25 Years
angelman
SYNDROME FOUNDATION
Research. Families. You.

2017 ANNUAL REPORT

CELEBRATING 25 YEARS!

75 Executive Drive, Suite 327 · Aurora, IL 60504 · 800.432.6435

DEAR FRIENDS AND FAMILY,

Each year, I am humbled by your generosity. Through your passion and unwavering determination, you continue to fill my heart, and the hearts of AS families everywhere, with hope, love, support and excitement for the future. The promising advances in research we are seeing, the daily help for families, and the exceptional AS Clinics are all made possible by your heartfelt gifts. I am forever grateful for your support and I hope that you can see and feel the difference you are making. Thank you!

Eileen Braun, Executive Director
Angelman Syndrome Foundation

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2017 ANGELMAN SYNDROME FOUNDATION WALK

Over a million dollars raised. Over a million thanks given.

Coordinators, volunteers and participants gather every year at the ASF Walk to raise essential funds for the AS community. Without these dedicated individuals, the ASF Walk and all of the research, family support and education opportunities it funds would not be possible. Our supporters' hard work and contributions to the ASF Walk touch so many families nationwide.

NEARLY
7,000
PARTICIPANTS HELPED RAISE
$1,197,198
IN 2017.

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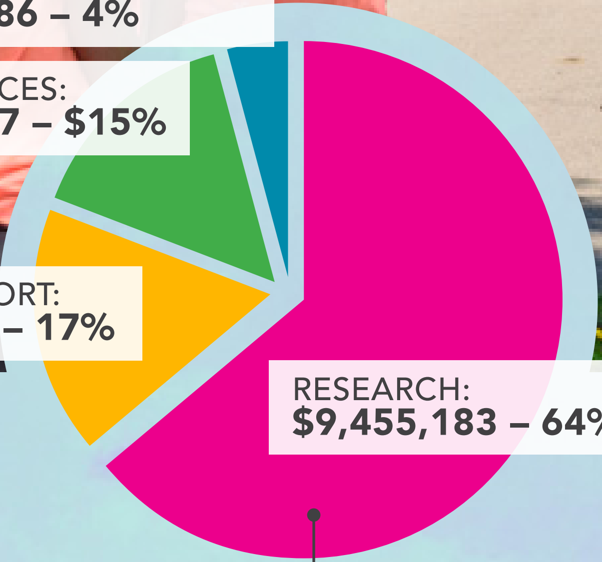
2017 ANGELMAN SYNDROME FOUNDATION WALK

"Besides fundraising and awareness for the Angelman Syndrome Foundation, it is the people! The one day a year when all can smile and celebrate life!"



GENERAL OPERATIONS:
$528,286 – 4%

CONFERENCES:
$2,235,107 – $15%

FAMILY SUPPORT:
$2,541,691 – 17%

RESEARCH:
$9,455,183 – 64%

"It was a true family event! This was my first time to attend a Walk and I was amazed at the effort and enthusiasm of the volunteers!"

"Seeing all those angels' smiles and being with them…there are no words! I enjoyed every minute of the Walk."

Since 1999, ASF Walk participants have raised **$14,760,267** for AS research, education, family support services and general operations.

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2017 COMMUNITY FUNDRAISERS

Giving their all for AS

Everyone can truly make a difference. Our community champions, including people like you, raised **$120,938** through fundraising events across the country in 2017, which can fund a one-year AS research grant! Your dedication has made more research and daily family support possible. We are so grateful for your commitment to finding better treatments and a cure for our loved ones with AS.

QUINN'S HOT COCOA STAND

Driven purely by his love for his twin sister, Emma, who has AS, Quinn—an eight-year-old boy—**organized a hot cocoa stand** that raised nearly **$30,000**, which will directly fund more research and much-needed daily support for AS families.

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ANDY MEERDO CHARITY GOLF TOURNAMENT

Inspired by his son, Zachary, who has AS, Andy Meerdo hosts an annual Charity Golf Tournament that gathers hundreds of family, friends and loved ones with AS to raise funds and awareness. This year, he also auctioned off a signed NHL Hall of Fame Mario Lemieux jersey. In total, both initiatives raised **$13,115** in 2017, and **$49,715** since the annual tournament began in 2014.

