WHAT IS THE INTELLECTUAL DISABILITIES PARTICIPANT REGISTRY?

The University of Alabama's IDPR (AKA "The registry") is a database of families and individuals with intellectual disability who are interested in participating in behavioral research studies. We match families and individuals to appropriate studies to facilitate research on intellectual disability. The registry currently covers Alabama, Mississippi, Georgia, and Florida. Call us at 205-348-4253 or email idlab@ua.edu for more information.

NOTE FROM THE REGISTRY COORDINATOR

Dear registry families,

Many of our families have had exciting news come their way in the past few months, and we along with these families would like to share these accomplishments with the larger registry group.

We also currently have several interesting research opportunities; within this edition of the registry newsletter you will find information on each of these studies. If you or your family would be interested in participating in any of these studies or if you would like more information, please let us know.

We also have a special interview with Dr. Fran Conners, Professor of Psychology at the University of Alabama and Principal Investigator for the registry.

All of this in the Summer 2018 newsletter!

Eric

Find us on Facebook @UAIDPR

Visit our website at www.uaidpr.ua.edu!

SPOTLIGHT ON JADEN WALKER!

Jaden was born 11 weeks early in June of 2017. He recently came home on July 16th after spending his entire life in the hospital (408 days)! He has enjoyed spending the past 2 weeks at home with his mom, dad, the family cat Meow Meow, and visiting with grandparents, aunts, and cousins. Jaden likes chewy toys, music, loud noises, and tummy time. He's also finding a love for water play, being outside, and discovering sunshine. Jaden brings everyone who meets him lots of joy, and always has a smile to share.

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- **Hannah Baker** spent the month of June volunteering at Birmingham Children’s Theater as a teaching assistant. She had a successful run with this fabulous opportunity and enjoyed “going to work and helping the counselors and campers”.

- **Katy Ann Killingsworth** recently graduated from high school and will be attending the University of West Georgia’s Inclusive Post-Secondary Education program Project WOLVES.

- **Beth Olive** attended the Self-Advocates Becoming Empowered (SABE) National Conference held in Birmingham in June.

- **Maren Mills** is volunteering for her second year at the McWane science center working with both kids camps and the science exhibits. Last year she was given the Volunteer of the Year Award!
George Merchant, a 3rd grade student at Paine Elementary in Trussville, scored near age/grade level in reading rate, accuracy, and fluency on a GORT assessment in May. The school utilized reading programs noted in the research of Dr. Chris Lemons at Vanderbilt University.

Isaiah Palos participated in the Special Olympics for the state of Alabama and won first place in the 200 meter race and second place in the 500 meter race!

Lilly Miller and family recently attended a red carpet event at the Radio Disney Music Awards in California!

Kari Balazs graduated from Hoover HS and is headed to Judson College in the Fall! She was also awarded a scholarship from Ruby’s Rainbow! rubysrainbow.org.
- **Erech Brown** is an aspiring, thriving artist. Erech hosted his first booth at the SABE 2018 National Conference held in Birmingham, AL. Erech's artwork is currently in the copyright stage and you can visit his website at www.erechbro-looza.com.

- **Anne Rogers and Sally Cate Hines** have completed a successful year at Verner Elementary. They are looking forward to the 1st Grade! They are having a great time at Tuscaloosa City School's Summer Enrichment Academy.

- **Stephen Clark** finished his baseball season with the All-Stars in Vestavia and will start his first year at Hoover High in August! Congratulations Stephen!
CURRENT REGISTRY-SUPPORTED STUDIES:

Well-being and the Social Experiences of Adolescents with Down Syndrome
Jenna Reardanz, Dr. Fran Conners, and Dr. Kristina McDonald

Research shows that children and adolescents with intellectual disability are at a higher risk to experience peer victimization compared to their typically developing peers. This study develops measures for this population that will be used in future research on the possible consequences of peer victimization, such as anxiety, depression, acting out, etc. The information learned in this study will be used to obtain federal funding for a larger study. The study focuses on adolescents with Down syndrome age 11-17 years.

Wayfinding Study
Trent Robinson and Dr. Ed Merrill

This study is being conducted by Dr. Ed Merrill at the University of Alabama and is designed to look at how individuals learn to navigate through an environment, a skill known as wayfinding. Past research has shown that wayfinding is difficult for individuals with intellectual disability. This study will help researchers understand how wayfinding knowledge develops with the long-term goal of developing ways of training individuals with difficulty in this area. This study is recruiting individuals with intellectual disability between the ages of 12-25 years.

IF YOU ARE INTERESTED IN ANY OF THESE STUDIES OR WOULD LIKE MORE INFORMATION PLEASE CONTACT THE REGISTRY COORDINATOR AT COOKS002@UA.EDU OR AT 205-348-4253.
Interview with Dr. Fran Conners

How long have you been working in intellectual disabilities research or what is your background in this field?

