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Clinical Trials Update

Clinical Trials Now Underway

By Jennifer Farmer

Once a potential drug or compound of interest is discovered in the laboratory, it is not a quick and easy path to testing in patients (clinical trials). In fact, many potential drugs and compounds never make it to clinical trials for a variety of issues – the compound may be too toxic or not biologically active in humans, for instance. So, when a drug or compound makes it through all of the necessary pre-clinical testing and regulatory approvals to enter human clinical trials it is only natural to have high expectations and hope.

Experience with other diseases has demonstrated that we need clinical trials to understand truly the risks and benefit of any potential drug or treatment. While the laboratory and animal studies can help us understand and predict how the drug may work in humans, we will only know for certain once we do the human studies. Okay – so it's not a straight path but still, once in humans, straightforward enough, right? Well, not quite… clinical trials are experiments, which means that design, controls, environment, and reproducibility are all very important and can impact the result and interpretation of the findings. Like any experiment (even those you may conduct in your kitchen or on your car engine) you start with what you believe to be the best design, but sometimes you need to go back, re-design, and try again. It really is trial and error for lack of a better phrase – the goal is to advance the drugs with the highest likelihood of benefit quickly and safely with well planned trials. The trick is not to let drugs that are destined to have benefit fall away because of misinterpretation or bad study

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In this issue:

Ride Ataxia III

190 Miles and $360,000 for FA Research

By Felicia DeRosa

Overcast, slightly rainy and threatening to do more – a typical day of March weather in Portland, Oregon – but not such a routine day along the streets leading out of the city. There, a group of nearly 70 cyclists strongly connected to one cause – Friedreich's ataxia research – were about to join Kyle Bryant and embark on Ride Ataxia III, a 190-mile journey to Seattle. They studied their maps, stretched, and anxiously debated just how much gear would be needed to protect against the elements.

The Ride Ataxia III team cycled from Portland to the National Ataxia Foundation's Annual Membership meeting in Seattle.

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What is Friedreich's ataxia?

Friedreich's ataxia is a debilitating, life shortening, degenerative neuro-muscular disorder. Onset of symptoms can vary from childhood to adulthood and can include loss of coordination (ataxia) in the arms and legs; energy deprivation and muscle loss; vision impairment, hearing loss, and slurred speech; aggressive scoliosis (curvature of the spine); diabetes mellitus; and a serious heart condition. While the mental capabilities of people with FA remain completely intact, the progressive loss of coordination and muscle strength in FA leads to motor incapacitation and the full-time use of a wheelchair. There is currently no treatment or cure for FA. FARA is a 501 (c) (3) tax exempt, non-profit organization dedicated to supporting research that will improve the quality and length of life for those diagnosed with Friedreich's ataxia and will lead to treatments that eliminate its symptoms.

President's Message

Dear friends,

The FA community's momentum continues to build in our drive to find treatments and a cure. With the recent announcement of the Varenicline (Chantix©) study, six trials are currently being conducted and additional FA trials are to begin this year (see Jen Farmer's Clinical Trials Update on page 1 for details). Most of these clinical trial drugs are aimed at different targets in the FA disease process and might be shown to provide more benefit in combination than when taken alone. Furthermore, the FARA pipeline of drug discovery and drug development continues to fill behind these current drug candidates. FARA will not stop filling the pipeline until FA is cured.

FARA fills this pipeline through an active research alliance that is at the center of the global FA research effort and is growing in size and effectiveness. The efforts of FA researchers continue to be recognized, while their work is garnering increased funding from additional sources. With the support of our generous donors, FARA and its partners fund promising research around the world, assemble leading scientists (as we will again this summer to share their insights and enhance collaboration), and constantly bring together the full range of required scientific expertise – from the leading FA "discovery" scientists to drug developers, pharmaceutical companies and clinical trialists – all to speed up dramatically the time it takes to "discover" a promising avenue and translate it into a treatment.

None of this would be happening without your support. The backbone of all the clinical trials, of course, is the FA patients who continue to step forward to participate in them. We know that not all of these trials will be successful in terms of approved drugs but we know that they would all fail without sufficient patient participation. Another vital ingredient in all the clinical trials, of course, and in all types of FA research, is funding. Because of your generous support, FARA is now able to take an increasingly active role in accelerating the pace of FA research and expects to fund about $2 million in FA research in 2009. FARA also expects to attract to FA research a similar amount from other funding partners.

We have all learned that clinical research in the "treatment era" is far more expensive than the basic research that precedes and accompanies it. With so many clinical trials to be conducted, FARA will need increased resources to support them and continue filling the pipeline behind them. To help us meet that need, FARA has recruited a very talented woman, Juliann Green, as our Chief Development Officer. Juliann is someone who shares our passion for this cause and brings expertise in communications and donor relations to the FARA staff. Juliann has hit the ground running in her efforts to work with individuals, foundations and corporations to encourage them to consider including FARA in their major giving programs, expand awareness of FARA's mission and extend its reach into the philanthropic community, and support FARA's community-based fund-raising leaders. Please see the "FARA Welclomes Juliann Green" article on page 12.

Thank you very much for all your support. There is no doubt that, together, we will treat and cure FA.

Warm regards,

Ron

NIH Launches Program for Rare Diseases

The National Institutes of Health (NIH) is launching a new program to help develop treatments for rare and neglected diseases. Called the Therapeutics for Rare and Neglected Diseases (TRND or "Trend") program, the initiative will receive $24 million per year and is designed to help move scientists' discoveries through the difficult and expensive period of pre-clinical drug development referred to as the "Valley of Death."

A rare disease is defined as one with fewer than 200,000 American patients. Probably fewer than 10,000 Americans have FA. The NIH estimates that more than 6,800 rare diseases afflict a total of about 25 million Americans and only about 200 of those illnesses have effective drug treatments. The new NIH program is intended to help identify promising drugs for rare diseases by screening hundreds of thousands of compounds and then to advance the most successful candidates promptly through pre-clinical drug development that typically takes two to four years, costs about $10 million and suffers an 80-90 percent failure rate. If a new drug clears these significant hurdles, the TRND program will, if needed, help identify a pharmaceutical company to assist in taking the drug into clinical trials.

