FAMILIES UNITED FOR A CURE

INTERNATIONAL FOXG1 FOUNDATION®

Board of Directors Updates

Please join is in saying thank you to Stefanie Helms and Tamra Evans, both founding Board Members who are stepping down after serving the Foundation and our families for the past 4.5 years.

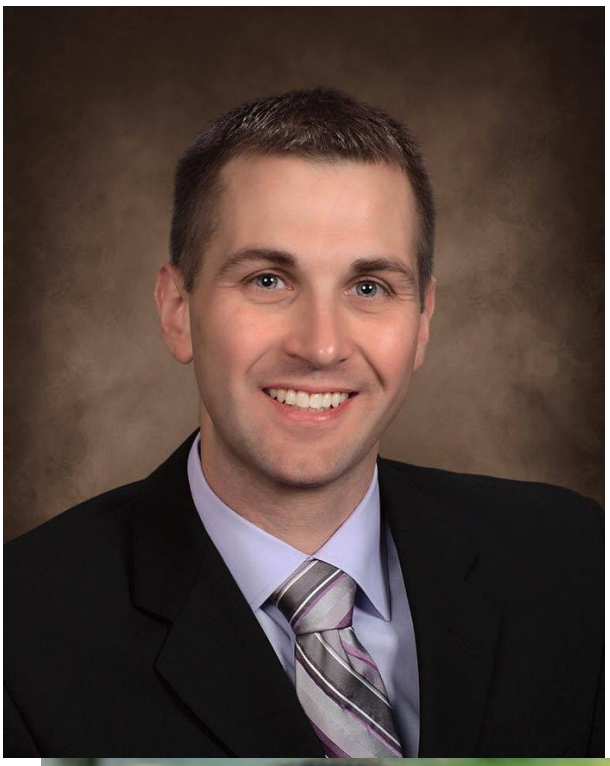
Stefanie, who served as our Secretary, was integral in registering IFF as a corporation, maintaining our recordkeeping and starting the Facebook Parent Group.

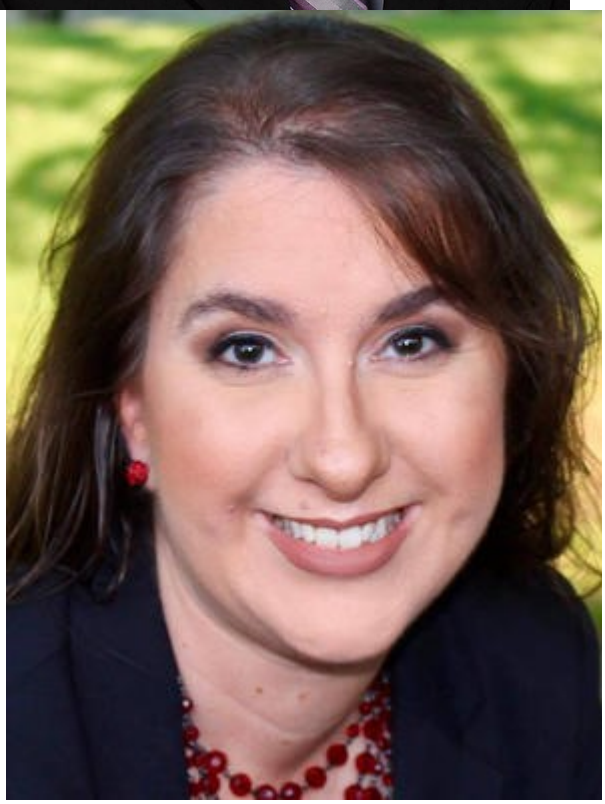
Tamra served as our Treasurer, setting up and maintaining our accounts and managing funds, and played a part in applying for our 501(c)(3) status.

Both will be sorely missed, but will always be a part of our virtual community and

Foundation history.

New Board Members





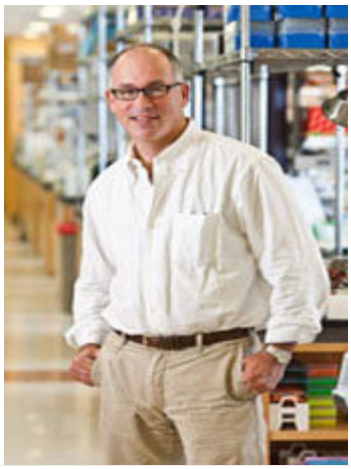
Say hello to our new Treasurer, Nik Feist!. Nik has his M.B.A from the University of North Dakota, is a CPA and Certified Auditor and Fraud Examiner. He and his wife, Christy, have two daughters, Annika, who happens to have a mutation on her FOXG1 gene, and her sister, Sofia.

