



2016 ANNUAL REPORT



PRESIDENT'S LETTER

Dear Friends:

There is no denying that 2016 was an extraordinary year, in every sense of the word. As we look ahead to a period of uncertainty, it's more important than ever that we stand together in support of scientific endeavor. Specifically, we all must step up to ensure that research advancing our understanding of autism – and how to translate that knowledge into improved treatments – continues to move forward.

The Autism Science Foundation is all about the science – as we like to say, “Science Is Our Middle Name.” We are laser-focused on being a catalyst for research that has a real impact on real people’s lives. Our approach is to be strategic in our investments, funding the researchers who are doing the most innovative work that also has the greatest potential for impact. Some of these scientists are household names in the autism research field, while others are emerging stars. All of them are making incredible, meaningful progress.

Here are a few highlights from 2016:

This year saw the expansion of our Autism Sisters Project. In addition to partnering with scientists at the Icahn School of Medicine at Mount Sinai, we are now also collaborating with researchers at the University of California, San Francisco, the University of Illinois at Chicago and the Broad Institute at MIT. Our goal is to learn all we can from the unaffected siblings of people with autism about a potential “female protective effect.” We want to continue to grow this critical initiative, and in 2017 we’ll be focused on new ways families can get involved by enabling online participation and DNA (saliva) samples collected by mail.

The third annual ASF “Day of Learning,” a science conference for the autism community, featured TED-style talks by top autism researchers, clinicians and service providers. It’s a unique setting for top researchers to talk directly with the stakeholder community about where the science stands today and where it needs to go.

We were proud to announce earlier this year that Dr. Thomas Insel, former director of the National Institute of Mental Health (NIMH) and currently Director of Clinical Neuroscience in Alphabet Inc.’s Verily Life Sciences division, has joined the ASF Scientific Advisory Board. Dr. Insel is one of the true heroes of autism science, and we are fortunate to be able to benefit from his insights in shaping our direction.

This year we proudly increased funding for our annual pre- and postdoctoral fellowship programs and undergraduate summer research grants. Our Research Accelerator Grant portfolio included the first international grant ever offered by ASF. We support the best research, no matter where it is taking place.

Our second annual Wall Street Rides FAR (For Autism Research) event was again a significant success this year, raising \$255,000 to support the work of ASF. Hundreds of bike riders – avid cyclists and family recreational bikers alike – had a fantastic time biking four different scenic Westchester routes and taking in the beautiful fall foliage.

All in all, it was an incredibly productive year for ASF as we continue to deepen our impact on the field of autism research, always with an eye on how to connect the science with the lives of our loved ones who have ASD.

As always, we thank you for your incredible support of our organization and its mission.

Sincerely,


Alison Singer
President, Autism Science Foundation



ACCOMPLISHMENTS

In 2016, our seventh year of operation, the Autism Science Foundation:



FUNDING SCIENCE

In 2016, ASF provided over \$450,000 in grant support primarily through our pre- and postdoctoral fellowships, Research Accelerator Grants and undergraduate research awards. Below are summaries of the projects funded by these awards.

POSTDOCTORAL FELLOWSHIPS



Dr. Tom Cariveau and Dr. Lawrence Scahill
Emory University

A new treatment for minimally verbal girls with ASD

This study will examine the feasibility and preliminary efficacy of Social Engagement Therapy (SET) in a group of traditionally underserved individuals, minimally verbal girls with ASD. The investigators will also explore the use of a new wearable technology worn by the therapist to examine orientation to social stimuli.



Dr. Aarti Nair and Dr. Susan Y. Bookheimer
University of California, Los Angeles

Brain changes following social skills treatment in adolescents with ASD

This research will identify markers of brain activity that will predict how different people respond to treatment on social communication skills. The findings will help ensure that everyone with ASD has the best opportunity for a favorable outcome.



Dr. Tychele Turner and Dr. Evan Eichler
University of Washington

Origins of genetic causes of autism

While many of the genes associated with autism are not seen in either parent, there are also cases where a mutation is passed from a parent who does not have autism. This study will go on to identify those specific genes, how they are passed on to either boys or girls with autism, and describe features in the children with autism who inherited them. This will ultimately help clinicians understand some of the differences in males and females with autism and possibly lead to individualized treatment targets.



Dr. Donna M. Werling and Dr. Stephan J. Sanders
University of California, San Francisco

The genetics of male sensitization and female protection in ASD

In order to understand what causes the difference in diagnosis of autism between males and females, this research will look at genes in both sexes that may increase the chance of males showing symptoms and decrease the chance of girls showing symptoms. This research may possibly lead to more specific therapeutics to mitigate the symptoms of both boys and girls.

