THE FARA ENERGY BALL

The FARA Energy Ball is a gala event that was founded by individuals and corporate sponsors dedicated to treating and curing Friedreich's ataxia. Friedreich's ataxia is a debilitating neuro-muscular disease that is caused by lack of energy production that our cells need for proper function and survival. FA robs individuals of balance and coordination leading to life altering loss of mobility, energy, speech and hearing. FA also presents serious risk of diabetes and life shortening cardiac disease.

THE FARA ENERGY BALL

In the last 10 years, The FARA Energy Ball has. . .

- Funded >$13Million in Drug Discovery and Development and Clinical Research; including five clinical trials 2013-2018 (2 of the funded trials at USF)
- Expanded the research capacity of the Collaborative Clinical Research Network (CCRN) CCRN in FA:
  - >1000 individuals with FA enrolled in clinical research
  - 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

2019 Initiatives- FARA needs to raise >$8million

- Advance drug candidates in a deep and diverse treatment pipeline
- Develop the genetic based research findings to therapeutic agents for people living with FA
- Grow the scientific community to bring new ideas and expertise to advance the field
- Support a worldwide network of clinical research and care centers for FA
- Reduce mortality caused by severe cardiac abnormalities
- Facilitate an International Collaborative FA Biomarker Consortium to accelerate therapy development for FA
- Restructure the FARA Patient Registry to be a worldwide registry and fully enroll all open clinical trials

FARA Friedreich's Ataxia Research Alliance

Acting alone there is very little any of us can accomplish
Acting together there is very little we will not accomplish.
-Ron Bartek, FARA Founder and President

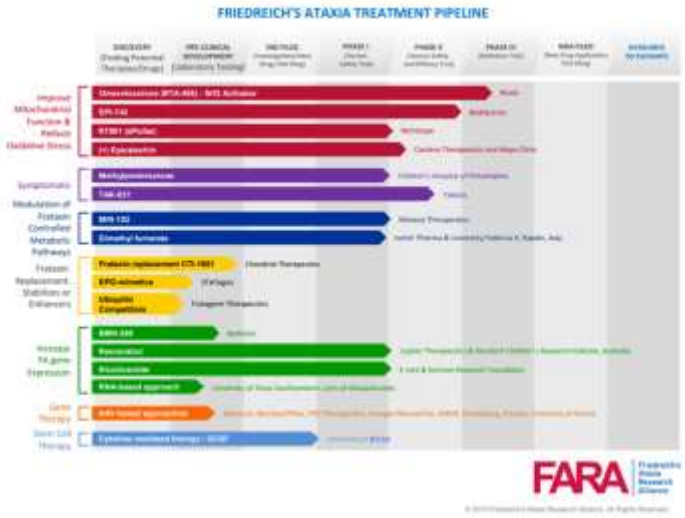
In the last 20 years, FARA has. . .

- Funded >$46 Million in FA Drug Discovery and Development and Clinical Research
- Leveraged an additional research dollars from co-funding partners
- Helped individuals with FA participate in clinical research and get improved medical care
- Educated the medical and patient communities regarding FA and research advances
- Raised awareness of FA so that those diagnosed are no longer isolated

For a complete list of funded projects, please visit our website at: http://www.curefa.org/grants

Because of supporters like you . . .

FARA has been able to dramatically increase the number of potential treatments for FA in just a few years (see graph below). To learn more about the progress of these additional approaches, please visit our website at: http://www.curefa.org/pipeline



Breakthroughs and Milestones. . .

- 1996 - The disease-causing gene mutation was identified
- 1998 - FARA was founded
- 2001 - The first animal models of FA were created
- 2006 - Number of researchers working in FA doubled and FARA Patient Registry was launched
- 2007 - International Collaborative Clinical Research Network for FA was established
- 2009-2011 - Number of new drug candidates and pharmaceutical companies interested in FA doubled
- 2012 - Gene therapy shown to reverse FA cardiac disease in a mouse model
- 2013 - 5 new clinical trials initiated and 3 new candidates added to treatment pipeline
- 2014 -FARA established Penn Medicine / CHOP Friedreich's Ataxia Center of Excellence; 3 new pharmaceutical companies formed to advance gene therapy in FA
- 2015-2017 -FARA implemented collaborative FA Biomarker initiative with industry & academic partners
- 2018 – Gene therapy shown to reverse FA neurological disease in mouse model
  - Completed enrollment for a phase II & a phase III trial with >175 participants

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