



Waisman Center
University of Wisconsin-Madison

Friends Annual Meeting

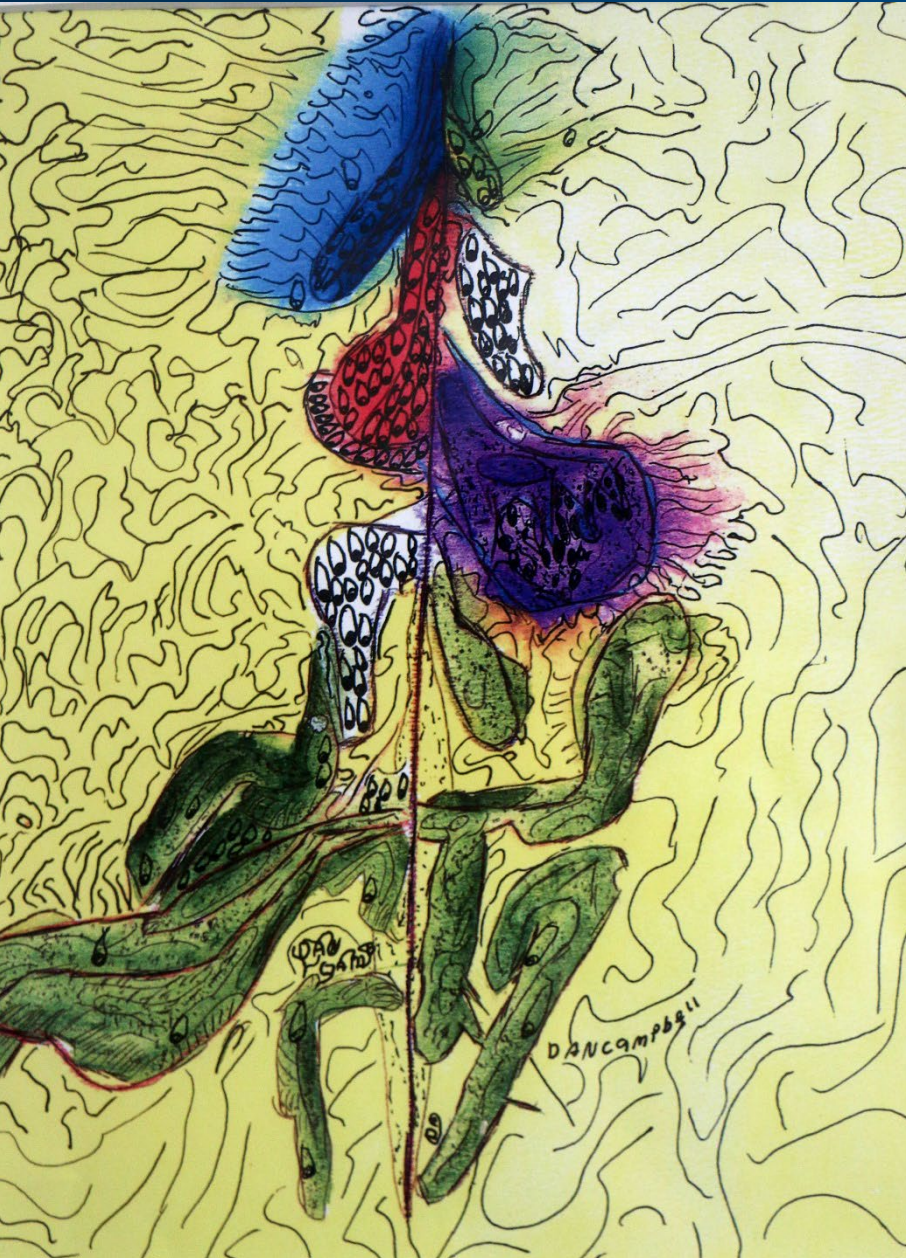
August 18, 2020

*Advancing knowledge of human development, developmental disabilities,
and neurodegenerative diseases throughout the lifespan.*

Milestones of Support Since 1976

More than \$1 million for Waisman Center programs and activities including:

