AUTISM SCIENCE FOUNDATION CANNUAL

DAY OF LEARNING

APRIL 22, 2021

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The Ireland Family Foundation and Extraordinary Ventures

Supporting autism research and direct services for adults on the autism spectrum. Employing men and women with autism and other developmental disabilities.

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The Ireland Family FOUNDATION











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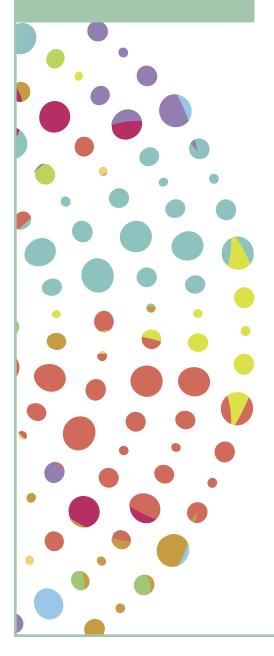




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The Autism Science Foundation provides funding directly to scientists conducting cuttingedge autism research to discover the causes of autism and develop better treatments. We also provide information about autism to the general public and support the needs of individuals with autism and their families.

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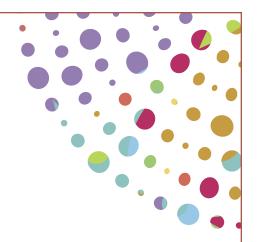
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CARYN SCHWARTZMAN SPIRIT AWARD WINNERS



Feda Almaliti first began her autism journey when her son Muhammed was 15 months old. She started noticing significant changes in his behavior, followed by an autism diagnosis. When Feda learned her insurance company, Kaiser, would not pay for comprehensive treatments for her severely affected son, she didn't just get mad. She took action. For two years Feda pushed Kaiser to provide treatment, fighting, writing letters, detailing denials. She finally got needed treatments including ABA approved for her son. But she didn't stop there. She then moved her efforts to the Autism Mental Health Insurance Project where she pushed insurance reform in California to expand access to behavioral health treatments to all affected by ASD. She was also a founding board member of the National Council on Severe Autism and Vice President of the Autism Society San Francisco Bay Area. She created local events to help her fellow autism families, including pool parties and the annual conferences. She also co-hosted a podcast called the Scoop and wrote for a number of publications where she openly discussed her challenges in hopes of helping other families with ASD. On September 26th, she and Muhammed were killed in a house fire. She will be forever missed, but never forgotten by those who knew and loved her, and those that have benefitted from her advocacy and tireless work.



Past Winners

2011 Pat Schissel

2012 Allyson Schwartzman

2013 Mark Krinsky

2014 Dr. Paul Offit

2015 Gregg and Lori Ireland

2016 Erin Lopes and Tim Bak

2017 Liane Carter

2018 Marjorie Madfis Jonah and Ellen Zimiles

2019 Bryan and Melissa Harkins

2020 Scott Badesch

CARYN SCHWARTZMAN SPIRIT AWARD WINNERS





Elise and Phil Orlando have been

trying to make a difference in the autism community for more than a quarter century.

They met while working at Donaldson, Lufkin & Jenrette (DLJ) in the mid-1980's, they married in 1989, and they had their first of three children (Jack) in 1992.

Jack was a relatively low-maintenance toddler who enjoyed listening to music and playing with a few mostly spinning toys. He was happiest running outdoors and swinging on his playset. When Jack was about 18 months old, however, Elise and Phil became increasingly more concerned about his slow development. But doctors assured them that "boys typically do things later." By 24 months, Jack's developmental delays became more pronounced, and he was diagnosed with Pervasive Developmental Disorder—Not Otherwise Specified (PDD NOS). According to the Center for Disease Control (CDC), Jack's diagnosis came at a time when the official rate of incidence of autism was a lottery ticket, roughly one in 10,000.

But Elise and Phil were desperate to help their son any way they could. This was pre-Google, of course, so their subsequent exploration into the largely dark and unknown world of autism must be how the early pioneers felt as they drove their covered wagons west. They simply didn't know what they were going to find on their journey.

