

WINTER 2015-2016

the Advocate

Your connection to the Friedrich's Ataxia Research Alliance



THIS ISSUE:

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Kickin' FA at the Energy Ball • Drug Development Series

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President's Message

By Ron Bartek

Dear friends,

Hope this finds you and your families enjoying the onset of the holiday season together. As you can see from the articles in this issue of *The Advocate*, all the combined efforts of the increasingly active FA family have resulted in exciting progress throughout the year. I wanted, here, to tell you briefly about a vibrant new partnership agreement FARA recently signed with an additional FA family member—a partnership I am confident will help accelerate the progress we are making together.

On Sept. 2, FARA and the Muscular Dystrophy Association (MDA) announced our two organizations have agreed to partner across a range of important efforts aimed at advancing FA research, therapeutic development, and clinical care faster and more effectively. That announcement followed several months of discussions and meetings in which it became clear that both organizations were convinced that, by acting together on specified programs and projects, we could accomplish more for FA families than by acting alone. The efforts on which we have agreed to collaborate initially include advocacy, the FARA patient registry, research grants, biomarkers, and newborn screening.

The FARA-MDA collaboration on advocacy is well under way. The MDA staff in Washington, D.C. and I, in close coordination with other partners such as the National Organization for Rare Disorders (NORD), the Alliance for a Stronger FDA, and Research!America, have been working extremely well together for a long time. Together we advocate before the Congress, the National Institutes of Health (NIH) and the Food and Drug Administration (FDA) for policies and budget lines intended to advance therapeutic development for FA and all rare diseases. Those policies and budget lines, of course, include our combined efforts to provide the NIH and the FDA with the authority and resources they need to do their very important jobs well and expeditiously.

FARA maintains and operates the world's largest FA patient registry and is intent upon enrolling as many FA patients as possible so as to empower all patients to participate in the research so vital to advancing treatments. The MDA is developing patient registries for some of the diseases other than FA in its portfolio and has agreed to facilitate enrollment in the FARA registry of FA patients in the MDA community. The exciting result should be that more and more FA patients will be in the FARA registry and more fully and promptly informed of opportunities to participate in research that will lead to treatments and a cure.

The new FARA-MDA agreement will also have our two organizations, once again, collaborating on and co-funding research grants. The initial focus of such awards will be on “training grants” intended to nurture newer, more junior investigators—so important in growing the field and keeping it strong and vibrant. At the same time, though, we will be alert to joint opportunities to help support later-stage projects that need active participation from other academic or industry partners to move further and more quickly through the development process.

In terms of biomarkers (biochemical changes that could be used to predict if a drug therapy would result in clinical benefit), FARA and MDA are committed to exploring such potential biomarkers that would be useful in FA and other neuromuscular disorders and to working with the FDA to qualify such biomarkers for use in FA clinical trials. The two organizations have already submitted to the FDA joint comments on this topic and a senior MDA representative recently participated in FARA's biomarker and animal model symposium.

The two organizations are also committed to collaborating in preparing, at the appropriate time, a submission requesting inclusion of FA in the newborn screening program across the United States. To be included in the program, a disease group must have ad-

equate natural history data demonstrating definitively the course of the disease without intervention, a validated, efficient newborn screening test and an approved treatment. Our FA community can meet those first two requirements. When we achieve approval of a treatment, we will want to be prepared to submit a compelling request to add FA to the program so we can begin to diagnose and treat infants.

Knowing that all these promising joint efforts will require open communication and close coordination, the two organizations have designated points of contact for overall coordination as well as for each of the particular collaborative efforts and joint work on each of these efforts is already well under way.

In MDA's announcement of the new agreement, MDA President and CEO Steven M. Derks stated, "By working with respected and capable sister organizations like FARA, we are able to hone in on real progress for FA. We are committed to saving and improving the lives of people with neuromuscular disease, and we can't do it

alone." My statement was clearly in the same collaborative spirit: "We know that, with FARA and MDA working closely together, we will accomplish our shared goals and get treatments to FA patients much sooner."

I'm sure we will all agree that it is great having the MDA as a partner and an active member of the FA family. We will keep you fully informed of all the progress we make pushing forward together on all these fronts.

Warm regards to you all,
Ron

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Friedreich's Ataxia Center of Excellence A True Partner in Our Efforts to Develop Treatments for FA

By Jennifer Farmer

On the third Thursday of every month, more than 25 researchers, physicians, nurses, study coordinators and students assemble in a conference room at the Children's Hospital of Philadelphia (CHOP) to share new research findings from the laboratory and insights from the FA clinic. All of these individuals are part of a growing Friedreich's Ataxia Center of Excellence.

In early 2014, three longtime allies, FARA, CHOP and Penn Medicine, joined forces to create the new Penn Medicine/CHOP Friedreich's Ataxia Center of Excellence. A \$3.25 million gift from FARA, in partnership with the Hamilton and Finneran families, catalyzed establishment of the center.

The Friedreich's Ataxia Center of Excellence is co-directed by David Lynch, MD, PhD, FA program director at CHOP, and Robert B. Wilson, MD, PhD, professor of Pathology and Laboratory Medicine at the Perelman School of Medicine. Dave and Rob both serve on FARA's Scientific Advisory Board, and Rob was a founding member of FARA's board of directors and first chairman of our Scientific Review Committee.

The center's mission envisions a translational research and clinical care center devoted to Friedreich's ataxia: expediting basic science and drug discovery findings to new treatments and dedicating resources to clinical research and care to further understand the disease, inform drug development and improve outcomes for individuals living with FA.

The early goals and objectives of the Center include:

- **Increasing capacity for more clinical research visits, clinical trials, and exploring unique clinical findings in patients for modifiers and mechanisms that can be translated to new treatment approaches, led by Dr. Dave Lynch.**
- **Adding cardiac expertise in FA research and clinical care under the leadership of Kimberly Y. Lin, MD, a cardiologist at CHOP**

with board certification in pediatrics, internal medicine, and pediatric cardiology. Dr. Kim Lin is also an assistant professor in the division of cardiology and the Department of Pediatrics at the Perelman School of Medicine.

