Williams Syndrome Association
National Convention 2018

Marriott - Waterfront
Baltimore, MD
July 11 - 14, 2018

Convention Program
# 2018 National Convention Committee

## Committee Chairs

<table>
<thead>
<tr>
<th>Category</th>
<th>Chairs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parent Educational Program</td>
<td>Terry Monkaba</td>
</tr>
<tr>
<td>Fundraising</td>
<td>Cyndra Cole</td>
</tr>
<tr>
<td>Registration</td>
<td>Nora Beger</td>
</tr>
<tr>
<td>New Family Welcome</td>
<td>Melissa Murphy</td>
</tr>
</tbody>
</table>

## Program Leaders

<table>
<thead>
<tr>
<th>Category</th>
<th>Leaders</th>
</tr>
</thead>
<tbody>
<tr>
<td>Childcare:</td>
<td></td>
</tr>
<tr>
<td>Infants:</td>
<td>Erica Diffenderfer</td>
</tr>
<tr>
<td>Toddler/Pre-school:</td>
<td>Julie Oglesbee</td>
</tr>
<tr>
<td>School Age:</td>
<td>Robiin Pegg</td>
</tr>
<tr>
<td></td>
<td>Alex Carricho</td>
</tr>
<tr>
<td></td>
<td>Bill Bentley</td>
</tr>
<tr>
<td>Teens:</td>
<td>Emma Thomas</td>
</tr>
<tr>
<td>Young Adults:</td>
<td>Alyssa Bauman</td>
</tr>
<tr>
<td></td>
<td>Kaitlin VanWyk</td>
</tr>
<tr>
<td>WSA GANG:</td>
<td>Ashley Johnson</td>
</tr>
<tr>
<td></td>
<td>Eleni Norskey</td>
</tr>
<tr>
<td>Dream Team:</td>
<td>Nancy Hanson</td>
</tr>
<tr>
<td>Therapy Initiative:</td>
<td>Pam Blevins</td>
</tr>
<tr>
<td></td>
<td>Jan Beard</td>
</tr>
<tr>
<td>IEP Review Program:</td>
<td>Christie Rovinsky</td>
</tr>
<tr>
<td>WS Programs/Volunteers:</td>
<td>Melissa Murphy</td>
</tr>
</tbody>
</table>

## WSA Staff

<table>
<thead>
<tr>
<th>Category</th>
<th>Staff</th>
</tr>
</thead>
<tbody>
<tr>
<td>Exhibits:</td>
<td>Laura Chesser</td>
</tr>
<tr>
<td>Finance:</td>
<td>Jessica Cummins</td>
</tr>
<tr>
<td>Online Registration/Mobile Communication:</td>
<td>Laurie Fundukian</td>
</tr>
<tr>
<td>Volunteer Registration:</td>
<td>Michele Bauer</td>
</tr>
<tr>
<td>WSA Store:</td>
<td>Anne Tipton</td>
</tr>
</tbody>
</table>

## Committee Members

- Jennifer Chaplin
- Julie Crosby
- Sean Crosby
- Jessica Cummins
- Lauren Decker
- Julie Edwards
- Laurie Fundukian
- Jenny Knox
- Amy Ladd
- Angela Langrehr
- Tara Momplaisir
- Gloria Morello
- Melissa Napoli
- Christine Otto
- Darian Packard
- Dean Packard
- Deb Payne
- Candy Phillips
- Racquel Requejo
- Erin Rupolo
- Sharon Schlaffer
- Ericka Schmitt
- Mike Sturtevant
- Lara Walt
- Tina Weigand
- Lori Wagner
- Carol Wheeler
- Wendy Balda
Welcome to the 2018 National Convention

Over the next four days, experts in Williams syndrome from across the United States will help us increase our understanding of Williams syndrome. We hope that each of you will leave here with valuable information that can be used to help your children reach their full potential.

WSA has “gone mobile” in 2018. All the information contained in this program (and more!) will be available on your smart phone and/or tablet throughout the convention. Once you’ve downloaded the App and opened the WSA Convention program it will be accessible to you at any time, regardless of WiFi access. All programming information, session powerpoints, exhibitor information, program location maps, etc., will be at your fingertips through the App. Please bring any questions you have (App related or otherwise) to the registration desk. If our registration crew cannot answer your question, they will know how to find someone who can.

Please wear your name tag at all times. It is necessary for entrance into all sessions. Your name tag will also help other attendees identify you as a convention participant. Some of the most valuable information you receive this week will come from other parents who have walked in your shoes. Make it a point to introduce yourself to other families, get to know the members of the WSA community and make friendships that will last a lifetime.

Remember that this is a FAMILY convention. It is not meant to be stuffy or formal. It is intended as a forum for the exchange of information - between and among parents and professionals. Don’t be afraid to ask questions - to both parents and speakers. They will be happy to talk with you.

We know that for many of you, this convention is your summer vacation. Thank you for spending it with us! If you need additional information on local attractions, please stop by the WSA registration desk for printouts provided by the Baltimore Convention and Visitors Bureau or consult with the hotel concierge.

Families have traveled from throughout the United States and around the world to be here. We’re excited to have you all with us, and we’d like to extend a special welcome to our international participants. You have all traveled a long distance to join us this week and we’re glad you did!

Special thanks...

It is only possible for a non-profit with a very small staff to put on a convention of the magnitude of ours through the assistance of many dedicated volunteers. Our convention committee has given a great deal of their time and expertise in the midst of busy family and work schedules for more than a year to bring you this convention.

This week, they are joined by more than 300 additional volunteers (in child care, teen and adult programs, at the store, in registration, and countless areas behind the scenes) to make sure that your convention experience is everything that you would like it to be.