LUKE'S LIONS

Drew and Sara Robinson's son, Luke, was diagnosed with AS in August 2017 when he was barely a year old. Drew and Sara quickly developed a passion to achieve a cure for their son when they started Luke's Lions—a fundraising initiative that has raised more than **$11,000** in less than six months, with a goal of raising **$1 million.** What's even more amazing is the incredible support the Robinson family has received. Anything is truly possible when your love is so strong that an entire community rallies around you!

TRACTOR CRUISE

Every year, the Keith Olsen Family of Horton, KS—who have a daughter, Ingrid, with AS—**hosts a tractor cruise** in support of all of our loved ones with AS. Their entire community in Brown County, Kansas comes together to support the family's passion of finding a cure for AS and has raised an amazing **$31,645** since 2009!

BORN 2 RICKSHAW RUN

This unique fundraiser, described as an "idiotic adventure to raise money for charity," involves three-wheeled "rickshaws" traveling across India. This year, this wild and crazy team of adventurists graciously chose to do it for the AS community! **Team "Born to Rickshaw Run"** embarked with no set route and no way of truly knowing if they would make it to the finish line—the only certainty was that they WOULD get lost! Needless to say, they made a huge sacrifice...but it paid off bigtime, as they raised nearly **$7,000** for a cure for AS!

"The Rickshaw Run forces you out of your comfort zone in every way. We couldn't control when our auto rickshaw broke down, or how we would fix it when it did. No matter how dirty, tired or frustrated we got, we knew it was all worth it if we could raise even one more dollar, or educate one more person about ASF."

SUMMIT FOR ANGELMAN II

Kevin Spight climbed to Mt. Everest Base Camp in honor of his friend Kyle Rooney's son, Madden, who is diagnosed with AS. We are so proud of Kevin's bravery to climb more than 17,000 feet (that's 3.3 miles above sea level!) to raise both awareness and funds for AS research. In total, **Summit for Angelman trips** have raised **$13,791** for the AS community.

Over the past 25 years, community fundraisers have helped raise $2,259,096. We are in awe of all of our amazing fundraisers—your generosity and commitment has given the AS community more hope, promise and life-changing research and support than ever before!

2016 BANK OF AMERICA CHICAGO MARATHON

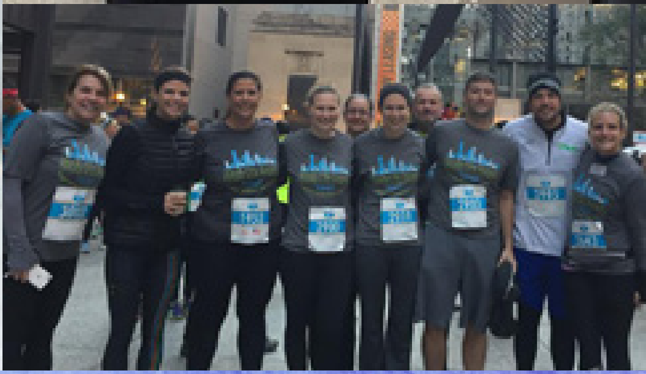
Running for a cure for Angelman syndrome.

The Windy City Angels put their bodies through months of intense training to run 26.2 miles, and on top of that they each raised thousands of dollars to help give our loved ones with AS the care and support they need. These runners are truly heroes for our families and we are so grateful!

THE 2016 WINDY CITY ANGELS,
INCLUDING 5K RUNNERS, RAISED

$23,637!

CLICK HERE FOR MORE INFORMATION ABOUT THE
WINDY CITY ANGELS AND BANK OF AMERICA CHICAGO MARATHON.



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HOPE IS HERE

Nearly a thousand supporters rallied around the **Hope is Here campaign** to support the AS Clinics. Because of their support, families can meet with specialists, who understand the intricacies and severe symptoms of AS, to effectively address the most serious health concerns of their person with AS. The comprehensive treatments for AS provided by the Clinics cannot be found anywhere else.

OUR AMAZING SUPPORTERS HELPED RAISE

$219,946

FOR LIFE-CHANGING AS CLINICS THROUGH THEIR GIFTS TO THE HOPE IS HERE CAMPAIGN.

Over the past 25 years during the holiday season, our generous donors have selflessly given **$754,188** to help fund research, treatments, family support, AS Clinics, ASF Conferences and symposia, and so much more.

