA.org/energyball)

# 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.

### **This Level Includes:**

- Verbal and logo recognition as a Technology Innovator during the Energy Ball broadcast
- Logo on event website [cureFA.org/energyball](http://cureFA.org/energyball)

## **\$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.

### **This Level Includes:**

- Verbal and logo recognition as a Groundbreaker during the Energy Ball broadcast
- Logo on event website [cureFA.org/energyball](http://cureFA.org/energyball)

# 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.

### This Level Includes:

- Name recognition as a Study Sustainer during the Energy Ball broadcast and on the event website [cureFA.org/energyball](http://cureFA.org/energyball)

## \$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.

### This Level Includes:

- Name recognition as a Resource Contributor during the Energy Ball broadcast and on the event website [cureFA.org/energyball](http://cureFA.org/energyball)

# R.S.V.P.

## The FARA Energy Ball 2020 Supporter Commitment

- \$50,000 Breakthrough Supporter       \$5,000 Study Sustainer  
 \$25,000 Capacity Builder             \$3,500 Resource Contributor  
 \$15,000 Technology Innovator  
 \$10,000 Groundbreaker

### Support-Other Amount

\$ \_\_\_\_\_

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

Name as it should be listed for Support: \_\_\_\_\_

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](http://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](mailto:ava.faraenergyball@curefa.org)

# SUPPORTERS

## ••• BREAKTHROUGH SUPPORTERS •••



The Avery Family  
Foundation

## ••• CAPACITY BUILDERS •••



Kurt & Amy Hull  
Diversified Asset Funding

## ••• TECHNOLOGY INNOVATOR •••



## ••• GROUNDBREAKERS •••



RAYMOND JAMES



Dr. Joseph Staffetti &  
Dr. Theresa Zesiewicz

Chris & Sandi Sullivan

Doug & Kathy Rothschild  
Family

The Bradley Family

Paul & Mary Jacobs

Eddie & Candy  
DeBartolo & Family

Bill & Heidi Wright



# THE FARA ENERGY BALL 2020

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



@FARAEnergyBall



@curefa\_org



@CureFA\_org



*FARA received a 4 star rating for the 10th consecutive year!  
(4 out of 4 stars)*