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Video game improves balance in youth with autism

Playing a video game that rewards participants for holding various “ninja” poses could help children and youth with autism spectrum disorder (ASD) improve their balance, according to a study led by **Brittany Travers**, Waisman Center investigator and UW-Madison assistant professor of kinesiology.

Balance challenges are more common among people with ASD compared to the broader population, says Travers, and difficulties with balance and postural stability are commonly thought to relate to more severe ASD symptoms and impaired activities in daily living.

“We think this video game-based training could be a unique way to help individuals with ASD who have challenges with their balance address these issues,” says Travers.

In this pilot study — the largest ever to look at the effects of balance training on individuals with ASD — participants showed significant improvements in not only their in-game poses but also their balance and posture outside of the game environment.

According to Travers, balance improvements outside the video game context are especially important. “Our participants are incredibly clever when it comes to finding ways to beat video games!” she says. “We wanted to make sure that the improvements we were seeing were truly balance-related and not limited to the video game.”


The gaming system uses a Microsoft Kinect camera and a Nintendo Wii balance board connected to software developed using Adobe Air.

“Players see themselves on the screen doing different ninja poses and postures, and they are rewarded for doing those poses and postures; that’s how they advance in the game,” says Travers.

Researchers are working to make the game more accessible to individuals within the autism spectrum. “Ultimately, we would like to move this video game-based training outside the lab, and help more people,” says Travers.

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

Waisman Center research into rare syndrome offers hope for families



Jason, Annalise, Heather and Laurel Cooper at their home (Photo by Clark Kellogg, Waisman Communications)

Laurel Cooper is 9 years old and full of sass and spunk. She finds it hilarious when her older sister, Annalise, gets into trouble. She loves music, and being in the thick of things.

Laurel also has Rett syndrome, a rare, non-inherited neurological disorder that mostly affects girls and causes severe deterioration in their ability to speak, move, eat, and even breathe easily. Rett syndrome has no cure.

Because of Rett syndrome, Laurel needs to use a feeding tube, and isn't always able to get enough nutrients. Despite being 3 feet, 7 inches tall, she weighs just 35 pounds. She cannot speak and has extreme difficulty communicating, though she manages by using her eyes and with the help of an assistive device.

Relatively few scientists study the rare disease, which is not well understood. But Waisman Center investigator **Qiang Chang**, associate professor of medical genetics and neurology, is trying to unravel the molecular mysteries of the disease and develop effective therapies for Laurel and patients like her.

One gene, many troubles

When people ask 12-year-old Annalise why her sister doesn't walk or speak, she has an answer ready: "I tell them that there's just one teeny problem in her little body."

For the vast majority of individuals with Rett syndrome that "teeny problem" is that a gene called MECP2 (pronounced mek-pea-too) is altered or mutated.

"I tell them that there's just one teeny problem in her little body."

But "the MECP2 gene is active in almost all the various types of cells in the body," says Chang, "and the protein made from the MECP2 gene can influence many seemingly unrelated aspects of human growth and physiology."

In fact, there are so many things at the molecular and cellular levels that are different in Rett syndrome patients that "it can be difficult to

know where to even begin," says Chang.

New findings, new clues

How does one change in a single gene lead to so many different physiological and behavioral symptoms? Researchers like Chang are beginning to uncover clues.

Recently, his lab found a connection between MECP2 and nerve cells in a mouse model of Rett syndrome: the abnormal MECP2 protein in those mice could no longer interact with several proteins involved in a process called RNA-splicing.

Cells use RNA as templates to make proteins. Much like how different parts of a movie need to be edited and put together to make a coherent story, most of the RNA in our cells need to be cut and joined together, or spliced, before they can be used to make working proteins.

If RNA splicing is altered, it can lead to proteins that don't function properly, and

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Thoughts of Gratitude: Marijo Bunbury



Marijo Bunbury loves a challenge, especially when she's passionate about the outcome.

Luckily for the Waisman Center, in 1994 someone told Bunbury that a congested events calendar would make it impossible to raise funds (to support the Waisman Center) through a golf benefit.

Twenty-three "Friends of the Waisman Center Golf Benefits" – and more than \$680,000 in fundraising – later, it's safe to say that Bunbury has proven she indeed loves a challenge and rises to it.

"Of course, it wasn't just me who made the golf benefit a success over the years," she says. "It happened because of the support from other Friends' board members, and all the people here at the Waisman Center who gave so generously of their time and, most importantly, believed like me that we could do it."

The funds raised at the golf benefits have helped sustain and expand research programs, clinical services and outreach efforts at the Waisman Center. More recently, they have supported the Waisman Center Early Childhood Program as well.

While the golf benefit was Bunbury's initial connection to the Waisman Center, "she has helped shape many Friends ventures over the years and continues to be a Waisman Center partner," says **Teresa Palumbo**, communications manager at the Waisman Center.

