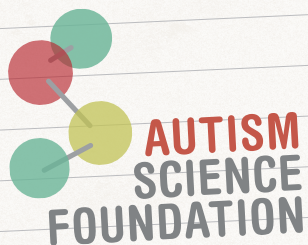


A **voice** for science



2011 Annual Report



Dear Friends,

When the prestigious journal *Nature* called the Autism Science Foundation “a voice for science” this year, it summed up our goals in four short words. Advancing autism science is at the core of all we do, through our research grant programs, our educational initiatives, and our family advisory services. Supporting science is what our family members deserve, what our donors expect, and what our staff and board live and breathe every day of the year.



And what a year it's been. Thanks to you, funding for our pre- and post-doctoral fellowship program rose by over 20%. Studies we funded in past years are already showing results, and our grantees are publishing papers in high-impact, peer-reviewed journals and presenting their findings at national and international conferences. They are advancing our knowledge of autism's causes and expanding our options for evidence-based treatments.

The contributions of ASF and its leaders in the field are being applauded as well. Our co-founder, Karen London, and her husband, ASF Scientific Advisory Board (SAB) Member Dr. Eric London, received the Advocates of the Year award from the International Society for Autism Research in honor of their years of dedication to autism science. Our founding board member, Dr. Paul Offit, was elected to the esteemed Institute of Medicine (IOM). The IOM provides unbiased, authoritative advice to Congress, helping guide our nation's health-care policy.



As an organization, ASF won its first award; nonprofit rating agency GuideStar named ASF the number one start-up nonprofit in the nation in the field of disabilities, citing our contribution to the field of autism research, our integrity, and our fiscal discipline.

However, the work we do isn't measured by the number of journal articles published or the number of awards we win. It's measured by the number of e-mails and phone calls we receive from families thanking us for steering them toward evidence-based interventions, sending them a relevant journal article, holding a day of learning with top autism scientists in their home city, and giving them a voice on our website and social media applications. Our thanks to all of those families and to our donors, supporters, volunteers, and friends who enable us to do the work we do. Together, we are one strong voice for autism science.

Sincerely,
Alison Singer

Co-Founder and President
Autism Science Foundation



a **voice** for science

Accomplishments

In just the first two years since our founding, the Autism Science Foundation has...

- Surpassed the half-a-million-dollars mark; **\$503,000** in autism research grants has been awarded.
- Launched a **third round of pre- and post-doctoral fellowship grants** to jump-start the early careers of promising autism researchers.
- Built a coalition of autism advocacy groups to fund the **first national study of autistic wandering** via the Interactive Autism Network (IAN). The data showed that half of the children with autism wandered from safe places. Those results were used to create a new medical code for autistic wandering to protect children.
- Sponsored three days of **learning and discovery** for special educators and parents through the Rockland County Autism Symposium, featuring Dr. Temple Grandin as the keynote speaker.
- Provided **scholarships** to 44 autism stakeholders, enabling them to attend the International Meeting for Autism Research (IMFAR).
- Served as a **strong scientific voice** within the autism community, in government affairs, and in major media, including through the *CBS Evening News*, *CNN*, *NPR*, *The Dr. Oz Show*, *Good Morning America*, and *USA Today*.

Inspiring
Loving
Hoping
Caring
Building
Connecting
Laughing
Surviving

Autism Science Foundation
searching • solving • sharing

Healing
Learning
Growing
Succeeding



Funding Critically Needed Research

Funding autism research is at the core of our mission. This year, we increased our funding for pre- and post-doctoral fellowships by over 20%. Our focus is on clever young investigators with cutting-edge ideas who need seed money to get their research off the ground. We pair these researchers with established scientists who provide mentorship and training. The government and other funders have cut back on training grants, but we are committed to helping young scientists gather the initial data they need to attract major funding from the National Institutes of Health (NIH), all while encouraging the best and brightest researchers to dedicate their careers to autism.

2011 Post-Doctoral Fellowships:

- Dr. Jill Locke and Dr. David Mandell, *University of Pennsylvania*: "Implementing Evidence-Based Social Skills Interventions in the Public School Setting."
- Dr. Portia McCoy and Dr. Ben Philpot, *University of North Carolina*: "Ube3a Requirements for Structural Plasticity of Synapses."
- Dr. Haley Speed and Dr. Craig Powell, *UT Southwestern University*: "Identifying Impairments in Synaptic Connectivity in Mouse Models of ASD."
- Dr. Elena Tenenbaum and Dr. Stephen Sheinkopf, *Women & Infants Hospital at Brown University*: "Attentional Distribution and Word Learning in Children with Autism."