- Establishing the Waisman Early Childhood Program Scholarship
- Contributing \$45,000 to the WECP Scholarship Endowment Fund
- More than \$200,000 for the Discovery Garden
- Initiating and overseeing the Harvey A. Stevens International Collection of Art by People with Developmental Disabilities
- More than \$210,000 for the Waisman Center Clinics
- \$50,000 to revitalize the Friends Auditorium
- More than \$100,000 for travel awards, scholarships, and mini-grants to faculty, staff and students

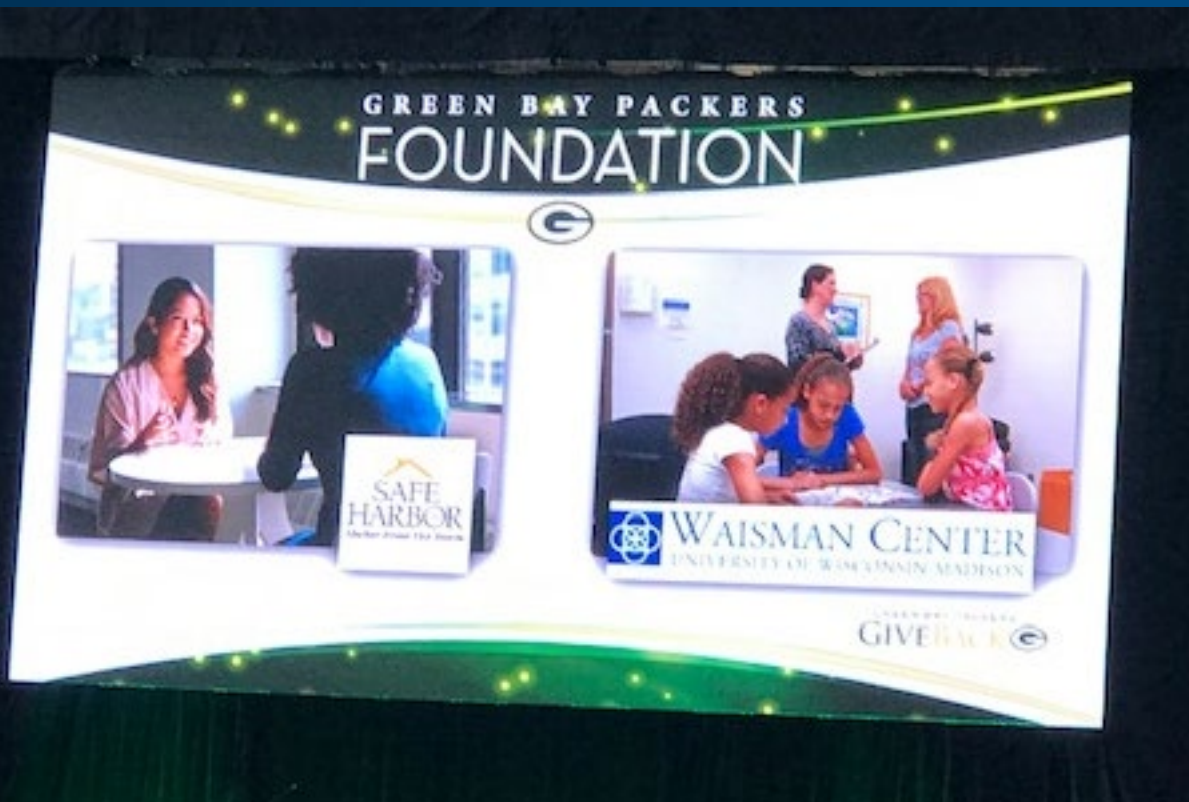


Foxglove, Dan Campbell, United States

2019-2020 Friends Support for the Waisman Center

More than \$50,000 in support for the Waisman Center in 2019-2020!