CURE CLUB

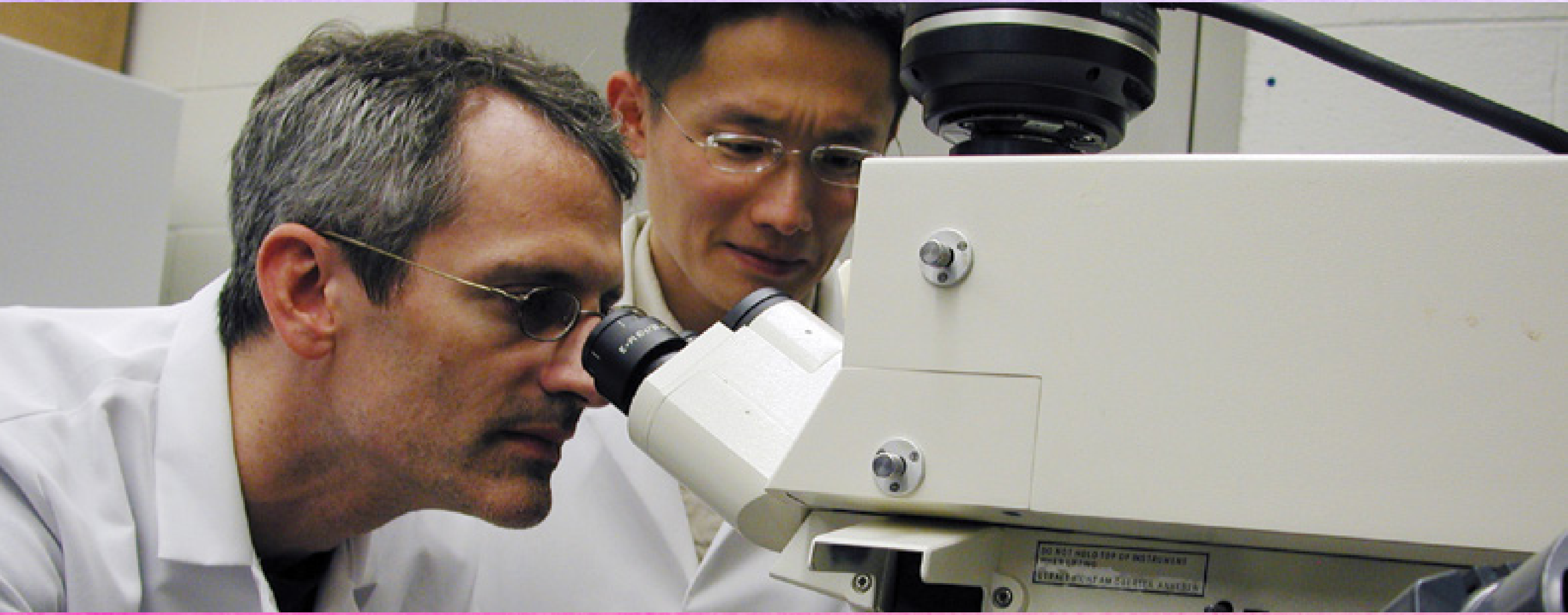
The Cure Club is a dedicated group of monthly givers who are passionate about finding a cure for Angelman syndrome. This very special group of donors truly walk the walk; they choose to open their hearts and commit monthly to achieving a cure for AS...and we are incredibly thankful.

Cure Club members are contributing nearly **$26,000 annually**!
Learn more about the Cure Club here.

RESEARCH

A cure will happen and together we will find it.

In 2017, our supporter's gifts were used to support exciting, new advances in AS research. In addition to continued funding of research in progress, 2017 research highlighted two new studies: **Dr. Steven Gray's pivotal gene therapy research** and **Dr. Ben Philpot's research** with new compounds to activate the paternal Ube3a gene. These are giant steps toward a cure for AS and we owe all of this progress to our supporters!



$1,058,591 invested in research in 2017 – our largest annual investment in research to date, which is all thanks to our community's incredible commitment to achieving better treatments and a cure for AS.

