



2016 ANNUAL REPORT

**BECAUSE OF YOU, 2016 WAS FILLED WITH HOPE
FOR THOSE WITH ANGELMAN SYNDROME AND
THEIR FAMILIES.**



WHY WE DO WHAT WE DO

Angelman syndrome is a rare, very severe neurogenetic disorder that is often misdiagnosed due to lack of awareness. People with Angelman syndrome experience significant developmental delays, lack of speech, debilitating seizures, and walking and balance disorders. Individuals with Angelman syndrome require life-long care.

Our families and loved ones of people with Angelman syndrome provide this life-long care, and it is our mission to help them with as many support services as possible and fund innovative research aimed at finding a cure. From our Family Resource Team to communications assistance to connections to resources to opening Angelman Syndrome Clinics, your support is what gives families the hope—and help—they so desperately need.

As we enter our 25th year of supporting individuals with Angelman syndrome and their families, we are taking a moment to reflect as well as look ahead.

YOUR SUPPORT SHINES

REFLECTING ON THE IMPACT YOU HAVE MADE

Every year, donors help us change the lives of those with Angelman syndrome and their families. Donations are used to fund research that is treating symptoms and is pushing us closer to a cure.

- **NOVEMBER 2015:** **Mayo Clinic Angelman Syndrome Clinic** opened in Rochester, Minnesota. Donor support helped the Angelman Syndrome Foundation open this clinic so individuals with AS can receive comprehensive and complex care from AS experts who understand the specific needs of AS. Let Stephanie Hays, mother to Beau, tell you how these clinics are so vital for families.

Thank you for all your devotion and hard work towards making the lives of those with AS better. Your work means so much to us.

– The Hoover Family



3 AS CLINICS OPEN ACROSS THE COUNTRY

AND THE MOMENTUM IS GROWING: 2 MORE ARE SCHEDULED TO OPEN IN 2017.



● DECEMBER 2015:

Supporters like you rallied around the “Give the Gift of Hope” campaign and brought record growth in support for AS families. Because of you, families can receive direct 1:1 assistance from the ASF Family Resource Team. The Family Resource Team is a lifeline that helps families with everything from recommended products to accessing local/state/national resources to education planning to many other areas—all of which are essential and immediate needs for families.

THE FAMILY RESOURCE
TEAM COMMITTED **129** HOURS
HELPING **83** FAMILIES IN 2016.



● JANUARY 2016:

Summit 4 Angelman – Kyle Rooney and his friends climbed to the summit of Mount Kilimanjaro as a tribute to Kyle’s son Madden and all other people with Angelman syndrome. Each climber documented their journey along the way and packed pictures and stories of children with AS, and placed those photos at the summit so those faces can take in the “Roof of Africa” forever. Together as Madden’s Crew, they raised nearly \$10,000 for Angelman syndrome research, as well as tremendous awareness.



From left: Pete England, Kyle Rooney, JW Wilson, Gary Wrotny



● FEBRUARY 2016:

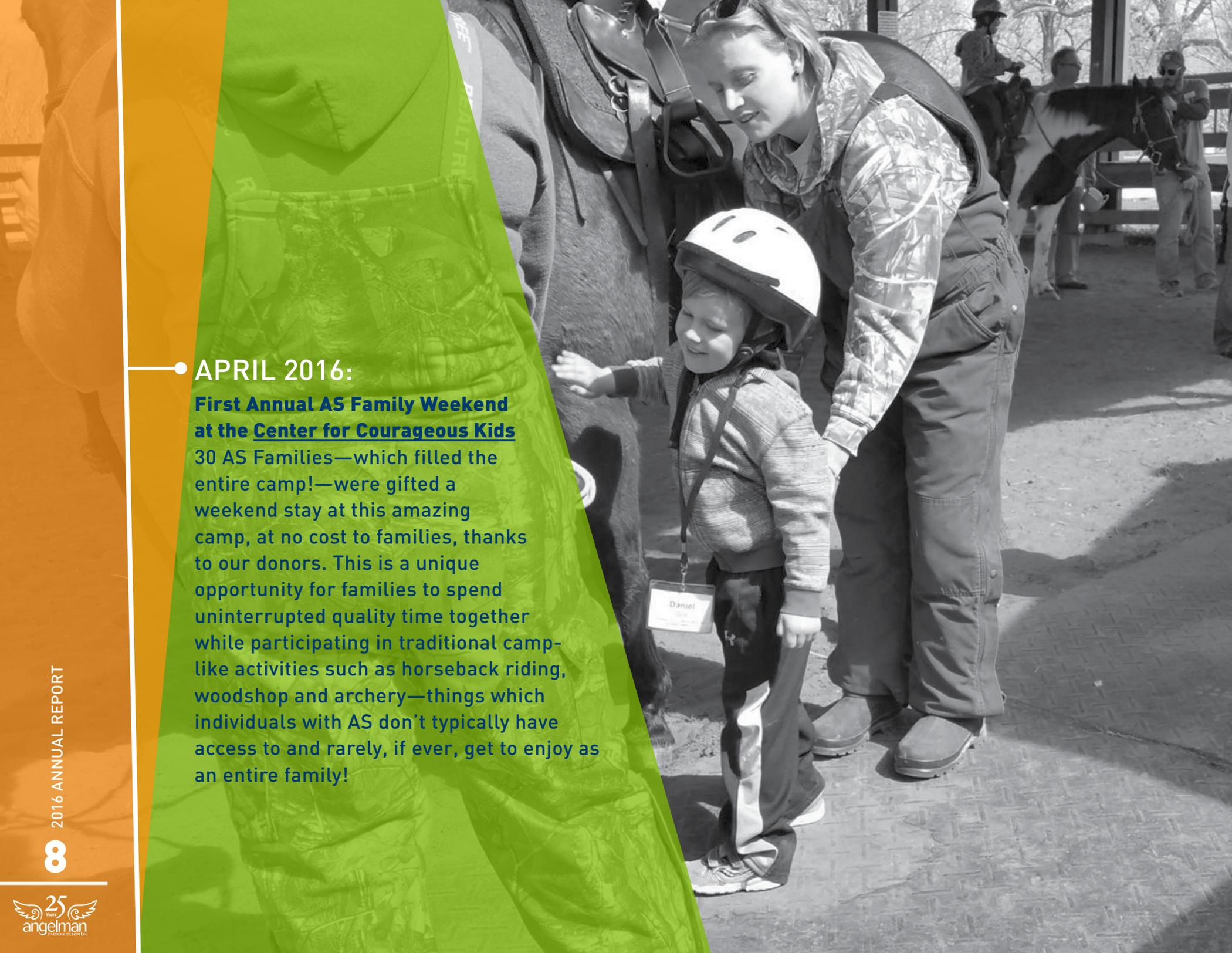
International Angelman Day

Every year we look forward to this day to shine a spotlight on the AS community while continuing to raise awareness. In 2016, the Angelman Syndrome Foundation's awareness campaign became a "trending topic" on social media—generating HUGE awareness for AS! More awareness means faster and more accurate diagnosis for AS families.

140,000

INDIVIDUALS
REACHED ON SOCIAL
MEDIA, BROADENING
AWARENESS LIKE
NEVER BEFORE

#WHATISANGELMAN



● APRIL 2016:

**First Annual AS Family Weekend
at the Center for Courageous Kids**

30 AS Families—which filled the entire camp!—were gifted a weekend stay at this amazing camp, at no cost to families, thanks to our donors. This is a unique opportunity for families to spend uninterrupted quality time together while participating in traditional camp-like activities such as horseback riding, woodshop and archery—things which individuals with AS don't typically have access to and rarely, if ever, get to enjoy as an entire family!

MAY 2016:

The ASF Annual Walk – This is our largest fundraiser of the year and a chance for families around the world to come together in support of Angelman syndrome. The Walk raises critical funds to support research and family services. You raised \$1.25 million in 2016, which directly funded more than \$1 million in AS research in 2016.

I love to see the smiles on all of the children's faces. It is so wonderful to have so many families come together.

— Courtney Dussault, ASF Walk Volunteer, Hartford, CT

CONNECTING
10,000+
ANGELMAN SYNDROME
SUPPORTERS NATIONWIDE IN 2016



● JUNE 2016:

Communication Training Series – The Communication Training Series created 43 FREE webinars to teach families, care providers and professionals how to help individuals with AS and their families learn and teach communication skills, a significant challenge for people with AS.

This unique, innovative program is taking the Alternative and Augmentative Communication (AAC) industry by storm. Because of you and the Foster Family Foundation, the ASF is the only family support nonprofit organization in the world that provides this type of training program for families for free.

After the webinars, families continue to have direct access to ask questions to the experts who have led the program.