A big welcome to Anna Perez Perry, who is stepping up as our new Secretary! Anna is an English teacher, and has her Master's of Education from the University of Alabama at Birmingham. Between Anna and her husband, Brooke, they have three children Ian, Olivia, and Aria, who has a FOXG1 mutation.

Jennifer Leonard, Director of Family Advocacy

Jennifer, who has served on our Board for the last year as our NIH Liaison and Assistant of Research is taking on a new role as our Director of Family Advocacy, while remaining as our NIH Liaison. She brings eleven years in the legal industry to our Board, and will be working with all the Point of Contacts to welcome new families and pass on information to promote communication, and assist families in finding medical professionals. Long term, she is looking at developing virtual welcome packets for new families and medical professionals, developing awareness cards, and a sibling group. Jennifer and Jed, her husband, have Corinne, 7 years old, and Abigail, 10 years old, with a FOXG1 deletion.

Scientific Advisory Board



Gordon Fishell, Ph.D.

Dr. Fishell, Julius Raynes Professor of Neuroscience, Associate Director of the NYU Neuroscience Institute, Broad Institute (where CRISPR was invented), joined our SAB this month He has studied FOXG1 for years, but is focused on the microbiology and basic science side, a critical of the puzzle as we work on rounding out our SAB.

Steven Gray, Ph.D

Steven Gray, Ph.D. Molecular Biology, UNC School of Medicine, Gray Lab, Assistant Professor, Department of Ophthalmology. Dr. Gray met our ED, Heather Norwood, by chance between sessions at the 2016 RETT Syndrome conference in Chicago. IL. They struck up a conversation, and a year later, after his success with the AveXis clinical trial for RETT Syndrome therapy, he accepted our invitation to join our SAB.

What's Available For Family Support

We've put together this deck (http://shoutout.wix.com/so/6Ls53Qht/click?w=LS0tDQplYjM0OTcwYy1hNjJhLTQ0Y2ItNzZmMy0zMDZlYTAxZjc5MDYNCmh0dHBzOi8vZHJpdmUuZ29vZ2xlLmNvbS9vcGVuP2lkPTBCMkMtX1NqNGpCWWlTR1J6YlZoU1VVMU9XakENCi0tLQ) to remind families what is available to you for support services through the foundation. If there's something specific that you

don't see on the list, please reach out and ask what we can do to help. We still have some funds available from the Equipment Lending Library, so if there's a specific piece you need, let us know. Right now, these pieces are available:

- Kid Walk 2
- Rifton Pacer, size small
- Embrace Monitor
- Ormesa Brillo pre gait trainer
- R28High/low base for a wheelchair
- Wooden corner chair

Contact heather.norwood@foxg1.org (http://shoutout.wix.com/so/6Ls53Qht/click?w=LS0tDQplYjM0OTcwYy1hNjJhLTQ0Y2ItNzZmMy0zMDZlYTAxZjc5MDYNCm1haWx0bzpoZWF0aGVyLm5vcndvb2RAZm94ZzEub3JnDQotLS0) if there's a piece you're interested in.

Research Update

As of July, 2017, only 20 of the 142 US-based FOXG1 families have enrolled in the Consortium Natural History Study, funded by the National Institute of Health***. It is critical that our families join this study; without data, there will be no interest from researchers and/or biotech's to focus on treatments and a cure.*** The goals of this grant are to understand the core clinical features of the disorder, identify if there are any treatments that can improve quality of life, and to understand the link between symptoms and brain imaging/eeg variations. Contact jennifer.leonard@foxg1.org (http://shoutout.wix.com/so/6Ls53Qht/click?w=LS0tDQpmZjEzYjM3My03NDI4LTQzYWItOTRmZS0xMDVkNjc2YWUxMjMNCm1haWx0bzpqZW5uaWZlci5sZW9uYXJkQGZveGcxLm9yZw0KLS0t) for the closest location to you, or check out this list (http://shoutout.wix.com/so/6Ls53Qht/click?w=LS0tDQpmZjEzYjM3My03NDI4LTQzYWItOTRmZS0xMDVkNjc2YWUxMjMNCmh0dHBzOi8vZm94ZzEub3JnL25hdHVyYWwtaGlzdG9yeS1zdHVkeS1zaXRlcy8NCi0tLQ). This study is open to our international families, should you be able to visit the US once a year.