FARA has begun and will continue to work closely with the leadership of TRND to see if there might be ways in which FA research and drug development can benefit from this new initiative. The program will select only a few diseases each year so, with 6,800 rare diseases needing help, the FA community would be very fortunate to be selected. FARA will keep you informed of developments in this important initiative. For more information, visit http://rarediseases.info.nih.gov/files/TRND%20Press%20Release.pdf.

Ride Ataxia III
(continued from p. 1)

Their four-day journey would take them through more rain than sun and even a couple of unpredictable hail storms. At times, they shared the road with logging trucks, but they also enjoyed pedaling through quaint towns and along scenic biking trails. On their journey, they'd conquer the crossing of a formidable bridge and a 20% grade incline – a wall of a hill. Some had to contend with flat tires, but they patched them and kept on going, meeting challenges with determination and perseverance. Each night, they sat down as a team, swapped stories from the day, and shared a meal generously catered by a local Outback Steakhouse.

Why did they come here? Why did they travel from all coasts and many states in between? Some rode on behalf of their family member with FA – son, daughter, brother, sister, nephew, niece, or cousin. Others came in support of their dear friend – college roommate, high school friend, co-worker, or family friend. One clinician did it for his patients, and six ataxians did it for themselves and to empower the greater ataxia community. Perhaps some of the cyclists were looking for something to ground them, something to steady their course amidst life with FA. Or maybe the appeal was the personal physical challenge of 50 miles a day for four soggy days on a bike. Some admitted later with a laugh that they didn't know what they were getting themselves into.

In the end, the trikes triumphantly led the Ride Ataxia team into the National Ataxia Foundation's Annual Membership meeting in Seattle, where they were enthusiastically welcomed and celebrated by the ataxia community. Ride Ataxia III raised an unprecedented $260,000 that will be combined with funds from the Freidreich's Ataxia Research Alliance and the National Ataxia Foundation to award a total of $360,000 in grant money to scientists conducting translational FA research.

Thank you to all the participants, volunteers, and supporters of Ride Ataxia III – your Portland to Seattle adventure brings us that much further in the journey towards treatments and a cure for Friedreich's ataxia.

Special thanks to:
Sponsors: *Outback Steakhouse, Sierra Self-Insurance Services, Brown and Caldwell, Dasani, and Powerade*

Cyclists: *Michael Bryant, Tess Kretschmann, Mary Caruso, Chuck Holding, Kyle Bryant, Susie Kocsis, Ron Duckstein, Paul Avery, Jim Brown, Edie Lie, Karen Staples, Joe Gatto, Bart Rupel, Jason Helms, David Lynch, John Lockwood, Stephanie Lockwood, Sean Roberson, Roberto Vanegas, Kacey Lacativo, Mark Peterson, Becky Prater, Chris Prater, Matt Rupel, Guy Tiphane, Neal Lacativo, Paul Konanz, John Towers, Steve Bryant, Tyla Kingston, Ryan Voreyer, Blaise Hadley, Elizabeth Lacativo, Angela Lacativo Greene, Ricky Greene, Daryl Bigley, Claudia Sieber, Mark Grassi, Francisco Arrieta, Sandy Lane, Andy Smith, Amanda Morrow, Blake Andrews, Marion Clark, Adam Payne, Lance Hershman, Shirley Truong, Diego Colorado, Diane Nascimento, Daniel Parker-King, Anthony Grappo, Tom Decotiis, Amy Koepnick, Tom Bridgman, Sam Bridgman, Max Bridgman, Mark Niebuhr, Patrick Kruk, Beth Bax, Tyler Bax, Ryan Niebuhr, Brad Barker, Dylan Helms, Mike Gore, Cole Hendricks, Owen Lowry, Alex Edelman*

SAG Team: *Diane Bryant, Wally Krill, Mary Krill, Wendy Krill, Felicia DeRosa, Marilyn Downing, Susan Konanz, Pam Andresen, Mike Andresen, Nick Andresen, Jennifer Helms, Calvin Andrews, Pat Rupel, Jim Voreyer, Lenny Roberson, Bob Staples, Mike Kingston, Julie Robertson* ■

See more Ride Ataxia III photos on page **17**

By Marilyn Downing

Since January 2009, there have been 23 fundraising events for FARA. The following stories highlight four fundraisers who embraced their own strengths to host events around the interests of their community. One fundraiser employed her artistic creativity to organize an orchestral concert. Another hosted a celebration for family and friends to enjoy a night out. A third used her elementary school as the setting for a family friendly athletic event. And a fourth used her public relations background to raise awareness for FA. Special thanks to all of our event planners and their volunteer committees who work tirelessly to raise funds and awareness for FA research.

Be Creative

Mairi Thompson, a music teacher at Fox Chapel High School in Pittsburgh, organized an alumni orchestral concert entitled A Cellist for a Cellist. The concert featured cellist Kathleen Caballero from the Pittsburgh Opera Orchestra and honored Thompson's former cello student Lauren Krivinko, who has FA. Mairi creatively interwove testimonials about Lauren – as a student, as a friend, and as a sister – throughout the evening. Mairi writes in her testimonial, "You could count on Lauren to be the one to give the extra hug, to wipe the tear, or supply the cookies. It was therefore striking when those tables turned and she needed the hugs, the tissues and the sustenance." The evening of music and personal tribute raised nearly $5,000 for Friedreich's ataxia research.

Alec belting out a tune at the Stars for a Night event in Pittsford, NY.

Celebrate!

If Dave Brown and Mary Hallett are planning it, you can count on it being not just an effort to raise funds for the cause but a true *party*. Their January event, Stars for A Night…A Glimmer of Hope, was held in Pittsford, a suburb of Rochester, NY. Guests to the Burgundy Basin helped to raise over $12,000 in honor of Dave's sons, Alec (12) and Colin (9), who have FA.

The evening included live music, dancing, food, a silent auction, a guest speaker (Dr. Bernard Ravina) and something special for the children. The "Kids' Hour" featured an ice cream bar for the children, who were able to play instruments and sing with the band.

When Alec walked in and happily remarked, "Wow, I can't believe how many people are here!" they all knew it was a success!

Get Active

About 350 of Evan's friends and family supported Evan's Race for the Cure and Family Carnival with a walk/run, basket raffle, magic show, balloon toss, guest speaker Kyle Bryant and a dunk tank (dunking the school principal—what could be more fun?). Tammy added additional kid's' games this year to make it even more appealing to families. This 5th annual event raised $25,000 for research.