I went to graduate school at Case Western University in a program specifically on intellectual disability research. This was a psychology doctoral program, with an emphasis on cognitive aspects of intellectual disability. After I got my PhD, I had a postdoc at the University of Colorado that focused on reading disabilities. After that, I returned to intellectual disability research and have been studying that ever since. So... about 30 years or so.

What are some of the biggest advances you've seen in your field over the years?

Probably the biggest advance is the understanding that people with intellectual disabilities can learn and can be a part of society. It is hard to believe now that this is an advance, but yes, there was a time when this was not understood. This knowledge has led to more inclusion in educational and community settings and better ways of teaching students with intellectual disabilities. Another advance has been understanding more of the causes of intellectual disabilities. Some intellectual disabilities are due to genetic causes (e.g., Down syndrome and fragile x syndrome), some are due to toxins (e.g., fetal alcohol syndrome), and some causes are unknown. Knowledge of these causes has led to prevention programs and even potential pharmaceutical treatments.

What is the goal of your lab?

We study behavioral aspects of intellectual disability, especially Down syndrome. We study aspects of cognitive, linguistic, and most recently social functioning to find out where the real challenges lie and where the relative strengths are. But we are concerned with how the challenges and strengths factor into everyday functioning of individuals with intellectual disability - such as the ability to read, the ability to find one's way, the ability to communicate and the ability to get along with others.

Why is it important to get families involved in research on intellectual disability?

By far, most of what we know about intellectual disability has been learned from individuals who have intellectual disability. Yet, the greatest barrier to our research is recruiting participants with intellectual disability. The more families get involved in research, the more we can learn, and the better life can become for individuals with intellectual disability. Research progresses slowly, so those who become involved today will be helping those of tomorrow.

For parents that want to get involved but are unsure of the process, what advice can you give them?

Call Eric Cooks, our registry coordinator, and talk about possible ways to get involved. Many families we work with join our participant registry. The registry will contact you when there is a study that might be a good fit for your child or family member. Some families want to participate in a study first, and then make a decision about joining the registry. Others may want to help promote research in other ways. Eric can talk with you about possible ways to get involved.
Upcoming Events

**Alabama**

Montgomery Buddy Walk  
10/20/2018  
John Mark Stallings Football Field, Montgomery AL  
montgomerybuddywalk@gmail.com  
**Contact: Paige Keeter**

Wiregrass Area Buddy Walk  
10/13/2018  
5622 South US HWY 231, Dothan AL  
334-718-3356  
**Contact: Alicia Sims**

2018 DSSM Buddy Walk  
10/20/2018  
Bienville Square 150 Dauphin Street, Mobile AL  
888-454-0317  
**Contact: Cathy Ogarek**

Rocket City Buddy Walk  
10/06/18  
Airport Road, Huntsville AL  
buds@budsonline.org  
**Contact: Susan Meyer**

Step Up for Down syndrome Walk  
10/7/18  
Veteran's Park, Hoover AL  
205-988-0810  
**Contact: Sue Tolle**

Registration is currently underway for the Miracle League of Tuscaloosa Fall 2018 season; game dates will be 10/6, 10/20, 10/27, and 11/3. Registration fee is $30 and can be completed at www.miracleleagueoftuscaloosa.com

**Mississippi**

21 United Buddy Walk  
10/22/2018  
1090 Augusta Drive, Oxford MS  
662-469-6160  
**Contact: Jenny Rayner**

CMDSS Buddy Walk  
10/13/2018  
Trustman Park 1 Braves Blvd, Pearl MS  
601-385-3696  
**Contact: Jennifer Babl**

GCDSS Buddy Walk  
10/20/2018  
Gulfport Sports Complex, Gulfport MS  
228-447-0270  
**Contact: Riley McIlwain**

**Georgia**

DSA of Southwest Georgia Buddy Walk  
11/03/2018  
Legacy Park, Albany GA  
**Contact: Kayla Luckie**

Atlanta Buddy Walk  
10/6/2018  
Atlantic Station, Atlanta GA  
404-320-3233  
**Contact: Sheryl Arno**

Low Country Down Syndrome Society Buddy Walk  
10/6/18  
Forsyth Park 13 E Park Ave. Savannah, GA  
912-436-3626  
**Contact: John Bogardus**
Upcoming Events

Florida

DSAf of Tallahassee Buddy Walk
11/03/2018
3196 Merchants Row Blvd, Southwood's Town Ctr FL
850-541-3981
Contact: Dana Rainey

DSAJ 16th Annual Buddy Walk
10/20/2018
Seawalk Pavilion 1st, North Jacksonville Beach FL
904-353-6300
Contact: Jennie Ponder

3rd FDSWF Buddy Walk
10/27/2018
4201 N Dale Mabry Hwy, Tampa FL
813-245-2782
Contact: Ann Foyt

FEDs of Brevard Buddy Walk 2018
11/03/2018
Cocoa Village Riverfront Park, Cocoa FL
321-392-5541
Contact: Dawn Bellerose
The University of Alabama
Intellectual Disabilities Participant Registry
Box 870348
Tuscaloosa, AL 35487-0348