Leave a Lasting Imprint
2012 annual report
Dear Friends:

We all have an important role to play in autism advocacy. We all have talents to share, support to offer, ideas to put forth. It is up to each of us to contribute our strengths so our community can continue to grow and we can continue to fund the research our family members deserve. By sharing our skills and talents, we all leave a lasting imprint on the autism community.

At ASF, we are proud to have been called “a valued collaborator in the public private autism research partnership” by the National Institutes of Health (NIH). Our grant funding grew by 50% in 2012, and in addition to funding pre- and postdoctoral fellowships we added a 3-year early career award and began offering funds to undergraduates pursuing autism research. Too often, promising researchers exit the autism research field due to lack of funding. ASF grants serve to support young scientists at critical points in their careers and encourage them to continue to make discoveries that help our families.

In 2012, we launched a new multi-media campaign to shine a bright light on the critical need for more donated brain tissue to propel the research forward. Understanding the brain is essential to unlocking the causes of autism and developing effective treatments.

Also this year our study on autistic wandering was published in Pediatrics and led to the implementation of a new medical classification code for “autistic wandering” which means doctors can now advise parents of children with autism about the potential for wandering and about implementing preventative measures.

My daughter Jodie spent the entire calendar year on the waiting list for residential placement making her not unlike the thousands of teens and adults suffering from the severe lack of appropriate services. We must do better! To this end, ASF launched three surveys to evaluate the services needs of adults with autism. Data from these studies will provide insight into successful and ineffective programs for adults and enable service providers to better direct their resources.

It’s critical that we keep investing in our future to keep this good work going. We hope you will be inspired by what you read in our 2012 Annual Report and will take even greater action in 2013. We could not do the work we do without the continued support of the donors, volunteers, staff members, scientists and parents who commit themselves to supporting individuals with autism and their families through research. Together we will leave a lasting imprint!

Sincerely,

Alison Singer
Co-Founder and President
Accomplishments

The Autism Science Foundation has worked to leave a lasting imprint in the autism community. In 2012, our third year of operation, ASF:

• Funded $330,000 in autism research fellowship grants; we’ve awarded almost a million dollars in autism research grants in our first three years.
• Launched a fourth round of pre- and postdoctoral fellowship grants to jump-start the careers of promising autism researchers.
• Added two new grant funding categories: a 3-year early career award and an undergraduate research fellowship.
• Helped families and other stakeholders learn about the latest autism research by providing scholarships to scientific conferences, as well as by hosting seminars and workshops, and reaching thousands through our websites and social media channels.
• Surveyed the services needs of hundreds of adults with autism not only to help service providers improve and expand programs, but also to enhance public awareness about the critical issues facing adults with autism.
• Launched an awareness campaign to encourage brain tissue donation so that scientists can investigate the neural underpinnings of autism spectrum disorders.
• Advocated successfully for a new medical classification code for autistic wandering, which became possible only after the ASF-funded wandering study was published in *Pediatrics*, the official peer-reviewed journal of the American Academy of Pediatrics.
Funding autism research is the core of our mission. In 2012, we increased our funding for pre- and postdoctoral fellowships by 50%. We focus on funding clever young investigators with new ideas and bright futures who need seed money to get their research off the ground. These young scientists are mentored and trained by established autism researchers. We are committed to helping young scientists gather the initial data they need to attract major funding, while encouraging the best and brightest researchers to dedicate their careers to autism. To date, ASF has funded autism research in a wide range of areas, including genetics, animal models, early diagnosis, and treatment development for individuals with autism of all ages.

