2020
ANNUAL REPORT

**AUTISM
SCIENCE
FOUNDATION**
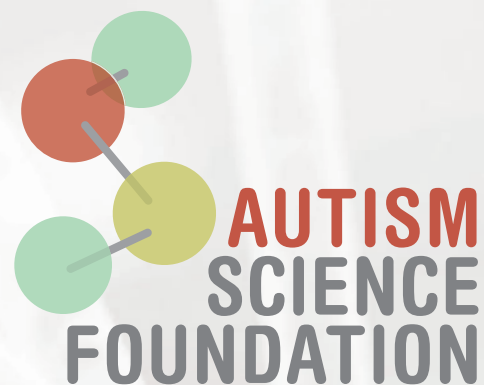
A Year Like No Other

PRESIDENT'S LETTER

Dear Friends:

Let's say it one more time for the people in the back: What a crazy year this has been! Life as we knew it changed dramatically because of COVID-19, but one thing that didn't change was our commitment to improving the lives of people with autism. As the world shut down, we stepped up, developing new programs and funding mechanisms to meet the changing needs of autism scientists and families.

ASF's new COVID-19 Pivot Grants were designed to help scientists adapt their research protocols, ensuring that critically needed work to discover the causes of autism and develop new treatments continued even amidst the most difficult circumstances. We heard from countless distraught families who watched their children struggle to adapt to telehealth therapy sessions and e-learning. In response, ASF gave a grant to a new nonprofit developing a therapy robot that interacts with a child in the room but is controlled by a therapist in real time via Zoom, helping children stay focused and on task. We moved our Day of Learning online, enabling us to greatly expand our audience to over 900 participants. We also launched several webinar series to help families, adults with autism and scientists share best practices around everything from mask wearing to adapting to working from home.

One other thing that hasn't changed this year: as always, we are incredibly grateful to all of you for supporting our work, and we wish you good health in the coming year.

Sincerely,

Alison Singer

CHIEF SCIENCE OFFICER'S LETTER

Dear Friends:

The entire autism community – from families to service providers to the scientific community – was devastated by the COVID-19 pandemic this year. This is why we moved quickly to support families through informational webinars and provided emergency funding to researchers who needed to change their protocols to adjust to social distancing regulations. ASF was the only autism-specific funding organization to do this. We also embraced the important concept of weathering the storm together with our collaborations with Autism Navigator, Els for Autism and Children's Specialized Hospital of NJ. Even with all of the challenges, there were important scientific accomplishments and discoveries that made a difference in the lives of families, outlined in the 2020 research summary.

All of this work cannot happen without your unwavering support for the mission of ASF, not only in this "difficult" year but in the years to come.

Sincerely,

Alycia Halladay, PhD

AUTISM SCIENCE FOUNDATION

COVID-19 ACCOMPLISHMENTS

The COVID-19 pandemic has created unprecedented challenges for families affected by autism, the clinicians and teachers who serve them and the scientists studying the causes of autism and developing new treatments. The Autism Science Foundation (ASF) has launched several new programs to respond quickly to the changing needs of the autism community and make sure that critically needed autism research continues to progress.

Launched a new funding mechanism, COVID-19 Pivot Grants, to enable researchers to adapt existing research projects to new pandemic-based restrictions.

Organized and hosted webinars for families to help address challenges with distance learning, telemedicine and disruptive behavior.

Partnered with Autism Navigator to create a "virtual community" for families where they can interact with clinicians and therapists to support their children's learning and development.

Collaborated with Els for Autism to launch a new program to support the pandemic-related needs of siblings of people with autism.

Created dedicated COVID-19 stakeholder-specific resource pages for families, scientists and clinicians.

Produced virtual "science fairs" to match families with researchers conducting online autism studies.

Converted Day of Learning events to free virtual conferences, greatly expanding access for those outside our typical geographic areas.

A YEAR LIKE NO OTHER...