- **Building on Dr. Rob Wilson's drug discovery research which has included high-throughput drug screening and development of a shRNA library to investigate novel genetic and epigenetic approaches to drug discovery to establish a drug discovery core laboratory.**
- **Establishing a biomarker development program with the expertise of Ian Blair, PhD, A. N. Richards Professor of Pharmacology, Perelman School of Medicine.**

Over the past 18 months, this team exceeded initial goals and objectives and expanded research efforts to incorporate additional research and medical professionals at Penn and CHOP and other institutions through collaborative projects.

It is challenging to provide a concise summary of all that is ongoing in FA research at the Penn/CHOP Center of Excellence, but some of the highlights follow below. The clinical research program at CHOP is the largest in the world with more than 350 individuals with FA participating in studies and receiving clinical care each year. This translates to more than 1,500 FA research appointments per year.

- **Clinical trials- Two clinical trials (EPI-743 and SHP622 (formerly VP20629) concluded this year and two new clinical trials (STEADFAST/Actimmune and MOXIe/RTA-408) are enrolling subjects. In addition, Drs. Lynch and Lin plan to introduce trials of drugs approved for other indications, such as the steroid methylprednisolone, based on past clinical experience or other research findings that show a preliminary or suggested benefit.**
- **Clinical research studies- In addition to the natural history study from which all this research has its foundation, there are:**
 - Three new cardiac studies enrolling subjects: Cardiac MRI, cardiac serum biomarkers and exercise tolerance and performance,
 - A new DEXA study that explores differences in body fat in individuals with FA,
 - A smartphone study exploring the use of a new app to measure gait, speech and coordination tasks in individuals, who can record results on a daily basis for 30 days from their home,
 - Three new studies that explore both old and new methods for measuring nerve and brain function in individuals with FA, and
 - A new study of the metabolic features of muscle, including mitochondrial function.

- **Biomarkers-** Two new biomarkers discovered by Dr. Blair and his team can be measured in blood that are directly linked to the downstream consequences of frataxin deficiency. One of these biomarkers is already in use in clinical trials. In addition, he continues to work on developing a more sensitive measure of the frataxin protein which was identified as the highest biomarker priority.
- **Drug discovery-** Several drug discovery efforts advanced by Dr. Wilson and his colleagues include: One that improves mitochondrial function and down-stream metabolic consequences in FA; one that targets increasing frataxin protein production; and one that could potentially bypass the cells need for frataxin. In addition, Dr. Wilson is developing improved cell models for use in early drug discovery and testing to help get earlier and faster reads on which discoveries are more likely to be successful.

The researchers from the Center of Excellence are working with multiple pharma and biotech partners; testing compounds in cell models, sharing blood samples as well as data from the natural history study, cardiac studies, neurological studies and biomarker studies. This collaboration helps design clinical trials, develop regulatory strategy and conduct clinical trials. The past and future accomplishments of the Center rely on the continued engagement and participation of the FA Community: individuals with FA participating in studies, researchers in academic and industry organizations working together collaboratively on research, and our generous supporters who allow us to fund the research. This Center of Excellence is a true partner in our efforts to develop treatments for FA. ●

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Along the vertical axis, lead candidates are grouped based on mechanism of action or approach to treatment, e.g., where or how each drug might work in the cell, technological approach, or problem being addressed. The horizontal axis indicates the stage of the research, or where the candidate is in development. Detailed information on each lead candidate can be found on FARA's

- *University of South Florida*

FARA Funds Research Progress

By Jennifer Farmer & Felicia DeRosa

FARA continues to fund a robust research portfolio including drug discovery, cellular and animal model development, biomarker research and clinical studies. In 2015, FARA received 35 letters of intent (LOI) and invited 23 researchers to apply for grant funding. After a rigorous peer review process, 14 new grants were approved for funding. Additionally, 17 ongoing research projects proved to meet their milestones for continued funding. A total of 31 grants plus the Collaborative Clinical Research Network have been funded by FARA in 2015.

The graph below represents the different research areas funded by FARA over the last five years. FARA continues to provide significant support to drug discovery to keep the research pipeline rich and filled with new ways to target treatment for FA. FARA is also the sole funder of the Collaborative Clinical Research Network. The network collaborates with pharmaceutical companies, government agencies and other research centers and the patient community to facilitate clinical research and trials needed to identify new therapies. Because pharmaceutical sponsors typically fund the majority of clinical trial expenses, lead candidates usually require a lower amount of funding from FARA's Grant Program. Lastly, you will notice an increase in support for biomarker research. You can learn more about this exciting work on page 7.

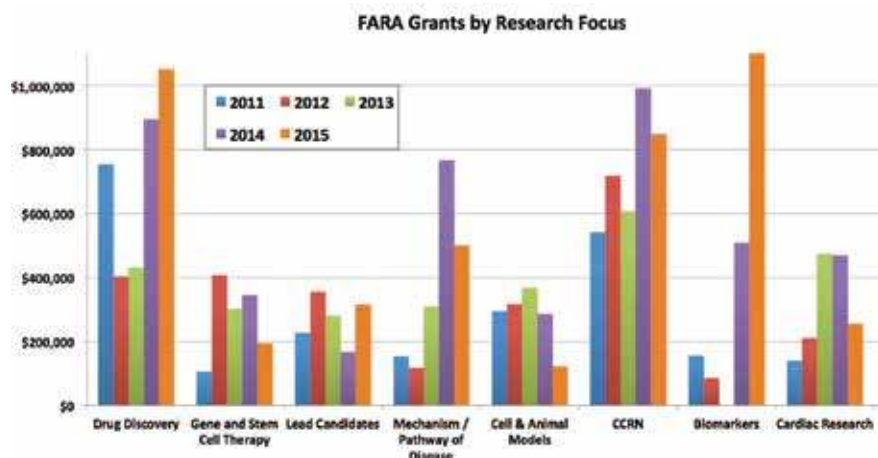
Titles and summaries of most of the projects presently funded by FARA are available at: www.curefa.net/RPMP/public/pg-grantlist.aspx. Complete listings of grants awarded by year can be accessed at: www.curefa.org/grant

In addition to the ongoing and new work funded this year, the results of over 20 FARA-funded research projects received publication in scientific journals. A comprehensive list of FARA-funded and other research publications on FA is available at: www.curefa.org/scientific-news

