Get Informed FAST

Newsletter for the Foundation for Angelman Syndrome Therapeutics

December 2010

Volume 2, Issue 3

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To visit the FAST homepage: ***http://www.CureAngelman.org/***

To volunteer to help FAST: ***http://www.cureangelman.org/involved***

FAST Research Funding Begins

Becky and her daughter, Sophie

When my daughter was first diagnosed with Angelman Syndrome (AS), I was overwhelmed with the struggles we would continue to face as we dealt with issues such as seizure control, poor muscle tone, and the need to develop an entirely new way to communicate that didn't involve speech. But I am also a scientist, and one of my first phone calls after the diagnosis was to a friend who performed ground-breaking research on imprinting in mice. Due to her connections, I was speaking with a researcher who worked on Angelman Syndrome that evening about the promise of research for Angelman Syndrome.

Since that inspiring conversation four years ago, Angelman Syndrome research has flourished in many ways. One of the most important concepts emerging is that Angelman Syndrome seems to be a biochemical problem, not a developmental problem. What that means is that the brain in a child with AS appears to develop and form correctly, but the resulting structure fails to function correctly. In a clumsy analogy, if the brain is like a car, the AS brain has all the pieces and parts needed to run, but the engine isn't tuned correctly.

At FAST, we strongly believe that a therapeutic aimed at helping the brain in an individual with AS function more efficiently is possible. But to find that therapeutic, we need to be able to support creative and original scientific research from the best and brightest the research community has to offer.

With that goal in mind, FAST was formed to raise the funds needed to move research in AS forward in new and rapid ways.

This year, FAST has taken a huge step towards our goal of finding a therapeutic for Angelman Syndrome. We have raised enough funds to start supporting research in three different areas. First, we have already received our first round of applications for our Postdoctoral Fellowship Competition and have started soliciting applicants for the next round. Postdoctoral researchers have finished their initial degree (typically Ph.D., M.D., or M.D., PhD.). The next step in their research career is to spend 4-6 years focusing intently on the area in which they will establish their own research programs. Thus, we believe it is fitting that as a young organization, we support the up and coming researchers in the Angelman Syndrome community with a fellowship award. This award will provide a salary and funds to support their work and allow them to attend a meeting or

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"Evening with the Stars"
Foundation for Angelman Syndrome Therapeutics (FAST)
3rd Annual FAST Gala

Dale Jackson Van Hal, a parent of a child with AS and attendee of this year's Gala said, "It's the most amazing night of my life to help my son's life."

December 4th, 2010 marked the 3rd annual FAST Gala, which was enjoyed by many including parents of children with Angelman Syndrome (AS), their families and friends. Three hundred people attended the event and shared in a night of entertainment, fine dining and the chance to meet Guest of Honor, critically acclaimed actor and Golden Globe winner, Colin Farrell. The event was described as an intimate gathering of individuals sharing in the common goal of finding a treatment or cure for individuals affected by Angelman Syndrome.

Colin Farrell with Dale Van Hal

Dale Jackson Van Hal, a parent of a child with AS and attendee of this year's Gala said, "It's the most amazing night of my life to help my son's life." Kim Giacomini, another parent, went on to say, "It's an evening where you don't have to explain AS to others and yet everyone knows what you are dealing with. Then you get the pleasure of hearing first-hand about the research from Dr. Weeber. It is an amazing event! Thank you again!!"

Colin Farrell with Kim & Jeff Giacomini

Prior to dinner, attendees enjoyed a cocktail hour and were offered special picture opportunities to capture their night out. As many families of children with AS know these types of outings, where you can dress to the nines, are generally far and few between. Colin Farrell honored the cocktail hour and everyone enjoyed the beautiful sounds of Jenna Urbaniak's vocals with accompanying pianist Adis Sirbubalo. Family members had the opportunity to meet and chat with Mr. Farrell while having professional photographs taken to capture this once in a lifetime occasion. Many parents of children with AS had met each other face-to-face for the first time after years of email, facebook and listserve communications. It was truly a night of many "reunions". Linda Yoakam, parent and attendee of the Gala said, "It's a night where you don't have to explain AS. And it's so international!" Fellow attendee Tami Mugler

Linda Yoakam & Lauren Pavlik

Colin Farrell, Destini Kirkpatrick, Tami Mugler, and Harli Kirkpatrick

Dinner kicked off with a surprise performance by the famous Shannon Rovers Bagpipe Band of Chicago, who has played all over the world as well as the White House.