So with their second child (Nina) now in tow in 1994, Elise retired from her career and started to work the phones with other affected parents (the world-wide web and the Internet weren't really a thing yet), learning on the fly about Applied Behavior Analysis (ABA). From there, she set up a home program for Jack, hiring from a small pool of trained ABA therapists and assembling a gaggle of willing volunteers.

At the same time, Elise and Phil also joined forces with a dozen other similarly situated Westchester families to help form what is now known as The Foundation for Empowering Citizens with Autism (FECA).

After two years of fundraising and planning, FECA partnered with the Devereaux Foundation to open a school for children with autism in Westchester County, based on the principles of ABA. The Devereux Millwood Learning Center (DMLC) opened in 1996 in Millwood, N.Y.

Jack was not yet eligible to attend DMLC at that time, but he would go on to spend most of his educational life at the school, from ages five through 16.

But Elise and Phil's fundraising efforts didn't end there. DMLC was an out-of-district placement for its students, and FECA's ongoing fundraising augmented the operation of the school to provide the more costly one-to-one ABA instruction for all 48 students.

As the students of DMLC grew older, their needs naturally evolved, and FECA also started and funded an Adult Program to teach them vocational skills. The Devereaux Adult Program (DAP) is still in operation today.

Many of DMLC's students eventually graduated and moved into residential programs. So six years ago, Elise and Phil, along with several other families, helped to establishment a new foundation, Extraordinary Ventures New York (EVNY), which created several microbusinesses that provide employment opportunities (with job coaches) for adults on the spectrum, to teach them some marketable job skills they can use in the real world.

At the same time, Elise and Phil are now also working closely with Cardinal McCloskey Community Services (CMCS), which runs the group home in which Jack (now 28) has lived with four other adults with autism for the past five years. Their financial support helps to fund CMCS's autism initiatives, including group homes and day-hab training.

So in addition to their professional lives and their family life with Jack and their two typical daughters (Nina, 26, and Jen, 22), Elise and Phil's philanthropy on behalf of the autism community has clearly defined their married life together.

SPEAKERS



Brian A. Boyd is Associate Professor and Director of the Juniper Gardens Children's Project (JGCP) at the University of Kansas. The JGCP is an applied research center primarily focused on children from vulnerable and underserved groups. Dr. Boyd has over 20 years of clinical and research experience involving autistic children and adolescents and their families. His research interests are the development and evaluation of evidence-based interventions; community-engaged research methods to ensure stakeholder participation; and understanding the impact of implicit racial bias on children's outcomes. Dr. Boyd has over 70 peer-reviewed publications and various federal agencies, including the Institute of Education Sciences and the National Institutes of Health, have funded his research. He earned a B.A. in psychology at College of William & Mary, an M.Ed. in special education at University of Virginia, and a Ph.D. in special education at University of Florida.



Orrin Devinsky is Professor of Neurology, Neuroscience, Neurosurgery and Psychiatry at the NYU School of Medicine, where he directs the Epilepsy Center. His epilepsy research includes development of autism; new epilepsy medical and surgical therapies including cannabidiol, genetic epilepsies, sudden death in epilepsy (SUDEP); and genetic therapies for rare neurodevelopmental disorders. Dr. Devinsky is the Principal Investigator for the North American Sudden Unexpected Death in Epilepsy (SUDEP) Registry and for the Sudden Unexplained Death in Childhood (SUDC) Registry and Research Collaborative. He founded Finding A Cure for Epilepsy and Seizures (FACES) and cofounded the Epilepsy Therapy Project and epilepsy.com. Other interests include behavioral neurology, evolutionary biology, nutrition and history of science. Dr. Devinsky rec his B.S. and M.S. degrees from Yale University (1977) and his M.D. from Harvard Medical School.



SPEAKERS



Dr. Pamela Feliciano is the Scientific Director of SPARK for Autism, leading the effort to build the largest autism research cohort in the U.S., which has enrolled over 60,000 individuals with autism. She works with a consortium of researchers that are analyzing genomic data from tens of thousands of participants. Feliciano also manages a unique aspect of Simons Powering Autism Research (SPARK)—returning genetic results related to autism to individual participants. She is also a senior scientist at Simons Foundation Autism Research Initiative (SFARI), the largest private funder of autism research in the U.S. At SFARI, she has been involved in efforts to fund the development of objective outcome measures for autism clinical trials. Previously, Feliciano was a senior editor at *Nature Genetics*, where she was responsible for managing the peer review and decision process of research publications in all areas of genetics. She has a B.S. from Cornell University and a Ph.D. from Stanford University. Feliciano is also the mother of a teenager with autism.



