

2018 Annual Report

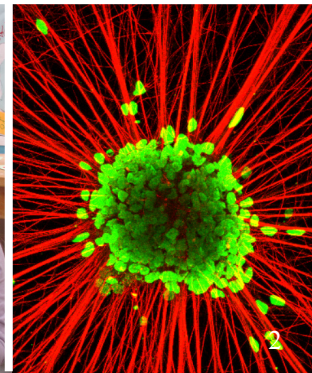
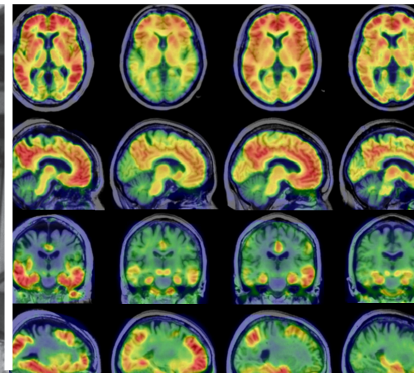
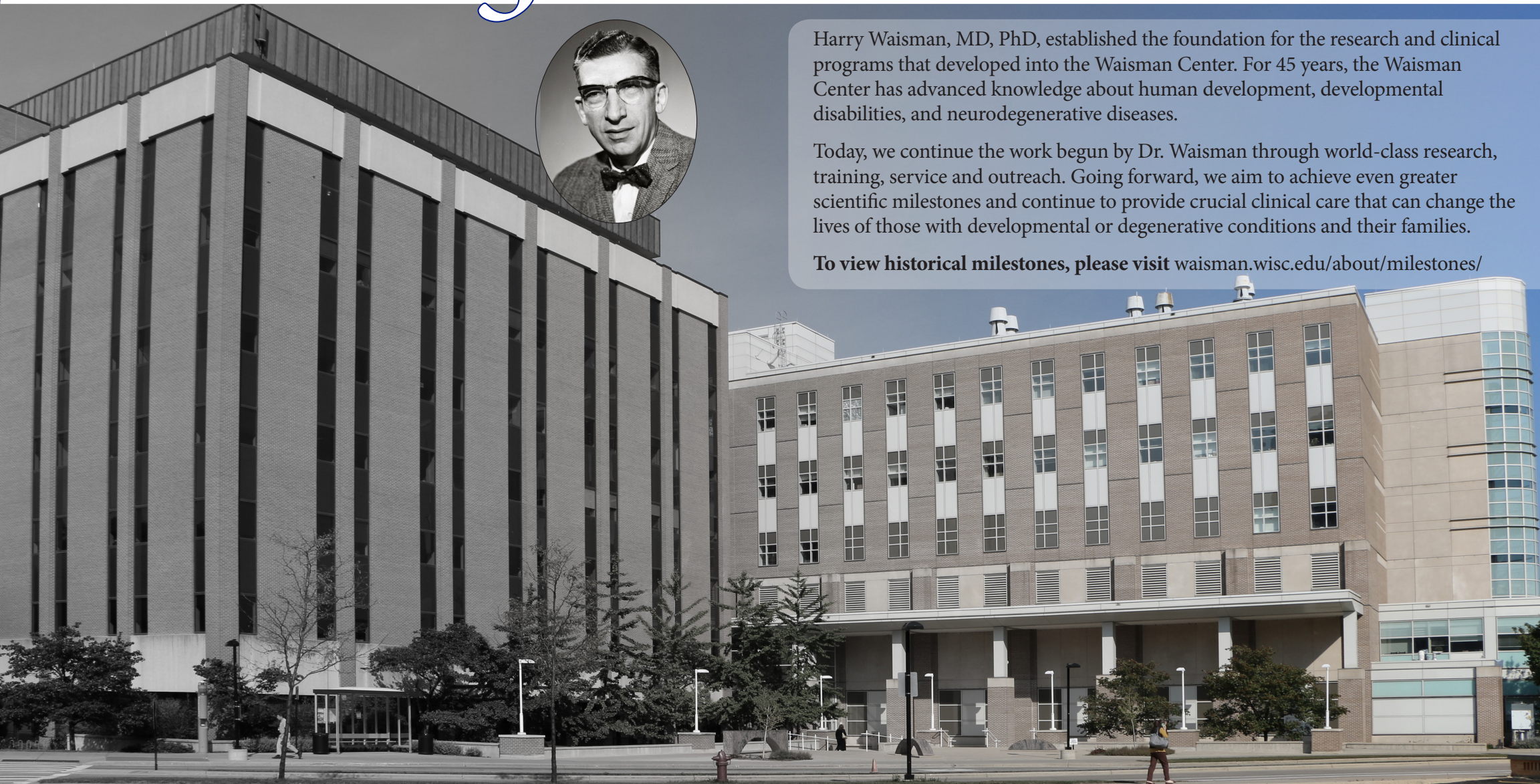
# Celebrating 45 years of discovery and innovation



Harry Waisman, MD, PhD, established the foundation for the research and clinical programs that developed into the Waisman Center. For 45 years, the Waisman Center has advanced knowledge about human development, developmental disabilities, and neurodegenerative diseases.

Today, we continue the work begun by Dr. Waisman through world-class research, training, service and outreach. Going forward, we aim to achieve even greater scientific milestones and continue to provide crucial clinical care that can change the lives of those with developmental or degenerative conditions and their families.

To view historical milestones, please visit [waisman.wisc.edu/about/milestones/](http://waisman.wisc.edu/about/milestones/)



## Message

### From the director



As the Waisman Center celebrates its 45<sup>th</sup> anniversary, we reflect upon what we have achieved and look forward to what is yet to come.

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 our shared vision of improving the lives of individuals and families impacted by intellectual and developmental disabilities and neurodegenerative conditions.

A handwritten signature in blue ink, appearing to read 'Qiang Chang', with a long, sweeping horizontal stroke extending to the right.

**Qiang Chang, PhD**  
Director, Waisman Center  
Professor, Medical Genetics  
& Neurology

## Our boards

### Waisman Board of Visitors & Friends of the Waisman Center

The Waisman Board of Visitors was established in 1996 to provide perspective and important linkages with the general public, business community, and public policy makers; to assist the Waisman Center in strengthening partnerships with the private sector; to provide an advocacy network; and to guide major fundraising efforts.

Phil Blake  
Jane Coleman  
Walter E. Dewey  
Sheri Edison  
Timothy Erdman  
W. Jerome Frautschi  
James F. Kress  
Jay Loewi  
Harold F. Mayer  
John McClure  
John Mielke  
Steven Mixtacki  
Carmen Skilton  
Jay Smith  
Thomas E. Terry  
Judith B. Ward  
Paul M. Weiss

Founded in 1975, the Friends of the Waisman Center is a nonprofit 501(c)(3) organization that supports the Waisman Center through fundraising, volunteer efforts, and community outreach. The Friends raise awareness and support for the center through three community fundraisers: a benefit concert, a golf outing, and the Waisman Whirl Run, Walk & Roll for All Abilities.

Linda Berman  
Robert Bishop  
Jody Bleck  
Joan Burns  
Betty Garvey  
Nancy Hansis  
Kendall Harrison  
Annette Hellmer  
Eric Horler  
Barbara Illman  
Sherri Kliczak  
Scott Kornstedt  
Eric Lund  
Christina Martin-Wright  
Dan McGown  
Carol Palmer  
Toni Richards  
Ellen Seufferer  
Carmen Skilton  
Guy Stratton  
Rich Vanden Boogard  
Lucy Williams

# It happened on Highland Avenue in 2017-2018...



## Waisman Center Children's Theatre

The Waisman Center Children's Theatre (WCCT) is a community outreach series hosted by the Friends of the Waisman Center and sponsored in 2017-2018 by the **American Girl Fund for Children**. The series enhances the arts for children of all abilities and their families. Shows are on the second Sunday of each month in the Friends of the Waisman Center Auditorium. The series features artists, musicians, educators, and all-children ensembles that are diverse and engaging. All shows are sign-language interpreted and wheelchair accessible. The WCCT partners with the **Autism Society of South Central Wisconsin** and **Badgers with a Heart**, a UW student group, to provide sensory-friendly performances each season.