- \$20,000 gift to the Waisman Center toward renovations in the Waisman Center Clinics
- Support for the John D. Wiley Seminar series
- “Mini grants” to faculty, staff, and students
- Free printing of posters for academic conferences



Grant to the Friends from the Green Bay Packers Foundation in support of the Waisman Safe While You Wait Program



2019-2020 Friends Support for the Waisman Center



Waisman Center Day with the Experts: Cerebral Palsy

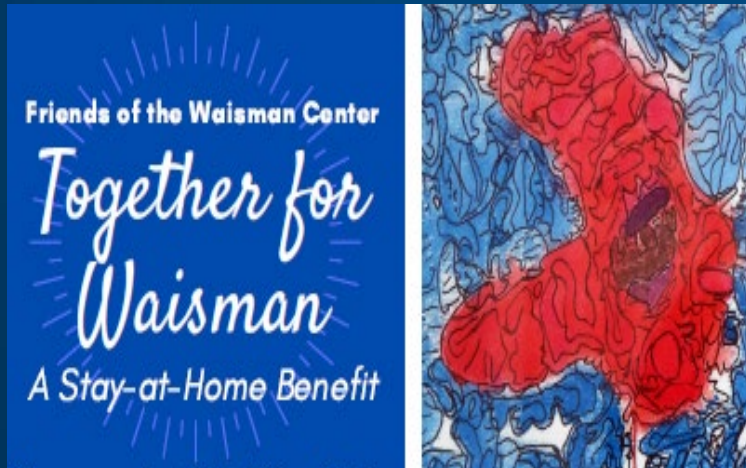
Sponsorship of:

- Sponsorship of four *Waisman Center Day with the Experts* events (autism, Down syndrome, cerebral palsy, and cochlear implants)
- Waisman Center Children's Theatre series
- Annual poster fair & quarterly Waisman newsletter
- Harvey A. Stevens International Collection of Art by People with Developmental Disabilities
- *Student, staff, and family awards—today!*

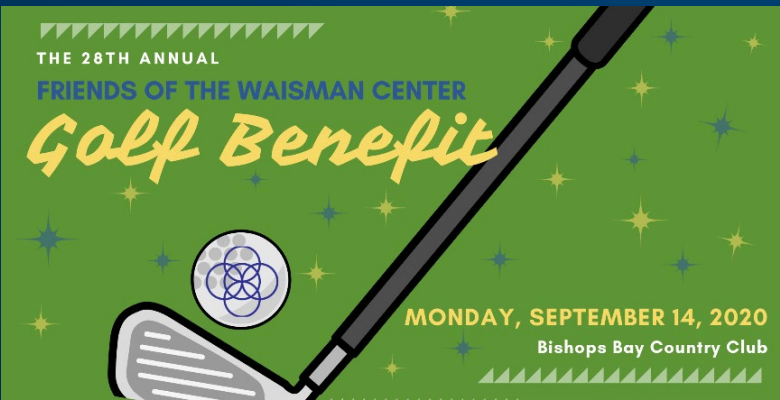
How do the Friends raise funds?



- **Fifth Annual Waisman Whirl**
Sunday, October 06, 2019
Register now for the virtual 2020 event the month of October



- **25th Annual Spring Benefit**
Saturday, May 30, 2020
Together for Waisman: A Stay-at-Home Benefit



- **28th Annual Golf Benefit**
Monday, September 14, 2020
Bishops Bay Country Club

Together for Waisman: A Stay-at-home Benefit

Raised \$25,000!

- gourmet meals prepared by Chez Vous
- wine donated by General Beverage
- meals delivered by EatStreet & board members
- goodies & bags by Orange Tree Imports
- Special thanks to the Irving & Dorothy Levy Foundation for the matching gift





Waisman "Walktober" Whirl

Virtual Run, Walk, & Roll for All Abilities

YOUR RACE. YOUR PLACE. YOUR PACE.

- Run, Walk or Roll for Waisman the entire month of October
- keep track of distance and consider collecting pledges
- create a team
- all participants receive t-shirt, personalized bib, & finisher certificate
- Register Now!



