



Autism Science Foundation

searching. solving. sharing.



2021
ANNUAL REPORT

PRESIDENT'S LETTER

Dear Friends:

Despite the many challenges brought on by the COVID-19 pandemic, ASF reaffirmed its commitment to supporting important progress in autism research in 2021 and to addressing the most urgent needs of our community. We maximized our impact by investing in the most promising science and in the researchers who are taking innovative approaches to our biggest challenges. Now more than ever, we have to keep pushing forward, leveraging new knowledge and putting it to work for people with ASD and their families.

Our focus on innovation and pilot projects paid off; each dollar we invested in autism research led to 54 dollars of funding by the NIH and/or other research funders.

Our commitment to the next generation of families was evident in our investment in the Next Gen Sibs project, as we launched sites at Emory University and UCLA to begin building a network to more efficiently identify, evaluate and diagnose the children of typically developing siblings of people with ASD, so they can receive critical interventions that will help them thrive.

Our advocacy resulted in *The Lancet* calling for use of the term “profound autism” and recommending that more resources be devoted to this underserved and vulnerable population. We also issued a position statement on the use of Applied Behavior Analysis (ABA), providing examples of how the science and research behind ABA indicate that it is safe and effective in improving the functional abilities of people with autism across the spectrum.

As always, heartfelt thanks for your continued support of ASF and its mission. We look forward to another year of progress, both in the lab and in the lives of those we strive to help every day.

Sincerely,



Alison Singer | President, Autism Science Foundation

CHIEF SCIENCE OFFICER'S LETTER

Dear Friends:

In 2021, research answered some of the most urgent questions from autism families — but many questions remain. As the COVID-19 crisis dragged on, autism families continued to struggle with mental health, psychological, educational and logistical challenges associated with pandemic-related isolation and stress. ASF continued to fund research through our COVID-19 grants to help understand the experiences of families during the pandemic so we can learn from past experiences and permanently change systems going forward. Additionally, I am proud that ASF was the first autism funding organization to provide grants exclusively to those from underrepresented groups or whose research addresses issues relating to disparities in diagnosis and treatment.

Personally, this year I was honored to be appointed to the Interagency Autism Coordinating Committee (IACC), a federal advisory committee that coordinates efforts and provides recommendations to the U.S. Secretary of Health and Human Services on issues related to autism.

This important role ensures that ASF has a voice on federal priorities that will impact families affected by autism for the next four years. This includes prioritizing issues relating to diagnosis, interventions, services, risk factors, COVID-19 and diversity, equity and inclusion. Despite the year's many challenges, I am optimistic about the future and hopeful that the lessons learned so far during the pandemic will help families find a new path forward amid extraordinary circumstances.

All my best,



Dr. Alycia Halladay | Chief Science Officer, Autism Science Foundation



ACCOMPLISHMENTS

In 2021, our 11th year of operation, the Autism Science Foundation:



COVID-19 AUTISM RESEARCH GRANTS:

ASF launched the COVID-19 Grants in early 2020 to enable scientists, many of whom were struggling to continue their research when institutions were shut down, to keep making progress. The mechanism then evolved to fund research examining the unique effects of COVID-19 on people with autism, and to study ways to make permanent improvements to diagnoses and treatment based on the service gaps the pandemic brought to light.

GRANT RECIPIENTS



Joshua Anbar, Ph.D., MPH | Southwest Autism Research and Resource Center, AZ
Mentor: Christopher Smith, Ph.D. & Nicole Matthews, Ph.D.

Expanding the Scope of Telehealth Evaluations in Children with ASD

The pandemic and related shutdowns prevented many standard assessments from being collected in person, including measures of cognitive ability. This grant supports work validating a cognitive measure called the Kaufman Brief Intelligence Test, and the related Naturalistic Observation Diagnostic Assessment, both of which are designed to be implemented via telehealth protocols. The findings will help clinicians better utilize effective telehealth resources for remote assessments and potentially reduce wait times for evaluations after the pandemic has resolved.



Kathryn Hauschild, Ph.D. | Stony Brook University
Mentor: Matthew Lerner, Ph.D.

