Intersections

Volume 2018 Issue 2



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Meet our New Director: Qiang Chang, Ph.D.

Cutting-edge scientist, family chef and former professional chess player...meet Qiang Chang, the new director of the Waisman Center!

Qiang Chang, a professor of medical genetics and neurology and Waisman Center investigator, began his tenure as the next director of the Waisman Center on July 1, 2018.

The transition to center director comes after more than 10 years in a breadth of leadership roles at the center, including serving as the associate director of the center's Intellectual and Developmental Disabilities Research Center.

Chang joined the Waisman Center in 2007 as part of a cluster hire initiative focused on translational neuroscience research. He studies Rett syndrome—a rare neurological disorder that primarily affects girls.

Originally from China, Chang grew up in Beijing. He completed his B.S. in biochemistry and molecular biology at Peking University, a prestigious university in Beijing. Chang furthered his studies in the United States where he earned his Ph.D. in neuroscience from the University of Pennsylvania School of Medicine.

As a postdoctoral fellow, he studied neural regeneration at Children's Hospital of Boston/Harvard Medical School and neurological diseases at the Whitehead Institute at MIT. During his postdoctoral work at MIT, Chang began studying mouse models of Rett syndrome. Opportunities to meet with patients and families affected by Rett syndrome inspired his research.

"When I met with patients and families, it put a human face on the project," says Chang. "It wasn't just scientific curiosity anymore; it became personal. It made me commit to studying this disease because I really wanted to help these families."

Pursuing knowledge and helping families continue to be important to Chang and his vision for the Waisman Center. "Through the integration of the center's research programs, clinical services, and outreach efforts, we have the infrastructure, expertise and synergy to make the whole bigger than the sum of its parts," says Chang.

One of Chang's first priorities will focus on implementing the Functional Genetics/Genomics in Neurodevelopmental and Neurodegenerative Diseases Cluster Hire.

"This initiative will bring three new tenure-track faculty members to the center and serve as a nucleus to help advance translational research and further the center's mission," says Chang.

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Outside of the lab, Chang has had some very interesting hobbies and experiences. As a young child, he developed skills and a passion for chess, which led to a competitive chess career during elementary and middle school. He also enjoyed playing soccer, which he continued to play throughout his time in graduate school and his first couple of years in Madison.

Chang is married to Jing Zhang, a professor of oncology and a researcher in the McArdle Laboratory for Cancer Research at UW-Madison. They have two children. A son, Sean, who graduated from West High School and plans to study computer science at Carnegie Mellon University. you feel that all the things you are doing are worth it."

Their daughter, Angelina, who is 10 years old, is a very gifted pianist with a passion for gymnastics. She attended the Waisman Early Childhood Program. Chang enjoys spending time with his family and loves being the family chef and prepares most of the family's meals.

> "Our kids are where we spend most of our time now. My daughter has gymnastics practice five days a week, and my wife and I split our time shuttling her to and from practices and meets. It is very nerve-wracking," he says of watching his daughter do gymnastics. "It's to the point where I don't want to watch all the time because it's scary should she fall from the beam or bars."

But he says it is all very rewarding. "I enjoy seeing the next generation grow up, doing well and doing things that are enjoyable to them. It makes



From the Director's Desk:

It is my pleasure to greet you as the new director of the Waisman Center!

I am honored to serve in this role and to help carry forward the center's rich legacy of discovery, innovation and service that began more than 45 years ago.

The future holds much promise and hope as our researchers, clinicians, staff and students continue to better understand and treat intellectual and developmental disabilities and neurodegenerative diseases through the seamless integration of research, training, outreach, and clinical services.

You are an integral part of our story and our success! Thank you for your support of the Waisman Center. I am deeply grateful for your partnership and shared vision of improving the lives of individuals and families impacted by intellectual and developmental disabilities and neurodegenerative conditions.

I look forward to getting to know you and encourage you to visit the Waisman Center to see our work firsthand.

Drawn to Art Works from the Harvey A. Stevens International Collection of Art by People with

Works from the Harvey A. Stevens International Collection of Art by People with Developmental Disabilities were featured in an exhibit at the Chazen Museum of Art, UW-Madison, from May 11-July 15, 2018. The exhibit was in conjunction with the launch of *Drawn to Art*, a book about the collection. For more information about the book, please visit, waisman.wisc.edu/friends/drawn-to-art/

Celebrating the Waisman Center's Harvey A. Stevens International Collection of Art by People with Developmental Disabilities





Artist Renata Berdes from Chicago, Illinois, stands next to her piece, *Hospital Bed*.



A Flower (above), Sally, Pakistan



Artist Phil Porter, from Mad ison, Wisconsin, next to his painting, *The Biggest House My Great-Grandfather Ever Built.*

Artist Billy Borgerd, from Chicago, Illinois, next to Road, his piece which is also the cover of the Drawn to Art book.

CREATIVE G R O W T H









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Idyll at the Sea, Annelise, Denmark





Study Offers First Look at How Children with Cerebral Palsy Develop Language Skills



A study led by Waisman Center investigator Katherine Hustad is the first to show that language comprehension skills of children with cerebral palsy can accurately predict their language skills later in life.

"This means that if we can identify children with cerebral palsy as young as 24 to 30 months of age who are very likely to have significant language problems later in life, we may be able to change or improve the course of their development through very early speech-



language therapy," says Hustad, professor and chair of the Dept. of Communication Sciences and Disorders at UW–Madison.