Evan's Race for the Cure: Felicia DeRosa, Greg Luebbe, Tammy Luebbe, Blair DeSaw, Kyle Bryant, Pamela Rasey, Graham Luebbe and Evan Luebbe at Evan's Race for the Cure in Liberty Township, OH.

Tammy Luebbe, Evan's Mom, starts planning early, making trips to local businesses, sending letters to past supporters, and meeting with her committee. She distributes race forms at local businesses and in the schools and is even on the morning announcements at Evan's school to generate support for the event. Neighborhood blocks pool their resources to create and donate sought after gift baskets for the event raffle. Evan says, "The walk is always a lot of fun and I feel really loved and supported by my friends, family and community. Everyone comes out to have fun, but the most important part to me is that we can help find a cure for FA..."

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Giovanni Manfredi, MD, PhD

Interviewed by Paul Marcotte

FARA's Scientific Officer Giovanni Manfredi was born in Rome, Italy on July 27th 1964. He attended a "Classical Studies" high school, where most of the teaching emphasized humanistic and literary subjects, such as Latin, ancient Greek, philosophy, literature, and history. His father was a criminal lawyer with a passion for history, classical music, and traveling to remote places around the world. His mother shared his father's interests, which they both passed over to their son. "Perhaps for these reasons, my intention after high school graduation in 1983 was to become a history major and begin an academic career in Italy. Things turned out quite differently!" Only a few months before university applications were due, Manfredi realized that medicine with a focus on research could provide him with the combination of intellectual challenge, human contact, and hands-on practice that he was seeking.

Can you tell us a bit about your educational and research background?
I attended the Catholic University of the Sacred Heart, Faculty of Medicine and Surgery in Rome. I graduated from medical school in 1989, and in the same year I enrolled in the residency program in neurology. In addition to the standard neurological training, I joined a group that focused on the clinical and pathological aspects of neuromuscular disorders, such as muscular dystrophy, mitochondrial encephalomyopathies, spinal muscular atrophy, ALS, and FA. After the rounds in the neurology ward, my afternoons in the lab were dedicated to processing and staining of muscle biopsies and learning the intricacies of histology and histochemistry. If I think about how little was known at the time about the genetics and the pathogenic mechanisms of these diseases, let alone their therapy, I feel quite satisfied about how far we have come along. Clearly there is a lot more to be done!

We were among the first laboratories to develop genetic and molecular screening for Duchenne muscular dystrophy in Italy, so I had the opportunity to learn techniques, such as the polymerase chain reaction (PCR) that were quite novel at the time – which makes me feel like a dinosaur. I also started to follow patients with genetic neuromuscular diseases in an ambulatory setting run by the Italian Union Against Muscular Dystrophy (UILDM), which later initiated the highly successful Italian Telethon initiative to raise funds for research in the field of genetic diseases.

In the last year of my residency, I earned a fellowship to come to New York City for a research elective at Columbia University, in the laboratory of Dr. Salvatore DiMauro and Eric Schon, who pioneered the research on mitochondrial disease associated with mitochondrial DNA mutations. In the course of the first year in NYC, I realized that disease-focused research in a great scientific environment constantly stimulated my curiosity and gave me a strong sense of accomplishment. Thus, I enrolled in a PhD program in neuroscience in Rome with the agreement that I could continue my research at Columbia University towards my thesis project. I obtained my doctorate in 1996. At that point my decision to pursue an academic career in the United States was made. I spent three more years at Columbia as a postdoctoral Associate in Dr. Schon's lab working on the molecular biology of mitochondrial disorders. In 1999 I was offered a faculty position in the Department of Neurology and Neuroscience at Weill Medical College of Cornell University in NYC.

I started my independent research, continuing to work on mitochondrial diseases and starting a new line of investigation on the role of mitochondrial dysfunction in ALS. Over the years, I have received funding for my work both from the NIH and from private foundations, such as the New York Academy of Medicine, MDA (Muscular Dystrophy Association), UMDF (United Mitochondrial Disease Foundation), ALSA (ALS Association), and The Robert Packard Center for ALS Research at Johns Hopkins University. My laboratory has progressively expanded, and now it includes two junior faculty, two postdocs, and one technician. In 2005 I was promoted to the rank of Associate Professor and in 2008 to full Professor of Neurology and Neuroscience.

You have a particular expertise in mitochondrial research. How does that apply to FA research?
FA is a genetic disease that affects a protein, frataxin, which is fundamental for mitochondrial function. Therefore, FA is a mitochondrial disease and shares common pathogenic mechanisms with many other genetic forms of mitochondrial disorders, such as impairment of energy production and excessive free radical production. Also, the tissues and organs that are preferentially affected in FA – neurons, heart, and pancreas – are frequently affected in several other forms of mitochondrial disorders.

Can you tell us about your research with ALS and how that may relate to FA?
Unlike FA, which has clear genetic causes, ALS is most commonly a sporadic disease, which means that there are no known inheritable causes. However, it is widely believed that in sporadic ALS there are genetic factors that predispose to disease. Such genetic "traits" are being currently investigated through worldwide linkage analyses. About 10% of ALS cases are familial. In these forms of

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design, or let drugs that are destined to fail continue on with test, retest, retest, retest – thereby draining precious resources.

Below are several clinical trial updates. For a complete list of all drugs that are in pre-clinical development or in the planning or implementation stages for clinical trials, visit the FARA website http://www.curefa.org/pipeline.html.

Varenicline (Chantix®)
Sponsor: FARA (Drug provided for the trial by Pfizer)

This is the first clinical trial funded primarily by FARA and is based on the work of Dr. Theresa Zesiewicz of the University of South Florida. Dr. Zesiewicz noticed that the uncoordinated movements (ataxia) and balance problems in a patient with fragile X tremor /ataxia syndrome improved greatly after he started Chantix® in an attempt to quit smoking. The symptoms worsened when the medication was discontinued. Dr. Zesiewicz found similar results when treating patients with other types of ataxia, including Friedreich's ataxia; Several of her case reports have been published in medical journals.

Chantix®, a Pfizer drug, acts at sites in the brain affected by nicotine. We currently do not understand how Chantix® might be working to improve symptoms of ataxia.