Examining the Effects of Pandemic-Induced Isolation on the Mental Health of Adolescents with ASD

At the start of the pandemic, Stony Brook University researchers initiated a longitudinal study of the effects of isolation on psychosocial functioning, mental health and stress in students with and without ASD. They later recontacted families already enrolled in other projects so they could see potential changes from pre- to mid-pandemic across a number of outcomes. This funding expands the work to collect data on the return to in-person activities and any resulting changes in social and mental health functioning in adolescents with ASD.



Allison Shana Nahmias, Ph.D. | Stony Brook University
Mentor: Matthew Lerner, Ph.D.

Evaluating an Online Intervention to Help Autistic Adolescents Deal with Pandemic Stress

The pandemic has increased stress for all, but particularly for adolescents already experiencing mental health challenges. Most mental health interventions require multiple clinician visits, can be costly and are not feasible for many families from diverse socioeconomic communities. This study examines the effects of a single-session intervention, successfully utilized with neurotypical adolescents during the pandemic, to see if it is also successful in supporting autistic adolescents.



Emily Neuhaus, Ph.D. | Seattle Children’s Research Institute, WA

Understanding and Promoting Factors That Confer Resilience to Pandemic-Related Trauma

While children and adolescents have had varying mental health responses to the pandemic, there may be factors that make some children more vulnerable and others more resilient. In this project, the research group is collecting information from a diverse population, including families with and without a member with autism and those with or without comorbid anxiety or ADHD, to identify factors that improve coping, reduce stress and promote physical and emotional well-being. This study also seeks to pinpoint factors that may help convey resilience to, or ameliorate, mental health issues.



Michele Villalobos, Ph.D. | University of Utah

Adjusting Telehealth Practices for Low-Resource Families

Early research has shown that, while there was an 80% increase in the overall use of telehealth during the pandemic, families living in rural communities, those of Hispanic heritage and those on Medicaid were not utilizing telehealth services to the same extent. This study examines the profiles of families who were using telehealth before and during the pandemic so that both telehealth and other models of care can be improved to alleviate disparities.



Shuting Zheng, Ph.D. | University of California, San Francisco

Improving Mental Health Service Delivery for Individuals with Autism

Only about half of autistic adults who reported experiencing symptoms of depression during the pandemic received treatment due to problems accessing services. This project expands a longitudinal study of autistic adults reporting their own experiences with mental health care to learn how this population receives and prefers to receive support, and how improvements can be made to the services they receive.

BABY SIBLINGS RESEARCH CONSORTIUM (BSRC) GRANTS:

The Baby Siblings Research Consortium is a collaboration of more than 40 researchers around the world who work together to study the developmental origins of autism and to search for the earliest signs of ASD. Analysis of the younger siblings of children with autism has shown how early motor features predict diagnosis and has uncovered biological markers that predict autism before behavioral signs are present. Members contribute to a centralized database to address questions that a single lab or dataset could not accurately answer. In 2021, ASF supported ongoing organization, support and expansion of the database (via a grant to Greg Young, Ph.D., at UC Davis) as well as data analytic projects using existing and newly submitted data.

GRANT RECIPIENTS



Rujuta Bhatt Wilson, Ph.D. | University of California, Los Angeles

Linking Early Fine Motor Skills to the Development of Gestures and Language in Infants

Motor development is one of the earliest benchmarks of developmental progress in infants, but most motor skills studies rely on scores that combine all motor difficulties together. This study allows for the inclusion and analysis of item-level scores of motor function, which are then linked to motor ability at age of diagnosis. The results of this study may help develop more specific avenues for early intervention to improve social communication for children with and without a later ASD diagnosis.



Jessica Girault, Ph.D. | University of North Carolina, Chapel Hill

Familial Factors Driving Behavioral Development and ASD

BSRC work has shown that symptom and behavioral profiles of older siblings with ASD may inform outcomes in younger siblings. This project uses data from the entire family to study how features in the older sibling with ASD might help predict the likelihood of a diagnosis in an infant sibling. The results will have implications for screening and monitoring in early life by identifying cost-effective markers of diagnostic probability that can be easily obtained from families. Early identification paves the way for early intervention, which has the greatest potential to improve long-term outcomes for children and their families.