Grant Type	LOI Deadlines	Application Deadlines	Maximum Budget (in US dollars)
General Research Grant	February 1 July 15	April 1 September 15	\$150,000 per year for 1 or 2 years
Keith Michael Andrus Cardiac Research Award	January 15	March 1	\$150,000 per year for 1 or 2 years
Kyle Bryant Translational Research Award	May 15	July 15	\$250,000 per year for 1 or 2 years
Bronya J. Keats International Research Collaboration Award	May 15	July 15	\$200,000 per year for 1 or 2 years

Exceptions to these deadlines are projects that the investigator believes may be of high priority to FARA. An LOI for such a proposal may be submitted at any time during the year. However, the justification for such special consideration must be compelling. Grant application guidelines are available at:

www.curefa.org/grant •





FARA's Biomarker Initiative

By Jane Larkindale, PhD

Everyone agrees that drug development is a frustrating process that takes too long, costs too much and has too many failures. While it is easy to point a finger at the problem, it is much harder to find ways to fix it. One major area of work is in figuring out ways to run informative clinical trials in less time and using fewer patients while still gathering sufficient evidence to be sure a drug does (or does not) work. One key part of this is in the development of informative biomarkers.

Biomarkers are biological measurements that in a relatively short timeframe can give us information indicating what result might be seen in a much longer study. FARA launched an initiative to look for novel biomarkers for FA, starting with a November 2014 meeting where experts came together to prioritize possible markers. A year later, FARA, with its industry and academic partners, launched three separate studies:

The Children's Hospital of Philadelphia and Hopital Erasme in Brussels have initiated a study to look at neurological biomarkers—markers that would show the degeneration of the sensory or motor nerves. They are looking at five different groups of measurements, which measure the signals from specific nerves and their route to the brain. These are exploratory measures—that is, while the experts think they could be useful biomarkers, many of the measures have never been studied in FA patients before. These may turn out to be highly useful biomarkers, in which case more detailed studies will be needed, or may prove to be useless, in which case they will be dropped. However, whichever the outcome, we will have learned more about the nature of the disease through completion of the studies.

The University of Rochester has launched a study looking at the nerves themselves, as opposed to the signals sent by the nerves. This study will look at four groups of measurements typically used in other nerve diseases to see if and how they change in the course

of disease progression in FA. Like the first study, this is highly exploratory.

Murdoch Children's Research Center in Australia and University of South Florida are working on studies looking at how gait and balance change over time. Each group has done small pilot studies of these measures and shown that they can detect differences in individuals with FA. They also have some data to suggest that over the course of disease, both measures change significantly. This study will gather more data over shorter periods of time (typical to a clinical trial of six months and 12 months), determining which precise measures are most sensitive and accurate.

All of these studies are looking for patients to enroll to determine which of the measurements could be used to speed up trials. If you are interested in being a part of this exciting research, check on the FARA website at <http://www.curefa.org/active-clinical-trials> to see who can take part in which study. Our goal is to get these studies enrolled as soon as possible, so we can start prioritizing the most exciting measurements and move them towards clinical application as fast as possible. •

The FARA Advocate is brought to you by:

Contributors: Ron Bartek, Kyle Bryant, Felicia DeRosa, Jennifer Farmer, Alex Fielding, Erin Goerss, Jane Larkindale, PhD, Ann Musheno, David Woods, PhD, Jamie Young

Editor: Karen Smaalders

Cover Design: Crystal Wade

Design/ Layout: Anne Myers

Graphic Support: Lawrence Phillips



The Drug Development Pathway

By Jane Larkindale, PhD

One thing that we all agree on in the FA community is the fact that we would like a treatment or cure for the disease, and we would like it now (if not sooner). This urgency drives everything that FARA does, as we try and get treatments to patients as soon as possible. However, drug development is a tricky business—it takes a lot of steps to go right in order to get an effective new drug to patients. In this series of articles, we will talk about the various steps that are needed in order for us to have a safe and effective new treatment (or at least one where the benefits outweigh the risks).

In this article we will talk through the steps that are required scientifically, and by the Food and Drug Administration (FDA), to go from a good idea to a drug that could be approved by the FDA through standard channels. In future articles (published mainly online) we will talk about the next steps – the process of approval in the US, how to get that drug to patients (through pharmacies and doctors), and how to get it paid for by insurance. In the final article in the series we will discuss the differences between drugs and supplements in how they are regulated and marketed, and the differences between approved drugs, approved drugs that are used off label and supplements, as well as the legal ways to access drugs that may not yet be approved in the U.S.

Drug Development and Clinical Trials

Drug development in FA is at a very exciting time right now. For the first time we have multiple drugs that are being tested in patients, and some are reaching the final stages of testing (see the FA pipeline on page 5). As such, it is an important time for FA patients to understand the process of drug development, so that they can make informed decisions about what role they wish to play.

Drug development is typically split into three areas:

Discovery research is where scientists try to understand the disease and figure out processes that can be affected by potential drugs. If researchers identify new targets and ways to affect those targets

the resulting molecules are called “drug candidates.”

Preclinical research is where a good idea is turned into something that could be a real drug. Chemists tweak the drug candidate to make sure it is as effective as possible. For example, Biomarin has been working on HDAC inhibitors to increase the amount of frataxin they induce, to increase the drug’s ability to get to the areas of interest (heart and nerves) and to reduce the possibility of side effects. Once the best molecule or “clinical candidate” has been identified, there are a series of standard tests that are completed to assure us that we understand the side effects of the drug (termed “toxicology studies”), and the appropriate dose range to try in humans. These studies are typically done alongside other work, such as figuring out how to make the compound in a reproducible way, how to deliver it (Orally? Intravenously? Injection?) and what happens to it in the body—which affects how often you would need to take the medicine and at what dose over time, as well as possible side effects. If all these studies are successful, the owner of the compound can apply to the FDA for an “Investigational New Drug” license, or IND.

Clinical Research is studies in human subjects. IND packages to the FDA are hundreds of pages long, and include all the details of the preclinical work and the plans for the next studies that will be done in humans. The FDA scrutinizes all of this information carefully to determine if the proposed studies are ethical and to determine risks to patients.

If the IND is granted, the sponsor (person developing the drug) is free to start trials in humans. However, depending on the drug, the first time a drug goes into humans it is not tested in patients. Phase I trials, the first trials on a new drug, are usually done on healthy people to look purely at the safety of the drug. However, in some cases the safety studies will be done in patients—for example in gene therapy studies where there is risk involved in undergoing the procedure that cannot be justified in someone that

could not benefit from the treatment. In these cases, the safety studies are done in small numbers of patients initially. In all Phase I studies, the dose of the drug is carefully monitored, and typically increases over time as lower doses are determined to be safe.