This new clinical study, sponsored by FARA, will investigate whether varenicline (Chantix®) improves neurological symptoms, such as balance, coordination, and sensory perception, all of which are significantly impaired in patients with FA. This study will also evaluate the safety of Chantix® in patients with FA. The double blind, randomized, placebo-controlled pilot study will be led by principal investigator Dr. Zesiewicz, at the University of South Florida College of Medicine, and co-investigator Dr. David Lynch, at Children's Hospital of Philadelphia. The study is being conducted in two phases. In the first phase subjects and investigators will be blinded, meaning that they will not know who is getting the active drug and who is getting placebo. In the second phase all subjects will receive the active drug.

For more information on this study – "Double-Blind, Randomized, Placebo-Controlled Pilot Study of Varenicline in the Treatment of Friedreich's Ataxia" -- go to www.curefa.org/ChantixStudy.pdf or www.CureFA.org/registry and select Clinical Trials.

We do **not** recommend that individuals who have FA and are not in the trial try Chantix® now. We strongly encourage people to wait for results of the clinical trial and until we understand how this drug might work.

Idebenone
Sponsor: Santhera Pharmaceuticals

Idebenone / Catena® - On May 19, 2009 Santhera announced that the phase III trial of Idebenone (Catena®) in the United States did not demonstrate benefit at the level of statistical significance. The company is hopeful that data from the U.S. extension study (in which all phase III participants are offered high-dose Catena® for one additional year) combined with data from the European phase III Catena® trial (twice as long, has three times as many patients and involves mostly adults) will achieve statistical significance so the drug can be submitted for approval as a treatment for FA. The U.S. trial did show that Catena® seems safe and well tolerated and that the patients taking Catena® improved their scores more than those on placebo.

A special thank you to everyone (patients, study investigators, coordinators and the sponsor) who has been involved in the U.S. and European studies. While the initial results of the US trial did not demonstrate statistically significant benefit, FARA is hopeful that the additional data from the U.S. extension study and the European trial will be sufficient to achieve that objective. It is therefore very important for everyone involved in these studies to complete them and to remain active and participate fully in all future evaluations. There is still much to be learned from the extension phase of the US trial and the ongoing European study.

Catena® does have conditional approval in Canada. Santhera has informed FARA that they are making every effort to communicate with Canadian physicians and regulatory agencies to ensure that individuals currently taking Catena® continue to have access to the drug until the additional results from both studies are available.

Deferiprone
Sponsor: ApoPharma

A phase I/II study of Deferiprone (iron chelator) was initiated at a number of international sites in France, Belgium, Italy, Spain, and Canada in 2008. The primary objective of this study is to demonstrate the safety and tolerability of Deferiprone in subjects with FA. The secondary objective is to evaluate the efficacy of Deferiprone for the treatment of FA. The study is fully enrolled and completion is estimated in July 2009. A special thank you to everyone (patients, study investigators, coordinators and the sponsor) who has been participating in this important study. We all are eager to receive results later in 2009.

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Outback Steakhouse Continues to Give Back

By Felicia DeRosa

"Let Go. Give Back." The banner hangs in the background of every Outback Steakhouse fundraising event. But it's more than a motto for Outbackers and their colleagues at the Bonefish Grill and Carrabba's Italian Grill. The slogan defines the culture of giving and community involvement fueled by those in the Outback organization, similar to the way FA research is advanced by the fundraising efforts of FA families.

Outback's giving extends beyond their generous financial support to the personal investment of time and resources to the cause. One Outbacker rode the Ride Ataxia III course with a picture in his helmet – to honor his friend with FA. Another told FARA, "We're really excited about the work you're doing and want to do everything we can to support it." Others have hosted luncheons and walk-a-thons and initiated restaurant fundraising campaigns for Friedreich's ataxia research.

In 2009, Outbackers and FA families teamed up again to host a series of successful luncheons across the country (Plymouth Meeting, PA; Toledo, OH; Jackson, MS; Oceanside, CA; Bakersfield, CA; Baton Rouge, LA; Bonefish Grill – West Chester, OH). Outback and Heineken also partnered to initiate a new campaign called Heineken with a Heart (Tampa, FL; Glendale, CA; Atlanta, GA; Baltimore, MD). Both organizations generously donated food, beverages, and raffle prizes to host a weekday happy hour in select cities to benefit FARA. Still other regions have organized a group of restaurants to host a large event or series of events.

Ride Ataxia
Eleven Outbackers braved rainy Northwest weather to join the Ride Ataxia III team in the journey from Portland, Oregon to Seattle, Washington to help raise an unprecedented $260,000 for FA research. Based on the success of this West Coast ride, the Outbacks in the Philadelphia area will host a one-day cycling event in October featuring 10-, 25- and 50-mile country road ride courses for all levels of cyclists.

Carolinas' WE Foundation
The Outbacks in the Carolinas initiated a year-long fundraising campaign, under the umbrella of the Carolinas' WE Foundation. One of their first events scheduled was a walk-a-thon on FA Awareness Day. A torrential downpour moved the quick thinking Outbackers inside, converting the event from a walk-a-thon to a bowl-a-thon. Several more walks and a golf tournament will be held later this year.

Stephanie Magness and Outbacker Julie Robertson at Glendale, California's Heineken with a Heart event.

Tammy and Evan Luebbe with the West Chester, OH Bonefish Grill team at their June luncheon.

Outbacker and Ride Ataxia III cyclist, Patrick Kruk and Valerie Bennett take time for a photo at the conclusion of the Ride.

Story and photos continued on p. 14

Suzy Zies (green vest) and her friend Lynn with the Toledo, OH Outback team at their fundraising luncheon.

Raise Awareness

When the Zies family was asked to get involved with an Outback luncheon, it turned into so much more than just showing up to eat lunch! Suzy Zies, from Toledo, OH, partnered with her friend Lynn Franck, calling themselves "two moms on a mission." With their combined marketing/advertising background along with lots of passion and energy, they enlightened their community about the disorder that plagues Suzy's son, Zac, 13. Zac is a humble guy, yet he's comfortable in the spotlight, as is his service dog, Zane.

Suzy approached Zac's teachers about using wheelchairs for a day in school to educate the other students about Zac's challenges, FA and the fundraiser. That day ended not only with the school highlighted on the local news, but with teachers reporting some very sore arm muscles.