2011 Pre-Doctoral Fellowships:

- Jessica Bradshaw and Dr. Robert Koegel, *University of California at Santa Barbara*: "Prelinguistic Symptoms of Autism Spectrum Disorders in Infancy."
- Christie Buchovecky and Dr. Monica Justice, *Baylor College of Medicine*: "Identifying Genetic Modifiers of Rett Syndrome in the Mouse."



National Institute of Mental Health (NIMH) Director Dr. Tom Insel, ASF Post-Doctoral Fellow Dr. Jill Locke, and IMFAR travel grantee Max Rolison, at ASF's 2011 Scientist Appreciation Dinner at IMFAR.



"It inspires me to know that \$10 and \$20 donations from affected families are paying for my work. On a bad day, if your equipment breaks or your experiment fails -which, at some point, they all do - it gives you an extra boost as you go pick yourself up and do it all again."

Dr. Haley Speed as quoted in *Nature* magazine.

Sharing Science

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 and scientists. Scientists benefit from hearing about the day-to-day experiences of families, and families hear directly about the latest autism research.

For the third year in a row, we hosted the **Rockland Autism Symposium** where individuals with autism, teachers, researchers, and parents shared information about school-based interventions and adult services.

Dr. Temple Grandin gave the keynote address.

ASF also cosponsored the **KiDA Autism Summit** in California. It focused on the impact of autism on the extended family. Former First Lady and ASF supporter Rosalynn Carter gave the keynote address, focusing on the need to care for and support caregivers.

Through our **IMFAR Travel Grants** program, we provided scholarships to 11 autism stakeholders, enabling them to attend the 2011 IMFAR in San Diego, CA. After returning home, the grantees shared the information they learned with their communities. The 2011 grantees were:

- Geraldine Bliss – *parent*
- Matthew Carey – *parent*
- Shannon Des Roches Rosa – *parent*
- Mark Fornefeld – *individual with self-identified autism*
- Abby Hare – *graduate student*
- Erin Lopes – *parent*
- Molly McGrath – *individual with self-identified autism and Massachusetts Institute of Technology Media Lab*
- Brianna Miller – *special education teacher, Newark Public Schools*
- Sharman Ober-Reynolds – *parent and senior research coordinator at SARRC*
- Megan O'Boyle – *parent*
- Max Rolison – *undergraduate student*



Travel grantees Matthew Carey and Shannon Des Roches Rosa at IMFAR 2011.



ASF Co-Founder, Karen London, and ASF SAB Member, Eric London, receive the 2011 Advocates of the Year Award from the International Society for Autism Research (INSAR).

Rockland



Dr. Temple Grandin, her mother Eustasia Cutler, and ASF SAB member Dr. Emanuel DiCicco-Bloom at the Rockland Autism Symposium.



Over 900 people attended the Rockland Autism Symposium.

KiDA



Dr. Wendy Goldberg, Dr. Matt Goodwin, former First Lady Rosalynn Carter, Dr. "Howard" Shane, Alison Singer, and Dr. Connie Kasari at the KiDA Autism Summit.

IMFAR
INTERNATIONAL MEETING
FOR AUTISM RESEARCH



Strong Voice for Science

ASF brings a **strong scientific voice** to the autism community. Our scientists and board members are widely sought by the media to speak about autism issues. In 2011, we provided insight and context to numerous national media outlets including NPR, USA Today, CNN, Nature Magazine, the New York Times, The Dr. Oz Show, and even the Colbert Report on Comedy Central.



Dr. Paul Offit faces off against Stephen Colbert.

Dr. Bob Schultz discusses building a top autism research center



Our **YouTube** channel has thousands of views every year thanks to insightful interviews with top autism researchers including Dr. Bob Schultz, Dr. Eric Courchesne, and Dr. David Mandell.



Dr. Mehmet Oz and Alison Singer before the show taping.

New checklist could detect autism in babies as young as 1

By Liz Szabo
USATODAY

An early screening test for autism, designed to detect signs of the condition in babies as young as 1 year old, could revolutionize the care of autistic children, experts say, by getting them diagnosed and treated years earlier than usual.

The 24-item checklist takes just five minutes to complete and can be filled out in a pediatrician's waiting room, when parents bring children for their routine 12-month checkup, says a study of more than 10,000 infants, published today in the *Journal of Pediatrics*.

The checklist — available online now — asks parents or other caregivers about their child's communication skills, from babbling and first words to eye contact. The study was funded by the National Institutes of Health and others.

Doctors referred children who failed the screening for more definitive tests and, if necessary, treatment. Researchers followed them until age 3. The screening accurately diagnosed about 75% of children.

On average, those with autism began therapy by age 17 months.