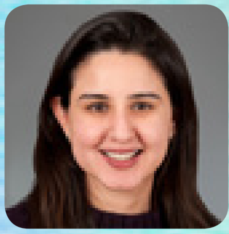
Kiyoshi Egawa
Hokkaido University
Graduate School of Medicine
Pathophysiological impact of diverse deregulation of tonic inhibition in AS

H.A. Moll
Erasmus University Rotterdam
CompAS

Ben Distel
Academic Medical Center Amsterdam, Netherlands
Identification and characterization of novel targets and activators of E6AP

Mark Zylka
University of North Carolina, Chapel Hill
Finding new ways of unsilencing Ube3a

Ben Philpot
University of North Carolina, Chapel Hill
Pilot study to validate three novel classes of small molecules to unsilenced paternal Ube3a allele



Anjali Sadhwani
Boston Children's Hospital
Speech generating devices in children with AS: an effectiveness trial

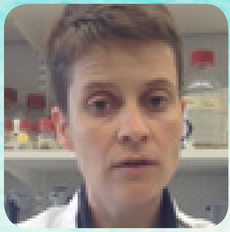
Steven Gray
University of North Carolina, Chapel Hill
Gene Therapy in AS

Christopher Keary
Massachusetts General Hospital
Evaluating anxiety in individuals with AS

Sasha Key
Vanderbilt University
Auditory brain responses as an indicator of cognitive function in Angelman syndrome

Paul Carney
University of North Carolina, Chapel Hill
Pre-clinical assessment of cannabidiol as a treatment for Angelman syndrome

Eric Morrow
Brown University
Shared cellular mechanisms in Angelman syndrome and Christianson syndrome



Geeske van Worden
The Netherlands
Understanding the ability for learning improvement if Ube3a is restored in a later life stage

Anjali Sadhwani
Boston Children's Hospital
Adaptation of a standardized neurodevelopmental assessment for individuals with Angelman syndrome

Dear Researchers,

THANK YOU to ALL Angelman researchers! Your work gives us hope and shows the world that TOGETHER we can and will CURE ANGELMAN SYNDROME! God bless you.

Sincerely,
Jeanie Fisher

Since 1996, our community has helped us **fund nearly $9.4 million in research**, directly resulting in treatments for seizures and other symptoms of AS as well as discovering the critical building blocks for clinical trials and a cure.

ANGELMAN SYNDROME CLINICS

AS Clinics are absolutely imperative to AS families, who get to meet with a team of AS experts who understand AS explicitly and can provide effective treatments for their loved ones' most significant health issues. The AS Clinics are essential to providing a holistic approach to all of the needs of a person with AS. Families are so grateful for our donors' support to keep these one-of-a-kind clinics going—and also open more.

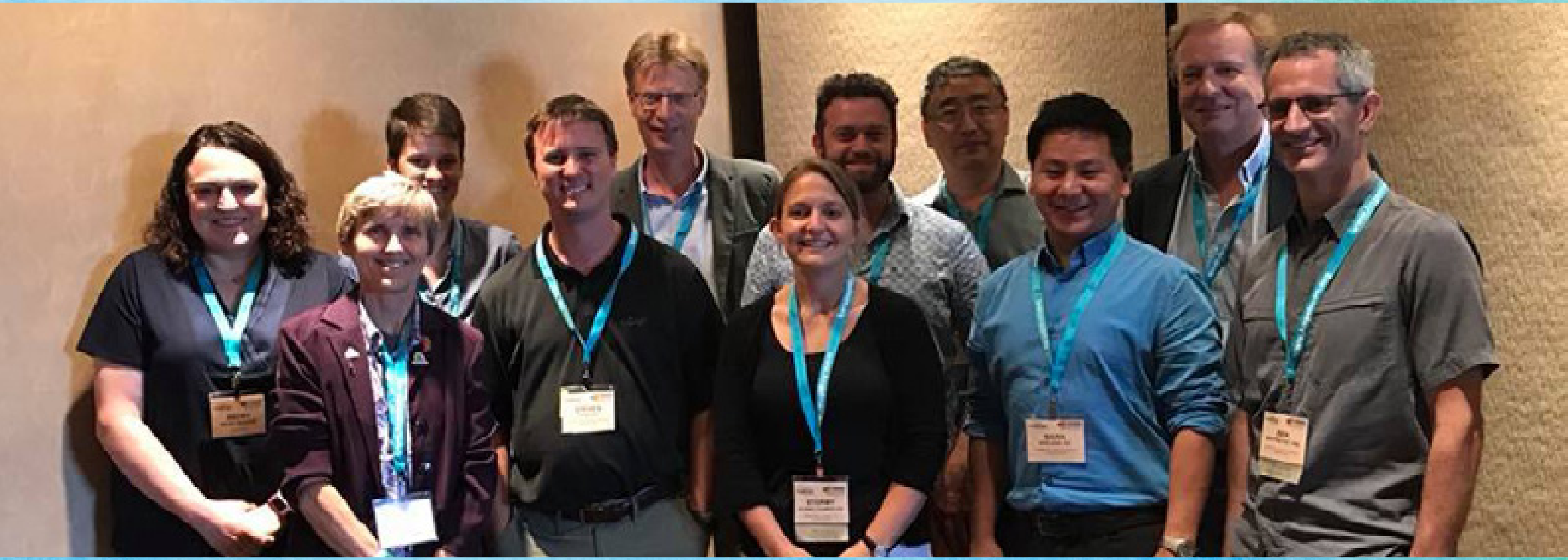
The generosity of our donors has made it possible to **open four AS Clinics** across the country that see more than **350 patients** each year. Continued funding keeps these clinics open. Watch for more AS clinics to open in 2018.

