

When the words did not come



Luke and Shannon Holzem at the Communication Aids & Systems Clinic

Photo: Clark Kellogg, Waisman Communications

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Luke Holzem sped from door to door, his orange t-shirt transforming him into a bright blur of 6-year-old energy. His grey-green eyes sparkled with anticipation ahead of his appointment at the Communication Aids & Systems Clinic (CASC) at the Waisman Center.

Luke's energy wasn't always channeled so harmlessly. Not too long ago, Luke and his family were facing severe aggressive and self-injurious behaviors. "He used to bash his head, he would hit me, he would kick the floor, and scream and cry," remembers his mother, Shannon.

Luke was diagnosed with autism spectrum disorder and his communication challenges meant that he would go on to have an appointment with CASC at the Waisman Center.

"When Luke began his CASC intervention he was using challenging behaviors in place of functional communication about 90% of the time," says Sarah Labaz, a speech-language therapist with CASC. "However, Luke immediately responded to speech-generating devices that were trialed, and we quickly learned that he had undiscovered skills in reading, writing and even basic math."

Shannon thinks that Luke has been able to spell

and read for many years without being able to communicate. The frustration at not being able to talk, of knowing the words but having no way to express himself, probably fueled his outbursts and meltdowns.

Within three therapy sessions, Luke was using the speech device in place of challenging behaviors approximately 80% of the time. "He was a completely different child who transitioned from throwing toys at me to running up and giving me a hug when he arrived for therapy," says Labaz.

With Luke able to communicate his needs and wants, the Holzem family can now plan and enjoy typical outings. "We can go out to eat and Luke will sit in a chair, like any 6-year-old, and spell out what he wants," says Shannon. Luke doesn't only communicate his wants though. He often spells out, 'I love you, mom' and remembers to say 'Happy Birthday, Laney!' to his sister.

But working with CASC and augmentative and alternative communication (AAC) is not a 'magic bullet', Labaz clarifies. "It takes a lot of hard work and commitment from all individuals involved."

To read the unabridged story, please visit
waisman.wisc.edu/newsletter.htm

A summer at Waisman



Waisman researchers Ed Hubbard (far left) and Leann Smith (far right) with Lawrence students Vijayashree Krishnan, Anna Kim and Katie Taber (from left to right); not pictured is Waisman Center researcher Kristin Shutts
Photo: Clark Kellogg

This summer, three students from Lawrence University exchanged the Fox River for Lake Mendota and became temporary Badgers.

Supported with grants from Lawrence University, Katie Taber, Anna Kim and Vijayashree Krishnan spent their summer conducting research with Waisman investigators Leann Smith, Ed Hubbard and Kristin Shutts, respectively.

Taber was involved with the Working Together program – an educational and support program for young adults with ASD and their families to help them transition from relatively structured school environments to the more chaotic adult world.

With prior research experience under her belt while at Lawrence, Taber “was able to jump in right away and start working in the lab,” says Smith. “That speaks to the quality of the education and research training she received while at Lawrence.”

“I was able to take my previous research experience to the next level and do more hands-on work,” says Taber. Being able to collaborate and learn from individuals with more experience was particularly valuable.

“It has been a lovely opportunity to have Katie working with us through the summer,” says Smith. “I can’t say enough good things about her!”

Having finished her freshman year at Lawrence this May, **Kim** started the summer “with no idea how a

research lab works.” Since then, her work in Hubbard’s Educational Neuroscience Lab has allowed her “to learn many aspects of the research process.”

Kim was involved in a project to better understand how our brains handle the concept of fractions. In this project—newly funded by the National Institute of Child Health and Development—Hubbard is using magnetic resonance imaging (MRI) to learn more about how second through eighth-graders learn fractions and how it impacts their future learning in math.

Providing research opportunities to undergraduate students is a no-brainer for Hubbard. “It’s directly tied to the Wisconsin Idea, that what we are doing here at UW-Madison should extend beyond the boundaries of just our campus and include the whole state,” he says.

When **Krishnan** started in Shutts’s Social Kids Lab she didn’t expect to be spending time at the mall.

“We walked up to complete strangers, talked to them about the lab and then asked them if they would be interested in signing up their kids to be research participants,” says Krishnan. “It was nerve-racking in the beginning but I think I did a good job.” She did indeed. “VJ recruited the highest number of families!” says Shutts. Krishnan did more than recruit research volunteers. She had the opportunity to learn new computer

programs and skills, such as animation.