That's a huge advance, experts say. About 1 in 110 children have autism or an autism-like disorder, says the Centers for Disease Control and

What to watch for

- ▶ No big smiles or other joyful expressions by 6 months.
- ▶ No back-and-forth sharing of sounds, smiles or other facial expressions by 9 months.
- ▶ No babbling by 12 months.
- ▶ No words by 16 months.
- ▶ No two-word meaningful phrases (without imitating or repeating) by 24 months.
- ▶ Any loss of speech or social skills at any age.

Source: Autism Speaks
▶ Q&A, 9D

Prevention. Today, most autistic children aren't diagnosed until age 5, the CDC says.

Children diagnosed that late miss opportunities to get therapy while their brains are growing and most easily shaped, says Geraldine Dawson of the non-profit Autism Speaks, which also helped fund the research.

Intensive behavioral therapy offers the best hope for helping autistic children improve language and behavior, found a recent analysis in *Pediatrics*.

Although the American Academy of Pediatrics recommends screening all children for autism at 18 to 24 months, relatively few doctors do, Dawson says.

That could change, thanks to the success of this study, says Alison Singer, president of the Autism Science Foundation, an advocacy group.

The study's authors note that the checklist won't catch all cases of autism, such as those that first appear in older children.

But because it is free and easy to use, and all pediatricians should quickly be able to begin using it, says Singer, who wishes her daughter, Jodie, now 13, had been screened early.

"We wasted a lot of time wondering and waiting before she received a diagnosis at 2," Singer says. "I can't help but wonder where my daughter would be today if she had been identified at 1 year old."



Advocating for Science

During 2011, ASF staff and board members spoke about autism's early warning signs and the latest autism research at state departments of public health **covering over 25%** of the nation in one year. Sharing the latest autism information with health professionals on the front lines is critical to supporting early diagnosis and intervention.

ASF also built a coalition of autism advocacy groups to fund the **first study to quantify and characterize autistic wandering**. The data showed that 50% of children with autism wander from safe places. These results were used to create a new medical subclassification code to protect children by prompting important discussions about safety between pediatricians and parents.

In April, several members of the ASF SAB and staff were **invited to the White House** to discuss autism policy issues with key administration leaders including Health and Human Services Secretary Kathleen Sebelius. The discussion focused on improving ways to meet the unique needs of individuals with autism.

ASF President Alison Singer continued to serve on the federal **Interagency Autism Coordinating Committee (IACC)**, having been appointed by the Secretary of Health and Human Services. The IACC writes an annual plan to guide federal autism research spending. The NIMH Director, Dr. Tom Insel, chairs the IACC.

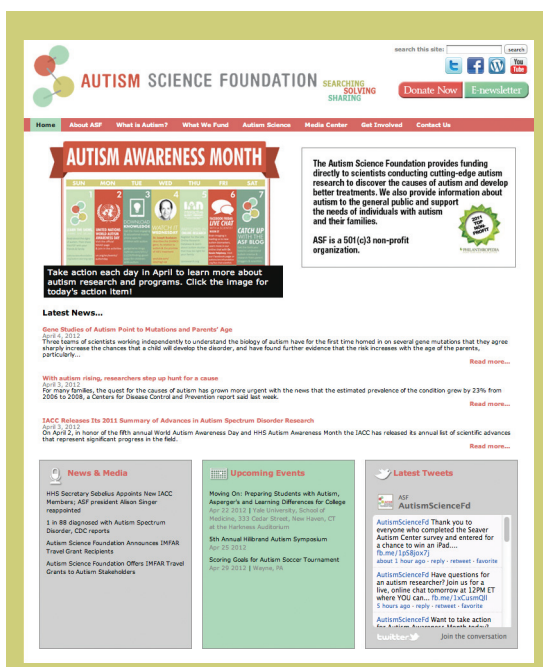


"The Autism Science Foundation plays an important role in moving science forward. It has quickly become a valued collaborator in the public-private partnership described in the federal strategic plan for autism research."

Dr. Tom Insel, director of the NIMH.



Dr. Eric Courchesne, Alison Singer, and Dr. Bryan King were invited to the White House for World Autism Awareness Day.



With the launch of ASF's expanded new website

and our continued dedication to social media, we now provide daily news about autism research to families around the world.

building our community

The generous donations we receive are the lifeblood of our work. We are thankful for all the volunteers in our community who are creating events to benefit ASF.

On May 8, ASF honored families raising children with special needs at its annual **Celebrating Families: Mother's Day Brunch**. This special event offered a relaxed day filled with joy, understanding, and, importantly, ice cream. Debbie and Larry Hilibrand received the Advocates of the Year Award. Pat Schissel, executive director and president of the Asperger Syndrome and High Functioning Autism Association (AHA), received the Caryn Schwartzman Spirit Award, named in memory of autism advocate Caryn Schwartzman. The event raised over \$35,000 to support autism research and education.