We have a good strategy for research, and are in the process of creating a roadmap on various trials that could bring therapies to market for treatment and a cure. To see info on what we've compiled on previously completed research, and currently available scientific assets, check this out. (http://shoutout.wix.com/so/6Ls53Qht/click?w=LS0tDQpkMzc0YjVkZi1hNjlhLTQ5MTYtY2M5OS1iZjc4NDFhYjc1ZTkNCmh0dHBzOi8vZHJpdmUuZ29vZ2xlLmNvbS9maWxlL2QvMEIyQy1fU2o0akJZaWVVMXlWR1JYUTNCTWRXcy92aWV3P3VzcD1zaGFyaW5nDQotLS0)

Funding Update

Earlier this year, Christine Revkin, a FOXG1 mom, had started a fundraising campaign for Dr Renieri, who proposed using CRiSPR/Cas9 technology on FOXG1 patients' Stem Cells that have been made from their own skin samples. This project will cut the mutated allele entirely and replace it with a healthy gene. To allow the CRiSPR/Cas9 correction system to enter the cells, a viral system (AAV = Adeno-Associated Virus) will be used as carriers. *We are thrilled to announce that an anonymous donor has stepped up and fully funded the two-year project!* Congratulations to Christine and all the families that helped!!

Point of Contact Project

We need your help! We are currently building a world-wide communication structure, and are looking for parents to step up and assist with data collection and communication. Check out this slideshow (http://shoutout.wix.com/so/6Ls53Qht/click?w=LS0tDQoyODVmZjQ1NS05NWU3LTRmOTItN2Q1Ni1lNzNmMTM0YTE5YWINCmh0dHBzOi8vZHJpdmUuZ29vZ2xlLmNvbS9maWxlL2QvMEIyQy1fU2o0akJZaU4xRjJNbXh0UW5oNU9UUS92aWV3P3VzcD1zaGFyaW5nDQotLS0) for more information.

Many of you will soon be contacted by our new POCs to update your information in our contact database. We have three worldwide regions,
1) Europe, Middle East and Africa (EMEA), with Christine Revkin as the Regional POC (R-POC)

2) Americas, with Jennifer Leonarda, R-POC
and
3) Asia/Pacific (AP)- R-POC position is open to applicants.

Current POCs are:

EMEA Region:

Belgium- Ondine Quackelbeen & Ralf Leesen
France-Nicolas Paolini
Germany-Marco Kobush & Tina Kouemo
Hungary-Lili Portoro
Iceland-Hildur Siguroardottir
Italy-Stefania Cuccarolo & Giulia Dynya
Norway-Christine Nilsen
Spain-Pura Gamo
Sweden-Katarina Bo
Switzerland-Christine Revkin
UK-Konnie Shankar & Judith Sheppard

Asia/Pacific:

Australia-Denise Kascak
UAE-Nora El Kaid

Americas:

Canada-Angie VanWingerden
South America-Leticia Piccoli Tergolina

The USA has been broken down into six regions:

Northeast-Elisha Hamburger
(Maine, Vermont, New Hampshire, Massachusetts, Connecticut, Rhode Island, New Jersey, New York & Pennsylvania)

Southeast-Stacey Bumpus
(Delaware, Maryland, Virginia, West Virginia, North & South Carolina, Georgia, Florida, Alabama, Mississippi, Louisiana, Arkansas, Tennessee & Kentucky)

Midwest-Julie Rognstad
(Ohio, Michigan, Indiana, Illinois, Wisconsin, Missouri, Iowa, Minnesota, North & South Dakota, Nebraska & Kansas)

Rocky Mountains- Deborah Nettles
(Montana, Wyoming, Colorado, Utah, Nevada & Idaho)

Southwest-Rashaan Hoggard
(Oklahoma, Texas, New Mexico & Arizona)

West Coast-Greg and Felicia Wells
(Washington State, Oregon & California)

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