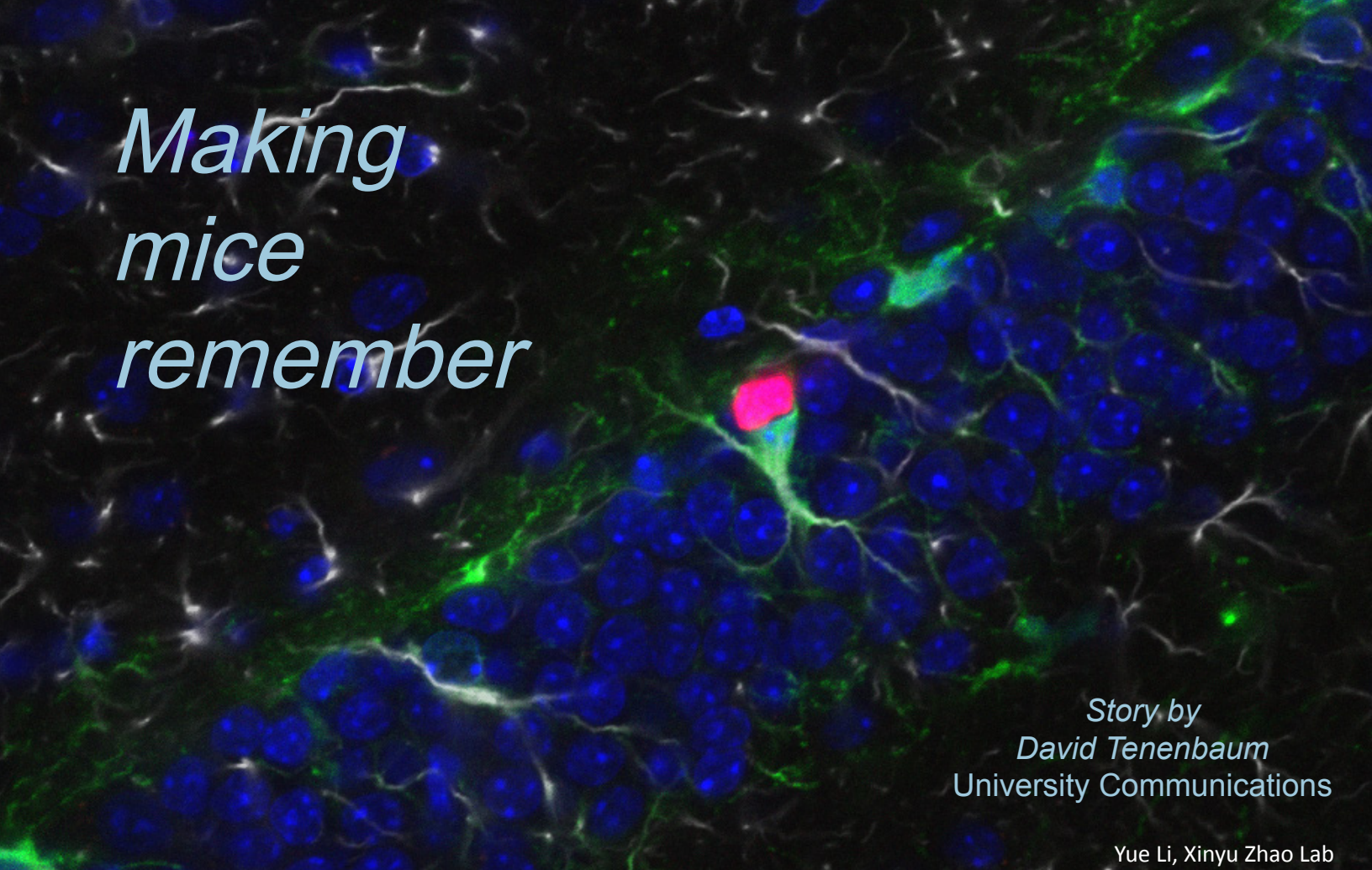
For Shutts, having undergraduate researchers from different institutions is a win-win. “It’s really nice to have a different perspective in the lab to offer fresh insights into the kinds of problems we are working on,” says Shutts. “It’s also fun for UW-Madison students to meet someone who goes to a different college or university.”

Of course, it is difficult to provide research opportunities to students without funding. As Hubbard says, “we can throw open our lab doors for students but if they can’t eat, it’s not much use.”

Funding for all three students was provided by Lawrence University. Additional support came from John and Sally Mielke, longstanding members of the Appleton community and the Appleton Education Foundation (AEF), a non-profit organization based in Appleton.

