

Education News

The WSA's Terry Monkaba, Laura Chesser and education consultant Robin Pegg attended the Learning Disabilities Association of America's annual conference in Baltimore (home of our next convention!) this month. In addition to participating in sessions, their main goal was to connect with teachers and administrators, as well as the college professors who teach special education. Outreach to educators is an essential element to improve futures for those with Williams syndrome, and we're happy to note that 1000 attendees, many of whom had never heard of WS, now have general information on the condition and the educational profile recently published by the WSA—a must have for anyone serving a student with WS.



Laura Chesser and a teacher

WSA Education Consultant, Robin Pegg, in collaboration with a team of our professional advisors and WS experts including Carolyn Mervis, Ph.D.; Bonnie Klein-Tasman, Ph.D.; Marilee Martens, Ph.D.; and Karen Levine, Ph.D. has defined the educational profile for Williams syndrome: the unique set of strengths and weaknesses that, when known by the teacher of a student with WS, can help them understand how their student learns and where they can draw on the students strengths to help overcome their weaknesses. We urge every parent/caregiver of a student with Williams syndrome to make sure that every member of your son or daughter's educational team has a copy of the [Educational Profile for Williams syndrome](#).

Online Safety Habits of Adults with Williams syndrome

Williams syndrome often presents with the trait of individuals having very social personalities, which can be a good thing. However, with the increase in online activity and popularity with connecting on social networks, the sociability and trusting natures of individuals with WS can pose some challenges. Being able to connect with like-minded individuals with developmental and intellectual disabilities is valuable, but so is safety.



Marisa H. Fisher, PhD, BCBA-D, Assistant Professor within the Dept. of Counseling, Educational Psychology, & Special Education at Michigan State University, along with her research partner E. Lough, Department of Psychology, Durham University, UK, published an article in the *Journal of Intellectual Disability Research* outlining their findings on the topic. Their research is based on adults rather than children with WS, who should be monitored the same as any minor online.

As part of their research, Fisher and Lough conducted a survey on internet use that included 28 adults with WS (22 male, 6 female) and their parents at the [Vanderbilt ACM Lifting Lives Music](#)

[Camp](#), (which Dr. Fisher runs). Their answers showed that adults with WS did better at understanding financial privacy concerns than they did relationships with strangers online, so parents and caregivers need to work with them on understanding the dangers. Fisher and Lough plan to continue their research on this topic: [read the full article](#) on their current findings and recommendations.

Research News

Join The Registry!

The WS Registry, is the WSA's boldest effort to help solve key medical issues in Williams syndrome. [Registry Day](#) on March 1 celebrates our success in enlisting several hundred families to join, and invites (we hope) thousands more to learn about the WS Registry and how you can help. You may wonder "why is the Registry so important?" or "how does it relate to me or my family?" In brief, when medical records are available, researchers are attracted. When researchers can see "up front" how many individuals with Williams have hypertension" or cardiovascular disease etc., they can hit the ground running with that data, and improve their studies by promoting them to the WS Registry participants.

The Registry is private, all information is received in an anonymous fashion and participants will not be contacted unless they give consent. Consider joining to be a part of this effort now, on March 1, and beyond. Visit the [Registry Day](#) site and find information about webinars (Feb. 23 and March 1) and more.

The registry has already helped us with research but it can do so much more. Please read about findings for both [thyroid](#) and [anesthesia](#) issues for individuals with WS--all gathered by the Registry--and plan on completing the health surveys, which will strengthen the research.

If you are not already in the Registry, please [sign up](#) today so that you, too, can be a part of this critical research effort!



SAVE THE DATE:
March 1, 2017

On March 1st, we are celebrating the WS Registry!

Stay tuned for more details on Registry related activities.

- Join a Webinar to learn about the Registry, how best to use it, and how it benefits the WS community!
- Be on the lookout for summaries of Williams syndrome data collected by the Registry!
- Set aside time to complete your unfinished Registry tasks and send us medical record release forms!

Questions? Comments?
617-726-5318 617-643-3190 WSRegistry@partners.org

Fundraising Gala

WSA is hosting a "first of its kind" fundraising event exclusively for research on March 9, 2017 in New York City. [White Night](#) will be held at Cipriani Wall St. The event will kick off a research fundraising effort in which we hope to raise \$1 M for research.

One million dollars will enable us to support research teams in ways that we never thought possible. Please join in providing the research community with vital resources for individuals with Williams syndrome.



The popular band O.A.R. will be performing at the event--and individuals with Williams syndrome in attendance (as well as their siblings), will have the opportunity to join them onstage for a song!

We will also have an exciting auction. Even if you can't attend in person, you can join the [auction](#) fun. Items up for bid can be viewed now and the auction will be live beginning on February 27th. Please share the links to the Auctions with your social media friends. Everyone is welcome to participate!

Join us on March 9th as we strive to meet our research goals.

WSA Camps and Other Activities

WSA camps and other programs we partner with are all available for [registration](#). This year, we are partnering with [Camp Blue Skies](#) for a special adult camp week on March 20-24. The camp will be held at Camp Twin Lakes in Rutledge, GA. The program promises to be engaging and exciting with varied adventure and music activities.



Camp Blue Skies for Adults

The WSA's Whispering Trails therapeutic and teen camps and other recurring camps and programs are all described [here](#) and registration is open. Make your plans now.

Still looking for something exciting to do with the family this summer? How about a cruise to Alaska with other WS families July 8-15? Registration is available through March. [Click](#) for information on how to register.