PREDOCTORAL FELLOWSHIPS



Jacqueline Barkoski, Dr. Sally Ozonoff & Dr. Irva Hertz-Picciotto
University of California, Davis

Examining prenatal pesticide exposure, genetic susceptibility and risk for autism

Scientists concur that a combination of genetic and environmental factors increases risk for autism. In this study, pesticide exposure during pregnancy and the interaction with both maternal and child genes will be studied. The results will help identify preventable risk factors and contribute to understanding the role of genetics and environment in autism diagnosis.



Spencer Moore and Dr. Alysso Renato Muotri
University of California, San Diego

Role of an autism-related cytokine in a genetic model of ASD

In the brain, the immune system is now known to influence the way cells are shaped and sculpted. This study will examine the role of specific immune system cells and an immune system chemical in cells with a specific genetic mutation, MECP2. The findings will more fully explain the role of immune molecules in neurodevelopmental disorders.

This fellowship is being co-funded with the Rett Syndrome Research Foundation.



Christine Ochoa Escamilla and Dr. Craig M. Powell
University of Texas Southwestern Medical School

Genetic mutations in chromosome 16 and their role in autism

This study will remove two autism-related genes from an animal model to better understand how these genes contribute to the shape and functioning of different areas of the brain. The long-term goal is to understand the role of these genes in brain cell activity and identify novel therapeutic targets for future studies.



Woon Ju Park and Dr. Loisa Bennetto
University of Rochester

Mechanisms of sensory processing in ASD

This study will investigate factors that influence processing and interpretation of sensory information, specifically visual input. This will ultimately lead to a better understanding of sensory processing in people with autism and help augment strengths of those with ASD so they can better cope with impairments.



Megha Subramanian and Dr. Mollie K. Meffert
Johns Hopkins University

Study of a potentially novel biomarker for features of ASD

In some people with autism, head size is enlarged starting very young, suggesting a type of autism that has a specific genetic signature. This study will focus on small fragments of RNA called microRNA (miRNA) that may lead to larger head size. By measuring the levels of this miRNA in blood, this biomarker could result in earlier detection in individuals with autism.

ACCELERATOR AWARDS

The accelerator grant mechanism is designed to rapidly fund novel findings, provide resources to build on an existing project or to explore unexpected opportunities. This year we funded our first international accelerator grant, which will expand the use of an instrument that will help assess gene/environment interactions in autism. We also continue to support research that will improve understanding of sex differences in autism and lead to better diagnosis in boys and girls.



Dr. Clare Harrop
University of North Carolina

Understanding what captures the attention of girls with ASD

While boys and girls with autism may both show symptoms, they also tend to exhibit them differently, making assessment and treatment studies challenging. This study will gain a deeper understanding of what captures attention in females vs. males with autism spectrum disorder, so that more sensitive and effective diagnostic instruments for boys and girls can be developed.



Dr. Astrid Vicente
Instituto Nacional de Saúde Doutor Ricardo Jorge (INSA)

Use of an Early Life Exposure Assessment Tool (ELEAT) for autism in Portugal

This award will support collection of environmental exposure data to be translated and culturally adapted into Portuguese, so it can be used to understand gene/environment interactions in Portugal, South America, Africa and Asia.

UNDERGRADUATE AWARDS

ASF is the only autism organization to offer summer support to undergraduate researchers, encouraging the best and brightest students to launch a career in autism science.



Armen Bagdasarov and Dr. Robert Schultz
Children's Hospital of Philadelphia

This research will closely examine several aspects of social communication in autism: word choice, gestures, turn taking and other conversational skills. This intensive focus on a core feature of autism will help improve communication intervention strategies for people with ASD.



Laura Bell and Dr. Meghan Miller
University of California, Davis

The team at UC Davis will utilize second-by-second behavioral coding of infants at risk for ASD at different ages. Instead of just focusing on autism-related behaviors, this research will expand evaluations to include features of ADHD to identify early signs and symptoms for infants with an older sibling with autism, since ADHD is a common outcome among these infants.



Elliot Keenan and Dr. Matthew D. Lerner
Stony Brook University

This research will examine the link between repetitive behaviors, perseverative thinking and autism symptoms in adults. It will also participate in validating a tool to measure IQ in autistic individuals with anticipated high IQ.