- 10 performances
- 1,500 attended the series



For more information, please visit [waisman.wisc.edu/friends/about-childrens-theatre/](http://waisman.wisc.edu/friends/about-childrens-theatre/)



## Waisman Whirl Run, Walk & Roll for All Abilities

The fourth annual Waisman Whirl 10k/5k/1 mile run, walk, and roll took place on Sunday, October 14. 265 people participated along with 100 volunteers and 250 supporters.

For more information, please visit [waisman.wisc.edu/event/run-2018/](http://waisman.wisc.edu/event/run-2018/)



## Waisman Center Day with the Experts

The Waisman Center presents four *Day with the Experts* educational events focused on autism, cerebral palsy, cochlear implants and Down syndrome. The series features presentations by Waisman Center researchers and clinicians, as well as a panel discussion with individuals and family members who share their experiences and expertise. The Waisman Center collaborates with community and campus partners to host and promote these events including the **Autism Society of South Central Wisconsin**, the **Madison Area Down Syndrome Society**, and the **Department of Surgery, Division of Otolaryngology**.

For more information, please visit [waisman.wisc.edu/outreach/waisman-center-day-with-experts/](http://waisman.wisc.edu/outreach/waisman-center-day-with-experts/)



## Friends Golf Outing

72 golfers took to the links FORE a good cause on Monday, July 16 at Bishops Bay Country Club for the 26<sup>th</sup> annual golf benefit in support of the Waisman Center.

For more information, please visit [waisman.wisc.edu/outreach/annual-golf-benefit/](http://waisman.wisc.edu/outreach/annual-golf-benefit/)

## Friends Spring Benefit Concert

*Tangled Up in Blue*, UW-Madison's premier women's a capella group, headlined the Friends' 23<sup>rd</sup> annual benefit concert on Saturday, April 28. 56 platinum, gold, silver, and bronze hosts sponsored the event. The evening began with a reception, catered by Chez Vous, followed by the concert. At the concert, the Friends annually presents the *Judith B. Ward Award of Excellence*. The 2018 recipients were **Marsha Mailick & Albee Messing**, both former directors of the Waisman Center.

For more information, please visit [waisman.wisc.edu/event/concert-2018/](http://waisman.wisc.edu/event/concert-2018/)



## John D. Wiley Seminar Series

The series is an opportunity to advance knowledge, expertise, and collaborations for Waisman researchers, clinicians, and trainees. The seminars are held on Fridays during the academic year and feature scientists from throughout the United States who speak on a broad range of research related to developmental disabilities and neurodegenerative diseases. The 24 seminars were attended by more than 2,000 people.

For more information, please visit [waisman.wisc.edu/wiley-seminar-series/](http://waisman.wisc.edu/wiley-seminar-series/)



# Drawn to Art

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

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 held 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/](http://waisman.wisc.edu/friends/drawn-to-art/)

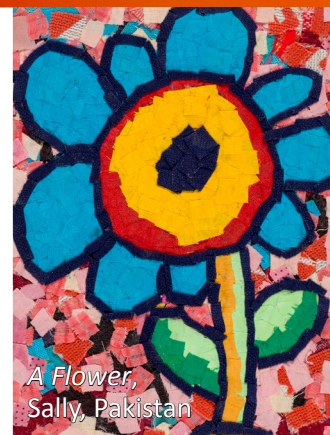
*"One of the most inspiring exhibits we have ever seen."*  
-Chazen visitor



Artist Phil Porter, from Madison, 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.



*A Flower*,  
Sally, Pakistan

*"Stirring to the soul, as all the best art is."*  
-Chazen visitor



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

*"It made me feel the support for individuals with disabilities (or 'diffability') that is all over the globe. It gives me hope."*  
-Chazen visitor




Tom di Maria, director of Creative Growth Art Center in San Francisco, was the guest speaker at the opening and presented, "From the Margins to the Mainstream: Artists with Disabilities in a Contemporary Context."



*"This collaboration with the Waisman Center was inspired. I was incredibly moved by the exhibit. Thank you for displaying such an important group of artists' work."*  
-Chazen visitor

## Study offers first look at how children with cerebral palsy develop language skills

"If we identify children with cerebral palsy (CP) as young as 24 to 30 months who are very likely to have significant problems later in life, we may be able to change or improve the course of their development through very early speech-language therapy" says **Katie Hustad, PhD**. The study is the first to show that very early language comprehension skills of children with CP can accurately predict their language comprehension outcomes later in life.

A portrait of Katie Hustad, PhD, a woman with long brown hair and bangs, smiling. She is wearing a red scarf and a green top. The background is a soft-focus image of yellow and green leaves.

**For more information, please visit**  
[waisman.wisc.edu/2018/06/04/study-offers-first-look-at-how-children-with-cerebral-palsy-develop-language-skills/](http://waisman.wisc.edu/2018/06/04/study-offers-first-look-at-how-children-with-cerebral-palsy-develop-language-skills/)

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**Unraveling the mysteries of a rare neurological disorder**

**Qiang Chang, PhD**, studies Rett syndrome, a rare, neurodevelopmental disorder that mostly affects girls and is caused by defects in the MECP2 gene. One of his recent studies is the first to uncover the molecular underpinnings of how the loss of MECP2 function can affect calcium dynamics in astrocytes, a specific kind of cell in the brain and spinal cord. “This study highlights a potential link between defects within astrocytes that have lost MECP2 function and more widespread problems in the brains of individuals with Rett syndrome.”



**For more information, please visit**  
[wisman.wisc.edu/2018/07/02/unraveling-the-mysteries-of-a-rare-neurological-disorder/](https://wisman.wisc.edu/2018/07/02/unraveling-the-mysteries-of-a-rare-neurological-disorder/)

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Dr. Yoon is a board member of the Korean Society of Environmental Health and a member of the Korean Society of Environmental Health and the Korean Society of Environmental Health.

## Researchers unveil new strategy to correct for motion during MRI scans

Individuals undergoing an MRI scan often need to stay still for up to 10 minutes at a time to maximize scan quality. This can be challenging for many people, including those with developmental disabilities. Waisman researchers developed a motion-correction strategy that can effectively correct artifacts in brain images caused by excess motion during MRI scans. The technique, called MPnRAGE, incorporates both low and high frequency information that compensates for movement made during MRI scans and maintains the usability of the resulting images. “This strategy will greatly enhance the ability to do neuroimaging studies in young children and individuals with intellectual and developmental disabilities,” says **Andrew Alexander, PhD**.



**For more information, please visit**  
[waisman.wisc.edu/2018/08/23/researchers-unveil-new-strategy-to-correct-for-motion-during-mri-scans/](https://waisman.wisc.edu/2018/08/23/researchers-unveil-new-strategy-to-correct-for-motion-during-mri-scans/)

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A headshot of Dr. David A. Clark, a middle-aged man with a grey beard and mustache, smiling. He is wearing a light blue button-down shirt under a tan blazer. The background is a plain, light grey.