2012 Postdoctoral Fellowships

- Dr. Inna Fishman and Dr. Ralph-Axel Muller, San Diego State University: Multimodal Imaging of Social Brain Networks in ASD
- Dr. Karyn Heavner and Dr. Craig Newschaffer, Drexel University: Evaluating Epidemiological and Biostatistical Challenges in the EARLI Investigation
- Dr. Haruki Higashimori and Dr. Yongjie Yang, Tufts University: Role of Astrocytic Glutamate Transporter GLT1 in Fragile X Co-funded by FRAXA Research Foundation
- Dr. April Levin and Dr. Charles Nelson, Children’s Hospital Boston: Identifying Early Biomarkers for Autism Using EEG Connectivity
- Dr. Klaus Libertus and Dr. Rebecca Landa, Kennedy Krieger Institute: Effects of Active Motor and Social Training on Developmental Trajectories in Infants at High Risk for ASD Co-funded by the Phelan-McDermid Syndrome Foundation
- Dr. Oleksandr Shcheglovitov and Dr. Ricardo Dolmetsch, Stanford University School of Medicine: Using Induced-Pluripotent Stem Cells to Study Autism & Phelan McDermid Syndrome Co-funded by the Phelan-McDermid Syndrome Foundation

2012 Predoctoral Fellowships

- Nina Leezenbaum and Dr. Jana Iverson, University of Pittsburgh: Postural and Vocal Development during the First Year of Life in Infants at Heightened Biological Risk for ASD
- Jennifer Moriuchi and Dr. Ami Klin, Emory University Marcus Autism Center: Gender and Cognitive Profile as Predictors of Functional Outcomes in School-Aged Children with ASD
- Rebecca Larke and Dr. Karen Bales, University of California Davis MIND Institute: The Role of Serotonin in Social Bonding in Animal Models

“I am grateful for the generous donations from the many families with children with autism that fund my research. It makes me work harder to find a solution, so I can give back to the families that have given so much to me.”

– Dr. Jill Locke, ASF Postdoctoral Fellow
ASF also provided **Scholarships** to 11 autism stakeholders, enabling them to attend the 2012 International Meeting for Autism Research (IMFAR) in Toronto, Canada. After returning home, the grantees shared what they learned on the ASF Blog. The 2012 travel grant recipients were:

- Catherine Blackwell – Sibling
- Debra Dunn – Parent, Center for Autism Research at CHOP
- Eric Hogan – Self-identified Individual with Autism
- Kadi Lichsinger – Parent
- Marjorie Madfis – Parent
- Mark Shen – PhD Candidate, UC Davis MIND Institute
- Jon Shestake – Parent, Founder of Cure Autism Now
- Melissa Shimek – Self-identified Individual with Autism
- Meghan Swanson – PhD Candidate, Hunter College/City University of New York
- Meagan Thompson – PhD Candidate, Boston University
- Emily Willingham – Parent, Thinking Person’s Guide to Autism Blog

“It inspires me to know that $10 donations from affected families are paying for my work. On a bad day it gives you an extra boost as you go pick yourself up and do it all again.”

—Dr. Haley Speed, ASF Postdoctoral Fellow
Through our educational programs, ASF fosters a learning environment that allows individuals with autism, their parents and siblings, students and scientists to share their knowledge and expertise.

Our **Science & Sandwiches** program brings together families, students and scientists. Scientists benefit from hearing about the day-to-day experiences of families, and families hear directly about the latest autism research. The 2012 Science & Sandwiches series included:

- **Science & Sandwiches with Dr. Joe Buxbaum** at the Seaver Autism Center at the Mount Sinai School of Medicine
- **Coming Back for Science (& Sandwiches): A Conversation about Autism with my Psychiatrist** with Dr. Andrés Martin, Yale Child Study Center and Paul Morris, an adult with autism
- **Science & Sandwiches with Dr. Connie Kasari** at UCLA

For the fourth year in a row, we hosted the **Rockland Autism Symposium**, an all-day learning event where individuals with autism, teachers, researchers and parents share new research and information about school-based interventions and adult services. Over 900 people attended and heard from Dr. David Mandell, Dr. James McPartland, and Dr. Jill Locke.