Heather Volk, Ph.D. | Johns Hopkins University

Linking Genetics to Behavior in Infant Siblings

Understanding the heritable influences of ASD can lead to better detection as well as open doors to determining the mechanisms behind an autism diagnosis. This project is generating polygenic risk scores (a marker of genetic influence) for families in the BSRC and linking that data to behavioral data at multiple time points from both the child with ASD and the sibling. These data will help better characterize the biological background of families in the BSRC (including those with no family history of autism) and will help better understand subtypes based on genetic factors that will be meaningful for clinical interventions.

NEXT GEN SIBS GRANTEES:

In October, ASF announced the first funding recipients in the Next Gen Sibs expansion of the Baby Siblings Research Consortium. **The goal of this project is to establish a collaborative network that will help in identification, evaluation, diagnosis and intervention of the “Next Generation,” i.e., the children of typically developing siblings of people with ASD.** Emory University, under the direction of Dr. Mikle South, and UCLA, under the direction of Dr. Catherine Lord, will work directly with families to determine how to develop and launch this new community resource.

UNDERGRADUATE SUMMER RESEARCH GRANTS

Undergraduate Summer Research Grants were awarded to students from traditionally underrepresented groups or **whose work focuses on reducing disparities in underserved communities.**

GRANT RECIPIENTS



Beza Ayalew | University of California, Los Angeles
Mentors: Brian Boyd, Ph.D. & Connie Kasari, Ph.D.

Understanding Autism Spectrum Disorder (ASD) Disparities in the California School System

This study aims to address longstanding disparities in ASD diagnoses in Black children by examining a dataset rich with information about underrepresented groups to study the rates of autism diagnoses. This will provide key information about diagnostic disparity in school settings and help us understand how diagnosis of Black children can be improved.



Jadon Mehringer | Indiana University
Mentor: Jill Fodstad, Ph.D.

Developing a Protocol for ASD Intervention in Acute General Psychiatry Inpatient Units

People with ASD are more likely to be hospitalized for psychiatric issues compared to those without a diagnosis. This study is addressing this crisis by developing an ASD-specific training and intervention package for use in acute care settings, which is being created by compiling data and incorporating stakeholder opinions into what needs to be stressed. This will ultimately improve care and services for autistic individuals and their families.



Daniel Nunez Huaracha | Boston Children’s Hospital
Mentor: Charles Nelson, Ph.D.

Early Links Between Motor Development and Language in ASD

In many cases, babies with delayed motor skills later receive an ASD diagnosis. This suggests that markers of motor delays could be a clue to a later ASD diagnosis. To examine this possibility, brain activity during motor and social communication tasks is being studied in two groups of infants: one with a family history of autism and a second group of babies likely to be typically developing. The goal of this study is to inform clinicians about which interventions will be best for which infants.



Jennifer Yu | California Institute of Technology
Mentor: Ralph Adolphs, Ph.D.

Smartphone-Based Eye Tracking for Assessing ASD

Early ASD detection methods such as eye tracking may help ease disparities in age of diagnoses in traditionally marginalized communities. This study is collecting eye tracking data from people with ASD over a smartphone app to develop a mechanism to obtain this data over the internet. This grant focuses on the targeted collection of data from families from Black and Latinx communities so that they are meaningfully included in the research findings.

PROFOUND AUTISM

In December, [The Lancet Commission on the future of care and clinical research in autism](#) formally recognized and clinically defined the term “profound autism.” ASF’s Alison Singer, a member of the Lancet Commission, explained in a [STAT op-ed](#) that this new term is “meant to call attention to the unique needs of this vulnerable, underserved community comprised of people who are minimally verbal or nonverbal and who require round-the-clock care throughout their lives.” She further explained the need for this new term in a widely shared [STAT podcast](#).

Since the publication of *The Lancet* report, ASF has heard from countless parents of profoundly autistic children who are scared about their children’s futures and feel bullied into silence by higher functioning self-advocates who often have a fundamental misunderstanding of what having profound autism even means. These parents tell us they are exhausted, both physically and emotionally, by the work it takes to keep their children healthy and safe each day, and by the difficulties in securing quality care for their children. ASF is committed to serving as a voice for these families.

#ThisIsProfoundAutism

ASF launched its #ThisIsProfoundAutism social media campaign shortly after *The Lancet* publication to highlight the reality of life with profound autism.