Dr. Rebecca Burdine

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said, “For this one magical evening we can come together and rejoice in each other, and for a moment we can rejoice in ourselves!”

Dinner kicked off with a surprise performance by the famous Shannon Rovers Bagpipe Band of Chicago, which has played all over the world as well as the White House. All attendees thoroughly enjoyed the spectacular performance especially Ireland native, Mr. Farrell, who took front row to fully experience the stunning performance.

Dr. Edwin Weeber

Guest speakers included Doctor Edwin Weeber, Doctor Rebecca Burdine, Paula Evans and Mr. Farrell. Paula Evans, Chairperson of FAST, discussed the progress the foundation has made to date and expressed the oganization’s gratitude towards the community for their support of FAST. Mr. Farrell, surrounded by fellow parents, spoke poignantly about his son. Drs. Weeber and Burdine discussed the current state of AS research as well as FAST’s specific aims and objectives in the mission to fund a therapeutic for this disorder. FAST has begun the process of funding scientific research and Dr. Weeber elaborated on one such initiative. Dr. Burdine spoke about the real promise of a therapeutic and to the need for increased funding. Prior to Drs. Burdine and Weeber, family members of individuals with AS took the stage to thank the FAST organization for their efforts and presented them with a stunning sculpture of the organization’s logo. It was a very touching tribute that left most of FAST’s Board of Directors in tears.

Regie Hamm

Dinner was accompanied by the wonderful music of Regie Hamm, award-winning producer and songwriter, and fellow parent of a child with AS. The crowd is always moved when Regie sings his 2008 hit “Time of My Life”.

FAST board members Sharon Claridge, Maiddy Dunigan, Rebecca Burdine and Kena Richert display the logo sculpture given to FAST by members of the AS community.

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The Haney's


Keith Semple of 7th Heaven

> *"It's important for us to raise awareness and funds to continue the great strides we've already achieved," said Paula Evans.*


Mark Kennetz of 7th Heaven


7th Heaven

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After dinner, the guests danced to the amazing talents of Chicago's #1 band, 7th Heaven. Becky Rubenow said, "It is a night where, although it is about AS, the night is not spent explaining AS as everyone there is familiar with it - whether they be a parent, grandparent, friend or donor. It is a night to celebrate all of the hard work, dedication and love the FAST board puts into making FAST and the gala such a huge success. It is a night for tired AS parents to get away and bond with other parents, many of whom they have never met before, yet all of whom are travelling down the same winding road. It is a night to celebrate all of the angels who make the fund-raising for research so worthwhile. It is a night one wishes would never end, as it is indeed, a night to remember."

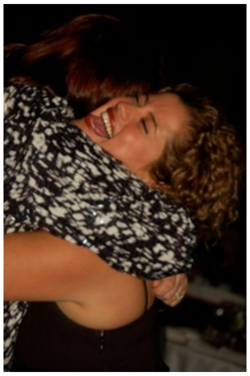
"We are excited about the progress we've made in helping to fund the science that will lead to a treatment or cure for Angelman Syndrome," said Paula Evans, parent, founder and chairperson of FAST. "It's important for us to raise awareness and funds to continue the great strides we've already achieved. We are pleased that FAST has surpassed last year's success and look forward to continuing our efforts to raise additional funds and awareness throughout 2011."


Paula Evans, Chairperson for FAST

FAST is extremely grateful for this year's Gala success, which raised approximately $50,000 for research.


Colin Farrell with Becky Rubinow

In addition, a special thanks to this year's sponsors that include Innovative Mag-Drive, Baroma Health Care and Morgan Stanley Smith Barney. We look forward to reaching our goals and continuing to bring those who are touched by Angelman Syndrome together on an annual basis.


Iris Faver

To read more about Angelman Syndrome and FAST, please visit www.CureAngelman.org

Enjoy more moments captured from the Gala at www.cureangelman.org.