If the Phase I trial is successful, the drug will be moved into Phase II studies. These studies are larger and involve only a couple of dose groups and usually include a placebo control. A placebo is a group of patients who do not get the drug—although neither they nor their doctors know who they are (they get a sugar pill or injection of salt water that resembles the treatment). The placebo is necessary to ensure that any effect seen in the trial is because the drug works, not because the patient thinks the drug works (the “placebo effect” where patients in trials improve slightly is well documented—a drug must help the patient improve more than they do on placebo to be deemed effective).

In traditional drug development, a successful Phase II trial is followed by an even larger Phase III trial that involves thousands of patients. In FA, of course, we couldn't find thousands of patients, even if they were willing! The FDA understands this, and in orphan diseases like FA, a drug may be able to be approved on a larger Phase II trial, or on a Phase III trial that is much smaller in size. However, the bar is still set high—the sponsor still needs to prove that the drug causes a significant improvement in a measure that is meaningful to patients' lives over the course of a trial. In FA, this typically means that you can measure a reduction in the decline of something important over the course of a one- to two-year period. Currently, the FARS score is the most common measure, but FARA is working with clinicians to develop additional endpoints that could be used.

Getting through all of these steps takes a long time. FARA is working hard to ensure that no time is lost, however—while a two-year trial will take two years, whatever you do, FARA is working to develop new trial designs, biomarkers and endpoints that can detect changes more quickly, particularly for the earlier phase trials, so that we can more quickly figure out if a treatment might work (or not). We also work to reduce the time lost at every other stage in development! One way that you can help is if you are interested in taking part in clinical research, make sure that you are registered with the FARA registry, and that your profile is up to date, so that you can be easily contacted if you are eligible to take part in a study. ●

Clinical Studies are Critical to Research Advancement!

For more information on the latest clinical research and to learn how you can participate, please visit:

Patient Registry

curefa.org/patient-registry

Collaborative Clinical Research Network

curefa.org/network

Clinical Trial Participation

curefa.org/trial

Memorials

FARA remembers the friends we have lost, and we thank all who chose to remember a loved one with a donation to FARA. In the past year, we have received over \$62,000* in memory of the following individuals:

Aaron Kittel, Alex Horchak, Andrew Serpa, Angel Pettit, Anne Sarah Cook, Art Biegel, Aubrey Olson, Carol C. Mailloux, Cecilia Dauterman, Charla Lindsey, Chelsea Lane, Christopher Bennett, Dan Kirkland Wells, David Smith, Donnie Hawthorne, Doris Ann Yarborough, Dorothy Troyer, Douglas Spooner, Edward A. Thomas, Eliza Jane Foster, Elizabeth Sloper, Eric Christensen, Esther Goldman, Eugene Hannemann, Evelyn McNett, Evelyn Ragland, Gerald Vroman, Hannah Saunders, Jack Reynolds, Jason Head, Jeanne Robbins, Joe DeVore, John “Jack” O'Brien, Joyce Morris, Judith Folkard, Karye J. Willard, Keith Andrus, Kenny Treece, Kevin Maher, Kristen Frey, Laura Busenlehner, Lena Nardi, Lillian Logan, Lora DiPietro, Margaret Hannemann, Mark W. Clark, Mary Ann Mulligan, Mary Maxwell Cook, Mary Norman, Maxine Stingle, Michael Soto, Mildred McNulty, Nathan Bell, Nicholas Johnson, Nick Olson, Pam Norman, Percy Penn, Phillip Bennett, Phyllis Burgoyne, Pop-Pop Andresen, Rick Cilenti, Robert Foster, Robert Petrini, Roger A. Regner, Ruth Frank, Samuel Longnecker, Sara Ferrarone, Thomas Barnett, Thomas Yiannis Hood, Toni Rossi, Trevor Smith and Vincenzo Consiglio.

To request envelopes to be used for memorials, please contact FARA at info@cureFA.org.

*December 2014 - November 10, 2015



It's All About The Family

By Kyle Bryant

rideATAXIA belongs to the whole FA community and their supporters. The success lies in numerous families and their communities planning, recruiting, fundraising, volunteering, and cycling. The 2015 rideATAXIA program welcomed over 2,000 participants, including representatives from 93 FA families, who raised more than \$750,000 in support of FARA's mission to treat and cure FA.

There are a number of contributing factors to a successful ride program. First, our generous sponsors, in particular our National Presenting Sponsor, Outback Steakhouse, make the ride possible. Outback Steakhouse, joined by Carrabba's Italian Grill and Bonefish Grill in some locations, prepares an unparalleled post ride meal that sets rideATAXIA apart from other area rides. In addition to working with some incredible sponsors, rideATAXIA is honored to work with many dedicated FA families who help us execute each ride.

At every ride location, there is one person (or a core group) holding it all together and filling in the gaps whenever there is a need. At rideATAXIA Orlando, this person is Jennifer Shaw and her MO is "whatever it takes." Jennifer organizes many volunteers, secures rest stop donations and post lunch beverages, stuffs registration packets, connects us with an awesome volunteer DJ and talented photographer (thank you Frank and Kerry!) and spreads the word to friends, colleagues and even strangers. Jennifer is co-captain of Team TARA for FARA with her daughter, Tara Ryan. Tara said, "Participating in the rideATAXIA events is a great and fun way to raise funds for research. I was just accepted to be a part of a clinical trial at the University of Florida starting next month. Without these fundraisers I know that this trial would not be available to me. I am so happy to do my part in finding a treatment or a cure for FA." Team TARA for FARA has consistently drawn a large team of riders and is always one of the top fundraising teams.

rideATAXIA Orlando welcomed 300 cyclists who raised over



Team TARA for FARA gathers for their traditional team photo after the 2015 Orlando ride.

\$80,000. The rideATAXIA program relies on a number of teams to recruit riders and raise funds, and Orlando is no exception. Here are some highlights from our top Orlando teams for number of participants and fundraising.



The largest team in rideATAXIA history- Team Gavin at the 2014 Orlando ride.