Friends Board of Directors

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- **Rich Vanden Boogard, Jacobson & Schmitt**

Waisman Center Year in Review

- **Noteworthy Events & Accomplishments**
- **On the Horizon**
- **Student, Staff, and Family Awards-Today!**

Launch of ECHO AAC and Autism ECHO WI



- Two new initiatives to help improve and expand teletraining services using the Project ECHO® (Extension for Community Healthcare Outcomes) program
- Serve as a diagnostic and treatment training hub to share the center's expertise on intellectual and developmental disabilities, such as autism and AAC, throughout the state and beyond.
- As ECHO AAC and ECHO Autism WI take root at Waisman, they pave the way for future ECHO programs in other Waisman clinics as well as a way to branch out and make new research and information more public-facing

Launch of Waisman BioLibrary



- Waisman BioLibrary established to learn more about the genetics and health of individuals with intellectual and developmental disabilities, such as Down syndrome.
- Recruiting 100 youth with Down syndrome from 0-17 years old.

Waisman Biomanufacturing Produces COVID Vaccine for Clinical Trials



- Partnership with Heat Biologics to manufacture COVID-19 vaccine for phase I and phase II clinical trials
- Vaccine will target those most vulnerable to COVID-19 such as the elderly and those with health conditions that weaken the immune system
- The vaccine uses a genetically engineered combination of a common protein already found in human cells (gp96) along with viral proteins to stimulate a response from the body's T-cells
- Two additional COVID-related therapeutic projects underway with other companies

On the Horizon

- Wiley Seminar Series begins – September 4, **virtual series**
- Friends golf benefit at Bishops Bay – September 14
- **Waisman Whirl Virtual Run, Walk and Roll for All Abilities during October**
- Day with the Experts: AAC– October 24, 2020 **(new!)**
- Day with the Experts: Fragile X Syndrome – November 2020 **(new!)**
- Day with the Experts: Autism – January 23, 2021
- Day with the Experts: Down Syndrome – March 14, 2021
- Day with the Experts: Cochlear Implants – May 2021

2020 Fellowships

2020 Fellowships

Wisconsin Distinguished Graduate Student Fellowships:

– **Sarah Furnier**, nominated by Maureen Durkin, PhD, DrPH



Sarah is a fourth year PhD student in the epidemiology graduate program. She was nominated for this award by Maureen Durkin for her work the last three years focused on population-based studies of autism spectrum disorder as well as newborn screening as a public health strategy for prevention of developmental disabilities. As Maureen states in her nomination:

“Sarah’s research is very much aligned with the mission and priorities of the Waisman Center. Her interest in and dedication to the study of developmental disabilities is long-standing. She is an outstanding student of epidemiology and could have gone almost anywhere but was drawn to our epidemiology program at UW-Madison because of the opportunity to work at the Waisman Center. Her dissertation work involves evaluating the validation and prevalence results for congenital hypothyroidism detected on newborn screening among preterm infants using data on more than 300,000 Wisconsin births. Another research area focuses on adaptive functioning in children with autism using data from the Autism and Developmental Disabilities Monitoring (ADDM) Network and the Study to Explore Early Development (SEED) program. Her long-term goal is to pursue an academic career in the epidemiology and prevention of developmental disabilities. Her accomplishments as a PhD student have been outstanding and have helped prepare her for a productive and successful research career.”



Maureen Durkin, PhD, DrPH

2020 Fellowships

Wisconsin Distinguished Graduate Student Fellowships:

– **Brianna Piro-Gambetti**, nominated by Sigan Hartley, PhD



Brianna was nominated by Sigan Hartley. She is in the School of Human Ecology PhD program in Human Development and Family Studies where she is developing expertise on promoting healthy aging in adults with Down syndrome. She was nominated by Sigan for her work on a multi-site longitudinal study funded by NIH called the Alzheimer's Biomarker Consortium – Down syndrome (ABC-DS). The objective of this study is to examine early unfolding of Alzheimer's disease in Down syndrome using cerebrospinal fluid plasma biomarkers and determine their relation to current decline and the development of Alzheimer's disease dementia. Sigan states in her nomination:

“Brianna is an exceptional critical thinker and doing work that is innovative and making an important contribution to the field. Her research is focused on understanding how lifestyle factors alter aging and Alzheimer's disease in Down syndrome. There is emerging evidence that lifestyle factors have marked importance for the timing of Alzheimer's disease in Down syndrome. Employment activities are an important aspect of lifestyle that has been theorized (but not studied to date) to be involved in this timing. Results from the study can be used to inform policy and interventions that support the need for more employment opportunities for adults with Down syndrome and IDD. She is one of the hardest working graduate students that I have had the privilege of working with at the Waisman Center and one of the most passionate for advancing the center's mission of improving lives of individuals with IDD and their family members.”