CHECK OUT

“PRACTICAL AAC’S”

GREAT BLOG ABOUT THE ASF COMMUNICATION TRAINING SERIES [HERE](#).



These webinars give us the power to teach our own children how to communicate. My son is 13 and I have always relied on professionals to teach him communication skills but nothing was working. Now I have people who understand my son and how he can learn. Thanks so much!

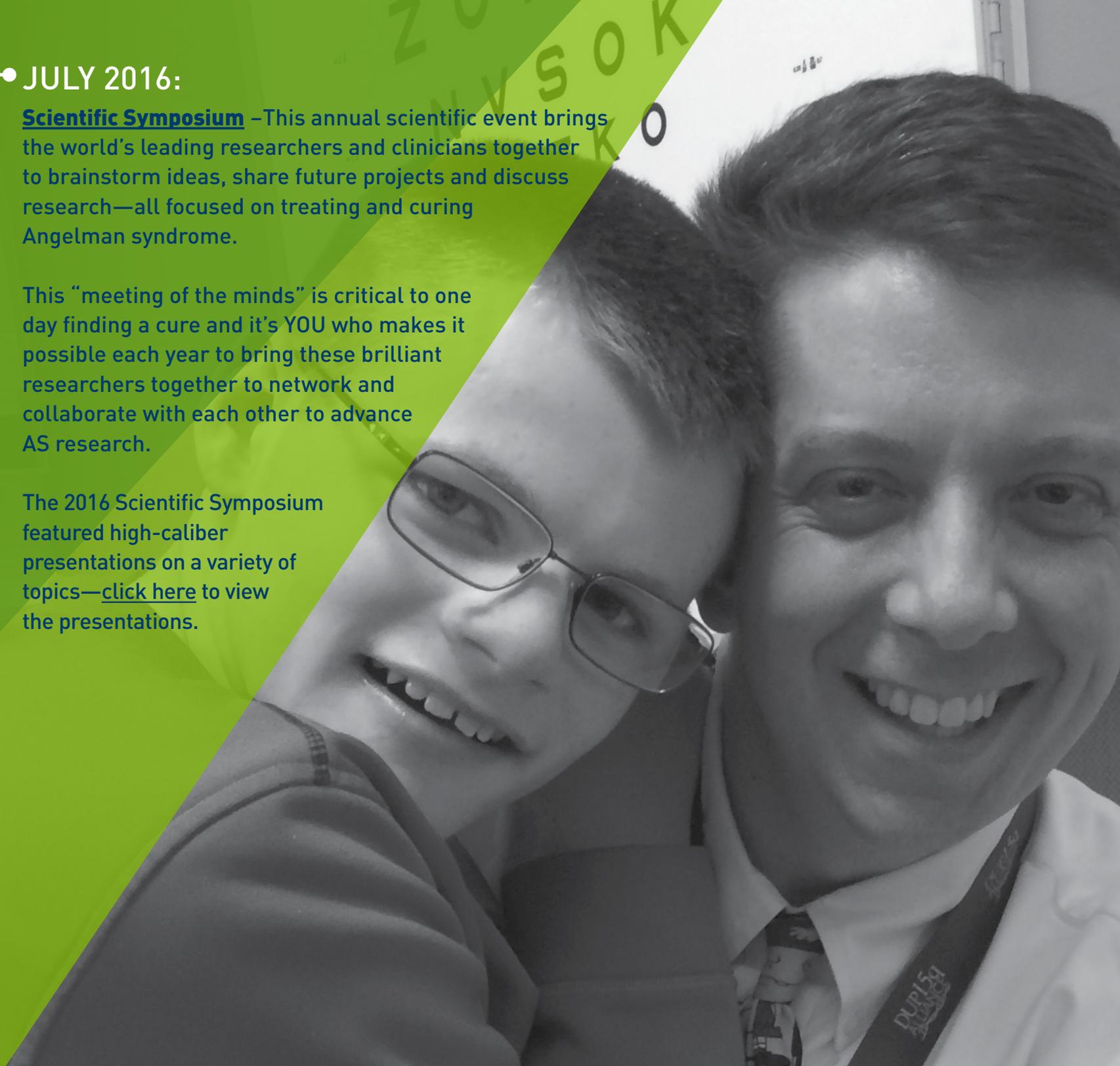
–Rosie Markiewicz

● JULY 2016:

Scientific Symposium –This annual scientific event brings the world’s leading researchers and clinicians together to brainstorm ideas, share future projects and discuss research—all focused on treating and curing Angelman syndrome.