ANGELMAN SYNDROME BEHAVIORAL CLINIC

The Angelman Syndrome Behavioral Clinic, which opened in 2017 at Massachusetts General Hospital, is focused solely on treating the behavioral symptoms in AS, such as anxiety and aggressiveness – very common challenges for people with AS. The Behavioral Clinic is extremely critical for people with AS of all ages, especially adults, as these symptoms often intensify as they grow older and require focused attention from AS experts. The remarkable contributions made by Fred and Renee Pritzker, the Fighting Angels Foundation and the Harvey Baseball Foundation now allow many AS families to discuss their individual's behavioral challenges with AS experts who are solely devoted to providing the care and support that all people with AS deserve.

2017 ASF RESEARCH SYMPOSIUM

Our community's support brings together the world's brightest scientists and clinicians working to find treatments and a cure for AS. The most prestigious annual AS research meeting in the world, the ASF Research Symposium brings together the premier, global AS researchers to collaborate and discuss the most current research in an open forum. This unique format encourages and accelerates new ideas and collaborations with scientists and clinicians to more rapidly find new treatments and a cure for AS.



Read the full summary of the 2017 Symposium from Dr. Chamberlain, ASF Scientific Advisory Committee Chair, here.

The 2017 Research Symposium was the 16th Symposium we have hosted in our 25-year history.

2017 ASF FAMILY CONFERENCE

AS families from across the world gathered to learn how to address the physical, emotional and life-changing challenges an AS diagnosis brings. They leave this Conference feeling renewed after being armed with the latest information on treatments and connecting with other families who experience the same challenges they face everyday. The ASF Family Conference is the most comprehensive AS meeting in the world, covering issues and topics relevant to all ages and stages in AS.

Supporters like you made it possible for AS families to experience this amazing, all-encompassing Conference free-of-charge. Thank you!

Since 1991, our supporters have enabled us to host 14 conferences that have given over **9,000 attendees** a place to learn, grow and engage.

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Over the last 25 years, our supporters have helped us offer much-needed family support resources to more than 3,000 people with AS in all 50 states and more than 70 countries worldwide. Without our generous donors, these support services would not exist **anywhere** for our families.

FAMILY RESOURCE TEAM

The Family Resource Team is a group of compassionate AS experts who have a child or family member with AS. This group serves as a lifeline for AS families, providing guidance and understanding on topics such as health, insurance, finance, education, transportation and much more.