COVID-19 Webinar Series
REDUCING CHALLENGES IN WEARING PPE
JUNE 30, 2020, 4PM EST

ASF & Children's Specialized Hospital produced a COVID-19 Webinar Series to help parents navigate new challenges in their everyday life brought on by the pandemic

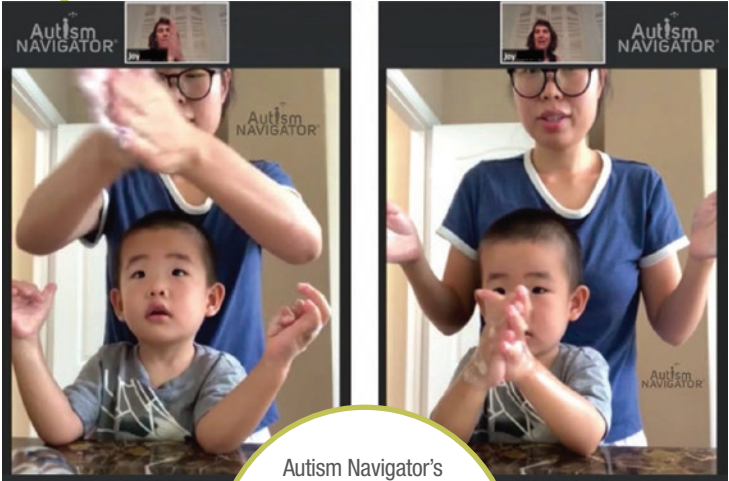Parents were taught best practices for getting their children to wear and keep on PPE while in public

To help healthcare providers, educators and families improve outcomes for young children with ASD during the pandemic, the Autism Science Foundation and Autism Navigator launched the Autism Navigator Virtual Community. This new community opens opportunities for communication for families by providing access to videos showing real-life examples of challenging behaviors and how to manage them.

Autism Navigator's video courses teach evidence-based intervention strategies for social communication, active engagement and addressing challenging behavior

Super siblings Jack & Amy Ursitti

The Autism Science Foundation worked directly with early career autism scientists to help them adjust to pandemic realities and keep their research studies moving forward.

Sisters and Sam's Sibs members Jodie & Lauren Singer

The Autism Science Foundation collaborated with Els for Autism to create a new sibling resource and webinar series, Sam's Sibs Stick Together. This sibling-run support network also presents research findings that focus on siblings and discusses resources available for siblings of all ages.

ASF Scientific Advisory Board Member Dr. Stephan Sanders & ASF Early Career Committee Member Dr. Donna Werling

ASF grant recipient Dr. Michael Sidorov runs his lab meeting virtually

FUNDING SCIENCE

In 2020, ASF launched two new COVID-19 related funding mechanisms, COVID-19 Pivot Grants and COVID-19 Research Grants, to enable researchers to adapt existing research projects to new pandemic-based restrictions and to study the unique effects of COVID-19 on people with autism.

COVID-19 PIVOT GRANTS

Jacquelyn Moffitt | University of Miami
Mentors: Michael Alessandri, PhD; Daniel Messinger, PhD

Home-based measurements of ASD features

Because of the pandemic and the utility of telehealth, scientists need better technologies to understand children with autism and the collaboration of parents to collect information about functioning. This project will support the use of a language recorder and a video camera to document progress and analyze information in a virtual way. This will tell researchers where the child is looking, what they are saying, how often they are babbling or talking, and other social communication measures. By doing so, the project can continue to collect information from families and also better understand the accuracy and utility of these newer technologies.

Jenny Root, PhD, BCBA | Florida State University
Mentor: Asha K. Jitendra, PhD, MSc

Virtual video-based math instruction

Mathematical skills are critical for postsecondary success in people with ASD. Unfortunately, there are very few math curriculums developed for people on the spectrum. For those that do exist in special education, they may not be able to be used as is because the schools will not be open or they will be on a modified schedule. Dr. Root and her colleagues have been working toward a program which improves problem-solving skills. They will adapt this program from being fully teacher-delivered to partially caregiver-delivered using video modules. The funding will allow the study of this intervention to continue, as well as study the efficacy of the online program for future use. They will also better understand how teachers, support staff, parents and individuals on the spectrum who receive the intervention like it.