Dr. Shafali Jeste is a behavioral child neurologist specializing in autism and related neurodevelopmental disorders. She is an Associate Professor-in-Residence in Psychiatry, Neurology and Pediatrics at the UCLA David Geffen School of Medicine; the director of the UCLA CARING Clinic; co-Director of the UCLA Tuberous Sclerosis Center of Excellence; and a lead investigator in the UCLA Center for Autism Research and Treatment (CART). Dr. Jeste's research is focused on developing methods to improve precision in the diagnosis and treatment of neurodevelopmental disorders from early infancy through late childhood. She has designed innovative studies in early predictors of autism in Tuberous Sclerosis Complex (TSC) that integrate biomarkers with behavior to define atypical development prior to the onset of autism. This work in TSC led to the first randomized controlled clinical trial of behavioral intervention for these infants and paved the way for other early intervention trials in rare genetic syndromes. Dr. Jeste's research is directly inspired by her clinical work. To address the many gaps in medical care for rare genetic forms of neurodevelopmental disorders, she founded and directs the Care and Research in Neurogenetics (CARING) Clinic. This clinic has become the hub for several new clinical trials for genetic syndromes. Dr. Jeste's work is funded by the National Institutes of Health, the Department of Defense and the Simons Foundation. She holds several national and international leadership positions. In 2019 Dr. Jeste was awarded the Presidential Early Career Award for Scientists and Engineers for her innovations in research in early predictors and intervention for genetic neurodevelopmental disorders. She earned a B.A. in philosophy from Yale University in 1997 and her M.D. from Harvard Medical School in 2002.



SPEAKERS



Dr. Sarah Spence is the Co-Director of the Autism Spectrum Center at Boston Children's Hospital. A child neurologist with a Ph.D. in neuropsychology, Dr. Spence has been involved in many initiatives in the clinical care and research of individuals with Autism Spectrum Disorder and related developmental disabilities, working with Cure Autism Now, Autism Speaks, the Simons Foundation, the Nancy Lurie Marks foundation, the Dup15q Alliance and the Tuberous Sclerosis Alliance. She spent five years as the medical director of the Autism Evaluation Clinic at UCLA, then another five years doing clinical research in autism at the National Institute of Mental Health. Dr. Spence was a member of the DSM 5 workgroup, which defined the diagnostic criteria for autism and other neurodevelopmental disabilities. She completed pediatrics and neurology residencies at UCLA and did a post-doctoral fellowship in behavioral neurogenetics—working with the Autism Genetic Resource Exchange (AGRE), a large publicly available genebank for autism, which changed the way investigators share data. Dr. Spence credits the families from AGRE for her expertise in ASD.



Dr. Lonnie Zwaigenbaum is the Stollery Children's Hospital Foundation Chair in Autism Research and is Professor in the Department of Pediatrics at the University of Alberta. He directs the Autism Research Centre based at the Glenrose Rehabilitation Hospital. Dr. Zwaigenbaum's research focuses on early behavioral and biological markers, and developmental trajectories in children and youth with autism spectrum disorders (ASD). He holds several national and international leadership roles in ASD research. Dr. Zwaigenbaum is the program director of the national Autism Research Training program, responsible for training and mentoring the next generation of ASD researchers in Canada. He is also project lead on the Kids Brain Health Network ASD research stream and a former vice-president of the International Society for Autism Research. Dr. Zwaigenbaum is the Chair of the Baby Siblings Research Consortium (BSRC) Executive Committee and directs one of the two Canadian sites of the Autism Speaks—Autism Treatment Network. In 2013 he was awarded a Queen Elizabeth II Diamond Jubilee Award, recognizing his contributions to autism research and clinical care. Dr. Zwaigenbaum completed his pediatric training at Queen's University and his clinical fellowship in developmental pediatrics at The Hospital for Sick Children in Toronto. He holds an M.A. in health research methodology from McMaster University





The Foundation for Empowering Citizens with Autism congratulates

Elise and Phil Orlando

as they receive the

Caryn Schwartzman Spirit Award

Elise and Phil have dedicated the past thirty years to advocating for and supporting critical programs and organizations that strive to enhance the lives and futures of individuals with autism.