Cerebral palsy (CP) is the most common cause of severe motor disability in children, affecting movement, coordination and communication skills. Up to 75%

of children with CP may face challenges communicating.

Hustad's research, the culmination of more than 12 years of work at the Waisman Center, is the first to quantitatively show how language comprehension develops over time in young children with CP.

For the study, Hustad and colleagues recruited 85 children with CP born between 2001-2009. Some of the children had no difficulties with speech or movement, others had some speech-motor challenges, and others had significant speech and communication challenges.

The researchers followed these children from the time they were 18 months old until they were 4.5 years old and tested how well the children understood language at various points as they got older.

They found that children with CP who didn't have speechmotor impairment actually surpassed expectations about language comprehension as they grew. "They may start out with some delays [compared to typically developing peers], but they catch up and even exceed them," says Hustad.

Children with some speech-motor impairment also made age-appropriate progress but a gap remained in their language comprehension levels when compared to typically developing children. "This finding suggests that we may need to target interventions to help these children over this persistent gap," says Hustad.

The group of children with significant speech and motor issues did not show marked improvement in language comprehension over time. But that may be because we do not yet have the tools to test precisely their ability to comprehend language, says Hustad, who is collaborating with fellow Waisman investigator Jenny Saffran to develop tests using eye-tracking software that may be better suited to test language comprehension in these children.

While the study did not test whether early interventions in children with cerebral palsy improved communication outcomes, it provides a platform for further work. "I think our findings from this study and our future work will ultimately help us develop interventions that improve communication and quality of life for children and adults with cerebral palsy," says Hustad.

To read the unabridged story, please visit: waisman.wisc.edu/waisman-intersections/

Down Syndrome Clinic Helps Jackie Cleveland Keep on DAN^CING!



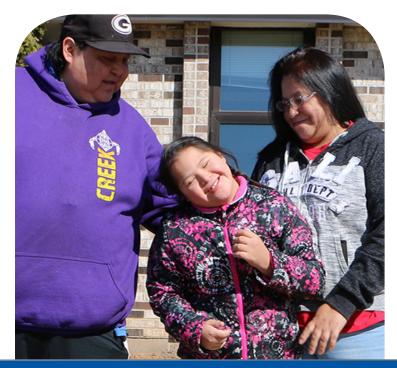
Brown eyes afire and colorful skirt awhirl, Jackie Cleveland has been dancing since she could walk.

Now in sixth-grade, Jackie, who has Down syndrome, performs at Native American pow wows across the country, dancing traditional Ho-Chunk dances with style and unabashed joy. "I think she was just born with the beat!" says Danielle Cleveland, Jackie's mother.

Helping individuals with Down syndrome, like Jackie, live a full and healthy life is an important aim of the Down Syndrome Clinic, says Maria Stanley, clinic director and a behavioral pediatrician. "We try to make sure that each individual is able to have the best life possible, however they define it. We also support the family so they can help each individual have that opportunity," she says.

For Jackie, that means working on her speech and communication skills. For her parents, that means helping them learn how to best help Jackie become more independent as she enters her teenage years.

The clinic – a partnership with UW Health and American Family Children's Hospital "really strives to understand the strengths of the individuals and families coming to the clinic," says Stanley. "Then we work together to promote healthy development and independence."



Listening to individuals with Down syndrome and their families is key, says Amy Lyle, clinic coordinator and a social worker. While working with the Cleveland family, Lyle was struck by their commitment to Ho-Chunk cultural traditions and how they have involved their entire family. For Jackie, that means dancing at pow wows all over the United States.

Whenever Jackie dances to the beats of a Ho-Chunk jingle dance, she is not only honoring tradition; she is also raising awareness about what individuals with Down syndrome can accomplish. "When we started going to the pow-wows, we didn't see any other children with disabilities," says Danielle. "But that's changing, and we have met several children with Down syndrome."

When Jackie was 9 years old, she was in an automobile accident. Her father, Garrick Cleveland, remembers pulling her out of the wreck. "She was bleeding from her head," he says. "Her eyes were open, but she wasn't responding." Thankfully, after some frantic, desperate CPR, Jackie would recover consciousness.

The head injury that Jackie sustained from the accident brought her to the Pediatric Brain Care Clinic at the Waisman Center. Then she received a referral to the Waisman Center Down Syndrome Clinic.

Others have a more direct referral route to the clinic, and people come from all over Wisconsin and even parts of Illinois and Iowa. They are seen by an interdisciplinary team, who collaborate to provide care. "We have a fabulous group of clinicians who have real passion for the work that they do and real care and concern for the individuals coming to the clinic," says Stanley.

Clinic visits have helped Jackie and the rest of her family, says Garrick. "As parents, you want to do what's best for your child. Coming to the Down Syndrome Clinic makes us feel confident that we are doing just that."

Today, Jackie is living a full and busy life. She goes to Olson Middle School in Mauston, Wisconsin – her favorite subject is math – and she enjoys spending time with friends and family, including her six brothers.

And she intends to keep on dancing!

To read the undabridged story, please visit: waisman.wisc.edu/waisman-intersections/



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4th Annual Friends of the Waisman Center

Waisman Whirl 5k & 10K



Run, Walk & Roll for ALL Abilities Sunday, October 14, 10:00 a.m. 10k Run & Roll; 5k Run, Walk & Roll

1 Mile Walk & Roll; Kids' Fun Run & Roll

waisman.wisc.edu/event/run-2018/

Proceeds benefit individuals and families impacted by developmental disabilities and neurodegenerative diseases