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# Research highlights continued



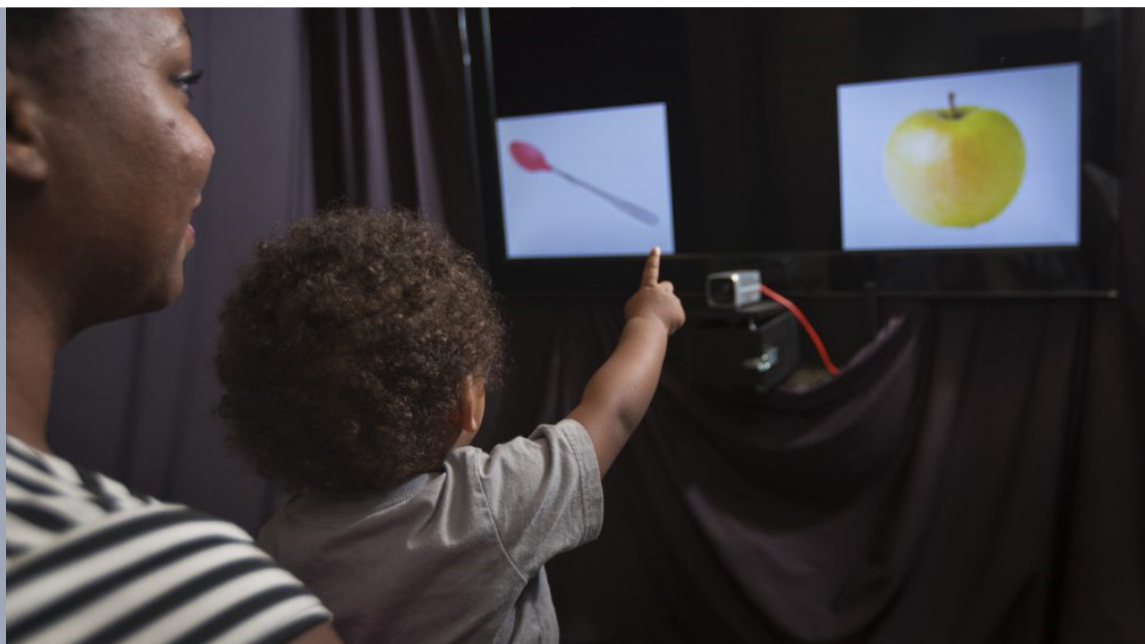
## How a cat can hinder children learning new words



While it may be universally accepted that familiar objects help children learn new words, a study by **Jenny Saffran, PhD**, and graduate student **Ron Pomper** indicated the

process may be more nuanced than originally thought. The study showed how familiar objects that are more interesting to children — brightly colored ones, or animals such as a cat, or food, for example — distracted them from focusing on novel objects and reduced their ability to learn new words associated with those objects. Saffran plans to expand upon this research in the future to better understand how the environment may influence children's ability to acquire new words and language.

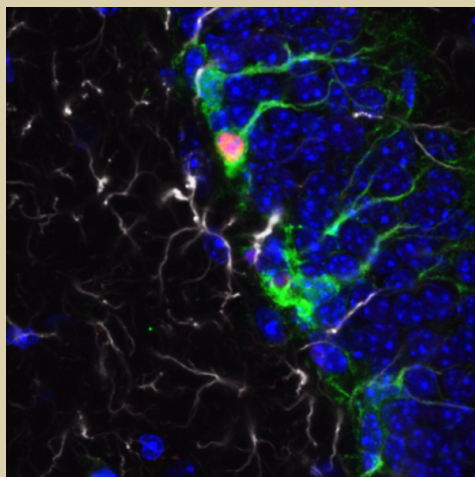
**For more information, please visit**  
[waisman.wisc.edu/2018/04/04/here-is-how-a-cat-can-hinder-children-learning-new-words/](http://waisman.wisc.edu/2018/04/04/here-is-how-a-cat-can-hinder-children-learning-new-words/)



## Study points researchers toward new therapies for fragile X syndrome

**Xinyu Zhao, PhD**, studies fragile X syndrome (FXS). A recent study showed that the absence of FMRP, a protein connected to FXS, can unbalance critical molecular processes within adult brain cells and lead to the neural and cognitive changes seen in FXS. The study indicates that FMRP is important for maintaining the population of neural cells that are essential for generating new neurons during adulthood. "Our study provides the mechanistic basis for potential new treatments that can be fast-tracked, especially for adults with fragile X."

**For more information, please visit**  
[waisman.wisc.edu/2018/06/28/study-points-researchers-toward-new-therapies-for-fragile-x-syndrome/](http://waisman.wisc.edu/2018/06/28/study-points-researchers-toward-new-therapies-for-fragile-x-syndrome/)



## Examining mid-life social outcomes for individuals with autism



"I would like to find out how we can help adults with autism who are not thriving, become successful and live the best life they want to live" says **Megan Farley, PhD**, a psychologist in the Waisman Center Clinics

and a researcher. Farley and colleagues examined social functioning, employment, independent living, and use of social services of adults with ASD with data from an epidemiological study begun in the 1980s. Given that three-quarters of the participants had co-occurring intellectual disability, the study provided an important contrast to studies of adults who have been more recently identified with ASD. Specifically, the participants in this study required high levels of support from caregivers and public assistance programs. The study demonstrates the importance of specific characteristics of ASD in adults and how they interplay with employment and other outcomes such as relationships, community participation, and residential situations.

**For more information, please visit**  
[waisman.wisc.edu/2018/02/02/examining-mid-life-social-outcomes-for-individuals-with-autism/](http://waisman.wisc.edu/2018/02/02/examining-mid-life-social-outcomes-for-individuals-with-autism/)

## On the horizon...

### Proposals by Waisman investigators selected for UW-Madison Cluster Hire Initiative



Several Waisman Center investigators played key roles in crafting proposals that were recently selected for the cluster hire initiative by the University of Wisconsin-Madison. The Cluster Hiring Initiative was launched in 1998 as an innovative partnership between the university, state and the Wisconsin Alumni Research Foundation (WARF). Waisman



investigators **Qiang Chang**, **Anita Bhattacharyya**, **Luigi Puglielli**, **John Svaren** and **Xinyu Zhao** are part of a team that proposed a Functional Genetics/Genomics of Neurodevelopmental and Neurodegenerative Diseases cluster hire. Waisman



investigator **James Li** is one of the researchers who proposed a cluster hire in Social Genomics.

"This is an exciting opportunity for the Waisman Center to establish a foothold in an up-and-coming research area," says Chang. "More importantly, the cluster will serve as a nucleus to integrate research, training, clinical service, and community outreach at the Waisman Center."

**For more information, please visit**  
[waisman.wisc.edu/2018/02/08/proposals-by-waisman-investigators-selected-for-uw-madison-cluster-hire-initiative/](http://waisman.wisc.edu/2018/02/08/proposals-by-waisman-investigators-selected-for-uw-madison-cluster-hire-initiative/)

# Developing therapies for a rare, fatal neurological disease:

## *The impact of philanthropy*

After more than a decade of work and nearly \$3 million of philanthropic support from patient advocacy groups and families, Waisman researchers reported promising results that could set the stage for developing a treatment for Alexander disease, a rare and usually fatal neurological disease with no known cure.



“This is the first reasonable chance to develop an effective treatment for Alexander disease,” says **Albee Messing, VMD, PhD**, professor of neuropathology, who pioneered the study of this disorder more than 20 years ago.