With word spreading about the Outback luncheon through newspaper articles and within the school system, Suzy received a call asking if the luncheon could be announced on 13 electronic billboards around the Toledo area! Other people with Friedreich's ataxia in the community, previously unknown to the Zies family, became involved and embraced the idea of the luncheon. The Outbackers were extremely generous in donating their time and food to feed 200 attendees. All of these efforts raised over $8,000 and great awareness for FA research. ■

For more fundraising photos, see pages 14-16.

2009 GRASSROOTS FUNDRAISING EVENTS

August

San Francisco Bay Area Walk
August 1 San Francisco, CA

Backyard Bash III
August 8 Harrisburg, PA

FARA Energy Ball
August 27-29 Tampa, FL
www.curefa.org/energyball

September

Find a Cure Dinner/ Auction
September 11 North Branford, CT

Fuzzy Buzzy Golf Tournament
September 13 Massachusetts
www.fuzzybuzzycharitygolftournament.com

Peters Golf Tournament
September 14 Peoria, IL

Team Donovan – Westchester Triathlon
September 27 Rye, NY

October

McDonnell Music Festival
October 3 Queensbury, NY

Lone Star Benefit Golf Tournament
October 9 Dallas, TX
www.benefitbash.org

Chicago Marathon – Team FARA
October 11 Chicago, IL
https://app.etapestry.com/fundraiser/FriedreichsAtaxiaResearchA/chicagomarathon/

Ride Ataxia – Philadelphia
October 25 Philadelphia, PA
www.rideataxia.org/philly

Shop to Cure FA

FARA has partnered with Alliance Charities, a non-profit organization, to make charitable giving a simple process. Alliance Charities has secured arrangements with Google and with hundreds of online stores like Amazon.com, Wal-Mart, Target, Disney and many other major retailers to offer Cash Rebates for searching and online purchases. When you enroll as a Preferred Buyer, every qualified search and online purchase made through this site earns money that is donated to FARA on your behalf.

Visit www.shoptocureFA.org to register and start shopping!

the disease, there are genetic mutations that impair the function of specific proteins. Our work is to define the toxic effects that these mutant proteins have on mitochondrial function and the role of mitochondrial impairment in the pathogenesis of the disease. Importantly, just like frataxin in FA, ALS mutant proteins are expressed in all cells of the body, and yet only certain specific neurons degenerate. One of the greatest research challenges in both diseases is to understand the mechanisms underlying this specific toxicity, because this would give us a greater insight on how to intervene therapeutically.

What brought you to FA research?
It was quite serendipitous at first. After my clinical training, I followed some of the FA research development especially through my friendship and collaboration with Dr. Grazia Isaya, a long-term FARA investigator and scientific advisor. Last year, because of my work on mitochondrial diseases, I participated as a discussant to the Summit in Arizona organized jointly by FARA and MDA. It was a great opportunity to meet with Ron Bartek, Jennifer Farmer, Paul Avery, Bronya Keats and other great FARA investigators. Listening to the presentations and discussion, I started thinking about FA not only as a tough scientific and clinical challenge, but also as a great opportunity for achieving therapeutic results in mitochondrial diseases. When Ron asked me to consider the possibility of joining FARA, I was flattered, but also thrilled by the opportunity of working with a great group of dedicated advocates and scientists with a very focused mission.

What is your role at FARA?
I am the Chief of Science. This is a part-time consulting position, to which I devote a portion of my effort, while fully retaining my position and research responsibility at Cornell University. My work with FARA is mostly dedicated to the grant evaluation process, the identification of new avenues of investigation and scientific needs or gaps, the identification of additional insights and scientific expertise in other disease groups that could be helpful in FA, the relationship with FARA investigators, and the organization of scientific meetings and symposia.

Can you provide us with an overview of some of the key areas of FA research now underway?
FARA is mostly invested in basic and clinical translational research. This means that the majority of our effort is devoted to identifying novel and effective measures to cure or ameliorate FA. This happens at different levels, from in vitro studies, where potential therapeutics are evaluated in a test-tube, to clinical trials, where compounds that have been successful in vitro or in vivo models of the disease are finally tested in patients. We try to cover all the bases, from increasing the levels of frataxin in the body, to promoting mitochondrial function, to protecting cells from oxidative damage. We also, support clinical trials for drugs that do not directly address the disease mechanisms, but can significantly improve the symptoms and improve the quality of life.

Which areas of research do you find to be the most promising?
It is my hope that developing strategies to increase frataxin in affected cells to levels that are at the threshold for normal function is a goal attainable in a reasonable timeframe. Different approaches are being currently undertaken. For the time being, the pharmacological ones seem to be of more immediate applicability to patients, but genetic and protein replacement approaches are the most desirable in the long-term. In parallel efforts, several strategies for ameliorating the downstream effects of frataxin loss are also being undertaken, with mixed results. It is likely that a combination of the two types of approaches will eventually become the routine treatment strategy for FA.

Where do you see gaps in that research?
As far as basic-translational research, in my opinion, there are still many problems to be solved. The functional consequences of frataxin loss in the mitochondria are still widely debated, in particular in regards to the role of free iron and free radical generation. Another major issue to be resolved is how much frataxin is actually needed to achieve a normal mitochondrial function, which may be quite different in specific cell types. Finally, we still need to perfect the cell and animal models of FA to be used for drug screening and to test the efficacy of candidate drugs.

You also serve as a scientific ambassador for FARA with the government, other researchers, and organizations. What kinds of things are you doing in this role?
Together with FARA's president Ron Bartek and Executive Director Jennifer Farmer, we interact with multiple public and private agencies to promote FA research, both in terms of funding and to raise awareness in the scientific community. We follow the latest development in basic and translational research that applies directly or indirectly to FA, and we work towards attracting talented scientists with diverse expertise into the FA field.

How have you been received by FA families who are living with the disease on a daily basis?
I was received very warmly and it has been a great pleasure to meet with many representatives of FA families and FA patients, in occasion of our board meetings. The contact with FA families involved with FARA has been inspiring and illuminating at the same time. I am truly impressed by the strength, the level

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Featured Scientist
(continued from p. 9)

of commitment, and the trust that FARA patients and families invest in their organization and their scientists. For me it has been an important learning experience.