This “meeting of the minds” is critical to one day finding a cure and it’s YOU who makes it possible each year to bring these brilliant researchers together to network and collaborate with each other to advance AS research.

The 2016 Scientific Symposium featured high-caliber presentations on a variety of topics—[click here](#) to view the presentations.



● **AUGUST 2016:**

Dr. Kellen Hassell's 1,000-mile bike ride – Kellen, father to Luc (diagnosed with AS), embarked on a 7-day, 1000-mile bike ride from Miami to Chapel Hill, NC to raise funds for AS research. Thanks to his supporters, he raised nearly \$19,000 in support of AS treatments and a cure! The AS community rallied around Kellen, and so did local media along his journey, raising tremendous additional awareness of AS.

Relive Kellen's bike ride with a virtual [map](#) [here](#), and watch Kellen's personal video about why he embarked on this incredible feat for the love of his son [here](#).



INVESTING IN RESEARCH THAT CHANGES LIVES.

We want a cure—and the only way to cure Angelman syndrome is through research. Part of reaching a cure is discovering treatments that help AS families TODAY. The ASF's research program is the largest financial investment the ASF makes, which is only possible because of you. Our highest priority remains advancing researchers' promising studies to find effective treatments and reach a cure.

Compared to 30 other pediatric neurological disorders, I would make the case that Angelman syndrome is at the top—it is THE single most optimistic possibility for a cure.

– Dr. Art Beudet, an AS researcher who has dedicated his life and career to advancing the understanding and treatment of Angelman syndrome.



THANKS TO YOU, IN 2016:

Your support enabled the ASF to invest more than \$1,000,000 in research grants during the fiscal year and start funding new research grants:

- Identifying new ways to manipulate the gene that causes Angelman syndrome, UBE3A
- Understanding how neurons in individuals with AS function in the brain
- A groundbreaking—and the community's first—study on anxiety in individuals with AS, a severe symptom that many of our individuals experience and that very, very few understand how to treat

The FDA approved the use of an orphan drug to treat Angelman syndrome. You helped us work closely with Ovid Therapeutics and other industry partners to bring clinical trials to life. We are so excited to see how these upcoming trials help individuals with AS and their families.

Three prior ASF-funded research studies were published in the industry's top peer-reviewed scientific journals this year (a symbol of their significance to the overall AS research landscape), including a groundbreaking study that proved the UBE3A gene can be turned on in mice models as well as two research studies conducted at our UNC laboratories.

Thank you for the work you do toward advancing research into AS. Were it not for individuals like you, the falls, the seizures, the 2 am wake up calls would be overwhelming to the soul without the hope for a cure that your efforts foster in the hearts of those affected by AS. I thank you for keeping the lamp of hope lit so that every day I can wear a smile because I believe that you will find something, anything, that can make all our lives better. Looking forward to what the future holds with your help!