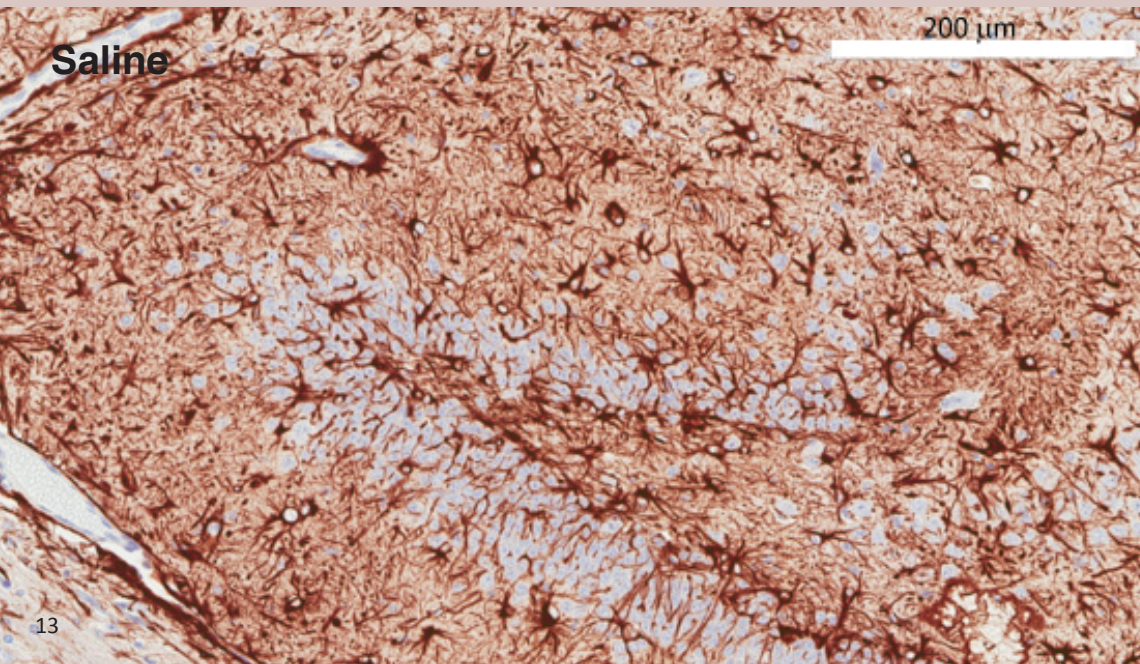
In the study, published online in the *Annals of Neurology*, researchers introduced short, chemically modified fragments of DNA—called antisense oligonucleotides—into cells in laboratory dishes or directly into the brains of mice with Alexander disease to lower levels of a protein called GFAP, which when mutated becomes toxic and leads to the disease.

The introduced antisense oligonucleotides—or ASOs, for short—were effective beyond expectations.

Levels of GFAP protein in the brains of mice with Alexander disease dropped within weeks to levels at or even below those in mice without the disease. As GFAP levels decreased, the mice also showed improvements in their symptoms.

“They started to put weight back on, and we found that there was less stress not only on their

*When treated with antisense oligonucleotides, levels of GFAP protein (brown) decrease dramatically in the brains of mice with Alexander disease. In the image below, the mouse was treated with saline; in the image on the right, the mouse was treated with antisense oligonucleotides. Image by Berit Powers, Ionis Pharmaceuticals*



astrocytes—the cell where GFAP accumulates in Alexander disease—but also on other cells in the nervous system,” says **Tracy Hagemann, PhD**, lead author of the study and a senior scientist at the Waisman Center.



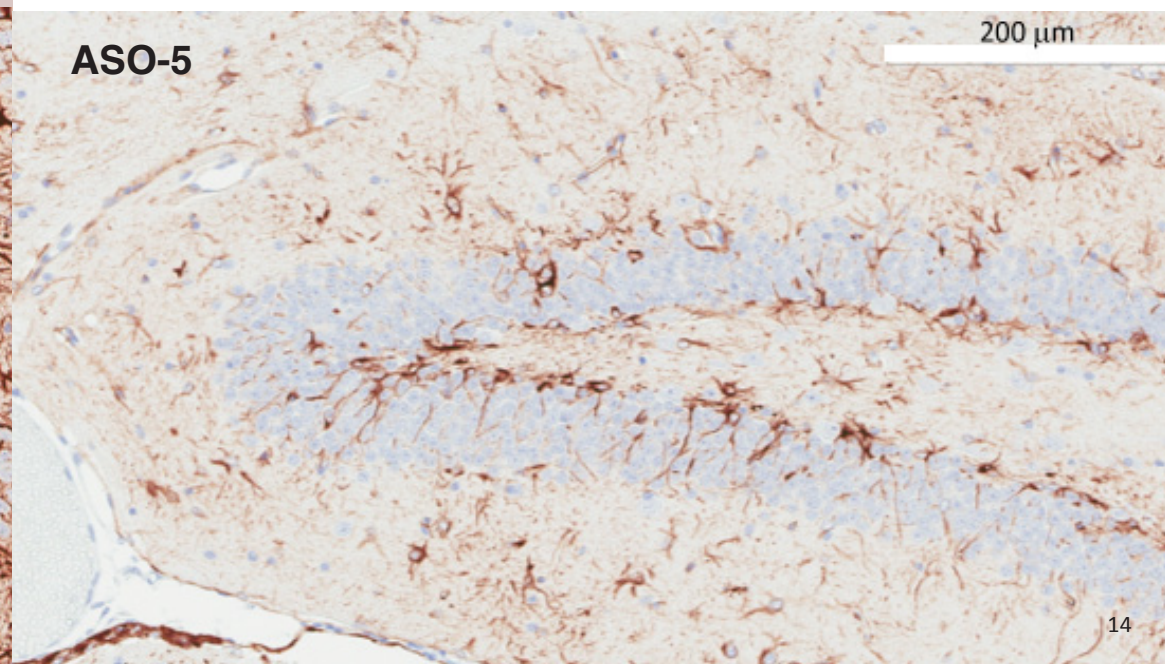
These findings have been a long time coming, according to Hagemann. “The Messing lab started exploring ways to lower GFAP protein levels in the early 2000s,” she says. “We had modest success with pharmaceuticals when tested on cells in a dish, but they didn’t work nearly as well in mice, or they caused unacceptable side effects.”

The researchers persevered, benefiting from substantial private fundraising efforts by patient advocacy groups and families. Then, in 2012, Messing learned of a study reporting that single injections of ASOs had long-lasting effects in mouse models of Huntington’s disease, another neurological disorder.

“That encouraged us to check if we could use a similar strategy to lower GFAP levels in mice with Alexander disease,” says Messing.

***“For the first time, we have a reasonable chance to develop an effective treatment for Alexander disease.”***

These ASOs are designed based on the DNA sequence of the GFAP gene. Once inside cells, the ASOs bind to RNA molecules that the cells use as blueprints to make GFAP protein. A specific cellular machinery detects these DNA-RNA hybrids and destroys them. Without the RNA blueprints, cells stop making GFAP protein.



# Stem cells @ Waisman

Twenty years ago a seminal discovery by researchers at UW-Madison introduced stem cells to the world. Since then, this new tool has transformed science and opened new avenues for translational research. Stem cells are undifferentiated “master cells” with the ability to differentiate into any of the body’s cell types. Waisman Center researchers have been at the forefront of stem cell research since its inception and have made pioneering advancements in utilizing these specialized cells to better understand brain development and in research focused on neurodegenerative diseases such as Parkinson’s, ALS, and Alzheimer’s as well as developmental disabilities such as autism, Down syndrome, and fragile X syndrome.

Listed below are milestones in stem cell research by Waisman Center investigators.

**2001:** The Waisman Center establishes a stem cell research program. The program is part of a \$25 million expansion – adding a north tower and an additional 71,000 square feet.

**2001:** Waisman Center investigator **Su-Chun Zhang, MD, PhD**, shows that human embryonic stem cells, coaxed into becoming early-stage brain cells, can be transplanted into rodent models and grow into neurons.



**2005:** Waisman Biomanufacturing, led by then-director **Derek Hei, PhD**, partners with the WiCell Research Institute and a team of UW investigators to establish the first National Stem Cell Bank.

**2005:** **Su-Chun Zhang, MD, PhD**, shows that human embryonic stem cells can be coaxed into becoming spinal motor neurons that relay messages from the brain to the body, and midbrain dopamine neurons that coordinate movement.