GRACE, 14, loves music, says mom Shannon Jungerman. “She is definitely our pop music-loving child, but really loves anything with a good beat! If she’s having a bad moment, we can turn on music and she calms down. Grace’s laughter and smile can change the entire feeling of a room, it’s so genuine and full of joy.”

Although Grace is nonverbal, Shannon says her daughter “wants to be included and involved in daily activities just like any 14-year-old girl.” Shannon also worries about Grace’s future. “What will her adult life look like? Who will care for her when my husband and I are gone? Will she always have self-injurious behaviors? Is she safe with her caregivers during the day? Can they predict her behaviors and needs when we aren’t around?”



CLAYTON, 21, loves VeggieTales, Pixar movies and riding in the car, says mom Erika Prater. “He loves to watch videos with the audio from other languages—I think that if he could speak, he would be fluent in about 10 languages!” He is also epileptic, mostly nonverbal and requires constant assistance and supervision.

“His father is his daytime caregiver while I teach school, and then I take over on evenings and weekends. Clayton is very sweet and content most of the time, but between his seizures and occasionally violent, aggressive meltdowns, we don’t dare to ask anyone else to care for him. One of his meltdowns last spring resulted in an injury to his dad which required surgery. Despite the impact on our family, I absolutely cannot bear the thought of him living anywhere but home. But I refuse to burden his siblings with the possibility of eventually caring for him, so I am willing myself to live forever (or at least long enough...)”



WESLEY, 14, loves swimming and is “quite a foodie,” says mom Jennifer Bush. “Nothing melts my heart more than when he takes my hand and stares deep into my eyes. Wesley has a remarkable way of connecting with people, despite being entirely nonverbal.

“We constantly worry about Wesley,” says mom. “At home, he’d often not sleep much, or at all, and can be aggressive and quite self-injurious. We made the heartbreaking decision to move him to residential care, and after two of his group homes in CA closed, he now lives out of state.

“We miss him terribly, and COVID has made it hard to visit as often as we’d like. We’re angry and frustrated at the lack of quality services for kids and adults like Wesley, especially in our home state of California.”

PANDEMIC SUPPORT

ASF continued to address the unique challenges faced by autism families and researchers during the pandemic. The lessons gleaned during this time will help shape not just further research directions but policy on telehealth beyond 2021.



Funded six new COVID-19 grants in 2021.



Worked with early career researchers to study their pandemic experiences. This study appeared in [Autism Research](#) and describes their unique experiences and needs.



Launched a special social media group for early career researchers to help them find funding opportunities and jobs.



Partnered with clinicians and parents to find ways to ease the challenges of socially distanced diagnostic evaluations to ensure that families still had access to accurate and efficient assessments during the pandemic. The group’s recommendations were published in the [International Society for Autism Research](#).



Debuted a free monthly Science Learning Series, allowing families across the globe to connect with top autism researchers.



SCIENCE
LEARNING
SERIES Autism
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Brain Development and Social
Interaction in Your Infant
November 19, 2021 | 3PM EST

8TH ANNUAL DAY OF LEARNING

ASF’s 8th annual TED-style science conference was fully virtual for the second year in a row, once again **breaking attendance records with over 1,100 registrants**. This year’s event addressed urgent pandemic-related topics, including the impact of COVID-19 on autism families and ways to rethink ASD assessment in the pandemic and beyond. It also addressed ways to improve diversity, equity and inclusion in autism research.





The **Baby Siblings Research Consortium (BSRC)** is a collaboration of more than 40 researchers and clinicians all committed to **searching for the very earliest signs of autism in infants with a high probability of a diagnosis**. ASF has provided logistical and financial support to the BSRC since 2017. This year, ASF funded four new BSRC grants, as well as providing funds to two sites to launch Next Gen Sibs, which will enable researchers to look for early autism signs in a cohort of grandchildren (i.e., the children of non-autistic siblings).



HELPING UNDERSERVED COMMUNITIES

In October, two articles were published summarizing the findings of an ASF-sponsored meeting that focused on engaging underserved ASD families in research. Specific recommendations were made to increase study participation in those from **traditionally marginalized racial, ethnic and socioeconomic backgrounds** and those with **intellectual disabilities**. Additionally, **ASF prioritized recent funding opportunities for undergraduate researchers from marginalized communities** and for studies that would help underserved populations gain more equitable access to services.