Sandra B. Vanegas, PhD | Texas State University

Ensuring access to technology for low-resource families in autism studies

Few autism studies have focused on the unique needs of culturally diverse families in low-resource households. The ASD Screening and Parent ENgagement (ASPEN) intervention program has been created to help parents develop skills to address challenges in communication, socialization and difficult behavior. Unfortunately, due to social distancing measures and closure of access centers for families, this intervention will now need to be delivered remotely. Many families participating in this study don't have access to computers, tablets or the internet. This grant will provide equipment to disadvantaged families in Texas to ensure they can continue to participate. It will also enable researchers to evaluate the effectiveness of this telehealth intervention.

Lonnie Zwaigenbaum, MD | University of Alberta

Converting in-person visits to virtual assessments

Longitudinal studies that track the same children from birth through adolescence have revolutionized our understanding of early detection and intervention delivery, and have improved the long-term outcomes of children with ASD. Because of the pandemic, assessments that provide information to both researchers and families need to be adapted to accommodate social distancing protocols. This grant will allow data collection to continue on a cohort of children from which significant information has already been collected. It will also provide additional funding to families to compensate them for their increased effort.

COVID-19 RESEARCH GRANTS

Hannah Rea, PhD | University of Washington
Shalini Sivathasan | Emory University

Measuring the validity of new virtual autism assessments

The sudden change from in-person assessments to telehealth delivered diagnosis provided much needed support to families during the pandemic, but the urgency of assessment meant there has been little time to determine the validity of these measures or get family feedback regarding these changes. Researchers at the University of Washington and Emory will collaborate and combine their resources to examine these new assessment practices in both children and adults with ASD. The goal is to determine what changes should be continued and which need to be further improved, ultimately helping clinicians conduct ASD assessments virtually.

Marika Coffman | Duke University
Mentor: Geraldine Dawson, PhD

Mental health consequences of the COVID-19 pandemic on children with ASD

Parents of children with ASD have reported huge changes in psychiatric and behavioral problems in their children over the course of the pandemic. To date, there has been no research on who is most vulnerable and what causes the biggest changes in adaptive behavior. This study will expand an existing project examining mental health issues in families with ASD by tracking families pre-pandemic through mid-pandemic to determine what contributes to the elevated anxiety, ADHD and challenging behavior, and how loss of services during the pandemic may have exacerbated these issues. The findings will help inform future efforts to understand who is most susceptible to mental health issues and what contributes to resilience.

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

Alana Eiland | Yale University
Mentor: James McPartland, PhD

Children, teens and adults with autism often are also diagnosed with anxiety. In this study, Ms. Eiland will look at brain activity in adults with ASD, anxiety and both diagnoses to try to find biological signatures for each condition. The results of this research could better inform treatment options for anxiety in autistic adults.

Kristen Enriquez | Yale University
Mentor: Ellen Hoffman, PhD

TBR1 is an autism risk gene on chromosome 2 that has only recently been identified. It is critical for proper wiring of brain regions associated with autism, like the amygdala and the cortex. Using CRISPR technology, Ms. Enriquez and Dr. Hoffman will use zebrafish to manipulate the expression of the TBR1 gene, which is associated with brain wiring in autism-relevant brain regions. The study design allows about 100 zebrafish to be screened at a time, making it an efficient model to screen for potential pharmaceutical interventions.

Joshua Glauser | Boston Children's Hospital/Harvard University
Mentors: Charles Nelson, PhD; Carol Wilkinson, MD, PhD

While autism is typically not diagnosed until 24 months, biological features can often be noticed much earlier. For example, it has been suggested that as early as 3 months, infants who go on to be diagnosed with autism might look at their mother less often. This project will examine how early brain responses to seeing their mother vs. a stranger are related to the development of social behavior and gestures in kids who go on to be diagnosed with autism. This would support the earliest possible diagnosis of autism, as well as development of language and social abilities.