In April, ASF launched a series of monthly live web chats with autism experts and scientists. Through the **Chat with Scientists** program, stakeholders from around the world can log on and pose questions directly to the nation's top autism researchers, practitioners and educators who respond live. In 2012, Dr. Kevin Pelphrey, Dr. Celine Saulnier, Dr. Stephen Shore, Dr. Peter Gerhardt, and Dr. Ami Klin chatted with ASF fans and community members.

“ASF has helped my family stay focused on relevant and accurate research in an ever-growing flurry of misinformation.”

–Jenny Foster, Stakeholder and ASF Facebook Fan
Social Media

Our website and social media channels provide daily news about autism research to families around the world. In 2012, families from France, India, Portugal, Australia and the United Kingdom joined our growing international community. Our social media channels not only serve as forums to exchange current research and enlightening opinion articles, but also provide countless opportunities for stakeholders to learn, share and connect.

**Flickr:** There are dozens of ASF-sponsored events throughout the year. Check out slideshows of our activities and search for photos of you and your family on our Flickr www.flickr.com/people/autismsf/.

**Twitter:** ASF staff members attend IACC meetings, IMFAR presentations and government-sponsored events throughout the year. Follow us on twitter @AutismScienceFd for live coverage of all the important autism research and policy activities.

**YouTube:** Our YouTube channel gives millions of viewers front-row access to the nation’s top scientists. Watch interviews with autism’s biggest names by checking out AutismScienceFdn on YouTube.

**Instagram:** A picture is worth a thousand words. Follow ASF @AutismScienceFd to see what’s going on in the autism community.

**Facebook:** Like “Autism Science Foundation” on Facebook to receive daily updates on autism research and join a community of well-informed stakeholders and advocates!

**Pinterest:** Sometimes all you need is a little inspiration. Check out Autism Science Foundation on Pinterest for quotes, pictures and stories promoting autism awareness!

**Wordpress:** Our blog is stocked with original articles from scientists who use it to share additional information about their published reports. These posts provide clarity that families cannot get elsewhere. See for yourself at autismsciencefoundation.wordpress.com/.

**Twitter:** Read about our newest SAB members and get a round up of the latest autism science in our October e-newsletter. Please call 1024999.

**Twitter:** The journal “Pediatrics” has published the first study to quantify the problem of autistic wandering. Nearly half... Please call 1024999.

**Twitter:** Contrary to their hypothesis, Sally Rogers and colleagues found that toddlers with ASD in a brief... Please call 1024999.

**Twitter:** Did you miss the Science & Sandwiches event last night? Get a great wrap up and read Paul Morris’ speech from the...Please call 1024999.

**Twitter:** ASF staff members attend IACC meetings, IMFAR presentations and government-sponsored events throughout the year. Follow us on twitter @AutismScienceFd for live coverage of all the important autism research and policy activities.
MARCH
Widely sought after by the media to speak about autism issues, our scientists and board members continued to bring a strong scientific voice to the autism community. In 2012, ASF provided insight and context to numerous national media outlets including PBS’ Charlie Rose, the New York Times, U.S. News & World Report, and Nature Magazine.

JUNE
The autism community faced a tragedy when a freezer failure resulted in the loss of nearly one third of the autism brain tissue samples collected over the past two decades. Researchers desperately need brain tissue to investigate the fundamental questions about autism. ASF responded by launching a multi-media campaign designed to increase awareness of the importance of brain tissue donation to advance autism research.

"No effort is more important than raising awareness among families and scientists about the need for research on human brain tissue...although brain donation is a difficult issue for many, it is one of the best ways to help families."

—Dr. Gerald Fischbach, Director of the Simons Foundation Autism Research Initiative

JULY
ASF published a new student club guide to assist young adults interested in establishing autism-related clubs at their schools. Through its high school and college student clubs, ASF encourages young people to pursue science education and engage in activities that will benefit individuals with autism. To ensure the success of its student clubs across the country, ASF provides examples of leadership structure, fundraiser and awareness suggestions, and even case studies of successful high school and college level clubs. In 2012, ASF student clubs were established at Regis High School, UC Santa Barbara, and Yale University.