Sam's Sibs Stick Together is a collaboration between ASF and Els for Autism that **aims to provide extra support for autism siblings, present research findings that focus on siblings and disseminate resources available for siblings of all ages**. This year we held three webinars and launched a new website that provides resources, research findings and recordings of conversations of interest to autism siblings. Learn more at samssibssticktogether.com.



ASF WEEKLY SCIENCE PODCAST

ASF Chief Science Officer Dr. Alycia Halladay continued to host her award-winning **ASF Weekly Science podcast** in 2021, which **spotlights the latest and most important autism science, often with help from expert guests**. She also published her annual **year-end science summary**, which distilled the most significant autism discoveries and related news of the past year.



WALL STREET RIDES FAR

FOR AUTISM RESEARCH

The 2021 Wall Street Rides FAR event shattered all previous fundraising records, **bringing in more than \$800,000 to fund critical autism research and other ASF initiatives.** We were thrilled to welcome riders and walkers back in person after last year's virtual event, and were especially excited about the debut of our satellite rides in Baltimore and Toronto. We look forward to expanding the Ride even more in 2022. Join us on October 1, 2022, in person or online!

Team Talos crosses the finish line, led by CEO Anton Katz



WSRF co-founders Bryan and Melissa Harkins present Ana and Mila Klevzon with the youth fundraising award



WSRF board member Marc Wyatt leads the T. Rowe Price team in Baltimore



Participation in our 5K trail walk increased 200%



NEO Exchange team members at the inaugural Toronto ride



2021 RESEARCH FINDINGS

ASF funding resulted in 36 journal articles, special reports and scientific publications in 2021. 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 with the ASF-funded researcher’s name in bold:

COVID-19:

A Lost Generation? The Impact of the COVID-19 Pandemic on Early Career ASD Researchers

Harrop C, Bal V, Carpenter K, **Halladay A** | [PubMed ID: 33759380](#)

Rethinking Autism Spectrum Disorder Assessment for Children During COVID-19 and Beyond

Zwaigenbaum L, Bishop S, Stone WL, Ibanez L, **Halladay A**, Goldman S, Kelly A, Klaiman C, Lai M, Miller M, Saulnier C, Siper P, Sohl K, Warren Z, Wetherby A | [PubMed ID: 34553489](#)

BIOLOGY AND BIOMARKERS:

Abnormally Large Baseline P300 Amplitude Is Associated with Conversion to Psychosis in Clinical High Risk Individuals with a History of Autism: A Pilot Study

Foss-Feig JH, Guillory SB, Roach BJ, Velthorst E, Hamilton H, Bachman P, Belger A, Carrion R, Duncan E, Johannesen J, Light GA, Niznikiewicz M, Addington JM, Cadenhead KS, Cannon TD, Cornblatt B, McGlashan T, Perkins D, Seidman LJ, Stone WS, Tsuang M, Walker EF, Woods S, Bearden CE, Mathalon DH | [PubMed ID: 33633603](#)

Long-Term Maturation of Human Cortical Organoids Matches Key Early Postnatal Transitions

Gordon A, Yoon SJ, Tran SS, Makinson CD, Park JY, Andersen J, Valencia AM, Horvath S, Xiao X, Huguenard JR, Pasca SP, Geschwind DH | [PubMed ID: 33619405](#) | ASF supported this research through a Post-Doctoral Training Award to Aaron Gordon.

Alterations in Retrotransposition, Synaptic Connectivity, and Myelination Implicated by Transcriptomic Changes Following Maternal Immune Activation in Nonhuman Primates

Page NF, Gandal MJ, Estes ML, Cameron S, Buth J, Parhami S, Ramaswami G, Murray K, Amaral DG, Van de Water JA, Schumann CM, Carter CS, Bauman MD, McAllister AK, Geschwind DH | [PubMed ID: 33386132](#)

Increased Aperiodic Gamma Power in Young Boys with Fragile X Syndrome Is Associated with Better Language Ability

Wilkinson CL, Nelson CA | [PubMed ID: 33632320](#)