Kyra Rosen | University of California, Los Angeles
Mentor: Shafali Jeste, MD

The goal of this research will be to identify and classify the major hurdles to positive lifestyle outcomes in adults with the most severe forms of autism and neurodevelopmental disorders (NDDs). Utilizing an existing database, Ms. Rosen will evaluate reports of medical comorbidities and conditions in adults, will examine service utilization and access to care and will interview caregivers via Zoom to better understand barriers to care. These data will help improve access to care for individuals with profound autism.

Bosi Chen | San Diego State University
Mentor: Inna Fishman, PhD

Examining cortical myelination as an index of brain maturation in the first years of life in ASD

George Chen, PhD, BS | University of California, Los Angeles
Mentor: Daniel H. Geschwind, MD, PhD

Enhancer-targeted correction of haploinsufficient autism risk genes

Eleanor Cole, MSc, PhD | Stanford University
Mentor: Antonio Hardan, MD

Optimizing transcranial magnetic stimulation treatment for restricted and repetitive behaviors in adolescents with autism spectrum disorder

Emily Ferguson | Koegel Autism Center, University of California, Santa Barbara
Mentor: Ty Vernon, PhD

Innovative approaches to quantifying outcomes in a social communication intervention for autistic adults with high support needs

Michele Gabriele | Massachusetts Institute of Technology | Mentor: Anders Sejr Hansen, PhD

Dissecting long-range chromatin looping and FOXG1 activation dynamics using live-cell imaging

Ashleigh M. Kellerman, MS | Purdue University | Mentor: A.J. Schwichtenberg, PhD

Temporal dyadic processes in autism risk and treatment

Jonathan D. Lautz, PhD | Seattle Children's Research Institute | Mentor: Stephen E.P. Smith, PhD

Identifying the role of a targeted GABAergic protein interaction network in excitatory/inhibitory imbalance in ASDs

WALL STREET RIDES FAR
FOR AUTISM RESEARCH

Because of the COVID-19 pandemic, our annual bicycling event went virtual. Riders and walkers from all over the world biked with their own teams and participated in other virtual activities. Over $400,000 was raised to fund ASF's scientific initiatives.

Animal models are critical for understanding genetics and the basic circuitry of the ASD brain, and for screening new treatments. Behaviors seen in mice and rats do not perfectly mirror autism in people, but these models are a key step in the process of understanding causes and developing interventions. In 2020 we convened a virtual workgroup of leading investigators in the field to discuss what behaviors should be modeled in animals and also provide recommendations to researchers on methodology and reporting to improve the quality of research.

PEERBOTS

In 2020, ASF awarded a grant to PEERbots to help that nonprofit develop social robot puppet software for children with autism.

The PEERbot system allows therapists to interact with children remotely through a social robot in the room with the child, while the therapist is on a virtual platform with the child. This results in a more tangible connection and could speed up the child's progress. Through PEERbots, the therapist is able to create tailored content in advance of a therapy session or in real time.

The Baby Siblings Research Consortium (BSRC) is a network of over 50 scientists aimed at better understanding the early signs and symptoms of ASD, including behavioral and biological signals which can be used to improve diagnoses and understand the lifespan of people with ASD. In response to the pandemic, the BSRC met online to discuss what was originally planned for an in-person meeting, created a video library for families on topics ranging from early concerns to genetics, and published dozens of scientific articles that are improving the understanding of the early signs of ASD.

Work also progressed on the BSRC "Next Gen Sibs" project, which will enroll a cohort of grandchildren of parents who have a child with autism to look for early warning signs of autism in this group.

ASF continues to work closely with the Autism BrainNet to encourage families to donate postmortem brain tissue for research. Brain tissue is now available to researchers worldwide and has helped identify new therapeutic targets and understand how brain connections are different in people with autism.

Our Autism Sisters Project continues to make tremendous progress. In 2020, Autism Sisters Project investigators investigated the role of sex in the diagnosis of both boys and girls with ASD and showed that diagnostic instruments do not bias males over females. As a follow-up, they utilized the largest genetic database in the world to confirm the presence of a genetic Female Protective Effect. Females showed more genetic mutations compared to males, despite being diagnosed less and having similar features. This group is now examining other factors which may influence the diagnostic bias.