Team Gavin's leader is the unstoppable 10-year-old, Gavin Lambert. Gavin has a strong co-captain in his friend, Tom Bradley. Together, these two guys have recruited the largest team from their hometown in Tampa and brought them to Orlando for the past two years. In 2014, they recruited over 100 riders which made their team the largest in the history of the ride program. Gavin's mom, Dawn said, "rideATAXIA has shown us that no matter the

ability or disability, everyone is going to give it their all and is really out there to enjoy the ride.”



Team Crizzy, the top fundraising team in Orlando, gets ready to ride.

Inspired by Christian and Isabelle Maugee, Team Crizzy has been the top fundraising team in Orlando, raising over \$20,000 annually. Team Crizzy travels over three hours from Ft Lauderdale, FL to participate in the ride. Team Captain, Caroline Maugee said, “We love to be surrounded by all the awesome families like us that are affected by FA. We know that by fundraising for FARA we are closer to finding a cure! Go Team Crizzy!”

In 2016, one of rideATAXIA's goals is to recruit more Family participants than ever before—whether that's on the planning committee, riding, fundraising, volunteering, or just coming to lunch to connect with the community. Please join us for one of our 2016 rides. ●

2016 Upcoming rideATAXIA Events

Dallas	April 9
<i>New Location!</i> Atlanta	May 15
NorCal	June 4
Chicago	July 24
Philadelphia	October 16
Orlando	November 13

Get all the details at www.rideataxia.org.



One of the top fundraising teams at rideATAXIA Philly, hope for toMORROW, gathers in their matching team shirts.



The 12 mile cyclists take off from Channahon Central Park for the 4th annual rideATAXIA Chicago.



Team Hook a Cure looking triumphant after another rideATAXIA Chicago.



Kickin' FA at the 7th Annual Energy Ball

By Jamie Young



Suzanne Avery giving special recognition to Honorary Chairs Tod and Tara Leiweke for their sincere generosity and dedication to FARA.

"We all have the things about us...that can cause so much pain, but we can choose how to feel it." These words, spoken by Liam Dougherty in the 2015 Energy Ball video, helped spark a packed ballroom of more than 700 attendees to choose to feel the energy and raise an all-time record of more than \$500,000 in just a few short minutes. The fund-a-cure donation drive helped the event gross \$2 million including in-kind gifts and financial contributions.

The "Kickin' FA" theme of the three-day event laid the groundwork for an elegant country decorated ballroom including studded cowboy boot centerpieces, but the symposium kicked the weekend into gear by creating energy through sharing tangible research progress. The Understanding a Cure symposium hosted by Drs. Theresa Zesiewicz and Cliff Gooch at the University of South Florida (USF) opened with USF President Judy Genshaft extending a warm welcome to all guests. Speakers from four pharmaceutical companies, Reata Pharmaceuticals, Horizon Pharma, Retrotope and Agilis Biotherapeutics attended; Reata, Retrotope and Horizon currently have drugs for FA in clinical trials. The pharma companies participated on a panel and discussed the science behind each of their FA drugs, where they are in the research

process, and what still lies ahead to reach the finish line of FDA approval. The symposium included the popular patient panel, featuring Jade Perry, Erin O'Neil, Kendall Harvey and Chris Nersessian giving insight on living with FA. To view the video from the symposium visit: <http://www.ustream.tv/channel/curefa>

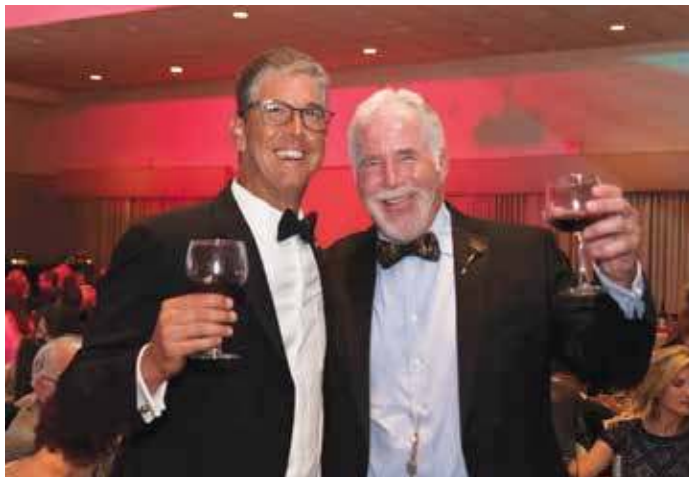
The Bourbon and Brew patron party sponsored by Agilis at Amalie Arena included delicious bites from Bonefish Grill. Beverages were flowing in custom Energy Ball Moscow mule mugs along with laughter and good conversation among old and new friends excited to be part of this annual event.

The Ball opened Saturday evening with Technical Sgt. (retired) Sonya Bryson, "The Voice" of the Tampa Bay Lightning, singing the national anthem. In addition to bringing an indescribable energy and pizzazz to the event, six-time Energy Ball Emcee and ABC Action News Anchor Wendy Ryan delivered an inspiring speech to set the tone for the evening. The legendary auction once again lived up to its name through its unique variety of items and experiences including generous trips and dining packages for the local Tampa area, a trip to Hawaii, a Billy Joel concert at Madison Square Garden, and the Ultimate NFL Fan Experience with Energy Ball Chair and NFL Chief Operating Office (COO) Tod Leiweke.

The evening ended with delightful sounds from the band Southern Train and the solidarity of friends and FAMily coming together once again to successfully fund research progress. As one of the 700 hundred people in the room I would describe the energy at



Beautiful ballroom for a beautiful night! – Thank you Ava Forney and A La Carte Event Pavilion.



FARA dedicated supporters Paul Jacobs and Shon Craig say cheers to a cure!

Thank You to Our Energy Ball Sponsors

The Avery Family Foundation



the 7th Annual FARA Energy Ball as a faithful friend that continues to wrap its arm around your shoulders and say I'm in this with you—let's get the job done.

Special thank you to Ava Forney, the planning committee, financial and in-kind supporters: your talent, time, generosity and dedication set the stage for a successful event.

"It really takes all of us—supporters, scientists, and individuals with FA. Together we are changing the world of FA, and together we are at the tipping point of meaningful therapies for people living with the disease."

—Laurel Avery •



FARA Store

For yourself, your family and friends, or to have customized FARA items at fundraising events, visit the FARA store!

www.cureFAstore.com

FARA caps, polo and t-shirts, wristbands, etc.