FAST Is Launched in Australia
Written by Megan Cross
Fast Chair Australia

Ursula Cranmer, Mary-Louise Bertram & Rohan Cranmer at Launch

Inspired by the mission and energy of FAST in the United States and driven by the lack of research and understanding into Angelman Syndrome on our shores, FAST Australia opened the "doors" for business in July of this year!

Australia is slightly larger in area than the United States (minus Alaska) and has a population less than the State of Texas, most of us live on the east coast in two of our major cities but a large percentage of us are still off the beaten track (*away from the main traffic*)! Consequently, if you mention Angelman Syndrome to anyone – including some medical professionals, you are likely to be met with a blank stare! Our incidence rate is the same as everywhere else in the world but the nature of our population means that there are often only one or a few cases in an area, and there is a suspicion that a large number of cases are still undiagnosed. Until recently tests for ube3a mutations were all sent offshore.

Don't get me wrong, we don't ride around on Kangaroos, have pet koalas and spend our days at the beach throwing shrimps on the Barbie (*in actual fact we don't even call them shrimps! To us, they are prawns*) , despite being renowned for our laid back lifestyle, we are aware that there is a lot to be done to ensure that the amazing resources created by FAST US are made available to families, therapists and professionals keeping them up to date with all the latest information.

After a lot of hard yakka (*hard work*) by volunteer parents of kids with Angelman Syndrome, FAST Australia received its charity status and celebrated with an official launch in Brisbane Queensland on the last weekend in September. A great group of parents, supporters and professionals came together from all the corners of Australia, New Zealand and even a distinguished guest from the UK - the amazing Professor Chris Oliver! We met together with some great music, food and enthusiasm as we shared dreams for our children and a desire to work together for our common goals.

Hitting the ground running (Starting quickly), we have already had a number of small fundraising events!

Hitting the ground running (*Starting quickly*), we have already had a number of small fundraising events! We are proud to be able to offer the first National charity dedicated to Angelman Syndrome. We have had teams getting sweaty in fun runs, a charity golf day, trivia nights and some amazing individuals that have been simply won over by our children and driven to raise money for us.

Megan Cross, Tony Vidray,Jen Kyriacou at David Segals' Talk

Money to date has been invested into brochures, information leaflets and media packs to get moving on raising the profile of Angelman Syndrome in an effort to increase understanding and reduce the wait time for diagnosis. In

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Angie &Jorja Ignatiou at Adelaide Fun Run

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August we were extremely lucky that FAST Scientific Advisory Board member Professor David Segal took time out from his holiday to speak with families in Sydney about his exciting Zinc Finger research. We are keen as mustard (*really really keen*) to see our research community contribute to the amazing work already being done in the States.

On a serious note, we don't all speak in slang and obscure phrases! We are a small country with a big heart, a reputation for helping out a mate, world renowned research scientists and we feel confident that we will make many valuable contributions towards our common goals.

Thank you for welcoming us into the FAST community.

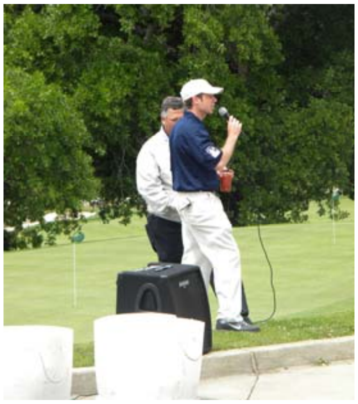
After a lot of hard yakka (hard work) by volunteer parents of kids with Angelman Syndrome, FAST Australia received its charity status.

KNCH Law Holds 2nd Annual 'Golfing for a Cure' Tournament

Golf is a game where you yell 'fore', shoot six and write down five. On May 21, 2010, approximately 100 golfers participated in the 2nd Annual "Golfing for a Cure" Tournament hosted by the Koeller, Nebeker, Carlson & Haluck law firm at The Ridge Golf Course in Auburn, California.

Chad Dunigan with Alan Phillips of Phillips Building Consultings

Chad Dunigan, a partner with KNCH and the main organizer of the event, started the day off with a quick motivating speech and then the golfers were off in their carts ready to tackle the beautifully-manicured course. The golfers enjoyed box lunches and an assortment of gifts as they played thanks to the generosity of the numerous corporate sponsors stationed at most of the holes. Most of the golfers had finished and were inside enjoying delicious appetizers and drinks when the skies opened up with driving rain to challenge the resolve of the remaining golfers.



