

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 idl原因@ua.edu for more information.

NOTE FROM THE REGISTRY COORDINATOR

Dear registry families,

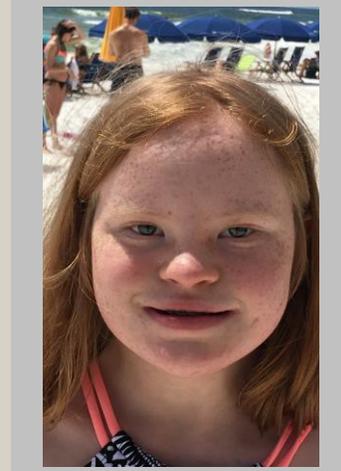
Thanks to your participation over the past year the registry has collaborated with 6 different research studies! As the results of these studies come in we will be sharing the overall findings with you. In this newsletter findings from Andrew Tungate's physical activity study are provided.

Over the summer we will continue to work with a few studies along with devoting significant effort to recruiting new families into the registry; our recent addition of online registration will assist in this effort. As always if you know of anyone who is interested in participating in research please direct them our way! Families can many times be the best spokespeople for the registry; we appreciate not only your participation in the registry but also in helping us to grow and serve more individuals and families of individuals with intellectual disability.

In addition to research studies we will also be working to update our database with new family contact information, so we will be making contact with most of you over the summer months and into the fall.

Eric

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



SPOTLIGHT ON LINDSAY DAVIS!

Lindsay Davis is 14 years old and will be in the 9th grade in the fall. She is active in her youth group in church and participates in many volunteer opportunities. She loves to perform in show choir with her typical peers and participates in many sports including TOPSoccer, ALLSTAR baseball, and basketball. During the school year she manages the volleyball, basketball, and softball teams for her grade. She loves summer camps especially when she gets to spend the night away from home!

ONGOING STUDIES SUPPORTED BY THE REGISTRY

Acquiring Route and Survey Knowledge in Down Syndrome, Ed Merrill, Zack Himmelberger, and Trent Robinson

How's the family? A Study of Family Communication and Coping, Ted Tomeny, Josh Pederson, and Lorien Baker

Improving Auditory Skills in Children with Down Syndrome, Fran Connors, Emily Mace, and Lani Shellhouse

RESEARCH REVIEW: PHYSICAL ACTIVITY AND EXECUTIVE FUNCTION

For his master's thesis, Andrew Tungate conducted an innovative pilot study to measure physical activity in youth with Down syndrome (DS). This is a hot up-and-coming topic for research, not only because of all of the known health benefits of physical activity, but also because of possible cognitive benefits. Many registry families participated in this study. Thank you!

Andrew's study focused on youth with DS ages 5-18. Participants wore a pedometer each day for a week to measure their number of steps, and their parents completed a questionnaire on their son or daughter's exercise habits.

There were several interesting findings. First, the pedometer measurement was successful with some but not all of the participants. Many of the younger participants did not wear it consistently, either because they didn't want to or because it fell off of them. Thus, one finding was that using a pedometer to measure daily physical activity may work well with teens with DS, but not so well with younger children with DS.

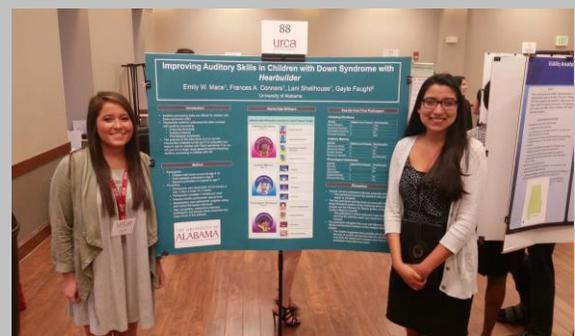
Another finding was that, for those who did successfully use the pedometer, their average steps per day were below the level expected for their age. This suggests that youth with DS may need more daily physical activity. In contrast to the pedometer measure, the parent report of the child's exercise habits was successfully completed by all of the parents. However, it was challenging for parents to report the number of minutes per day their child spent in different types of exercise. Parents' feedback on the questionnaire will be helpful to further refine this measure.

In future studies, we would like to improve the measures of physical activity so that we can look at how they relate to cognition, everyday functioning, and quality of life in youth with DS.

Get your child moving!

1. Consider getting an inexpensive pedometer or Fit Bit for your teen. In Andrew's study, teens seemed to like wearing the pedometer. Wearing it could remind them to be active.
2. Consider enrolling your child in a team sport or exercise class – something he or she likes. This is good for the body and brain, and adds a social dimension.
3. Encourage your child to exercise for fun whenever possible.