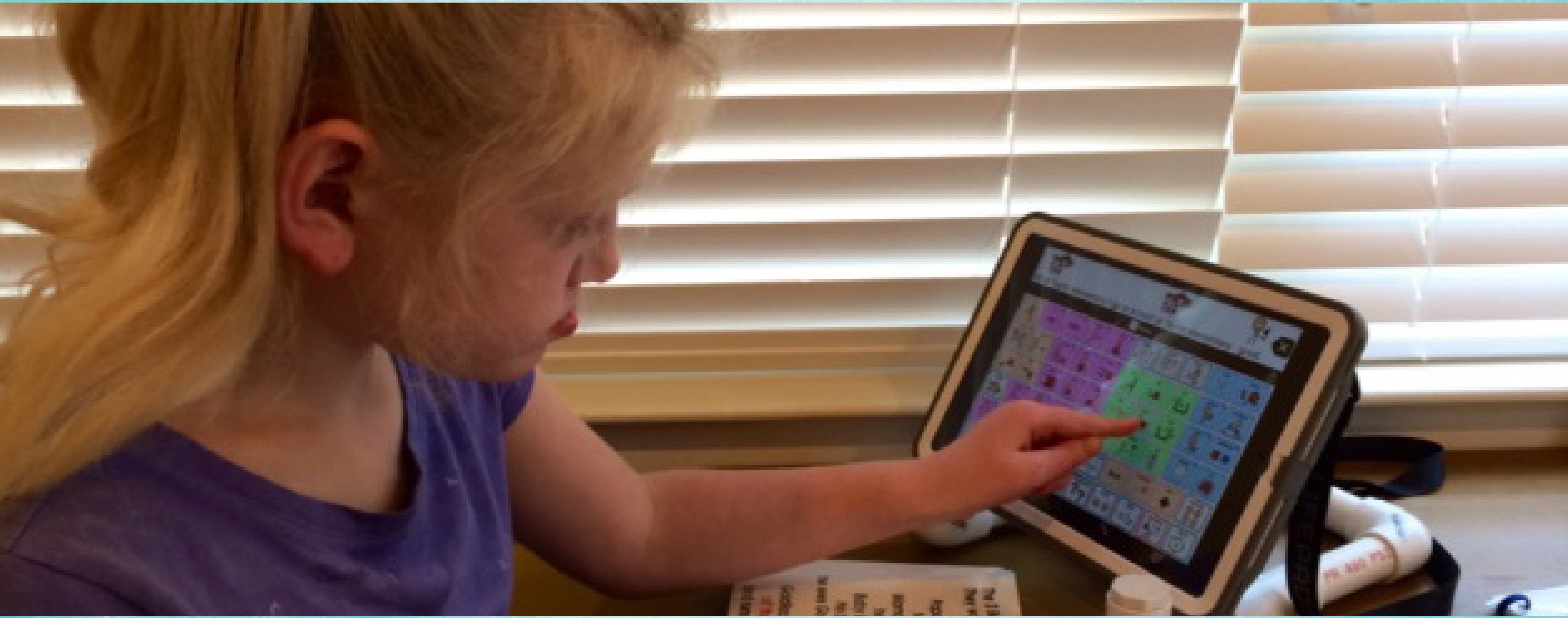
Michelle Harvey

Lizzie Sordia

Dr. Eric Wright

COMMUNICATION TRAINING SERIES

The Communication Training Series is a webinar series that gives families and caregivers valuable guidance on how to model effective communication with individuals with AS. We are the only nonprofit organization in the world that provides this type of training program, and because of our generous supporters we are able to offer this webinar series for free.



"The Angelman Syndrome Foundation has put together a truly amazing set of videos and support materials to help us get started in Augmentative & Alternative Communication (AAC) implementation. While developed in support of children and adults with Angelman Syndrome, the information has much broader applicability and is appropriate for a wide range of developmental disabilities."

– PrAACtical AAC

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BEHAVIORAL INFORMATION SERIES

Challenging and aggressive behaviors are common in people with AS, and they can be difficult to navigate without proper guidance. **The Behavioral Information Series** was created to help families learn what's causing these behaviors and how to improve them. In 2017, informational sessions were accessed on average 378 times per month.

In 2017, the series helped people from 73 different countries.

AS FAMILY WEEKEND AT THE CENTER FOR COURAGEOUS KIDS

It's more than a camp; it's an experience unlike any other.

For the past two years, generous donors have allowed many families to attend a weekend at CCK for free. While at camp, families are able to spend stress-free time together in an environment that is accepting and understanding of children with AS, and they are able to enjoy traditional camp activities that would otherwise not be possible.

"We loved this camp! Everything about CCK was amazing. Carter has never felt so successful and accepted."