Bunbury served as a board member of the Friends of the Waisman Center – a nonprofit 501(c)(3)

organization that engages community members and volunteers in fundraising and outreach activities to support the Waisman Center – for a decade, and eight of those years as the chair of the golf committee.

She even got her family involved! Her daughter, Nicole, served on the Friends' board for six years. "My family – husband Tom, five daughters, their husbands and 12 grandchildren – has been a blessing; I am so grateful for the time they are willing to put in to support the Waisman Center," she says. For the Bunbury family, it's about giving back. "The community of Madison has been very good to us and it's important for us to pay that forward."

In appreciation of her many contributions to the Waisman Center and her support over the years, Bunbury was awarded the Judith B. Ward Award of Excellence in 2017. This award is presented annually at the Friends' Spring Benefit Concert to an extraordinary Friends volunteer or donor.

When presenting the award, **Albee Messing**, then director of the Waisman Center, said: "Marijo is an extraordinary ambassador for the Waisman Center and we are so grateful to her for her efforts. She and Tom are generous supporters who have risen to every occasion when there has been a need for volunteers or philanthropic support."

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***"Marijo is an
extraordinary
ambassador for the
Waisman Center."***

UPCOMING EVENTS

Waisman Center Day with the Experts

Down Syndrome
Saturday, April 14, 2018 at 9 a.m.



waisman.wisc.edu/event/experts-down-syndrome-2018/

26th Annual Friends of the Waisman Center

GOLF

Benefit at Bishops Bay



Monday, July 16, 2018

waisman.wisc.edu/outreach/annual-golf-benefit/

FRIENDS OF THE WAISMAN CENTER 23RD ANNUAL SPRING BENEFIT CONCERT & RECEPTION

Tangled Up in Blue

SATURDAY, APRIL 28, 2018

FRIENDS OF THE WAISMAN CENTER AUDITORIUM
1500 HIGHLAND AVE. MADISON WI 53705

Join us for an evening of lively music
and delectable food and drinks in support of the
Waisman Center, University of Wisconsin-Madison.

This year we feature

Tangled Up in Blue

UW-Madison's premier women's a cappella group

At the concert we will honor
Marsha Mailick & Albee Messing
as the 2018 recipients of the Judith B. Ward Award of Excellence

5:30 p.m. Wine, beer & gourmet hors d'oeuvres
catered by *Chez Vous*

7:15 p.m. Concert

For more information visit:

waisman.wisc.edu/events/concert-2018/
608.263.5837 or palumbo@waisman.wisc.edu

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discovery and hope!



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waisman.wisc.edu/giving/

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this can disrupt many different processes in our bodies.

In the mice lacking typically-functioning MECP2, Chang's group found that the RNA-splicing machinery was affected and several proteins were altered, including a key component of a structure that allows nerve cells to communicate with each other.

Searching for therapies

It can be hard for Laurel to communicate with her parents when something is awry. "Some mornings she will wake up happy, but other mornings her breathing will be all over the place, she might be grinding her teeth. We call these Rett mornings," says Laurel's father, Jason Cooper. "She will try very hard to communicate, but it's difficult to know exactly what's wrong."

But Rett syndrome hasn't stopped Laurel from making friends at school. And she has many, her family says. She is fully included in school activities and exercises.

"It's great to watch the other kids



with Laurel," says Heather Cooper, Laurel's mother. "They read to her, they push her wheelchair, they include her in their play, all without being prompted. I think they know that if she could be up talking and running with them – and getting into trouble – she would."

Researchers have made significant progress since the discovery that linked MECP2 to Rett syndrome. A recent study from Chang's lab used stem cells donated by individuals with Rett syndrome to show, for the first time, that a protein called CREB is involved in Rett syndrome biology and could prove to be a therapeutic target to treat the disease.

For Chang, laboratory research on Rett syndrome is tied to the search for a cure. "Without

basic research, we won't know which genes to target for therapies," he says. "Then, if we can demonstrate that the therapies work in cell-based and animal-based assays, we can look to develop them further for Rett syndrome patients."

Looking to the future

The Coopers focus on taking things one day at a time. "For us, it's making sure that Laurel has a good quality of life" says Jason.

On warm Madison weekends, the entire Cooper family tends to head downtown in search of fun. "We start at the farmers' market, have lunch, walk down to the (Memorial) Union and next thing you know, it's 4 p.m., so you might as well get a brat and a pitcher and then it's time to go home!" says Jason.