TAKE HOME TIPS FOR PARENTS



Emily and Lani presented a poster on their Hearbuilder research at the annual Undergraduate Research Competition. Nice job!!

PRESENTING EARLY
RESEARCH FINDINGS

UPCOMING EVENTS:

Decatur BBQ, Blues & Bluegrass Festival: 8/13/2016. Decatur, GA. One of Atlanta's favorite festivals, the Decatur BBQ, Blues & Bluegrass Festivals bring some of the South's best BBQ together with great live blues and bluegrass music from local and national artists. Come celebrate the end of summer with the Decatur BBQ, Blues & Bluegrass Festival. <http://www.decaturbbqfestival.com/>

Will Kimbrough in Concert: Rosenzweig Arts Center, Columbus, MS. August 19th at 7:30pm. Save the date for Will Kimbrough in concert! Tickets available at the Columbus Arts Council for \$10 in advance/ \$12 at the door. Visit Columbus-arts.org for more information

Babypalooza Baby & Maternity Expo: Birmingham, AL. Legacy Arena at the BJCC. August 13th, 10:00 am - 12:00 am. At Babypalooza you will have the opportunity to learn things like how to make your own baby food, the basics of cloth diapering, baby wearing 101 and many other topics. It is a premier event in the Baby, Kids & Maternity industry.

2016 Florida Kids and Family Expo: Orlando FL. Orange County Convention Center. August 27-28. The Florida Kids and Family Expo is your opportunity to discover what Central Florida has to offer moms-to-be, babies, toddlers, kids, teens, and families. Beat the heat and get indoors for some epic family fun while discovering new ideas and opportunities for your family.

THINGS TO NOTE:

- Visit our website is at www.uidpr.ua.edu. Let us know what you think!
- We need your pictures! If you have any family pictures you would like to share with the Registry, or if your children would like to draw us a picture we would love to have them! Any pictures sent in will be used either on our website or to decorate our offices!
- We would really like to expand the Registry to include more families. If you know someone who would like to join the Registry, please ask them to email or call us.

REGISTRY ASSISTANTS

The registry is fortunate to have great assistants! They are bright, enthusiastic, and caring. Please meet Emily Mace, Lani Shellhouse, and Alida Babcock.

EMILY MACE



Emily is from Spanish Fort, Alabama and is a senior at UA. She is a New College major with a depth study in psychology and civic engagement. Her research interests are in cognitive and auditory processing in children with intellectual disability. She enjoys going to the beach, spending time with her friends and family, and watching Alabama football.

LANI SHELLHOUSE



Lani is from South Florida. She received her B.A. in Psychology from the University of Alabama in December 2015. She currently works in two labs as a research volunteer, including the intellectual disabilities lab. Lani enjoys kayaking and camping through state parks, reading historical and science fiction, and traveling whenever possible.

ALIDA BABCOCK



Alida is a sophomore from Baton Rouge, Louisiana. She is majoring in Interdisciplinary Studies with a depth study in neurolinguistics and minoring in Spanish. She is a member of the University Fellows Experience. In her spare time she enjoys reading, running, and research!

UA IDPR

SUMMER 2016

Look Here for an Upcoming Buddy Walk in your Area:

Alabama

Montgomery Buddy Walk. October 1, 2016. Montgomery, Alabama

DSA Buddy Walk. October 2, 2016. Hoover, Alabama

Rocket City Buddy Walk. October 15, 2016. Huntsville, Alabama

Wiregrass Area Buddy Walk. October 29, 2016. Dothan, Alabama.

Georgia

CVDSA Buddy Walk. October 15, 2016. Columbus, Georgia.

Atlanta Buddy Walk. October 1, 2016. Atlanta, Georgia.

Mississippi

Central Mississippi Buddy Walk & BW 5k. October 8, 2016. Pearl, Mississippi

GCDSS 13th Annual Buddy Walk. October 19, 2016. Gulfport, Mississippi

Florida

DSAJ 14th Annual Buddy Walk. October 22, 2016. Jacksonville Beach, Florida.

Buddy Walk & 5k Run 2016. October 16, 2016. Sunrise, Florida.

Step Up For Down Syndrome Buddy Walk. October 22, 2016. Orlando, FL

2016 DSAT Buddy Walk. October 22, 2016. Tallahassee, Florida.

GET INVOLVED!!

If you would like your group's event to be listed in our future newsletter, please let us know.

Sincere thanks to everyone who is helping the Registry to promote research on intellectual disability!



tuscaloosa
alabama

PROMOTING RESEARCH ON INTELLECTUAL DISABILITY

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