“We want to help educate the students and open the doors to what might be,” says John Mielke, who is on the board of directors at the AEF (and on the Waisman Center board of visitors). “Whether or not the students go into research, they will always have an appreciation of what it takes to do good research and what science is all about.”

For the unabridged story, please visit waisman.wisc.edu/newsletter.htm



Making mice remember

Story by
David Tenenbaum
University Communications

Yue Li, Xinyu Zhao Lab

Xinyu Zhao, a Waisman Center researcher who studies the most common genetic intellectual disability, has used an experimental drug to reverse—in mice—damage from the mutation that causes the syndrome.

The condition, called fragile X, has devastating effects on intellectual abilities. Fragile X affects one boy in 4,000 and one girl in 7,000. It is caused by a mutation in a gene that fails to make the protein FMRP.

In 2011, Zhao, showed that deleting the gene that makes FMRP in a region of the brain that is essential to memory formation caused memory deficits in mice that mirror human fragile X. The deletions specifically affected neural stem cells and the new neurons that they form in the hippocampus.

Tantalizingly, Zhao's 2011 study showed that reactivating production of FMRP in new neurons could restore the formation of new memories in the mice. But what

remained unclear was exactly how the absence of FMRP was blocking neuron formation, and whether there was any practical way to avert the resulting disability.

In a study published in *Science Translational Medicine*, Zhao and her colleagues at the Waisman Center have detailed new steps in the complex chain reaction that starts with the loss of FMRP and ends up with mice that cannot remember what they had recently been sniffing.

“Affecting this gene’s pathway does seem to reverse the memory impairment” - Xinyu Zhao

This study's newfound understanding of the biochemical chain of events became the basis for identifying an experimental cancer drug called Nutlin-3, which blocks the reaction. In the new study, mice with the FMRP deletion took Nutlin-3 for two weeks.

When tested four weeks later, they regained the ability to remember what they had seen and smelled in their first visit to a test chamber.

Statistically, the memory capacities of normal mice and fragile X models that were treated with Nutlin-3 were identical. “I’m encouraged because affecting this gene’s pathway does seem to reverse the memory impairment,” says Zhao.

The Wisconsin Alumni Research Foundation has applied for a patent on the discovery. Nutlin-3, which can block the last stage of the chain reaction set off by a mutation in the FMRP gene, is in phase 1 trials for the treatment of some cancers.

In any case, it's far too soon to declare victory over fragile X, Zhao stresses. “There are many hurdles. Among the many questions that need to be answered is how often the treatment would be needed. Still, we’ve drawn back the curtain on fragile X a bit, and that makes me optimistic.”

To learn more about Zhao's research at the Waisman Center please visit waisman.wisc.edu/pi-Zhao-Xinyu.htm

UPCOMING EVENTS

Waisman Center Day with the Experts

Cerebral Palsy

SATURDAY, Nov. 4, 2016 at 9 a.m.



Autism

SATURDAY, Jan. 21, 2017 at 9 a.m.

waisman.wisc.edu/events-day-with-the-experts.htm

The Friends of the Waisman Center



Waisman

Whirl 5k&10k

Run, Walk & Roll for ALL Abilities

2nd Annual

Sunday, October 16, 10:00 a.m.

Start and finish at the Waisman Center, 1500 Highland Ave.



10k Run & Roll (NEW!)

5k Run, Walk & Roll

1 Mile Walk & Roll

Kids' Fun Run & Roll



waisman.wisc.edu/run2016.htm

Proceeds benefit individuals and families affected by developmental disabilities and neurodegenerative diseases.



Waisman Center Children's Theatre

2016-2017 Schedule

All shows are on the second Sunday of each month

- ♦ Sunday, Oct. 9 @ 1:00 Doug the Jug – *Juggling Extravaganza*
- ♦ Sunday, Nov. 13 @ 1:00 & 3:00 Playtime Productions –
If The Shoe Fits... A Cinderella Story
*Sensory-friendly performance at 3:00 in partnership with the Autism Society of South Central Wisconsin
- ♦ Sunday, Dec. 11 @ 1:00 & 3:00 Dance Wisconsin – *Nutcracker* preview
- ♦ Sunday, Jan. 8 @ 1:00 Wayne the Wizard – *Winter Magic Show*
- ♦ Sunday, Feb. 12 @ 1:00 David Stokes - *Wildlife Fun*
- ♦ Sunday, Mar. 12 @ 1:00 Mad Science – *Sounds Like Science*
- ♦ Sunday, Apr. 9 @ 1:00 & 3:00 Playtime Productions – *WWW.OZ*
*Sensory-friendly performance at 3:00 in partnership with the Autism Society of South Central Wisconsin