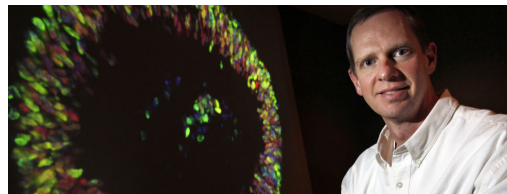
**2007:** Waisman Center investigator **David Gamm, MD, PhD**, shows that neural progenitor cells protect and sustain retinal cells in rodent models with degenerative eye diseases akin to those that afflict humans.

**2009:** **David Gamm, MD, PhD**, successfully grows multiple types of retina cells from two types of stem cells, opening the door to laboratory models for studying

genetically linked eye conditions, screening new drugs to treat those conditions, and understanding the development of the eye.

**2009:** The Waisman Center establishes an induced pluripotent stem cell (iPSC) core to streamline the production of iPSCs allowing investigators to focus their time and resources on the application and use of the cells in their research.

**2011:** **Xinyu Zhao, PhD**, discovers a connection between neurogenesis – the process of generating neurons – and learning deficits in animal models of fragile X syndrome. Her findings suggest that promoting neurogenesis using stem cells may have therapeutic potential for people with fragile X syndrome and other neurological disorders.



**2011:** **David Gamm, MD, PhD**, generates three-dimensional structures that are similar to those present at the earliest stages of retinal development, making them potentially valuable not only for studying how the human retina develops, but also how to keep it working in the face of disease.

**2011:** **Su-Chun Zhang, MD, PhD**, discovers that neurons, forged in a lab from human embryonic stem cells and implanted into the brains of mice, can successfully fuse with the brains' wiring and both send and receive signals.

**2011:** A group of scientists led by **Su-Chun Zhang, MD, PhD**, directs embryonic and human induced stem cells to become astrocytes in a lab dish, giving researchers a powerful new tool to devise new therapies and drugs for neurological disorders.

**2012:** **David Gamm, MD, PhD**, and several Waisman Center scientists create a laboratory model for macular degeneration using induced pluripotent stem cells.

**2013:** **Su-Chun Zhang, MD, PhD**, transforms stem cells into nerve cells that helped animal models regain the ability to learn and remember. This novel study is the first to show that human stem cells can successfully implant themselves in the brain and then ameliorate neurological deficits.

**2013:** Using cells derived from skin samples of individuals with Down syndrome (DS), **Anita Bhattacharyya, PhD**, cultivates a line of DS brain cells. These cells provide insight about early brain development in individuals with DS and will potentially be used to test or design drugs to target symptoms of DS.



**2014:** **Su-Chun Zhang, MD, PhD**, pinpoints an error in protein formation that could be the root of amyotrophic lateral sclerosis (ALS).

**2015:** **Su-Chun Zhang, MD, PhD**, develops a new technique to “edit” or silence genes in human stem cells at any stage of development. This discovery has the potential to revolutionize biomedical research and provide unprecedented understanding of how stem cells function.

**2016:** **Su-Chun Zhang, MD, PhD**, using a new gene editing technique, inserts a genetic switch that alters the production of dopamine in nerve cells through specialized drug therapy.

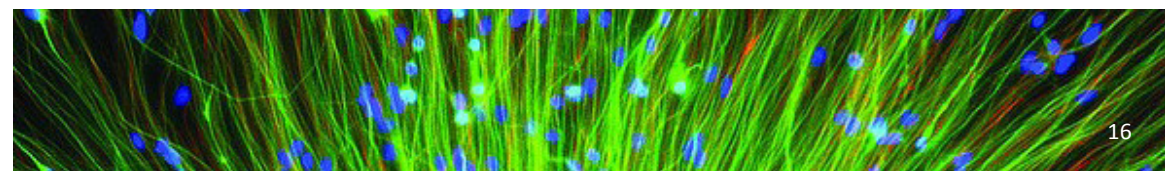
**2016:** **Anita Bhattacharyya, PhD**, and **Xinyu Zhao, PhD**, use CRISPR-Cas9 to position a reporter cell line in the genomes of stem cells derived from individuals with FXS that gives off a luminescence signal if the FMRI gene is turned off.

**2017:** **Xinyu Zhao, PhD**, conducts one of the first studies to show that the MBD1 gene plays a pivotal role in maintaining the 'stemness' of neural cells.

**2018:** **Qiang Chang, PhD**, uncovers how the loss of MECP2 function can affect calcium dynamics in astrocytes and the potential link between defects within astrocytes that have lost MECP2 function with more widespread problems in the brains of individuals with Rett syndrome.



**2018:** **Su-Chun Zhang, MD, PhD**, and **Albee Messing, VMD, PhD**, show that GFAP buildup in astrocytes, using iPSCs donated by two Alexander disease patients, disrupts organelles and cellular communication via calcium waves, expanding our understanding of the fundamental biology of the commonly studied cells.



# Autism prevalence and socioeconomic status: What's the connection?

Children living in neighborhoods where incomes are low and fewer adults have bachelor's degrees are less likely to be diagnosed with autism spectrum disorder compared to kids from more affluent neighborhoods.



This finding is part of a multi-institution study of autism spectrum disorder (ASD), led by **Maureen Durkin, PhD, DrPH**, at the Waisman Center. Durkin and her team found that during the eight years of the study, the overall prevalence of ASD in children more than doubled, increasing from 6.6 to 14.7 cases per thousand children.

“We wanted to see if part of this increase in ASD prevalence was because advances in screening techniques and medical training meant that more children from disadvantaged backgrounds were gaining access to ASD diagnoses and services,” says Durkin, a professor of population health sciences and pediatrics. “It doesn’t seem that’s the case.”

Durkin’s team analyzed education and health care data for 1.3 million 8-year-old children from a Centers for Disease Control and Prevention population-based surveillance program, with sites in 11 states across the U.S.: Alabama, Arizona, Arkansas, Colorado, Georgia, Maryland, Missouri, New Jersey, North Carolina, Utah and Wisconsin (see map). The study merged this autism surveillance data with U.S. Census measures of socioeconomic status, such as number of adults who have bachelor’s degrees, poverty and median household incomes in the census tracts studied. The researchers found that regardless of which indicator of socioeconomic status the researchers used, children living in census tracts with lower socioeconomic development were less likely to be diagnosed with ASD than children living in areas with higher socioeconomic indicators.

The study does not prove that children from lower socioeconomic backgrounds are not getting the diagnoses and support they need, Durkin says, but it does indicate that’s the most likely scenario.

In support of this hypothesis, the study found that children who had intellectual disabilities were equally likely to be diagnosed with ASD irrespective of their socioeconomic backgrounds.

That could occur because “children with intellectual disabilities usually have developmental delays that get noticed earlier in life,” says Durkin. “They may get referred for comprehensive medical follow-ups, which could lead to a diagnosis of their ASD as well.”

In addition, studies in Sweden and France — which have universal health care and fewer barriers for citizens to access medical care — found no association between socioeconomic status and rates of autism diagnoses.