Alison Singer, Deborah Hilibrand, Larry Hilibrand, Karen London, Eric London, and Marty Schwartzman at the Celebrating Families: Mother's Day Brunch.



Over 100 families enjoyed games, music, dancing and baked ziti.



Autistic Self Advocate Dr. Stephen Shore enjoys the ice cream sundae bar.



In June, we kicked off the first annual **Scoring Goals for Autism** adult soccer tournament in Philadelphia.

Volunteers Erin Lopes and Tim Bak, who have a son with autism, organized the tournament. Erin said she wanted to organize an event where people could get a good workout, have fun, and raise money for autism research.

For Erin and her family, funding autism research is a critical step toward understanding why so many children have autism and determining which treatments will help children living with the disorder.



Kristie Keenan, Eevee Bak, and Lauren Windsor kick off the Scoring Goals for Autism event.



AML Bikers for Charity riders Thomas Slome, Ride Founder Barry Koch, Alison Singer, David Chenkin, and Michael Chenkin.

The **AML Bikers for Charity** chose to support the Autism Science Foundation with its annual fundraising motorcycle ride in June. The event was so successful that beginning in 2012 the event will be renamed the **AML Bikers for Autism Science Foundation**.



The Neiman family celebrating their completed snowman.

December brought the launch of our annual year-end **Recipe4Hope** campaign which raises funds specifically for our pre- and post-doctoral autism research fellowships. The centerpiece of the campaign was a short video showcasing the Neiman family of Colorado. They built a snowman together, highlighting how we all have to work together to further autism research. The campaign saw a 70% increase in online donations from the previous year.

Student Activities



Members of Yale for Autism Awareness: An Undergraduate Organization at Yale College organized an ice cream social at Ashley's Ice Cream parlor to raise money for ASF. The event is held annually before finals.



The Scarsdale High School Autism Science Foundation Student Club was founded this year and held its first Halloween bake sale.



In April, Alyson Schwartzman, whose brother has autism, organized a fashion show at Cardozo High School in New York City to raise funds and awareness for autism. Student models wore the colors of the rainbow to symbolize autism.



In 2011, we were named the number one start-up nonprofit in the disabilities category by nonprofit rating agency Philanthropedia/GuideStar. GuideStar called ASF "a shining star to those interested in real science and evidence-based interventions." GuideStar also wrote, "We find this group to operate with the highest level of integrity. They have extremely low overhead. Every dollar possible is put toward autism research."

Statement of Financial Position – As of December 31, 2011

ASSETS

Cash and cash equivalents	\$	248,216
Investments		36,755
Security Deposits		2,625
Prepaid expenses		<u>844</u>
Total Assets	\$	<u>288,440</u>

LIABILITIES

Accounts payable and accrued expenses	\$	<u>12,830</u>
Total Liabilities		<u>12,830</u>

COMMITMENTS AND CONTINGENCIES

NET ASSETS

Unrestricted		<u>275,610</u>
TOTAL NET ASSETS		<u>275,610</u>
TOTAL LIABILITIES AND NET ASSETS	\$	<u>288,440</u>

Statement of Activities – For the Year Ended December 31, 2011

SUPPORT AND REVENUE:	Unrestricted	Temporarily Restricted	Total
Special events - revenues	\$ 18,100		18,100
Less: cost of direct benefits to donors	<u>(1,160)</u>		<u>(1,160)</u>
Net revenue from special events	16,940		16,940
Contributions	386,411	12,000	398,411
Program Fees	15,000		15,000
Contributed services	90,000		90,000
Other income	50		50
Interest income	175		175
Investment income	15,343		15,343
Net assets released from restrictions	<u>12,000</u>	<u>(12,000)</u>	
TOTAL SUPPORT AND REVENUE	<u>535,919</u>		<u>535,919</u>
EXPENSES:			
Program services	426,089		426,089
Management and general	42,550		42,550
Fundraising	<u>69,554</u>		<u>69,554</u>
TOTAL EXPENSES	<u>538,193</u>		<u>538,193</u>
Change in Net Assets	(2,274)		(2,274)
Net Assets - Beginning of Year	<u>277,884</u>		<u>277,884</u>
Net Assets - End of Year	<u>275,610</u>		<u>275,610</u>

The complete audited financial statements including related notes and the Lederer, Levine & Associates, LLC opinion as independent auditors, may be obtained by writing to Autism Science Foundation 28 West 39th Street, #502, New York, NY 10018 or to the New York State Department of Law, Charities Bureau, 120 Broadway, New York, NY 10271.



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