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Jordi Magrané: A Barcelona fan with goals in mind for FA

By David Woods, PhD

Barcelona born Jordi Magrané says that his interest in mechanisms of neurodegeneration and the role of mitochondria in neurodegenerative disease led him at first into research on Alzheimer's and ALS.

But since working with Friedreich's Ataxia, he has found a greater sense of collaboration and less competitiveness than in the other areas of research he has tried. Research in Friedreich's Ataxia is an area, he says, in which he's felt really comfortable. And he credits FARA for much of that. His interest in abnormal mitochondrial axonal transport is especially applicable in FA.

Jordi, who is an assistant professor of neuroscience in Cornell's Brain and Mind Research Institute, has dedicated his efforts towards developing novel microscopy-based live imaging assays to assess the role of mitochondrial dynamics in diseases like Friedreich's Ataxia.

His research work has attracted support from a number of institutions, including grants from FARA. Jordi has served as a reviewer for several science journals... and is the author or co-author of some 25 articles, as well as giving multiple presentations at conferences and workshops.

But when he is outside of the scientific community, Jordi spends time at his Roosevelt Island home swimming, and also cooking, which, he says are the only hobbies that relax him; in fact, he says, as a relatively recent US resident, he has organized barbecues and is 'always at the grill.'

But as well as that, he enjoys the theater, music and movies and is also an avid reader, mainly of science texts. Reading not just science, Jordi lists Nick Hornby, Jonathan Franzen and Miranda July as his favorite authors. "And every time I enter a bookstore, I end up buying something," he says.

Jordi is a proud Catalan, although not necessarily a separatist for that region of Spain; but of course, as a native of Barcelona,



Jordi Magrané

he's also a big soccer fan and tries to watch his home team, which is a symbol of Catalan culture, as often as he can. Like its players, Jordi has goals in mind.

In his case, it's helping to find a cure for FA. ●



Applications for the 2016 Ataxian Athlete Initiative will be accepted from February 1 to April 30, 2016.

The AAI provides, through a competitive grant process, adaptive cycling equipment to people with all types of ataxia who have demonstrated the desire to stay active and healthy despite their disabilities.

For more information visit:

curefa.org/ride-ataxia



Yogesh Chutake: a love of research; and especially its ‘bench to bedside’ approach

By David Woods, PhD

Yogesh Chutake has always loved research since the time of his being a research scholar at the University of Mumbai in his native India.

Yogesh was offered research opportunities in the UK and Europe but decided on the US, coming to the United States as a PhD student and continuing as a post-doctoral research fellow at the University of Oklahoma Health Sciences Center.

His great mentor is Professor Sanjay Bidichandani -- one of the scientists involved in discovering the gene and specific mutations that cause FA. Yogesh co-authored a number of peer-reviewed publications with Professor Bidichandani including one titled ‘altered nucleosome positioning at the transcription start site and deficient transcriptional initiation in Friedreich’s Ataxia.’

That’s where you’ll find him today, working in his area of expertise—genetics and epigenetics, biochemistry and molecular biology.

As well as the work, though, he discovered something else: In India, he says, some students tend not to question or even contradict their teachers, who are looked upon as authority figures. But in the US he found greater give-and-take between student and teacher, thus fostering curiosity, which, Yogesh believes, is the basis for research. Not only that, but he’s also discovered that the higher up the academic scale one goes, the more likely one will find down to earth attitudes and a willingness to engage in dialectics.

As is entirely appropriate for someone interested in probing mysteries and seeking solutions, Yogesh is a huge Sherlock Holmes fan. He is also interested in tennis and in camping and trekking... and engages in such socially active works as Habitat for Humanity—an international nonprofit that helps people all over the world build affordable homes.

Above all, Yogesh has a special interest in what he calls ‘bench



Yogesh Chutake (far right) with members of his lab team and the FARA Ambassador Program during an ambassador visit to the University of Oklahoma.



Yogesh and his friend Sam Brown, from Oklahoma, at rideATAXIA Dallas.

to bedside training.’ In other words, he sees little point in doing research unless you can see how it benefits individual human beings. ●



Shoppers Gather for 10th Year at Stephanie's Hope Holiday Boutique!

By Ann Musheno

Shoppers raised \$13,500 for FA research at the 10th Annual Stephanie's Hope Holiday Boutique on November 14 in Valencia, CA, a festive event with more than 30 vendors, a 12 Days of Christmas raffle, a bake sale, food trucks, as well as special Stephanie's Hope T-shirts and reusable shopping bags.

Event organizer and FARA Ambassador, Stephanie Magness, said the first boutique was planned at the suggestion of one of her best friends and her mother. She says, "I thought it sounded great, so my family, friends and I jumped right into the planning!" They had so much fun the first year, they decided to make it an annual event. Since then, the event has raised approximately \$100,000 as part of our Grassroots Fundraising Program.

Central to the event's success is the dedicated group of family and friends that help put the event on each year. Stephanie says, "My favorite part of the Stephanie's Hope Holiday Boutique is the overwhelming reminder of how much and how many people I have to be thankful for."

Another factor contributing to the event's success is Stephanie's careful attention to evolving marketing trends, which has shifted her promotional focus to social media. An important social media strategy is to post a lot about herself on the Stephanie's Hope Twitter, Facebook, and Instagram pages because as she puts it: "People relate to people, to real life."

Even with a dedicated group of supporters and social media savvy, putting on a fundraiser of this magnitude is not without its challenges. As Stephanie will tell you, one of the hardest things about fundraising can be putting yourself out there. "Fear of being judged and found wanting has been a struggle, but you kind of just have to squash it and embrace who you are. It's a learning process that I doubt ever ends," she says.

For new FAmilies interested in fundraising, Stephanie says the best way to fundraise is to do "something you enjoy and to always



Holiday shoppers enjoying the variety of talented vendors at the 10th annual boutique.

have fun while you're doing it." She adds that "fundraisers should not be afraid to keep trying new things and don't be discouraged if you fail. Failures turn into great learning experiences! Corny and cliché but so true."

Stephanie has decided that this year's Holiday Boutique will be the last, but she has no intention of stopping her fundraising efforts for FARA. She is already laying the groundwork for a new fundraiser in summer 2016. She foresees "a beautiful southern California summer night, outdoors, twinkly lights, country music, great food, great people and lots of fun!"