- The Pettit Family

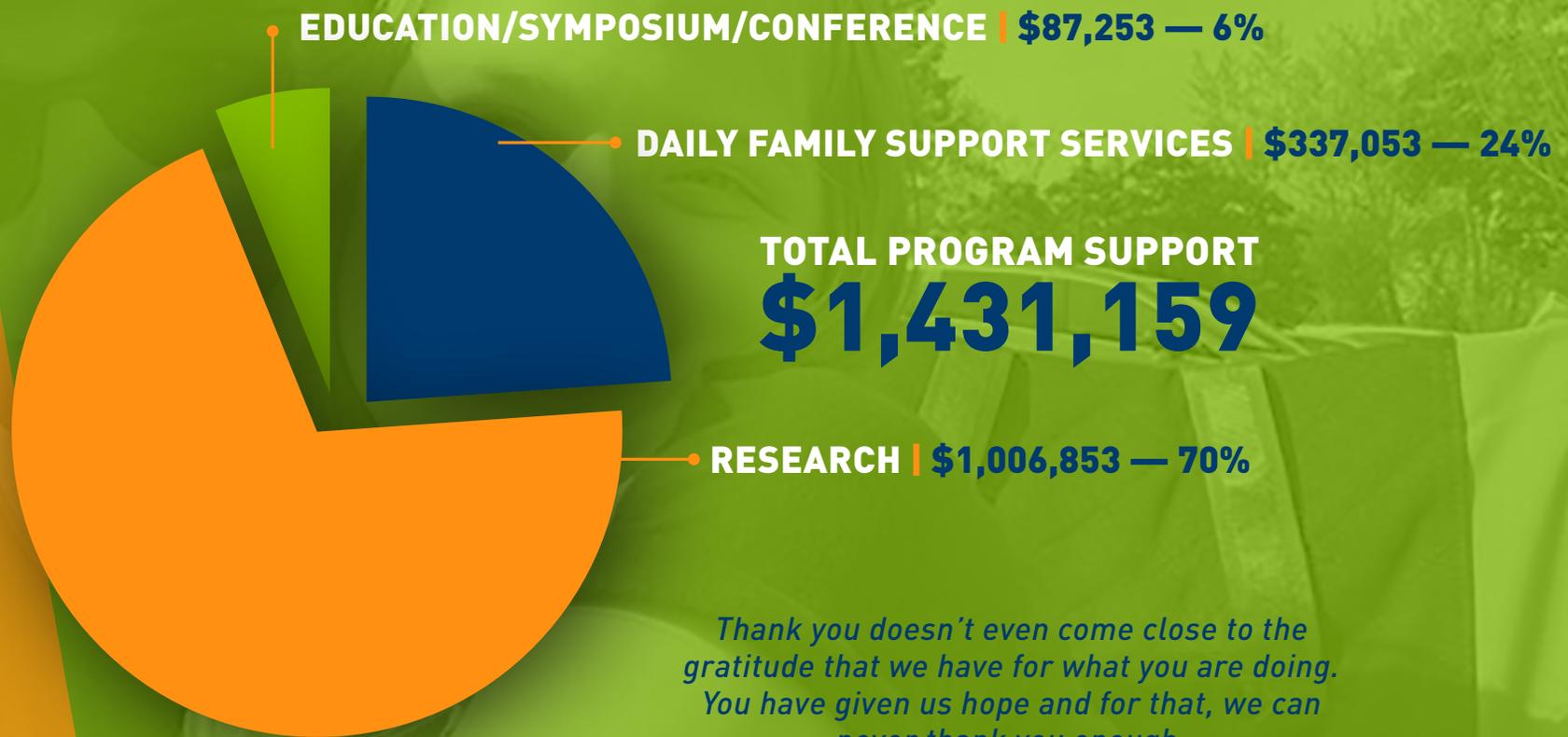
RESEARCH GRANTS AWARDED:

1	Dr. Ben Philpot	University of North Carolina, Chapel Hill, NC	\$84,350
2	Dr. Heather Hazlett	University of North Carolina, Chapel Hill, NC	\$44,990
3	Dr. Ronald Thibert	Mass General Hospital, Boston	\$18,645
4	Dr. Anjali Sadhwani	Boston Children's Hospital, Boston, MA	\$99,387
5	Dr. Chris Keary	Mass General Hospital, Boston, MA	\$90,900
6	Dr. Mark Zylka	University of North Carolina, Chapel Hill, NC	\$100,000
7	Dr. Stormy Chamberlain	University of Connecticut Health Center, Farmington, CT	\$100,000
8	Dr. Eric Levine	University of Connecticut Health Center, Farmington, CT	\$100,000
9	Dr. Samuel Sennott	Portland State University, Portland, WA	\$52,431
10	Dr. Geeske van Woerden	Erasmus Medical Center, Rotterdam Netherlands	\$61,325
11	Dr. Hanoch Kaphzan	Haifa University, Haifa, Israel	\$100,000
12	Dr. Shalaka Muhlerkar	Baylor College of Medicine, Houston, TX	\$55,000
13	Dr. Ype Elgersma	Erasmus Medical Center, Rotterdam Netherlands	\$99,825



YOU ARE THEIR LIFELINE

All the work that you make possible improves the lives of AS families every day. We and they are forever grateful for you making a real difference.



Thank you doesn't even come close to the gratitude that we have for what you are doing. You have given us hope and for that, we can never thank you enough.

– The Ray Family



2015-2016 ANNUAL REPORT

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angelman.org

Thanks to you, 2016 was a tremendous step in the right direction for the Angelman syndrome community. Your constant passion and care for such a wonderful group of families and individuals with AS is deeply appreciated by all of us. Without you, significant and promising advances in research, daily and direct help for families, our AS Clinics—and so much more—simply would not be possible. Thank you!

**—Eileen Braun, Executive Director
Angelman Syndrome Foundation**