Do you see any lessons learned by the disappointing results of the Idebenone trials in the U.S. this year?
Yes, there is an important lesson, which is not new. It is harsh, but necessary, to understand the way clinical trials work, especially in rare diseases. They need to be well designed and powerful enough to reach firm conclusions. That is why they take such a long time to set up and complete. Idebenone still needs to be fully evaluated and the phase III trial needs to be extended. I would not be too discouraged, although I personally do not believe that Idebenone alone can be the only answer to FA.

What are your expectations for FA clinical trials over the next two to three years?
In the short term, we can expect more human trials with compounds that increase protection against cell damage by raising the natural cell defenses and boosting mitochondrial function, such as pioglitazone, which incidentally also appears to increase frataxin levels, at least in vitro. The pioglitazone trial is already ongoing in France. We will also see the beginning of trials with other compounds that are aimed at increasing frataxin levels, for example HDAC inhibitors. Gene therapy and protein replacement will probably take a little longer, and will have to pass through a series of validation steps in animal models to show feasibility.

How far away do you think researchers are now from a treatment for FA?
This is difficult to say, but considering that the cause of FA has been discovered in recent years, there have been very significant developments, both in the basic understanding of the disease mechanisms and in potential approaches to treat them. Much more needs to be done, but let's remember that FA still holds the status of rare (orphan) disease. In view of the limited resources available to the clinical and basic FA scientists, the steps that have been undertaken are remarkable. Many of these successes are the result of the support of advocacy groups like FARA, whose example is often mentioned as a model for many other organizations. More drugs will be put to the test in the coming few years, and many more will be discovered through novel and powerful high throughput assays that are currently being developed. The next challenge will be to choose the most promising ones and set up well-designed clinical trials. ■

Clinical Trials Update
(continued from p. 6)

Drug – A0001
Sponsor: Penwest Pharmaceuticals

A0001 is a compound discovered by Edison Pharmaceuticals, then licensed to Penwest Pharmaceuticals, that shows real promise of improving mitochondrial function (energy production) in FA patients and other patients with mitochondrial dysfunction disorders. Penwest initiated a phase Ia of the A0001 trial in July 2008 and phase Ib in February 2009. The Phase Ib trial is a placebo-controlled, multiple ascending dose clinical trial in healthy subjects designed to evaluate the safety and tolerability of A0001 and characterize the pharmacokinetic profile following repeat dosing. We anticipate that Penwest will announce data from this trial by this summer. Following completion of this safety trial, Penwest expects to conduct a Phase IIa trial in patients in the second half of 2009.

Your participation is critical. Please ensure that FA patients sign up on FARA's patient registry (www.curefa.org/registry) so they can be notified regarding clinical trials for which they appear to be eligible. This website also contains postings and information on clinical research studies. Our drug development partners and clinical research network physicians have told us that patient participation in clinical research studies is absolutely necessary for success, and they are looking to us for that support. ■

Newborn Screening Study

Researchers at the Mayo Clinic are working to develop a newborn screening test for FA. This type of screening will be very important in the future as treatments become available as it will allow individuals to be diagnosed and treated before symptoms appear.

You can help researchers to develop this newborn screen by sharing your newborn screening card with them to validate the test.

For more information on how to participate visit www.curefa.org/NewbornScreeningProject.pdf or call Mayo Clinic's Biochemical Genetics Counselor at (507) 266-8158 or email: biochemicalgenetics@mayo.edu

Sign Up in the Patient Registry Database for Future Clinical Trials: Visit www.cureFA.org/registry

The following essays were written by two teens with FA, Evan Luebbe and Sam Bridgman.

Sam Bridgman wiith his brother Max and friends Alex, Mike and Owen during Ride Ataxia III.

My Life is a Pinball

By Sam Bridgman, 17

When it comes down to it, I am just a regular 17-year-old who wants to do anything but listen to my parents. There is one little side order to the whole teenage package, though. I walk like I am drunk out of my mind, and there isn't a thing I can do about it. I'll be walking down the aisle at a grocery store, and I'll suddenly ram into a shopping cart and make a ruckus at the same time. I get momentum, and then carry it with me. I bounce from thing to thing until I get to my destination, and that is how it works day in and day out. I am like a pinball inside a pinball machine, however, I am standing on planet Earth.

My journey through life began as a young child living in Seattle, Washington. In the beginning, I cruised through life. I was a phenomenal athlete, excelling at baseball and basketball. I was a smart kid as well, breezing through class without even trying. I made friends easily and just had pure fun, whether it was playing tag or dominating in four square. At that young point in my life, it seemed as though I was going to blossom into a great athlete. Life was an ongoing winning streak, and it was getting better every day. Life was fun, and I was having a blast.

As I grew older, I began to have odd symptoms and instances where I would just fall over or run into something randomly. My parents were concerned, yet I was unaware and unconcerned at the same time. Whenever I fell, I would just say "The floor just jumped out at me! Stupid floor!"

Baseball and basketball, the two sports I excelled at, became harder as the years went on. This was particularly confusing to me because I expected to get better as I got older, yet I did the exact opposite. Life began to feel like I was playing a bunch of baseball games, yet none of them counted. My mom made countless appointments to figure out what was wrong, but the docs had no clue. Then, I took a blood test. It came back positive for FA, which decreases muscle mass and in most cases the patient is put in a wheelchair permanently. This was a huge shock to my system at the time, and I was furious. My dream had always been to play major league baseball, and then I figure out that will never happen.

As a result of the diagnosis, I am forced to have multiple doctor appointments and basically become an experiment. Now, being unbalanced is almost a constant for me. It almost defines me. It is a part of me that I would love to get rid of, yet I know I am stuck with it for life. I am used to running into the occasional door or tripping over the flat floor. My friends and I crack jokes about it as if it were just a regular thing. Being a pinball never felt so good and I can't wait to see what I bounce off of next time.

Embrace the Positives

By Evan Luebbe, 13

I was 8 years old when I was diagnosed. I was too young to understand the severity of FA. But I quickly did once the effects started hitting me. Once you discover the severity of it, you can't change the fact that you have it, but you can embrace the positives of it.

You might ask yourself "How are there any positives to such a severe disease?" Without FA I would not be the person that I am today. The biggest positive is maturity. Not physical, but mental. Sometimes you go through periods where it's all you think about, but you eventually get over it and that makes you so much stronger than you previously were. Personally, I just clam up and don't say anything because nobody can relate to me. Nobody has been through what I've been through.