Stephanie's Hope Holiday Boutique is one of over 80 grassroots fundraisers held by families across the country each year. In 2014, FARA set an ambitious annual goal to raise \$1 million called Mission 1 Million. Fundraisers exceeded that goal and the program is expected to once again reach \$1 million in 2015. To learn more about grassroots events occurring across the country or how you can host your own grassroots fundraiser, visit curefa.org/grassroots. Together we will cure FA! ●



Members of the Magness, Bryant and Brown families take a Family photo in their Stephanie's Hope Cure FA t shirts.



FARA Honors 2015 Partner and Friend & Ally

By Felicia DeRosa

They gather in the early mornings and the late evenings. They spend countless hours and weekends preparing auction displays, raffle baskets, registration lists, recruiting vendors and sponsors and promoting their events. They give us their time, their talents, their creativity and their resources. They are the hundreds of volunteers that advance FARA's mission to treat and cure FA. Whether you host an event of your own, serve on a planning committee, volunteer at an event, act as an advisor or provide services—thank you most sincerely for sharing our passion to advance FA research and taking action.

Partner of the Year

FARA is pleased to announce that the recipient of the 2015 Partner of the Year award is Amalie Oil and the Barkett Family. For many years, they have exceeded the criteria for the award including:

- **Leadership and/or employees/constituents within the partner organization are directly supporting FARA's mission and demonstrate a commitment to curing FA faster than thought possible (e.g., fundraising, in-kind contributions, professional services, etc.).**
- **Organizational culture that values community, helping others, volunteerism.**
- **Commitment to increasing awareness of Friedreich's ataxia or FARA.**

As a family-run business, Amalie Oil and the Barketts have demonstrated a strong commitment to community by giving their time, talent and treasure to support FARA's mission. The Barketts have been long standing members of the planning committees for both the FARA Energy Ball and Ace for a Cure tournament. Members of the Barkett Family roll up their sleeves to volunteer at several Tampa area fundraisers including registration at the Pull for a Cure event, auction preparation for the FARA Energy Ball, and event planning for Ace for a Cure. Additionally, Amalie Oil has repeatedly been a presenting sponsor of the Ace for a Cure tournament, silver sponsor for the Energy Ball, and a lead con-

tributor to the Fund a Cure initiative at the FARA Energy Ball. As individuals, a family, and a company, the Barketts and Amalie Oil have championed FARA's cause and been valued partners in our efforts to advance FA research to meaningful therapies to people living with FA.



Partner of the Year, Anthony and Lorraine Barkett.

Friend & Ally

FARA is honored to present the 2015 Friend and Ally award to Sandy Callaghan. Sandy started as a good neighbor but quickly became a treasured friend and long time ally of FARA. Upon learning that a family in her neighborhood was living with Friedreich's ataxia, Sandy teamed up with Roger Cypriano and Avila Golf & Country Club to initiate the first Ace for a Cure event in 2009. Ace for a Cure is a three-day fundraiser that includes a meet

Continued on Page 19



Sandy Callaghan with Kyle Bryant at the 2014 Ace for a Cure event in Tampa, FL.



The FARA Ambassador Program

By Alex Fielding



Members of the The FARA Ambassador Program photographed by Rick Guidotti for Positive Exposure at the CHOP Symposium.

“The FARA Ambassadors are positive, supportive, peer representatives for the FA community, actively raising awareness and funds for FARA.” The FARA Ambassadors live each day by this mission. But to fully understand what we do, it’s best to understand who we are.

We are outgoing individuals from different walks of life, diverse educational and professional backgrounds, with unique hobbies and interests, living in homes across the globe. We all have FA, each at various stages of progression and with personalized experiences living life with the disease. Aside from a FA diagnosis, we all share one thing—the energy and ambition to put life before FA, for ourselves and everyone battling FA.

We do this by supporting FARA and their mission to “...marshal and focus the resources and relationships needed to cure FA...” You will see us at fundraising events—drawing crowds, laughing, and meeting new friends. You will hear us through social media—advocating for FARA, spreading awareness, and amplifying the voice of all FA patients. You will talk to us as friends—eas-

ing nerves for newly diagnosed, sharing tips for living with FA, and imparting optimism at troubling times. You will touch us with your inspiring stories, creating a chain reaction that spreads through the FAmily, offering encouragement and hope.

Besides serving as peers and dedicated activists in the FA community, we work together on several projects to advance our efforts. Below are brief descriptions of the five active projects the FARA Ambassadors bring to the community:

• **The FARA Ambassador Blog**

As the primary means of communication between the Ambassadors and the community, the blog serves to share inspirational stories from FAer’s across the globe, highlight fundraising success stories, introduce key FARA initiatives, and much more! It is a mechanism for everyone to stay abreast of the global headlines happening every day in the FA world. With FARA Ambassadors continually authoring new posts, the blog is a must-have bookmark on any web browser, and the best daily medicine we have to offer. We love when you share your comments! curefa.org/ambassadors

• **FA Hangouts**

For two nights every month, the Ambassadors host online video meetings using Google hangouts. The name is fitting – the several hour sessions develop into an open discussion around a general topic, such as pets, movies, fundraising, or hobbies. It’s a convenient, fun forum for fellow FAer’s around the globe to meet, laugh, and share their perspective on enjoying life with FA.

• **Card Program**

In the modern age of technology and electronic communication, the written word still holds the most value. With so many individuals sharing their personal stories, organizing fundraising events, championing rideATAXIA teams, and supporting FARA’s initiatives, the Ambassadors created a team of people to personally

thank each one. The Card Team handwrites personalized notes to every major contributor in the community. We feel a written message is the only way we can come close to conveying our sincere appreciation for all the dedicated efforts shared by our supporters.

• *Speaking*

As FARA Ambassadors, we find ourselves in situations where our voice can impact a crowd. We practice telling our personal stories to convey at fundraisers and major FARA-sponsored events. We visit research labs and pharmaceutical companies to express our appreciation for their work and offer a personal attachment to motivate their efforts. Rehearsing speeches with each other, we focus our message into a powerful instrument to advocate for FARA and draw an emotional connection to everything this community does.