AGENDA

Alliance for Genetic Etiologies in Neurodevelopmental Disorders and Autism

The Alliance for Genetic Etiologies of Neurodevelopmental Disorders and Autism (AGENDA) is a partnership of research and advocacy organizations focused on improving outcomes of individuals with all forms of autism by fostering a genetics-first approach to autism science. This year, the organization focused on collaborative activities to help families across the spectrum of autism in the face of the pandemic. This included a needs assessment survey to understand how our families were struggling in unique ways.

JIDR Journal of Intellectual Disability Research
Published on behalf of mencap and in association with IASSIDD

Original Manuscript · Free Access

Changes in access to educational and healthcare services for individuals with intellectual and developmental disabilities during COVID-19 restrictions

S. Jeste, C. Hyde, C. Distefano, A. Halladay, S. Ray, M. Porath, R. B. Wilson, A. Thurm

First published: 17 September 2020 | https://doi.org/10.1111/jir.12776

IMPACT OF ASF'S FUNDING

ASF funding resulted in 41 journal articles, book chapters and scientific publications in 2020. Publishing enables research to be shared with the community, advances the pace of research and enables evidence-based interventions to be implemented in community settings. Here's a broad sample:

Implementation of findings into the community
ASF grantee: Gazi F. Azad, PhD
Partners in school: An implementation strategy to promote alignment of evidence-based practices across home and school for children with autism spectrum disorder | Published in: Administration and Policy in Mental Health and Mental Services Research

Gender differences in ASD
ASF grantee: Somer Bishop, PhD
Sex differences in scores on standardized measures of autism symptoms: a multisite integrative data analysis | Published in: Journal of Child Psychology and Psychiatry

Understanding comorbidities in people with ASD
ASF grantee: Michelle D. Failla, PhD
Increased pain sensitivity and pain-related anxiety in individuals with autism | Published in: Pain Reports

Utilizing animal models to advance treatments
ASF grantee: Thomas Jaramillo, PhD
Early restoration of SHANK3 expression in SHANK3 knockout mice prevents core ASD-like behavioral phenotypes | Published in: eNeuro

Molecular underpinnings of brain development
ASF grantee: Jason M Keil, MD, PhD
Symmetric neural progenitor divisions require chromatin-mediated homologous recombination DNA repair by Ino80 | Published in: Nature Communications

Epidemiology and recurrence in families
ASF grantee: Natasha Marrus, MD, PhD
Inherited risk for autism through maternal and paternal lineage | Published in: Biological Psychiatry

Gene/environment interactions in ASD
ASF grantee: Nicholas Page
Alterations in retrotransposition, synaptic connectivity and myelination implicated by transcriptomic changes following maternal immune activation in nonhuman primates | Published in: Biological Psychiatry