Chad Dunigan

Following the tournament, happy to be inside and away from the untimely rain and wind, the golfers enjoyed a video display of photographs taken throughout the day. As an appetizing dinner was enjoyed, FAST Chairperson, Paula Evans was introduced. Paula thanked everyone for their generosity and detailed the types of research opportunities on the horizon thanks to such charitable donations. Also on hand was Associate Professor at the UC Davis Genome Center Department of Pharmacology School of Medicine, Dr. David Segal. Dr. Segal

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Sean DeBerg & guests

The tournament was a tremendous success, securing approximately $30,000 to directly support scientific research funded by FAST.

Mike Robertson, guest, Joel Agnew and Jerry Satran

made a wonderful presentation to the group that was aimed at providing them with an understanding into Angelman Syndrome as well as an exciting explanation of his current research. Dr. Segal provided a promising timeline and an example that the guests could appreciate. Chad then wrapped up the night with hole prizes both from KNCH as well as several from sponsors.

The remainder of the evening was spent perusing numerous raffle prizes. The prizes ranged from drivers, to San Jose Sharks and San Francisco Giants autographed jerseys, to an array of amazing photography and art work. Finally, after a successful day of golf and with satiated appetites, the guests listened with baited breath anxiously reading ticket numbers to see what was won and what was missed.

Overall, the tournament was a tremendous success, securing approximately $30,000 to directly support scientific research funded by FAST. This momentous achievement was made possible by the generous sponsors and donors who opened their hearts and businesses toward the cause. We at FAST recognize and appreciate the time and commitment required to put on such an event and we thank everyone at Koeller, Nebeker, Carlson & Haluck, as well as the donors and sponsors for providing us with the resources to drive forth our mission statement of funding a cure.

Pulte Homes Representatives, Andre Robin and Tyler Happe

Tyler Happe

Mike Ratliff, Alan Ryce, Ed Heugenin & Chad Dunigan

"A Night for the Angels"
hosted by Western Beef & Christina Castellana

The Castellana family has shown us that you don't have to have a child affected by Angelman Syndrome to care about finding a cure and helping others, you just need a desire and a vision for a better life that these children can have.

The Foundation for Angelman Syndrome Therapeutics announced its partnership with well-known grocer, community advocate and supermarket chain, Western Beef, Inc. Joining the effort to find a cure for Angelman Syndrome (AS), Western Beef will offer their customers the opportunity to make a one-dollar donation to AS research at the check out register in its New York, New Jersey and Florida supermarkets. Western Beef has been part of the New York community since 1978 and is a family owned business that prides itself on catering to the large and ethnically diverse communities where each of its 27 stores are located.

Christina Castellana

To kick off Western Beef's commitment to FAST, a fundraising event was held and organized by Christina Castellana, daughter of the owner of Western Beef. Celebrating the power of growth and opportunity, Western Beef presented "A Night for the Angels," a FAST fundraising gala, which was held on November 5th at the Crest Hollow Country Club, located in Woodbury, New York. The event included a cocktail hour, open bar, dinner, dancing, raffles, silent auction and grand prizes. The evening was a huge success and sold out at approximately 350 attendees, which included friends, family, and partners of Western Beef, in addition to local family members of individuals with Angelman Syndrome. The event raised a stunning $105,000. All proceeds for the night will be donated to The Foundation for Angelman Syndrome Therapeutics.

Iris & Scott Faver

Michael Evans, Melissa Elkins, Melanie Kotsonis, Natalie Hansen, and Rebecca Burdine

"Western Beef is thrilled to be working with FAST and helping to find a cure for Angelman Syndrome," said Peter Castellana III, co-owner of Western Beef. "We are eager to be a part of such a community-based organization and look forward to kicking off our partnership with the 'A Night for the Angels' fundraising event."

The night itself was astonishing, even more so given the fact that the Castellana family had never heard of Angelman Syndrome. A dear friend of

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the family and editor for Spectrum magazine, Mr. Cris Italia, was approached by the family and meetings with the FAST organization were set in motion. Christina Castellana, daughter of Western Beef owner, met with select FAST board members and began learning more about Angelman Syndrome.