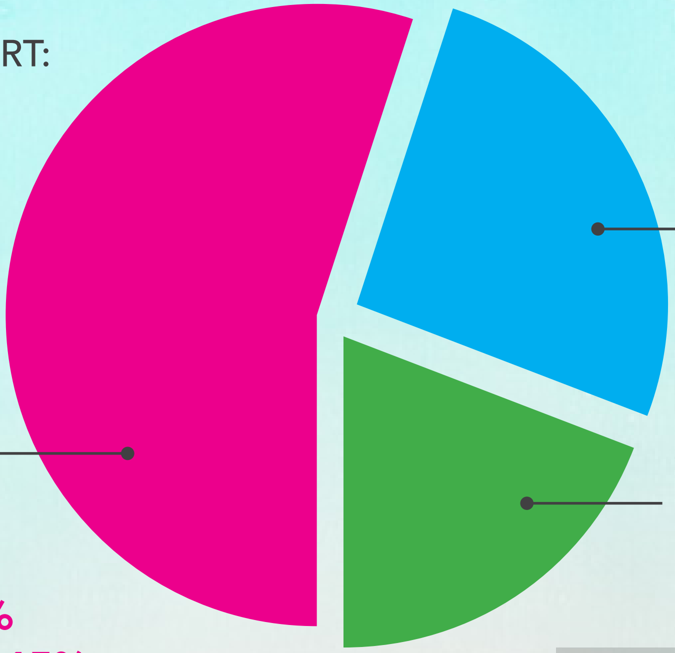
Since the first camp in 2016, 63 Angelman families have been gifted a special family weekend at CCK.

FINANCIAL SUPPORT

We, and all of our AS families, are humbled and grateful for the continuous generosity we see year-after-year. Your donations help make a difference in the lives of those with AS and their families every day, and continue to bring us closer and closer to a cure.

TOTAL 2017 PROGRAM SUPPORT:

$1,930,374



DAILY FAMILY SUPPORT SERVICES:
$499,519 – 26%

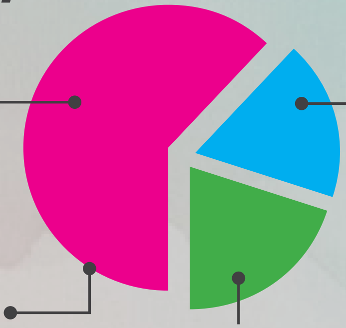
RESEARCH:
$1,058,591 – 55%

EDUCATION/SYMPOSIUM/CONFERENCE:
$372,264 – 19%

PROGRAM EXPENSES – **79%**
FUNDRAISING EXPENSES – **15%**
MANAGEMENT/GENERAL – **6%**

25 YEARS OF TOTAL PROGRAM SUPPORT:

$15,093,577



RESEARCH:
$9,351,352 – 62%

DAILY FAMILY SUPPORT SERVICES:
$2,734,934 – 18%

EDUCATION/SYMPOSIUM/CONFERENCE:
$3,007,291 – 20%

Together, our community has raised **$15,093,577** for AS research, family support and education opportunities since our founding 25 years ago.

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CHANGES TO OUR BOARD OF DIRECTORS

NEW OFFICERS & MEMBERS


Dr. Justin Grill
President


Tim Bousum
Vice President

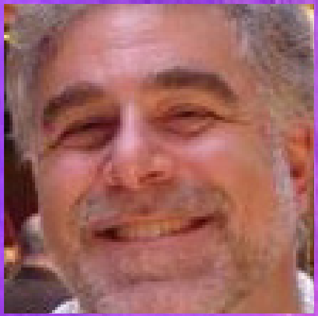

Kathy Rokita
Treasurer


Michael Cecere
Secretary


Amanda Moore
Director

MEMBERS ROTATING OFF


Greg Dohrmann


Dr. Steve Katz


Mary Wagstaff

We are excited to welcome new executive board officers and members Dr. Justin Grill, Tim Bousum, Kathy Rokita, Amanda Moore and Michael Cecere. We would like to extend immense gratitude to Greg Dohrmann, Dr. Steve Katz, and Mary Wagstaff as they step down after completing their full terms as board members. We are truly grateful for the hard work, dedication and passion of our past board members and we know that our new members will bring the same commitment and compassion.


Stormy Chamberlain
NEW SAC CHAIR

We are excited to announce Dr. Stormy Chamberlain as the new **Scientific Advisory Committee** (SAC) Chair. Stormy is a 10-year researcher in the field of Angelman syndrome and brings great knowledge and passion to our organization.

THANK YOU, FROM THE BOTTOM OF OUR HEARTS!

After another amazing year of progress in research, family support, AS Clinics, education and so much more, I want you to know just how thankful we are for your continued support. The lives of AS families are made better every day by the support of kind, generous people like yourself who help us offer the expert care we need to treat the challenging symptoms of AS. With every dollar, ASF-funded research takes us one step closer to a cure. I can't wait to see what the future holds. Thank you for continuing to keep the AS community close to your heart.

With humble gratitude,
Dr. Justin Grill, ASF President
Angelman Syndrome Foundation

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