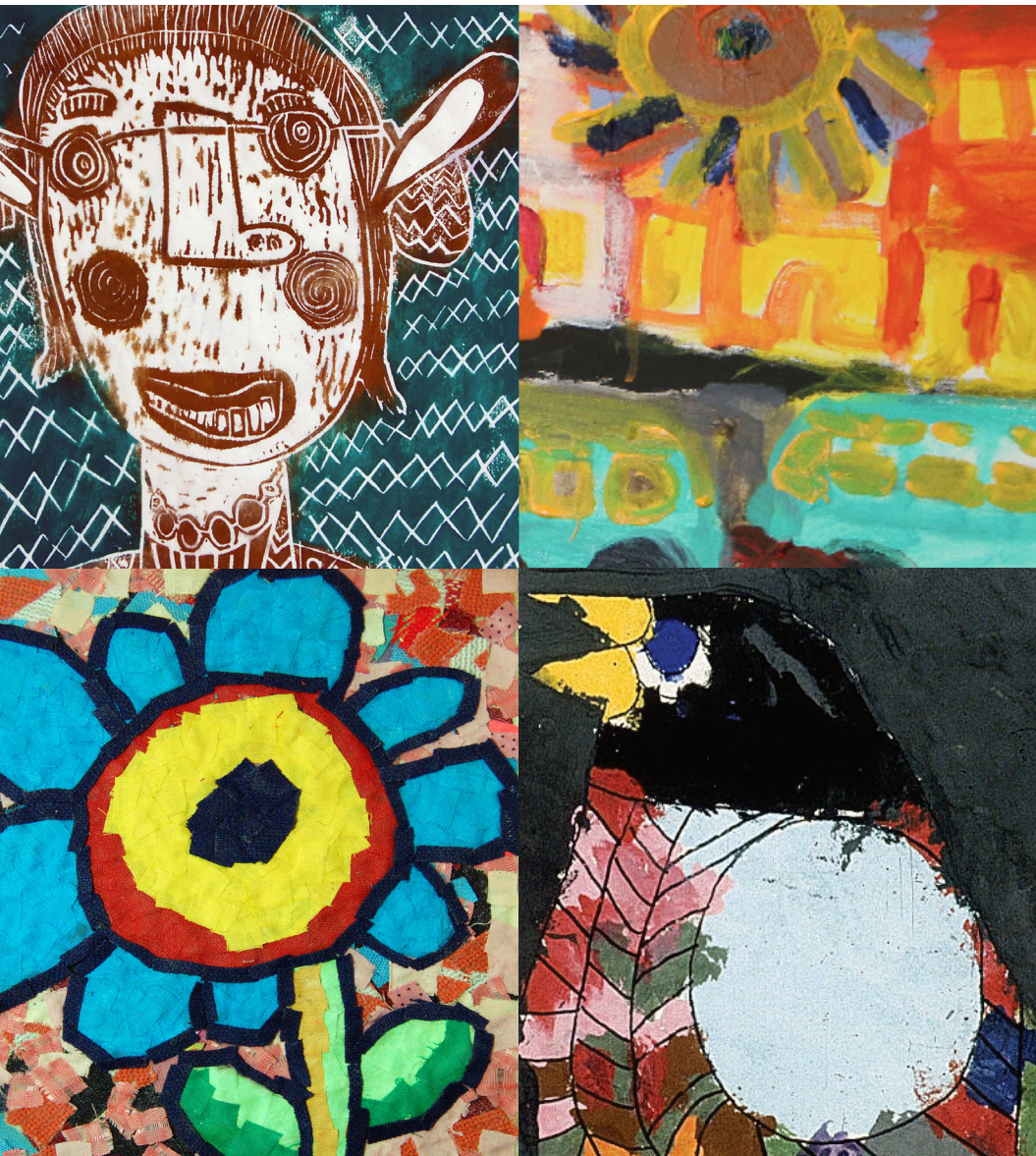
"I think, as human beings, we have a natural tendency to want to help people."

Chang has met with Laurel and her family several times, and these meetings fuel his commitment to researching Rett syndrome.

"I think, as human beings, we have a natural tendency to want to help people," Chang says, "and when you interact with people in need, it reminds you that what you are doing in the lab is not just to satisfy intellectual curiosity, it's also about trying to help people as much as you possibly can."

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Drawn to Art

Art brings the world together. *Drawn to Art* is a new book that showcases art from the *Harvey A. Stevens International Collection of Art by People with Developmental Disabilities* and shares the unique perspectives of artists of all abilities.

The book is edited by **Neil Heinen** and includes a foreword by **Timothy Shriver**, the son of the late Eunice Kennedy Shriver, whose family has had a great impact on the history and mission of the Waisman Center.

Copies are available for \$25.00. You can request copies at waisman.wisc.edu/friends/drawn-to-art/ or via email at artbook@waisman.wisc.edu or by calling 608.263.5837.

Art from the collection will be featured in an exhibit at the UW-Madison **Chazen Museum of Art**. The exhibit opens May 10 and runs through mid-July.