Using Head-Mounted Eye Tracking to Examine Visual and Manual Exploration During Naturalistic Toy Play in Children With and Without Autism Spectrum Disorder

Yurkovic JR, Lisandrelli G, Shaffer RC, Dominick KC, Pedapati EV, Erickson CA, Kennedy DP, Yu C | [PubMed ID: 33574367](#)

GENDER DIFFERENCES:

Towards Robust and Replicable Sex Differences in the Intrinsic Brain Function of Autism

Floris DL, Filho JOA, Lai MC, Giavasis S, Oldehinkel M, Mennes M, Charman T, Tillmann J, Dumas G, Ecker C, Dell’Acqua F, Banaschewski T, Moessnang C, Baron-Cohen S, Durston S, Loth E, Murphy DGM, Buitelaar JK, Beckmann CF, Milham MP, Di Martino A | [PubMed ID: 33648569](#)



GENETICS, GENE/ENVIRONMENT INTERACTIONS:

In Utero Pyrethroid Pesticide Exposure in Relation to Autism Spectrum Disorder (ASD) and Other Neurodevelopmental Outcomes at 3 Years in the MARBLES Longitudinal Cohort

Barkoski JM, Philippat C, Tancredi D, Schmidt RJ, Ozonoff S, Barr DB, Elms W, Bennett DH, Hertz-Picciotto I
[PubMed ID: 33220244](#)

EARLIER DIAGNOSIS:

Age of Walking and Intellectual Ability in Autism Spectrum Disorder and Other Neurodevelopmental Disorders: A Population-Based Study

Havdahl A, Farmer C, Schjølberg S, Øyen A, Surén P, Reichborn-Kjennerud T, Magnus P, Bresnahan M, Hornig M, Susser E, Lipkin WI, Lord C, Stoltenberg C, Thurm A, **Bishop S** | [PubMed ID: 33369747](#)

A Prospective Evaluation of Infant Cerebellar-Cerebral Functional Connectivity in Relation to Behavioral Development in Autism Spectrum Disorder

Hawks ZW, Todorov A, Marrus N, Nishino T, Talovic M, Nebel MB, Girault JB, Davis S, Marek S, Seitzman BA, Eggebrecht AT, Elison J, Dager S, Mosconi MW, Tychsen L, Snyder AZ, Botteron K, Estes A, Evans A, Gerig G, Hazlett HC, McKinstry RC, Pandey J, Schultz RT, Styner M, Wolff JJ, Zwaigenbaum L, Markson L, Petersen SE, Constantino JN, White, DA, Piven J, Pruett JR, Jr. for the IBIS Network | [DOI: doi.org/10.1016/j.bpsgos.2021.12.004](#)

UNDER-RESEARCHED GROUPS:

The Lancet Commission on the Future of Care and Clinical Research in Autism

Lord C, Charman T, Havdahl A, Carbone P, Anagnostou E, Boyd B, Carr T, de Vries PJ, Dissanayake C, Divan G, Freitag CM, Gotelli MM, Kasari C, Knapp M, Mundy P, Plank A, Scahill L, Servili C, Shattuck P, Simonoff E, **Singer AT**, Slonims V, Wang PP, Ysraelit MC, Jellett R, Pickles A, Cusack J, Howlin P, Szatmari P, Holbrook A, Toolan C, McCauley JB | [PubMed ID: 34883054](#)

Biases, Barriers, and Possible Solutions: Steps Towards Addressing Autism Researchers’ Under-Engagement with Racially, Ethnically, and Socioeconomically Diverse Communities

Maye M, Boyd BA, Martinez-Pedraza F, **Halladay A**, Thurm A, Mandell DS | [PubMed ID: 34529251](#)

TREATMENTS, INTERVENTIONS AND SERVICES:

Partners in School: An Implementation Strategy to Promote Alignment of Evidence-Based Practices Across Home and School for Children with Autism Spectrum Disorder

Azad GF, Minton KE, Mandell DS, Landa RJ | [PubMed ID: 32653973](#)

Let’s See That Again: Using Instructional Videos to Support Asynchronous Mathematical Problem Solving Instruction for Students with Autism Spectrum Disorder

Cox SK, **Root JR**, Gilley D | [DOI: doi.org/10.1177/0162643421996327](#)



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