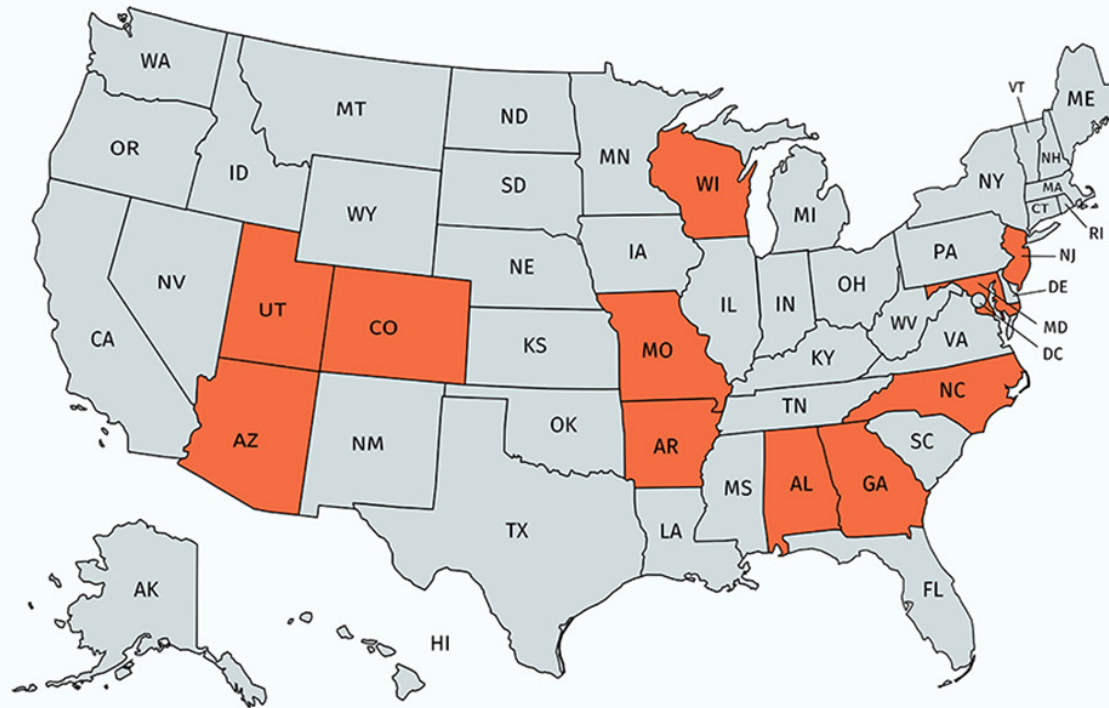
These findings collectively support the idea that children living in poorer or less well-educated areas in the U.S. are being diagnosed with ASD at lower rates because they have less access to health care providers who could make the diagnosis and provide needed support.

Future research will focus on assessing if more universal screening can lower the socioeconomic gap in ASD prevalence.

That’s important to know, Durkin says, because “if we are under-identifying ASD in certain socioeconomic groups — as seems likely — we need to be prepared to provide services at a higher level to more people. We need to find cost-effective interventions and supports and make sure they are distributed equitably and in a way that reaches everybody who needs them.”

Durkin is now working with researchers and clinicians at the Waisman Center to improve access to ASD screening, diagnosis, and care for underserved communities through a federally-funded program called the Wisconsin Care Integration Initiative.

“This program is focused on ‘moving the needle’ to improve access to a coordinated, comprehensive state system of services that leads to early diagnosis and entry into services for children with ASD, particularly for medically underserved populations,” says Durkin.



***This study was selected as one of the top advances in 2017 ASD research by the federal Interagency Autism Coordinating Committee.***

# Waisman Center Clinics

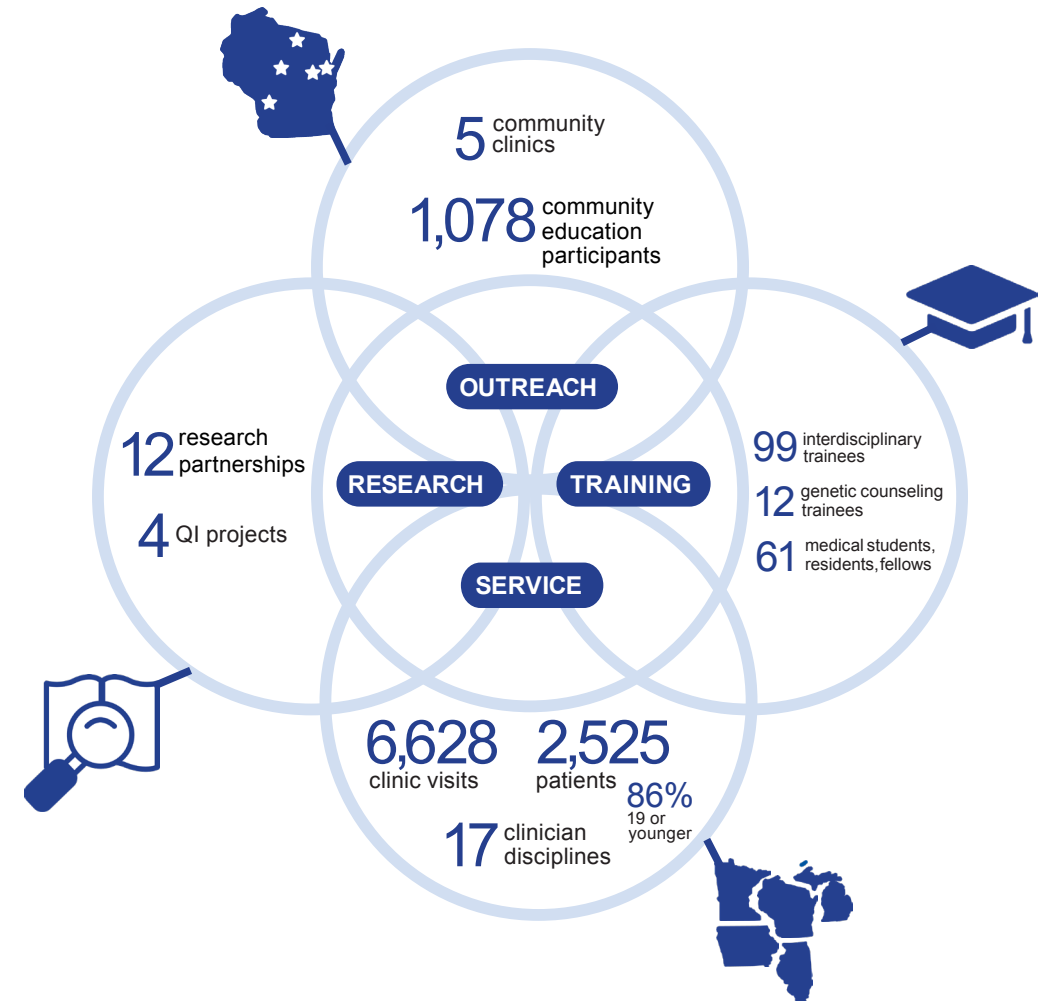
## By the Numbers – FY 2018



The Waisman Center Clinics, in partnership with UW Health, Maternal Child Health Title V and other key partners, provide comprehensive clinical care and support for children, youth and adults with disabilities and/or genetic conditions and their families through 10 specialty clinics.

Professionals from many disciplines work together, combining knowledge in the following areas: audiology, genetics, genetic counseling, nursing, nutrition, occupational therapy, orthopedics, pediatrics, pediatric neurology, pediatric rehabilitation, physical therapy, psychology, social work, and speech and language therapy.

Throughout the service delivery process, professionals work with families and community personnel to identify the needs of each client and family. These considerations include the involvement of school psychologists, teachers, social service agency personnel, residential and vocational providers, therapists, and physicians.



### The Waisman Center Clinics include:

- Autism and Developmental Disabilities
- Biochemical Genetics
- Bone Dysplasia
- Cerebral Palsy
- Communication Aids & Systems Clinic (CASC)
- Down Syndrome
- Medical Genetics
- Neuromotor Development
- Newborn Follow-Up
- Pediatric Brain Care

[waisman.wisc.edu/clinics/](http://waisman.wisc.edu/clinics/)

# Down syndrome clinic helps Jackie keep on



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 joy. “I think she was just born with the beat and a need to move!” says Danielle Cleveland, Jackie’s mother.