Sigan Hartley, PhD

2020 Awards

2020 Awards

Student Awards: Graduate Student Award

– **Kiley McLean**, UCEDD, nominated by Anne Bradford Harris, PhD, MPH & Lauren Bishop, PhD



Kiley is a third year doctoral student in the social welfare program in the School of Social Work. She was nominated for this award by Anne Bradford Harris, PhD, MPH and Lauren Bishop, PhD for her varied and significant contributions to multiple projects with the WI Leadership Education in Neurodevelopmental and Related Disabilities. Her overall career goal is to spearhead a program of translational research focused on reducing disparities through innovative disability policies at a research-intensive university. During her first year as a LEND trainee she stood out as passionate about research, policy, and committed to being a champion for the needs of people with developmental disabilities. She wrote two editorial on Medicaid expansion and the impact of COVID-19 that were published in the Capital Times and the national Association of University Centers on Disability (AUCD) Policy Talk blog. As stated in their nomination:



Anne Bradford Harris, PhD, MPH



Lauren Bishop, PhD

“Kiley has capacity to build bridges between research and its community application. What is most impressive about her research is that she successfully combines rigorous scientific methods with her lens as a clinician and advocate in order to address some of the most pressing questions in the field.”

2020 Awards

Student Awards: Graduate Student Award

– **Emily Burg**, IDDRRC, nominated by Ruth Litovsky, PhD



Emily is a graduate student in both the Audiology Doctorate and PhD programs in the Department of Communication Sciences and Disorders—one of the only people in the state of Wisconsin pursuing the AuD/PhD dual degrees. Emily was nominated for this award by Ruth Litovsky for her work on how to evaluate and treat people who are deaf and are fitted with cochlear implants either in one ear or both ears. She is designing studies aimed at providing insight into the benefit that patients experience from having received their devices. As Ruth states in her nomination letter:

“Her questions are unique to the field and raise the bar as far as the methodology and analysis of the data and dissemination. Her work will have clinical implications that can impact best practices. Through her dual degrees, she will have a combination of clinical and basic research training so that she can pursue a career as a clinician-scientist in a much-needed area in our nation. She is a model student, an amazing peer who connects deeply, respectfully, and meaningfully to other students, researchers, and clinicians.”



Ruth Litovsky, PhD

2020 Awards

Student Awards: Undergraduate Student Award

– **Keegan Schoeller**, IDDRC, nominated by Xinyu Zhao, PhD



Keegan is entering his senior year at UW-Madison. He was nominated for this award by Xinyu Zhao, for his work in her lab that was focused on the function of RNA binding protein FMRP and FXR1. FMRP deficiency leads to fragile X syndrome—a neurodevelopmental disorder; FXR1 has been associated with neurodevelopmental delay and psychiatric disorders. Using mouse models, he studied how FMRP or FXR1 deletion from either inhibitory neurons or excitatory neurons affect neuronal maturation and behaviors. He also spent one year testing and optimizing software which helped determine the best software and set-up to use for mouse behavioral testing and analysis. His efforts have helped improve speed and quality of data using this platform. As stated in her nomination:



Xinyu Zhao, PhD

“Keegan is a very hard worker. He is dedicated to his research projects and highly accountable for carrying out tasks and finishing experiments. Even while at home during the pandemic, he continued to analyze data that were included in revisions of manuscripts and several grant applications that were submitted.”

2020 Awards

Staff Awards: University Staff Award

– **Lisa Fisher & Manda Ratcliff**, nominated by Amy Whitehead, MPA



Lisa and Manda was nominated for this award by Amy Whitehed for their work in the Waisman Center Clinics as medical program assistants. They provide exemplary administrative support to the faculty and staff in the Department of Pediatrics Division of Genetics and Metabolism and Division of Developmental Pediatrics and Rehabilitation Medicine. Manda also provides administrative support for the Communication Aids and Systems Clinic. As stated in her nomination letter:



Amy Whitehead, MPA

“Lisa and Manda consistently demonstrate superior job performance; fully competent in their understanding of the work needed, in managing their workloads and prioritizing independently. Their written and oral communication skills are excellent and reflected in their daily interactions with their colleagues. They are highly productive and proficient at maintaining faculty, resident and learner calendars, tracking expenses, facilitating faculty candidate visits and coordinating events. They demonstrate respect to their colleagues and have become essential to the teams which they support. Each has gone above and beyond in their productivity, demonstrating their commitment to the work.”