Baby Siblings Research Consortium – early identification
ASF grantee: Gregory Young, PhD
Developmental trajectories of infants with multiplex family risk for autism | Published in: JAMA Neurology
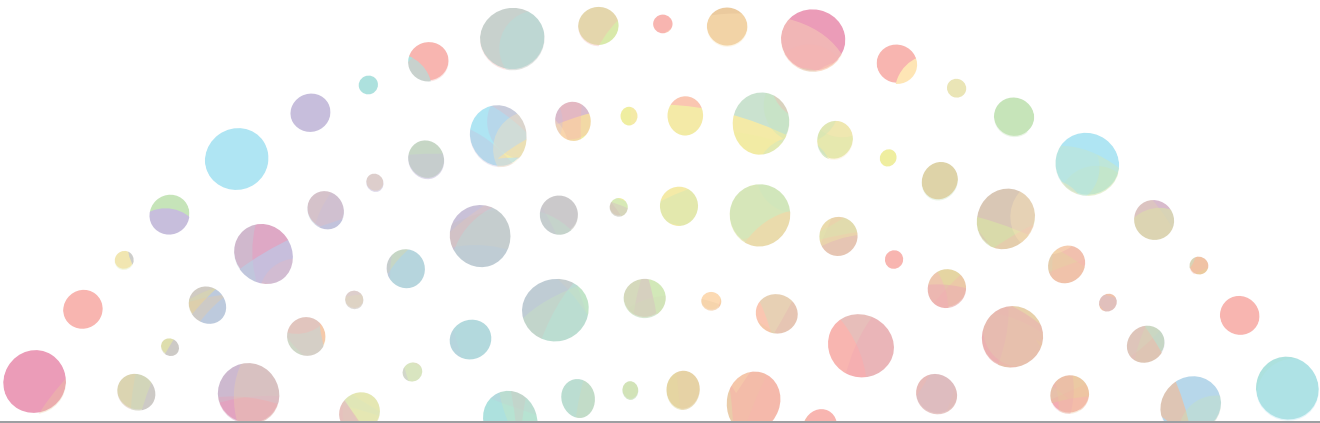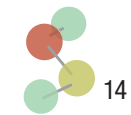
Genetic influences on brain development and ASD
ASF grantee: Donna Werling, PhD
Whole-genome and RNA sequencing reveal variation and transcriptomic coordination in the developing human prefrontal cortex
Published in: Cell

Early biological markers of ASD
ASF grantee: Carol Wilkinson, MD, PhD
Use of longitudinal EEG measures in estimating language development in infants with and without familial risk for autism spectrum disorder | Published in: Neurobiology of Language

Every year ASF summarizes the major highlights in autism research, regardless of funding source. Our 2020 summary includes findings in multiple areas of research and explains why these findings matter to families and individuals with ASD. You can read the 2020 summary at bit.ly/asfresearchrecap20, or listen to the ASF year-end podcast here: http://bit.ly/asfpodcastrecap2020.
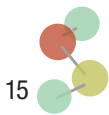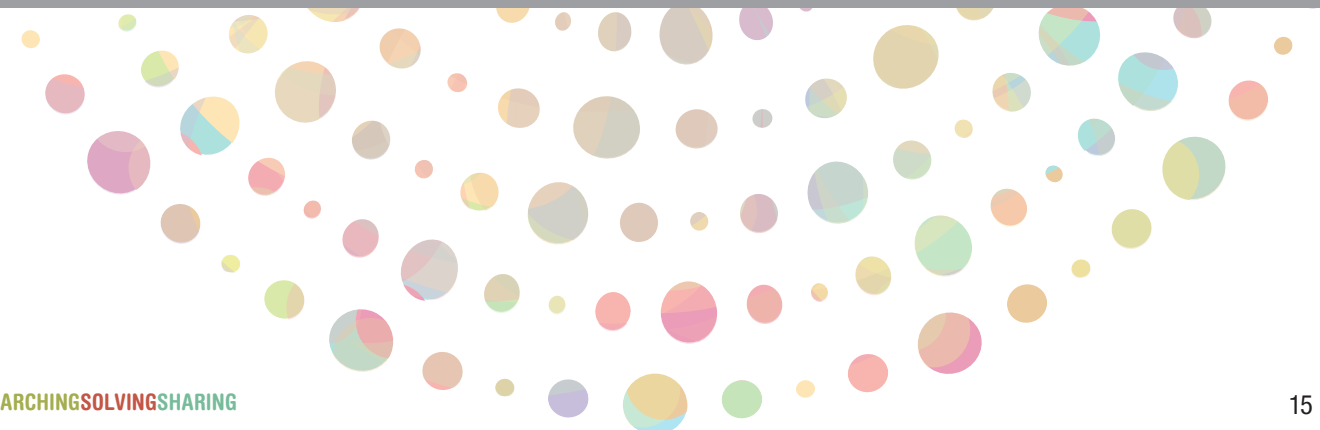
CORONAVIRUS PANDEMIC
VACCINE RELIEF COMES TO DISABLED COMMUNITY

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