In fact, the first time Jackie came to the Down Syndrome Clinic at the Waisman Center, she showed off new-found cartwheeling skills. “Everyone was very excited,” says Danielle.



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, MD**, clinic director and a developmental behavioral pediatrician.

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 goes through puberty and enters her teenage years.

Others come to the clinic needing help with different challenges, such as feeding or sleep issues. “Some health problems co-occur more often with Down syndrome, and we want to make sure we are addressing those challenges because we know they can have a significant impact on quality of life,” says Stanley.

***While Jackie has been dancing for years, she started visiting the Down Syndrome Clinic relatively recently, and her path to the clinic was anything but straightforward.***

The clinic—a partnership with UW Health and American Family Children’s Hospital—doesn’t focus solely on challenges, though. “We really strive to understand the strengths of the individuals and families coming to the clinic,” says Stanley. “Then we work together to promote healthy development and maximum independence.”

Listening to individuals with Down syndrome and their families is key, says **Amy Lyle, MSSW**, clinic coordinator and a social worker. “We not only talk about physical or emotional health but also about life, school, employment, friendships, and other aspects of life.”



For instance, 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 has meant dancing at pow wows all over the U.S., from Wyoming to Florida. “Jackie loves it,” says Danielle. “Other girls her age can be shy sometimes, but Jackie goes right up to the microphone and introduces herself. She even blows kisses!”

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 slowly changing, and we have met several children with Down syndrome. I feel proud that we are making a difference.”

While Jackie has been dancing for years, she started visiting the Down Syndrome Clinic relatively recently, and her path to the clinic was anything but straightforward.

When Jackie was 9 years old, she was in an automobile accident and sustained a serious head injury that 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.

Clinic visits have helped Jackie and the rest of her family, says her father, 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!



# Waisman Early Childhood Program

The Waisman Early Childhood Program (WECF) provides exceptional inclusive education to preschool students of all abilities. One-third of the enrollment is reserved for children with special needs, such as autism, cerebral palsy, and Down syndrome.

The WECF optimizes each child's unique abilities through a supportive and enriching environment that fosters development and learning. All children play, learn and work together. Teachers are highly-skilled professionals in areas related to early childhood development. Many of the teachers have been with the program for more than 10 years.

A unique component of the WECF is that students can access in-house therapeutic services as part of the preschool program. An occupational therapist and a speech-language pathologist work with children who need these services and supports.

**For more information visit, [waisman.wisc.edu/wecp/](http://waisman.wisc.edu/wecp/)**

The WECF is a model inclusive early childhood program that serves **82** children of all abilities with a staff of **16** full-time teachers, **2** therapists, and **2** administrative staff who have more than **265** combined years of experience. In 2017-2018 the WECF planted **5** vegetable gardens, **3** flower beds, participated in more than **12** campus and community field trips, and completed a renovation of the Discovery Garden—a **1.5** acre outdoor learning and play space. **7** families received scholarships for tuition and therapy services and more than **30** undergraduate students from a broad range of child-related disciplines received training.



# Waisman Biomanufacturing



Waisman Biomanufacturing (WB) is a key component of the UW and Waisman Center's efforts in translational

***"We're in a good position to help the field succeed faster, and we are ready to help with new ideas and projects from across campus and from the growing Wisconsin biomedical industry."***

—Carl Ross, WB Managing Director

research — the translation of basic research discoveries to clinical applications. WB encompasses a state-of-the-art cleanroom facility that provides manufacturing and testing services to academic researchers and industry partners for a broad range of pharmaceuticals. The only cGMP (current Good Manufacturing Practice) facility of its kind on campus, WB has manufactured more than 350 clinical-grade products since opening in 2001. "Usually the researchers who are doing basic science have made the molecule in the lab on a small scale, but they don't have the expertise, equipment and time to make it on the larger scale needed to treat patients in a clinical trial, and to make it in a way that the FDA considers suitable," says Carl Ross, managing director of Waisman Biomanufacturing. "WB provides the next step in this process."

In 2018, WB expanded its services to include Adeno-associated virus (AAV) manufacturing. AAV may be an integral tool in developing treatments and therapies for mono-genetic diseases of the eye and nervous system. AAV is used to insert replacement genes and its role in gene therapy trials is expanding quickly.

**For more information visit, [gmpbio.org](http://gmpbio.org)**

**On the horizon:** WB is partnering with several campus researchers on one of the largest current stem cell research projects at UW-Madison. The project is focused on using stem cells to treat cardiovascular disease through the establishment of an artery bank that would provide surgeons with material to replace diseased veins. WB will manufacture the arterial cells that meet FDA requirements for eventual clinical trials.

**In the last year...**

- **6,700** vials filled
- **9,670** liters of sterile water used
- **6,750** pairs of shoe covers used

# University Center for Excellence in Developmental Disabilities

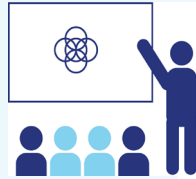
## By the Numbers – FY 2018

The University Center for Excellence in Developmental Disabilities (UCEDD) supports the inclusion and self-determination of people with developmental disabilities and their families by educating health care professionals, providing services, technical assistance and knowledge-based information, and contributing to cutting-edge research in the field of developmental disabilities.



Provided health, education, employment, housing and recreation services to **5,792** people

Hosted **186** continuing education & community trainings with **7,611** participants

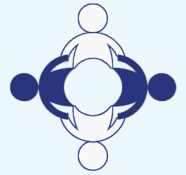


Trained **53** long-term LEND students from **12** academic departments

Assisted **56** agencies and organizations that serve individuals with disabilities with **1,015** hours of technical assistance to improve outcomes, services, management or policies



UCEDD staff served on **52** local boards, councils and committees



Leveraged more than **\$9 million** with core funding from the Administration on Intellectual and Developmental Disabilities



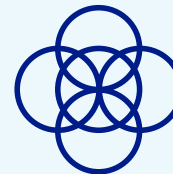
That's a return of more than **\$18** per dollar of funding



**36** presentations at state and national conferences



Worked on **21** projects with the Board for People with Developmental Disabilities & Disability Rights Wisconsin



To learn more about the Waisman Center UCEDD, please visit: [ucedd.waisman.wisc.edu](http://ucedd.waisman.wisc.edu)

# New estate gift to support research and training at the Waisman Center

A new estate gift will help support research and expand undergraduate and graduate student training in the area of developmental disabilities at the Waisman Center. This significant gift comes via the Lyda Family Fund, a permanent endowment of more than \$1,000,000 established for the Waisman Center from the estate of Genevieve Lyda.

"We are truly grateful for Genevieve's generosity and thoughtfulness. This estate

gift will enhance our ability to continue vital, innovative research and training programs" said Qiang Chang, PhD, director of the Waisman Center.

Genevieve passed away in May 2007, and her estate helped support her daughter Jane, who had cerebral palsy. Jane passed away earlier this year. "This gift shows how it is possible to ensure loved ones are cared for throughout their life and still leave a lasting and impactful legacy with the remainder of the estate," says Lisa Karnes, development manager at the Waisman Center.

Genevieve's gift was motivated in part by Jane's visits to the Waisman Center Communication Aids and Systems Clinic (CASC). Jane worked closely with Julie Gamradt, a speech-language pathologist, and current director of CASC to develop her communication skills. Gamradt spent extensive time with Jane in and out of the clinic, says Jami Brown, a friend of Genevieve's and Jane's.

Brown met Genevieve and Jane in 1995 and became Jane's legal guardian after Genevieve passed away. Some of Brown's favorite memories of Genevieve and Jane include "spending Saturdays with the two of them in their home and helping them set up their Christmas tree, purchasing and wrapping gifts and listening to Bing Crosby," she says.