2020 Awards

Staff Awards: Academic Staff Award

– **Carrie Arneson**, nominated by Leann DaWalt, PhD & Anita Bhattacharyya, PhD



Carrie was nominated for this award by Leann DaWalt and Anita Bhattacharyya for her work with the Waisman Clinical Translational Core (CTC). The CTC provides researchers with a broad range of support for conducting translational research including recruiting participants, research coordination with the clinics and early childhood program, access to biobank data and specimens for biomedical research. As stated in their nomination letter:

“Carrie has been working with the Waisman human stem cell core for the past 10 years and has been invaluable in helping this “wet lab” by administering a blanket IRB protocol for multiple Waisman PIs, consenting subjects both at Waisman and remotely, traveling to conferences to recruit subjects, communicating directly with stem cell core staff to coordinate sample collection and, most recently, resolving an IRB reportable event triggered by a collaborator. These duties required her to gain a deep understanding of the research questions, the experimental processes and the unique human subjects issues that come with human stem cell reprogramming. The Waisman stem cell core is so successful in large part because of her involvement. Carrie always is extremely diligent in “doing her homework” as new projects emerge and takes great care to understand the needs of research teams in order to support them in their work. She is timely, positive, inquisitive, and very reliable, making her a great asset to researcher at the Waisman Center.”



Leann DaWalt, PhD



Anita Bhattacharyya, PhD,

2020 Awards

Staff Awards: Academic Staff Award

– **Elizabeth Hecht**, nominated by Amy Whitehead, MPA



Liz was nominated for this award by Amy Whitehead for her work as the public policy and systems change senior outreach specialist within the University Center for Excellence in Developmental Disabilities. As stated in her nomination letter:

“It has been Liz’s lived experience, inspired by her son Will, that positioned her to approach all of her work with a profound passion and commitment to improving the system of supports for individuals with disabilities and their families. She was instrumental in convening and chairing a group to redesign state supports for families and children with disabilities and draft recommendation for reforms in policy and practice. This group evolved but has continued its charge and twenty-two years later, Liz is still the chair for the Council on Children’s Long Term Support Needs and through this work has been greatly influential in our state in promoting the full inclusion and self-determination of IDD and their families. Liz has been actively training learners throughout her career educating legislators, LEND trainees, medical students, residents, about the needs of families and how to share information with policy makers so that we move the needle in systems change. Liz has produced several materials, documents and issue briefs which have been effective in educating decision makers.”



Amy Whitehead, MPA

2020 Awards

Family Award: Sharon, Steve, & James Manlick, nominated by Audra Sterling, PhD



Audra Sterling, PhD

Sharon, Steve, and James were nominated for this award by Audra Sterling for their participation in studies related to fragile X syndrome in the Research in Developmental Disabilities Language Lab. As stated in her nomination:

“For nearly a decade, the Manlick family has shown an impressive level of dedication to research in fragile X syndrome through countless visits to the Waisman Center, which often extend over multiple days. Their level of commitment to research allows the field to move forward and contributes to knowledge on better understanding and supporting individuals with neurodevelopmental disabilities and their families. At the start of each new study, the Manlick family has enthusiastically agreed to participate, traveled from out of town, and given their time and energy to research. At every visit, they have brought such positive energy and have truly been a joy to work alongside. They have participated in a host of studies, which have included behavioral assessments, physiological measures, and magnetic resonance imaging. These studies have often involved countless assessments and questions, which touch on vulnerable aspects of a family’s life. The Manlick family has willingly shared this information, thus contributing to research aimed at furthering our understanding of fragile X syndrome as well as developing better ways to support children and families.”

Thank you!