Each one of those periods is like coming over a big hump in life. You cannot explain what it's like to have FA. Sometimes it feels like a mean little troll is making you miserable and you can't do anything to stop it. It will eventually become just a part of your everyday life and you will get over those humps and become stronger. Even if it seems impossible, you will get over it.

Everyone out there – just keep believing and together, we will have a cure very soon!!!! ■

FARA Welcomes Juliann Green

The FARA Board of Directors and Staff are pleased to introduce Juliann Green as our Chief Development Officer. In her role, Juliann is responsible for creating and implementing a development plan that will fund FARA's efforts. Juliann works to cultivate new and existing individual and corporate donor relationships and to help FARA maximize its fundraising potential.

Juliann joined FARA in February of this year after being introduced to us by a fundraising consultant. Juliann has over 20 years of experience in client relations and business development work with large corporations and Universities. While in these other roles, she worked closely with executives and university administrators, along with large committees, to create highly customized programs that fit the individual needs and culture of each organization. She has expertise in many areas related to development including strategic relationship building and formal presentations. Juliann's resume also includes development of marketing and communications programs, along with detailed proposal writing.

Juliann has long been involved actively in non-profit work in her community. She served on the Board of Directors of Bridge of Hope, LCC, a charity that provides long-term solutions for single mothers at risk of becoming homeless. It is no surprise that Juliann chaired the organization's Development Committee and still supports their efforts. Juliann also serves on her church's Missions Committee that interfaces with many local and international non-profits working to support those in need. Juliann has also combined her passion for horses with her desire to help by volunteering in a therapeutic riding program.

Juliann received a Bachelor of Fine Arts Degree from the Maryland Institute College of Art in Baltimore, Maryland. Juliann resides in Glenmoore, PA with her husband Steve. She hopes to become a cyclist, as it seems to be an important skill at FARA!

Of her introduction to the FARA family so far, Juliann shares this observation… "I am overwhelmed at the generosity, grace and determination of all whom I've met. It is an honor to be a part of this amazing organization and to know that, together, we can make a difference in the lives of so many." ■

FARA Grants Expected to Reach $2 Million

By Jennifer Farmer

The FARA grant program has funded 11 grants exceeding $750,000 in direct support for research from January – June 2009. One of these grants is providing funding for a clinical trial proposed by Dr. Theresa Zesiewicz, "Double-Blind, Randomized, Placebo-Controlled Pilot Study of Varenicline in the Treatment of Friedreich's Ataxia" (please see the clinical trial article for more information on this study). We anticipate funding additional grants through the remainder of the year for a total grant support of about $2 million for 2009. For a complete listing of grants funded for 2009, please visit the FARA website at http://www.curefa.org/grants-awarded.html

FARA's Grant Program Priorities

- Advance drug discovery and have a diverse treatment pipeline
- Facilitate the drug development process and translational research so that the most promising discoveries are rapidly brought to treatment trials
- Support the clinical research, infrastructure and biomarker discovery required to ensure effective and efficient clinical trials in a rare disease
- Support young/new researchers with innovative ideas and a commitment to FA research
- Reduce the morbidity and mortality caused by cardiac disease in FA

Spotlight on newly funded research

Stem cell research
FARA and a partner organization, FARA Australia, have joined forces once again to fund an exciting new research study that brings the latest insights and approaches to stem cell research to Friedreich's ataxia. Drs. Mirella Dottori and Alice Pebay from the University of Melbourne have proposed to investigate a new technique for creating nerve cells from FA patients and to conduct experiments in these cells to explore gene therapy approaches aimed at increasing frataxin in these patient derived cells.

Project Title: Generation of induced pluripotent stem cells from Friedreich ataxia patients

Lay Summary: *Stem cells have the potential to develop into nerve cells and perhaps represent a possible new therapy to replace the nerve cells that die in those with Friedreich ataxia (FRDA). We will use stem cell*

technologies to develop cellular models of FRDA in which we can correct the inherited trinucleotide expansions found in the frataxin gene of FRDA patients. We hope to demonstrate that frataxin protein levels can be increased on a long term basis in these human cellular models of FRDA, starting with stem cells derived from patients using new techniques that are universally agreed to pose no ethical issues.

New developments in the field of stem cell research are making it possible for researchers to create stem cells through cellular reprogramming of other cells. For example, skin cells can be induced to become stem cells and those new stem cells can be programmed to become nerve cells. These advances are significant not only for this study but for other studies where having patient-derived cell models enhance testing of new compounds or treatment approaches.

2009 FARA New Investigator Award
FARA offers a special grant award for young or new investigators who have demonstrated an interest in FA research and want to further that commitment. We believe in welcoming, mentoring and supporting new scientists in the FA research community so that they have the necessary resources and motivation to launch successful independent careers or translate their experience from a related field to FA.

We are proud to announce that our 2009 New Investigator Award is going to Dr. Marguerite Evans-Galea, Murdoch Childrens Research Institute, Australia. Dr. Evans-Galea graduated with her PhD degree from the University of New South Wales in 1999. Through her graduate and postdoctoral training she has a strong background in molecular biology and genetics, which included research on understanding oxidative stress response in biological systems and direct experience with developing gene therapy approaches for other genetic conditions.

Project Title: Evaluating the Molecular and Epigenetic Alterations in Friedreich's Ataxia

Lay Summary: *This project proposes to utilize our extensive set of established FRDA resources and our well-characterized FRDA patient population to systematically evaluate the molecular and epigenetic alterations inherent in individuals with FRDA to characterize their correlation with clinical observations. In addition, we propose to extend epigenetic analyses to regions neighboring the FXN gene. Our cross-disciplinary research group with a diverse array of expertise in basic and clinical FRDA research and epigenetics is ideally positioned to perform these studies. Findings have the potential to offer novel insights into the pathology and prognosis of FRDA, indicate new biomarkers for use in evaluating clinical trials and guide the development of new therapeutic interventions.*

Through this study Dr. Evans-Galea and her colleagues will investigate the variability in FA and explore genetic-based explanations or controls, beyond the DNA sequence of the FRDA gene, for such variability. This type of research would not be possible without all of the patient-based research and natural history studies that have been conducted by Dr. Martin Delatycki and colleagues who are collaborators in this study and who are part of the Collaborative Clinical Research Network in FA. ■