According to Brown, "Genevieve also thought highly of and wanted to support the work and research that's done at the Waisman Center every day." Research at the Waisman Center includes developing new and innovative ways to communicate for those who may be unable to do so in traditional ways.

"I think Genevieve would be happy to know that the gift may be used for research that helps people communicate to their best potential," says Brown.



Jane and Genevieve Lyda in 2004

## There are many ways to give...

Gifts provide integral support for groundbreaking research, comprehensive clinical services, and outreach programs that enhance the lives of individuals and families affected by developmental disabilities and neurodegenerative diseases. A planned gift is one of the many ways to support the Waisman Center that include:

- Sign-up to make automatic monthly donations
- Give in memory or tribute of a loved one
- Make a gift of appreciated securities, including stocks and bonds
- Include the Waisman Center in your will or estate plan
- Make a gift of your retirement assets or life insurance policy
- Contribute through a donor advised fund, community foundation, or grant
- Underwrite a scientific talk
- Sponsor a Waisman event
- Support a postdoctoral student
- Participate in a Friends of the Waisman Center fundraising event

For more information on giving or to give online, please visit:  
[waisman.wisc.edu/giving/](http://waisman.wisc.edu/giving/)

or contact

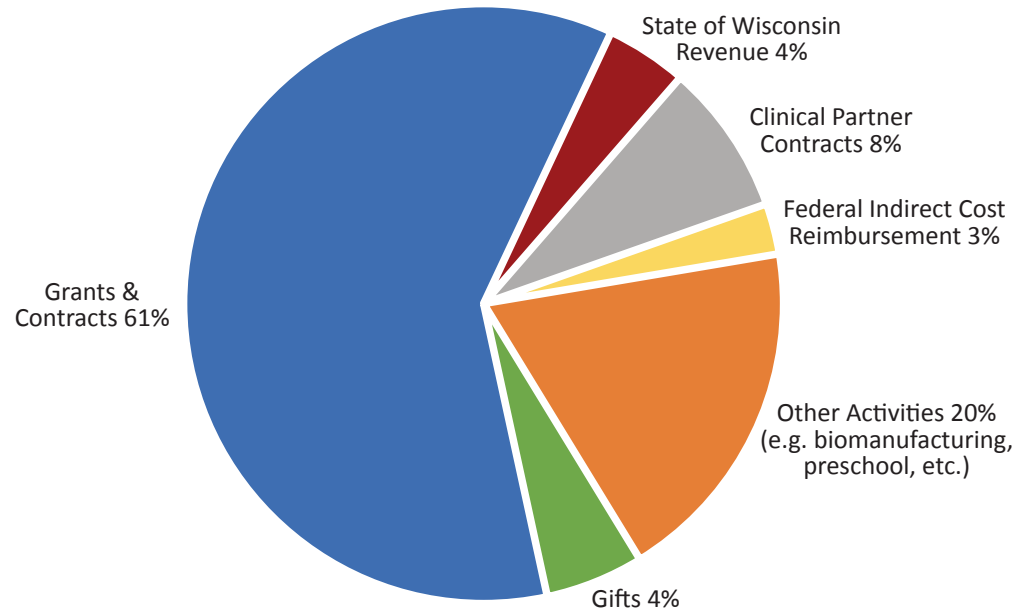
**Lisa Karnes**  
Development & Donor Relations Manager  
lkarnes@wisc.edu  
608.262.6503



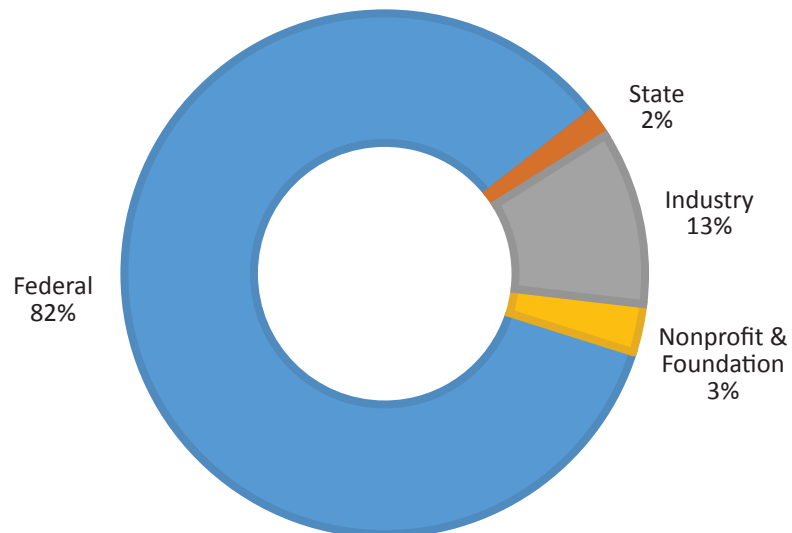
Jane at her 70<sup>th</sup> birthday in 2016

# Funding Sources

## Waisman Center FY 2018



## Breakdown of Grant/Contract Funding by Sponsor Type



Thank you to those who gave to the **Waisman Center** through the **Friends of the Waisman Center** for the period of **September 1, 2017 - August 30, 2018** and the **University of Wisconsin Foundation** for the period of **July 1, 2017 - June 30, 2018**.

### \$100,000 +

Bleser Family Foundation  
W. Jerome Frautschi  
Genevieve Lyda Estate  
Mancheski Foundation Inc

Thomas & Martha Beach  
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Carson Family Foundation  
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Twelve Twenty-One Fund  
Judith & David Ward  
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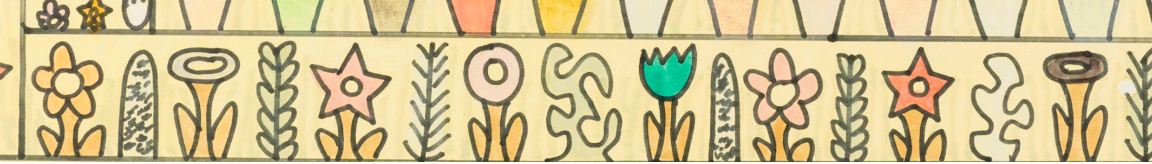
The Kids Fund, Inc.  
The Lenore & Howard Klein Foundation Inc  
John Larson & Sherri Kliczak  
Jay & Janet Loewi  
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Madison Community Foundation  
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Kristin Haslow Weiss  
Working Partnerships LLC

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Achieving Collaborative Treatment  
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Bank First National

### \$2,000 - \$9,999

Advanced Bionics LLC  
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\$500 - \$1,999 continued

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Mark Petersen  
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Linda Petersen

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 Petznick Rentals  
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 Robert Agasie  
 Ale Asylum  
 Carly Amurao  
 Glen & Jeanne Anderson

Marilyn & Richard Anderson  
 Irmgard Andrew  
 Angelo's  
 Tammi & Roger Angle  
 Anonymous  
 Justin Aronoff &  
 Christy Harms-Aronoff  
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 Jean & Jerry Balestrieri  
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 Elements Massage  
 Susan Ellmaurer  
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 Quench Gum  
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The Waisman Center is dedicated to the advancement of knowledge about human development, developmental disabilities, and neurodegenerative diseases. One of only 14 centers of its kind in the United States, the Waisman Center encompasses laboratories for biomedical, behavioral, and clinical translational research, a brain imaging center, and a biomanufacturing facility for the production of pharmaceuticals for early stage human clinical trials. In addition to its research efforts, the Waisman Center provides an array of services to people with developmental disabilities, offers numerous clinical, educational, and outreach programs to children and their families, and trains scientists and clinicians who will serve our nation in the future. The Waisman Center is supported by core grants from the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (U54 HD090256), the Administration for Community Living (90DD0804), and the Maternal and Child Health Bureau's Leadership Education in Neurodevelopmental Disabilities (T73MC00044) Program.

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