"ASF plays an important role in moving science forward. It has quickly become a valued collaborator in the public-private partnership described in the federal strategic plan for autism research."

—Dr. Tom Insel, Director of the National Institute of Mental Health
SEPTEMBER
ASF created an extensive library of autism research studies dating back to 2008, organized into 64 categories from animal models to eye-tracking to service delivery. ASF President Alison Singer remarked, “It’s how we, as stakeholders, think about research; not by publication date or publication title or author, but by topic.” This catalog is the first resource available that allows stakeholders to find autism research by topic.

OCTOBER
The American Academy of Pediatrics named ASF Co-founder and President Alison Singer an “Autism Champion” for her advocacy work.

NOVEMBER
“Occurrence and Family Impact of Elopement in Children with Autism Spectrum Disorders,” a study on autism-related wandering funded by an ASF-led coalition of advocacy groups, was published in the journal Pediatrics. The study, the first to quantify and characterize autistic wandering, found that nearly half of children with ASD wander. The results were used to create a new medical classification code to protect children by prompting important discussions about safety between pediatricians and parents.

“This project is especially exciting because the information collected will not only have an immediate effect on improving services for adults with autism, but it will also advance autism research involving adults – a group that is sorely underrepresented”

–Dr. Paul Law, Director of the Interactive Autism Network at Kennedy Krieger Institute
“ASF continues to serve the community by disseminating information and offering a place for individuals to gather and exchange common experiences. This is key to aiding families in dealing with the daily struggles of this often misunderstood disorder.”

–Ezra Lockhart, Stakeholder and ASF Facebook Fan
It is through the generous contributions of our donors that the Autism Science Foundation can continue its mission of funding groundbreaking autism research and sharing critical research findings with families around the world. We are thankful for all of the volunteers who strengthen our community by holding events to benefit ASF and by participating in our programs.

In April, volunteers Erin Lopes and Tim Bak, who have a son with autism, kicked off the second annual Scoring Goals for Autism soccer tournament in Philadelphia. For Erin and her family, funding autism research is a critical step toward understanding why so many children have autism and determining the treatments that will help children living with the disorder.

In June, ASF volunteer Jason Roth launched CDSweep, a project that gives people the opportunity to recycle their old, unwanted CDs and turn them into cash to help fund autism research.

The AML Bikers for Autism Science Foundation hosted their third annual fundraising motorcycle ride in June. The 100-mile ride benefited autism research and education.

In December, ASF honored families raising children with special needs at its annual Celebrating Families Brunch. This special event offered a relaxed day filled with smiles, faces, understanding and ice cream. Meredith Grossbach received the Advocate of the Year award while Paula Krenkel, Jane Kersting, Ivy Marcus, and Rosanne Schoeps-Kahn of the JCC of MidWestchester’s Toward Tomorrow Program were honored as Therapists of the Year. Allyson Schwartzman received the 2012 Caryn Schwartzman Spirit Award, named in memory of her mother.

December also brought the launch of our annual year-end Recipe4Hope campaign, which raises funds specifically for our pre- and postdoctoral autism research fellowships. ASF supporters Eric & Marion Congdon and their entire family in North Carolina were the centerpiece of the 2012 campaign. They worked together to prepare a holiday meal, highlighting the teamwork and all of the “ingredients” necessary for autism research. Just as it takes a whole family to fix a holiday feast it takes a community of supporters to fund all the research our community needs.
“Autism Science Foundation is funding the science that leads to real answers. I want to know that my donation will fund the best research possible.”

–Lauren Rimland, Mother of 19-year-old Jake
The Autism Science Foundation is a non-profit, 501(c)(3) public charity. Donations are tax-deductible to the full extent allowed by law.
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