"We are thrilled to Partner with Western Beef," said Paula Evans, founder and chairman of FAST. "The Castellana family has shown us that you don't have to have a child affected by Angelman Syndrome to care about finding a cure and helping others, you just need a desire and a vision for a better life that these children can have."

FAST is extremely grateful for the Castellana family and we look forward to a strong and successful relationship in 2011.

First Ever Simply Divine Angels Soiree
Written by Jason Bernstein


Air Force TSgt Jason Bernstein

The first annual "Simply Divine Angels Soiree" took place in Jackson, Michigan on August 20, 2010. Arbor Hills Country Club Golf Course hosted the charity event. Awareness and funds were raised for the Foundation for Angelman Syndrome Therapeutics (FAST). As guests entered the drive of the elegant golf course, signs were placed with special notes. Each sign informed visitors about Angelman Syndrome characteristics.

When guests entered the building they were asked to autograph a seven foot tall white wooden angel. The angel was designed and crafted by Ted Piotrowski whose daughter, Deb Brockie, organized the event.

Attendees enjoyed a fun filled event which began with a cocktail reception, a gourmet buffet, and some heart filled speeches. The welcome speech was given by Technical Sergeant (TSgt) Jason Bernstein. He thanked the guests on behalf of two children, Molly Brockie and Reese Vescelius, and their families. Pastor Ned Bernstein gave the invocation speech.

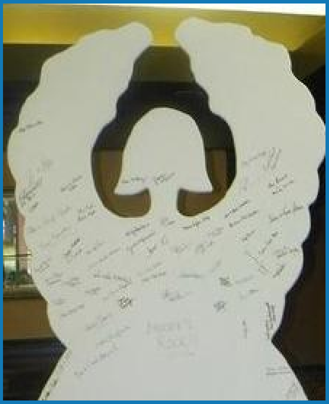

Mike & Mollie Brockie

Molly Brockie took her first steps on December 19, 2009, and she was making everyone smile as she walked around the dance floor. TSgt Bernstein explained that most Angelman children do not walk until they are between the ages of three to seven years old, with 10% never walking. Reese is age five and is still far from walking on his own.


Reese Vescelius

Arbor Hills had a separate room designated for the silent auction. Guests were able to bid on items ranging from $10-$4,000 in value. Malibu Tan, Caledone Golf Course, Daytona International Speedway, Chicago Bulls, Biggby Coffee, Jackson Country Club, Finley's Family Restaurant, Detroit Lions, and Maggie Moos ice cream parlor along with dozens of other sponsors contributed to this huge success! Kay Piotrowski and daughter Deb Brockie recruited sponsors from all over the country. Family and friends of Reese & Molly also donated handmade items including afghans, baby clothes, and quilts.

Paula Evans, founder and chairperson of FAST, gave a speech regarding current success in research. She informed everyone on the studies being performed by genetic scientists including Dr. Edwin Weeber who is the head of the FAST Scientific Advisory Board. Dr. Weeber is best known for his work in reversing the cognitive deficits in the mouse model of Angelman Syndrome. Paula mentioned that scientists usually try



Molly Brockie took her first steps on December 19, 2009, and she was making everyone smile as she walked around the dance floor.


Paula Evans
Chairperson for FAST

SpeakOut4AS is a campaign of no words. It's an acceptance event, in which children are challenged to remain silent for a set period of time.

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to find a cure for well known syndromes such as Autism, Cerebral Palsy, or Cancer, because there is more money for research.

Debbie Guargliardo
Vice-Chairperson for FAST

Debbie Guagliardo, vice-chairman of FAST, gave a speech that had many in the crowd choked up. Her daughter Gina, at the age of nine, came up with an idea for a fundraiser called Speakout4AS, because she wanted to "someday hear Ainsley speak," referring to Ainsley Evans, daughter to Paula. SpeakOut4AS is a campaign of no words. It's an acceptance event, in which children are challenged to remain silent for a set period of time. Debbie explained that "in order for our children to have a better understanding of what a child affected with AS must feel like when they're unable to speak, we will ask SpeakOut4AS participants to remain totally silent, to not speak a word." Every table at the Simply Divine Angels Soiree had a Speakout4AS sign for guests to see.