Their efforts have positively and immeasurably impacted countless lives.

We offer our profound and heartfelt gratitude on their behalf.

The Ireland Family FOUNDATION

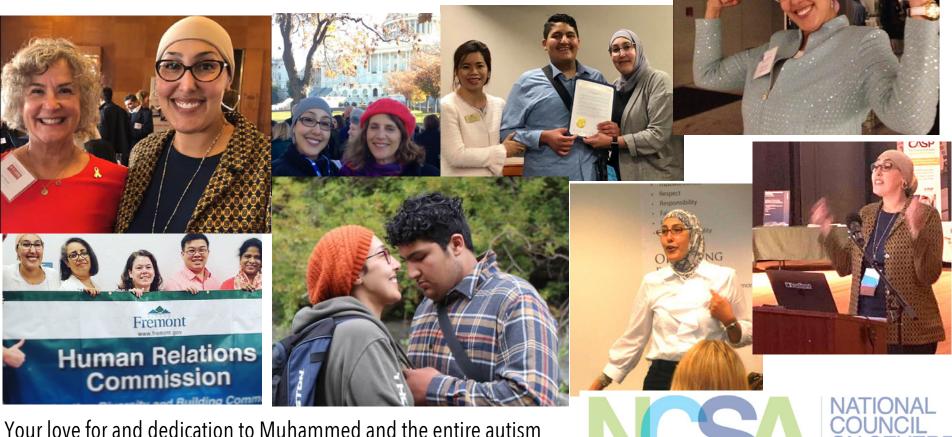
Congratulations to Elise and Phil Orlando on being honored with the

2021 Caryn Schwartzman Spirit Award

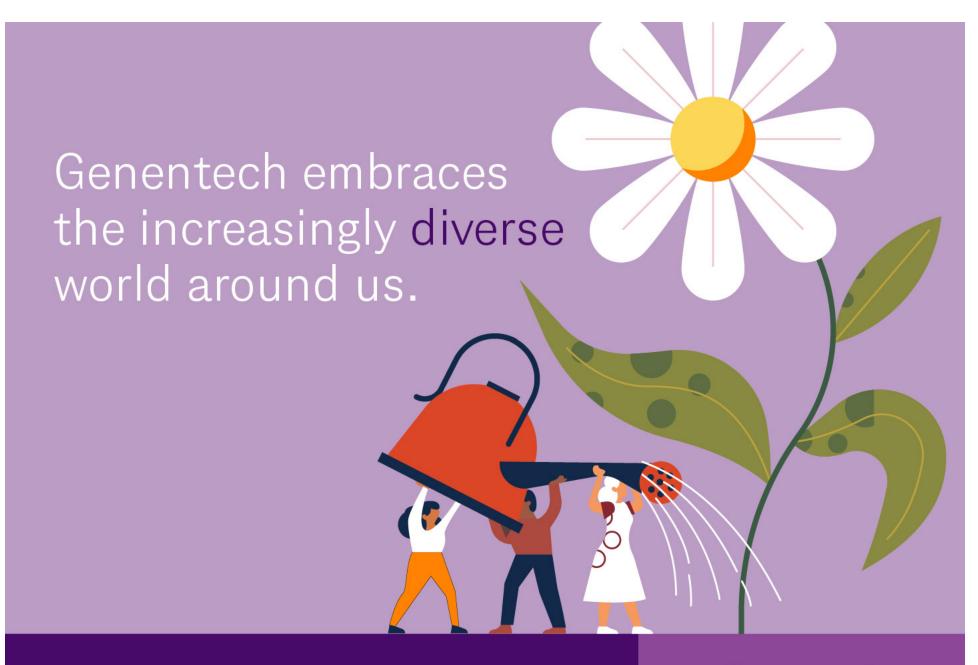
- Lori and Gregg Ireland

Our love and congratulations to Feda Almaliti, 1977-2020

2021 Autism Science Foundation Caryn Schwartzman Spirit Award



Your love for and dedication to Muhammed and the entire autism community will never be forgotten. Thank you, ASF, for honoring Feda.



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