Admission: \$2.00, adults; \$1.00, children
Tickets: Advance tickets for any show in the series can be purchased beginning at NOON on performance days
Sign Interpreters: All shows sign-interpreted
Location: Friends of the Waisman Center Auditorium, 1500 Highland Ave.
Directions: waisman.wisc.edu/wc-map.htm
Parking: Free. Park in far end of lot 82, **overflow parking in lots 60 and 76**
Questions? 608.263.5837 weekdays or palumbo@waisman.wisc.edu

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Kids Fund
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waisman.wisc.edu/events-ct.htm

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A rare gift: Family endows professorship



Terry Geurkink and Sally Wilmeth (center) and their children Jenni (left) and Kyle (right)

In their photographs, Jenni and Kyle Geurkink look like happy, healthy children. Jenni has a captivating smile and a twinkle in her eyes. Kyle is a sturdy toddler who loves brooms, mops and any occasion to laugh.

"They were regular, healthy children, who were meeting all of their developmental milestones," says their mother, Sally Wilmeth. "We had no idea what was coming."

Jenni and Kyle would both succumb to an unknown and unidentified degenerative neurological disorder before their fourth birthdays.

In Jenni and Kyle's memory, Sally and Terry Geurkink—her husband and their father—recently established the Jenni and Kyle Professorship in Novel Neurodevelopmental Diseases at the Waisman Center.

Their \$500,000 gift was matched by funds from John and Tashia Morgridge's recent \$100 million gift to UW-Madison to support faculty excellence. The Jenni and Kyle Professorship began September 1, 2016 and includes \$40,000 per year in research funding for five years.

"The Jenni and Kyle Professorship is an extraordinary gift and investment in rare disease research, and gives hope to future generations of children and their families who face these challenges," says Albee Messing, VMD, PhD, director of the Waisman Center.

For Sally and Terry, the difficult journey began when Jenni was 18

months old. Until then Jenni was an active child who was on track, developmentally, for her age—she sat, crawled, rolled over and cruised but she hadn't yet begun to walk independently.

One day Sally noticed that Jenni's balance didn't seem quite right and decided to seek a second opinion. She called the Waisman Center, where Jenni was seen by Tina Iyama, a developmental pediatrician, who agreed that Jenni's condition was more serious than delayed walking.

Doctors were unable to diagnose Jenni's deteriorating health. The general consensus, at that time, was that her condition was not genetic. This was a relief to Sally and Terry, as shortly after they began investigating Jenni's condition, Sally had become pregnant with their son, Kyle.

Kyle was born in November 1982 and as he thrived, Jenni continued to decline. She celebrated her third birthday in May 1983, and that summer her health abruptly took a turn for the worse. By the end of August, Jenni was functionally paralyzed and unable to speak.

Around this time, Kyle developed an ear infection, which was accompanied by slight tremors. After consulting with their pediatric neurologist and doctors at the Waisman Center, Sally and Terry suspected that Kyle had the same medical condition as Jenni.

"We still didn't know what to expect," says Sally, "but at least we

knew we had to prepare ourselves emotionally for what would happen to Kyle."

In May 1984, just short of her fourth birthday, Jenni passed away. Two years later, a few months short of his fourth birthday, Kyle passed away.

"When we could not get a diagnosis or answers about our sick children...we had no idea about what the future might hold. It was devastating," says Sally.

Establishing the Jenni and Kyle Professorship is a way for Sally and Terry to honor the memory of their children. "We want to support innovative research that will provide answers about unknown disorders and help families," says Sally. "There is so much still to learn and discover."

The first recipient of the Jenni and Kyle Professorship is Xinyu Zhao, a professor in the Department of Neuroscience and a Waisman investigator.

Zhao's research focuses on understanding the development, behavior and function of neural stem cells and their implications for developmental disorders, such as fragile X syndrome, Rett syndrome, and autism-related disorders.





A Call for Art

Encompassing a breadth of subject matter and artistic media, the **Harvey A. Stevens International Collection of Art by People with Developmental Disabilities**, showcases unique and visually powerful pieces that encourage people of all abilities to express themselves and expand their world through art. The collection is maintained by the Friends of the Waisman Center, who are expanding the collection through an international Call for Art by individuals with disabilities.

Deadline: November 1, 2016.

For more information, please contact Teresa Palumbo at palumbo@waisman.wisc.edu or 608.263.5837

Pictured here:
Sea with Boats by Peter Nielsen