• *Social Media*

Growing awareness depends not only on capturing inspiring stories, but the ability to communicate them. To spread all the great stories we coordinate, the FARA Ambassadors continually update accounts on several social media platforms. Like and share our stories on Facebook. Experience events with us through Instagram photos. Follow our Twitter to keep informed on FA-related news. Accessible online and on mobile devices, we want to ensure you're never disconnected from your FAMily.

This is who we are and this is what we do. And these are a fraction of the inspirational messages we have the privilege of bringing to the community...

"FA doesn't control or define me. I hope I am known for my strengths rather than my weaknesses."

—Brian Bianchi, Meet the Community

"Life is fun and way too short not to enjoy. Even on wheels. Especially on wheels."

—Mandy Davis, Meet the Ambassadors

"For the last 12 years every second Sunday in September is the Fuzzy Buzzy Golf Tournament. I am always overwhelmed and amazed by all the support and generosity I experience."

—Erin O'Neil, Fundraiser Recap •

Partner, Friend & Ally of the Year

Continued from Page 17

and greet with a professional tennis player, a round robin tennis tournament, a teach-a-thon and a series of tennis exhibition matches. In the first few years of the tennis event, Ace featured professional tennis player James Blake. In 2011, Blake passed the torch to professional tennis player John Isner who still headlines the event, now in its seventh year. With the support of generous sponsors, Ace has increased its fundraising proceeds every year and in 2014 raised over \$70,000! Sandy has been at the helm of this event—assembling a dynamic planning committee, promoting sponsorship, and preparing a live and silent auction, to name just a few of the key tasks.

Sandy's efforts for FARA grew into a year-long endeavor when she joined the FARA Energy Ball planning committee and became a critical member of the auction committee. If you've been to the Energy Ball and seen the displays for the 300+ auction items, you've encountered Sandy's work. Every item has eye-catching photos and a detailed description, capturing the guests' attention and encouraging them to bid. As she heads up the auction check-out station, Sandy ensures that all guests leave with the appropriate items, and often times, she is the last person to leave the event.

Sandy invests long hours behind the scenes ensuring the success of her events. In the many years FARA has called her a friend, she has never sought recognition or anything in return. Sandy has remained a constant, quiet presence with work ethic beyond measure. We are truly honored and grateful to call Sandy both a Friend and an Ally. •

**For accessories, home decor,
toys and more, visit
<http://shopping4.org/kickinfa>
5% of all purchases
will be donated to FARA.**

Fundraising



Pete, Brendan, Francine and Eilish Welsh pose for a family picture at Welsh Bash in the Backyard on July 31. (Harrisburg, PA)



Golfers take a break on the course to pose for a selfie at the Century 21 King Golf Classic on September 24. This annual event honors Josh Lamsacus and his family. (Fontana, CA)



Christophe Lenglet high-fives spectators while competing in the 2015 Ironman Wisconsin on September 13 on behalf of FARA and rideATAXIA. (Madison, WI)



Golfers show off their unique sense of style to FARA Ambassador Erin O'Neil at The Fuzzy Buzzy Charity Golf Tournament on September 13. (Windham, NH)



The crowd poses for a group shot at the 33rd Annual Claxton Classic Golf Tournament on July 31. (Windsor Mill, MD)



Members of the Key Club at Parkersburg South High School throw up colored powder at the "Unlocking the Cure 5K Color Run" on October 17th in support of Anna's Army. (Parkersburg, WV)

Fundraising



Students and friends participated in the F.A.T. Run at SUNY Oswego on September 26. The was held in honor of SUNY Oswego student Patrick Schrader and the name stands for "Fight Ataxia Together." (Oswego, NY)



Volunteers decked out in 1920s garb sell candy and balloon pop chances at "FA-ITH: A Night in the Roaring Twenties." The November 7th event, planned by cousins Matt and Sam Rupel, featured card games, a balloon pop, live jazz music, a silent auction, drinks, and dinner catered by Outback Steakhouse. (Sunnyvale, CA)



John Lagedrost looks back while running The Marine Corps Marathon on October 25 as part of Team FARA. (Arlington, VA)



On July 25, this team of 8 cyclists took part in the Bob Cook Memorial Mt. Evans Hill Climb. The race takes place on the highest paved road in North America, starting at an altitude of 7,540 feet and terminating at 14,130 feet. (Idaho Springs, CO)



Many FA Families came out to the Stacks family's 6th Annual Swing Away at FA Wiffle Ball Tournament & Family Fun Day on October 24. The event featured a wiffle ball tournament, silent auction, face painting, food, t-shirts and more! (Dawsonville, GA)



FARA Ambassador Paige Myers smiles with friends at "FA Halloween Bash! Costume for a Cure" on October 25. Planned by Chelsea Conley, the family-friendly costume party featured food, music, and games. (Flushing, OH)

Fundraising



Participants and supporters of TEAM DONOVAN gather together before the Zoot Westchester Triathlon on September 27. (Rye, NY)



Attendees pose with the check after the Funny 4 Funds comedy night on July 31. The event featured a 90 minute stand up comedy show and all funds raised went to The Race for Matt & Grace campaign for FARA. (Cranston, RI)



Alex Fielding poses with some of "Alex's Avengers Against FA" at the 6th Annual Race for Matt & Grace on September 26. (Smithfield, RI)



Participants run, roll, and skip at the Slim's Journey 5K Run and Walk on September 12 (Warrenton, MO)



Clay shooters pose at the Rocky Mountain Bird & Birdie on September 25. (Brighton, CO)



Rob Perreault is pulled up to the tree tops at FA Adventure Days. This event, hosted by Project Adventure, gives Families the chance to get to know each other, solve problems, build trust, and take risks. (Beverly, MA)

Fundraising



*Families bond at South Tampa Bowling for a Cure on July 16.
(Tampa, FL)*



Slim's Journey participants celebrate at the finish line. (Warrenton, MO)



Team FARA member, Hannah Feinberg cycles in the Lake Placid Ironman in honor of her friends Alison and Laurel. (Lake Placid, NY)



The planning committee gathers for a photo at the Great Pumpkin Run on October 3. (Bakersfield, CA)



*Competitors at the Tough Enuff to Jump dog jumping contest on October 3.
(Summit, MO)*



The Family at FA Woodstock on the Flying H Ranch. (LaPorte, IN)

FARA

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WINTER 2015-2016

the Advocate

Your connection to the Friedreich's Ataxia Research Alliance



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