Adriana Mendez Leal and Dr. April Levin
Harvard University

Past studies of brain activity in infants have shown promise in using electrical signals in the brain to establish a very early biomarker of ASD. This research will compare brainwaves at 6 months to language scores at 18 months, further testing the idea that these are early biomarkers.



Eleonora Sadikova and Dr. Elizabeth Redcay
University of Maryland, College Park

This research will examine brain activity in individuals with autism in real time while individuals participate in a communication program called "Let's Chat." It will focus on areas of the brain involved in social reward to determine how social communication may or may not be reinforcing in people with ASD.



Tatiana Winkelman and Dr. James McPartland
Yale University

Individuals with autism often suffer from poor sleep, which has long been a huge concern for families. This unique study will examine brain activity during waking hours and compare it to sleep quality in an effort to understand how these variables contribute to behavioral issues.

“ Thanks to the Autism Science Foundation, I spent my summer researching early predictors of ASD and working with families affected by autism. This experience deepened my interest in neurodevelopmental disorders and gave me skills to use in my future career. ”

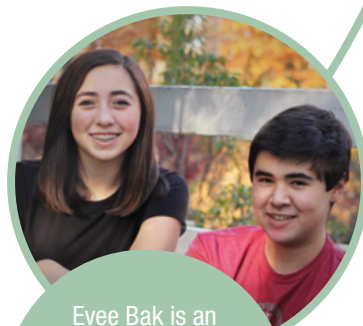
– LAURA BELL, UNIVERSITY OF CALIFORNIA, DAVIS



In 2016, ASF expanded its Autism Sisters Project, which is funded in conjunction with the Hilibrand Foundation. In addition to partnering with scientists at the Icahn School of Medicine at Mount Sinai, we are now also collaborating with researchers at the University of California, San Francisco, the University of Illinois at Chicago and the Broad Institute at MIT. Our goal is to learn all we can from the undiagnosed siblings of people with autism about a potential “female protective effect.” We want to continue to grow this critical initiative, and in 2017 we’ll be focused on new ways families can get involved by enabling online participation and DNA (saliva) samples collected by mail.



Rory and Grace Stephens participated in the Autism Sisters Project at the Seaver Autism Center at the Icahn School of Medicine at Mount Sinai.



Evee Bak is an important advocate for her brother Tommy and for the Autism Sisters Project.



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Bryan Harkins, Melissa Moo Harkins and Alison Singer at the Ride FAR event.



Advocates in Northern New England urged others to register for the Autism BrainNet.



The Briesch family poses for an “It Takes Brains” ad.



The Autism Science Foundation continues to serve as a key player in the Autism BrainNet, which is building a repository of postmortem brain tissue for autism research. This year, a total of 911 people registered for this important program, an increase of 10% over 2015.



Rebekah Travis and Kelly Gleason represented the Autism BrainNet at Southfork Ranch in Dallas.



This past year we announced that ASF will provide significant funding over the next year for essential work to ensure the continuing viability of the Baby Siblings Research Consortium (BSRC) database, which scientists from around the world rely upon for a range of important autism research initiatives. The BSRC database contains longitudinal behavioral assessment data for more than 5,000 infant siblings from over 30 separate research projects worldwide. Each year, all of the BSRC member sites contribute data to the database, steadily expanding its size and power. This resource has led to findings and discoveries that have had a substantial impact on the lives of families with autism.

THIRD ANNUAL DAY OF LEARNING

April 14, 2016

Our third annual TED-style autism conference featured talks by top autism researchers from across the country for a full day of learning. More than 250 parents, individuals with autism, regular and special education teachers, students and other stakeholders participated.



Dr. Theresa Hamlin demonstrated new technologies that help to identify stress reactions in students before they manifest into meltdowns in the classroom.



Dr. Jeremy Veenstra-VanderWeele, Dr. John Constantino and Dr. Peter Szatmari



ASF Undergraduate Research Award recipient Max Rolison and SAB Member Dr. Celine Saulnier



Paul Morris, ASF Board Chair Greg Ireland, Lori Ireland and Larry Hilibrand



SAB member Dr. Ami Klin and Inna Needelman



Dr. Peter Szatmari presented data supporting the hypothesis that females are protected from certain symptoms of autism.



Dr. Ruth Fischbach, Dr. Gerald Fischbach and Dr. Marilyn Simons



Erin Lopes received the Caryn Schwartzman Spirit Award in recognition of her outstanding efforts as an autism advocate.

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