After the uplifting and emotional speech it was time for Regie Hamm to perform. He had the crowd laughing, dancing, and even singing along as he jammed on his keyboard. Mr. Hamm shared a little bit about his life story, and the roller coaster ride. He shared about adopting his beautiful daughter Isabella and how he had to fly to China on March 18, 2003 to get her. At this time he was on his way up the pop charts with his hit "Babies" from his American Dreams CD. He went on to explain how when he returned to America everything began falling apart including cancelled tours with the Goo Goo Dolls and Cher.

Regie Hamm

He explained how they racked up medical bills and how all the money he had made was going to Vanderbilt Children's Hospital in Nashville, Tennessee. His story finished with a happy ending as he shared about his wife Yolanda talking him into writing a song for the 2008 American Idol contest. Over 40,000 people took a "Hail Mary" toss at the contest, but it was Mr. Hamm who won with his song "Time of My Life". David Cook would then sing the song and make it a #1 hit for sixteen straight weeks.

Mr. Hamm spent much of the night autographing his book "Angels & Idols" and his new CD "Set it on Fire". He sold the combo pack for $25 and donated the proceeds to FAST as part of the benefit. Attendees were drawn to his life story and wanted to read more. After listening to him sing they needed to hear more.

Continues from p. 11: First Ever Simply Divine Angel Soiree

Much awareness was created by this event, and many said they can't wait until the second annual Simply Divine Angels Soiree. The funds that were raised will go toward research that will hopefully lead to the cure of Angelman Syndrome.

The band "Scoot Magoo" played for the final three hours. People asked that they play again next year, and they have already pledged to do so.

Many parents of AS children travelled to attend this event. Thank you to everyone who helped support the first annual Simply Divine Angels Soiree.

A special thank you to Regie Hamm! He had to fly into Detroit, rent a car, and drive out to the small town of Jackson, Michigan. TSgt Bernstein said, "Friends are asking when we can have another event, and they are begging Regie return." Deb Brockie has already begun the process of planning the second annual event.

Mark & Julie Diaz

TSgt Bernstein said, "Friends are asking when we can have another event, and they are begging Regie return." Deb Brockie has already begun the process of planning the second annual event.

Continued from P.1: "FAST Research Funding Begins"

conference that will be most helpful to their research project.

Our second funding area is the Grant-in-Aid. This program will provide rapid funding to researchers currently working on projects that have real promise in Angelman Syndrome. If a researcher needs additional funding for supplies or equipment, we want to provide that funding to them quickly so that their research doesn't have to wait while funding is secured through slower mechanisms. Grant applications to the National Institutes of Health, for example, can take up to 9 months before a funding decision is reached, and even longer before awarded funds are available. As our name implies, we would like research to move forward as rapidly as possible and we hope this award mechanism will help to facilitate rapid discoveries.

Finally, we have established a Targeted Research to Advance a Cure (FAST-TRAC) mechanism to direct funds towards especially promising research ideas that have the potential to significantly impact the way we approach therapeutics in Angelman Syndrome. We are pleased to announce that we have funded our first FAST-TRAC grant to Dr. Ed Weeber at the University of South Florida to explore the ability of a set of FDA approved compounds to provide therapeutic benefit in the Angelman Syndrome mouse model. These compounds were chosen because they have shown promise in other neurological disorders such as Fragile X and Rett Syndrome, both of which have molecular mechanisms that may intersect with those affected by AS. This project will determine if any of these existing, approved compounds help alleviate the learning or motor dysfunctions in the AS mouse. If so, this data would provide the crucial first step towards establishing a clinical trial for the efficacy of these compounds in individuals with AS. Dr. Weeber has already started the project, and we hope to report the results within the year. This award is specifically supported by funds provided to FAST by the Morgan family, thus we have named this award the Kendall Morgan FAST-TRAC Award in honor of their support for their daughter/granddaughter, and for FAST.

It is an exciting time for Angelman Syndrome research and we at FAST are proud to be part of it.

By Rebecca Burdine, Chief Scientific Officer for FAST.

Happy Holidays from everyone at FAST

Happy Holidays from everyone at FAST