The FARA eAdvocate is brought to you by:

Contributors: Ron Bartek, Felicia DeRosa, Marilyn Downing, Jennifer Farmer, Juliann Green, Paul Marcotte

Editor & Design/Layout: Meg Giaconia and Karen Smaalders

Attention FA Researchers

FARA has posted new grant opportunities and guidelines on the FARA website: http://www.curefa.org/grant.html

Request For Applications:

Kyle Bryant Translational Research Award
Letter of intent: July 15, 2009
Application/Proposal due date: July 31, 2009
Award announcement: October 1, 2009
Grant start date: October 15, 2009

2010 New Investigator Award
Letter of intent: August 15, 2009
Application/Proposal due date: September 1, 2009
Award announcement: December 1, 2009
Grant start date: January 1, 2010

There is a new grant submission and management system. All grant proposals must be received through this new online program:
http://www.curefa.org/RPMP/public/pgrpmphome.aspx

If you have questions, please contact Jen Farmer, jen.farmer@curefa.org

Jesse Woodward at the Baton Rouge, LA Outback luncheon next to raffle prize - a signed poster from The Cake Eaters.

Chesapeake Area Charities
The Chesapeake Bay Area Charities Foundation comprised of several Maryland Outback restaurants recently hosted a clay shoot. A trek across the Chesapeake Bay Bridge did not deter the participants. Avid clay shooters joined with first-timers for a day of gentlemanly sport (ladies, too!) fueled by Outback hospitality. The fine team of Maryland Outbackers will also be hosting a motorcycle Poker Run and a Golf tournament later this year. We are grateful FARA was added as a beneficiary in addition to their long-time support of pediatric cancer research at Johns Hopkins.

Special thanks to all of the Outback fundraising teams for their continued commitment to FA research. Heartfelt thanks to the rest of our event planners as well as families partnering with Outback for the first half of 2009 including: Paige Barnett, Kim Bellnier, Karen Brown, Donna Davis, Marie Early, Hannelore Federspill & Lisa Wojenski, Rob Franz, Dynah Haubert, Holly Hedrick, Gene Hedrick, John and Patricia Jacquin, Carrie Laird, Donna Littel, Marjorie Londregan, Stephanie and Sharon Magness, Barbara McCaffrey, Stacia McCann, Paul Miller, Brenda and Bart Rupel, Cindy and Charles Timbie, the Van Schoick Family, Dennis Wood, Becky Young, Pam and Jesse Woodward, Dave and Linda Zilles. You are all so appreciated for helping us to move the research forward!

For more fundraising photos, see pages 15 and 17. ■

Jerod and Carrie Laird at the Bakersfield, CA Outback luncheon.

Upcoming 2009 Outback Events

Cooper Bridge Run/ Walk –
Carolinas' WE Foundation
July 12 Charleston, NC

Family Fun Day –
Carolinas' WE Foundation
July 18 Proehlific Park, Greensboro, NC

Outback Luncheon
July 21 Dewitt, NY

Outback Luncheon
July 21 Yonkers, NY

San Francisco Half Marathon –
Outback Team for FARA
July 26 San Francisco, CA

Outback Luncheon
August Rohnert Park, CA

Heineken with a Heart
August 18 Chicago, IL

Golf Tournament & Party –
Carolinas' We Foundation North Carolina
October 4-5

Ride Ataxia – Philadelphia
October 25 Royersford, PA

Dynah Haubert, the Children's Hospital of Philadephia's FA Team and friends at the Outback luncheon in Plymouth Meeting, PA.

Zac Zies and friends at their Outback luncheon fundraiser in Toledo, OH.

Friedreich's Ataxia Symposium
November 13-14, 2009
Sponsored by The Children's Hospital of Philadelphia

Worldwide, Friedreich's ataxia (FA) affects roughly one in 50,000 people, making it the most common in a group of related disorders called hereditary ataxias. While there is currently no cure for FA, efforts continue to be made towards research that will one day halt or even reverse disease progression. The Friedreich's Ataxia Program at The Children's Hospital of Philadelphia is pleased to present this symposium providing patients and families with up-to-date clinical information, therapeutic approaches and current research being conducted in the field of Friedreich's ataxia.

For more information, please contact the Continuing Medical Education Department at The Children's Hospital of Philadelphia at (215) 590-5263.

Ronald J. Bartek, President/Director/Co-Founder
Retired U.S. Government Official; Business Consultant

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Grassroots Fundraising

(continued from p. 8)

Jon Zilles, Laura Beth Jacquin, Ron Bartek, Robbi Van Schoick, and Becca Van Schoick at the Van Schoick's Benefit Bash in Athens, Georgia. The Bash complete with dinner, live music, dancing, and an auction followed a successful golf tournament held during the day.

Participants in Jonestown, PA's first annual Walk for a Cure organized by Dennis Wood and the Jonestown Community.

Jessica Wojenski. Glenna Stevens, Lisa Wojenski, Hannelore Federspill and Kathe Glauser getting ready to sell Holly's Hope jewelry for a cure at the Bedford High School Talent show in New Hampshire. Holly's Hope jewelry was created by Holly Franz, her mother Hannelore Federspill, and friends Lisa and Jessica Wojenski , who are exercising their creativity and craft skills to benefit FARA. You can view a full selection of items at: http://hollyshope.pbworks.com/Jewelry-for-a-Cure.

Dennis Wood receives a donation from a Northern Lebanon School District representative from the school's fundraising efforts on behalf of his walk.

Barbara McCaffrey and her cousin Mary Frances at Barbara's fundraiser in Massachusetts. Guests were treated to an evening of live Irish music live featuring The Wild Rovers.

Ride Ataxia III Photos

(continued from p. 3)

Ride Ataxia III Cyclists FARA Board Chairman Tom DeCotiis, Ride Ataxia Founder Kyle Bryant, and Ride Planning Committee member Andy Smith get ready for a 62-mile ride on day three.

Cyclist Bart Rupel covered from head to toe in rainwater and mud but still smiling at the conclusion of day one.

Friedreich's ataxia Moms Sandy Lane, Mary Caruso, Marion Clark and Amy Koepnick stop to stretch along the Ride Ataxia III route.

Dylan Helms and his Dad, Jason during the awards presentation at the end of the Ride Ataxia III journey.

Thank you to all those who participated in Ride Ataxia III!

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