We are extremely grateful for their support! If you see one of our committee members (you can spot them by their special ribbon) please take a moment to say “Thanks.”
PARENT/PROFESSIONAL PROGRAM INFORMATION

Our speakers are doctors, educators, therapists and parents - each of whom has an excellent knowledge of their topic and of Williams syndrome. The age (for example: 13+) in parenthesis indicates which audience will be most interested in the content (i.e. parents of teens). However, the ages listed are meant to be guidelines. Every session is available for every attendee.

Parent sessions will be held in the room indicated to the right of the session title. Sessions will occasionally be moved to accommodate a last minute change -- Watch your phones for notice of these changes if/when they occur.

What if you don’t see a session that truly peaks your interest? Or a topic you would really like to discuss is not included in the program? Take advantage of our Lunch & Learn Discussions.* On Wednesday, Thursday and Friday, many of our speakers are hosting small group (10 people) discussions in the exhibit area during the lunch break. Purchase a sandwich or salad from our cash and carry concession and join the table of your choice (sessions are by pre-registration only). Check the registration link to find openings – https://form.jotform.com/8152225823959
*Lunch and Learn sessions are for adults only. Unfortunately, we are not able to provide childcare for infants and toddlers during the lunch hour.

Still can’t find what you are looking for? Attendees will have the opportunity to reserve a table for a “pop up” discussion on the topic of your choice. Each day, the topics will be listed and others with similar interests can sign up to these “topic driven” networking sessions on the White Board in the Exhibit area. Tables and time slots will be reserved on a first-come, first served basis each day throughout the convention.

Feel free to reserve a table personally or join a table as often as you wish.

The IEP Advocate Drop-In Center, Therapy Initiative and Lunch and Learn sessions are available for

Meals
Continental Breakfast will be provided each morning - Location noted on daily schedule.

Lunch: Lunch is “on your own” for all convention participants, except children, teens and adults who are off-site during the lunch hour. In addition to the hotel’s full-service restaurant, there will be “cash and carry” options available in the exhibit hall area for those who are registered for the lunch and learn sessions and others who prefer a simple salad or sandwich option. There are several lunch options within walking distance of the hotel for those who prefer a change of scenery.

Please note that all children in the hotel (ages birth - 5) MUST BE PICKED UP FOR LUNCH EACH DAY, and returned to the program before the start of the afternoon sessions.

WSA GANG & Dream Team members will also be “on their own” for some lunches. If your young adult is not able to navigate restaurants on their own, please arrange to meet them for lunch.

Dinner will be “on your own” each evening. There are several restaurants within walking distance. A list of local restaurants can be found in the APP and in the materials you receive when you register.

Supporting the community.
That’s the Enterprise Way.

Proud supporter of “Set Sail: Dream, Believe, Achieve”
Williams Syndrome Association National Convention.
enterprise.com • 1 800 rent-a-car
### PROGRAMMING FOR PARENTS AND PROFESSIONALS

**Wednesday, July 11, 2018**

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>9:30 - 11:00 AM</td>
<td>New Family Welcome</td>
<td>Harborside DE</td>
</tr>
<tr>
<td></td>
<td>Special reception for everyone who is attending the national</td>
<td></td>
</tr>
<tr>
<td></td>
<td>convention for the first time. Pre-registration required.</td>
<td></td>
</tr>
<tr>
<td>11:00 - 12:30 PM</td>
<td>Bee Strong Therapy Initiative Overview</td>
<td>Dover ABC</td>
</tr>
<tr>
<td></td>
<td>Join us for a special introduction to the brand new Bee Strong</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Therapy Initiative. Initiative experts in physical therapy,</td>
<td></td>
</tr>
<tr>
<td></td>
<td>occupational therapy, aqua therapy and more will explain what you</td>
<td></td>
</tr>
<tr>
<td></td>
<td>can expect from the special workshops and evaluations that will</td>
<td></td>
</tr>
<tr>
<td></td>
<td>be presented throughout the convention.</td>
<td></td>
</tr>
<tr>
<td>11:45 - 12:45</td>
<td>Lunch &amp; Learn Conversations</td>
<td>Harborside DE</td>
</tr>
<tr>
<td>1:00 PM</td>
<td>Welcome</td>
<td>Harborside C</td>
</tr>
<tr>
<td></td>
<td><em>Melissa Murphy, Esq. WSA Board President</em></td>
<td></td>
</tr>
<tr>
<td></td>
<td><em>Terry Monkaba, MBA WSA Executive Director</em></td>
<td></td>
</tr>
<tr>
<td>1:30 - 2:45</td>
<td>Importance of Community KEYNOTE</td>
<td>Harborside C</td>
</tr>
<tr>
<td></td>
<td><em>Michael Porath, The Mighty</em></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Mike will discuss the different communities that parents of</td>
<td></td>
</tr>
<tr>
<td></td>
<td>individuals with WS need to create/join in order to</td>
<td></td>
</tr>
<tr>
<td></td>
<td>successfully navigate the changing journey that they will be on</td>
<td></td>
</tr>
<tr>
<td></td>
<td>throughout their child’s lifetime.</td>
<td></td>
</tr>
<tr>
<td>2:45 - 3:00</td>
<td>Break</td>
<td></td>
</tr>
<tr>
<td>3:00 - 4:15</td>
<td>Breakout Sessions</td>
<td></td>
</tr>
<tr>
<td>3:00 - 4:15</td>
<td>The Boy Who Loved too Much</td>
<td>Dover ABC</td>
</tr>
<tr>
<td></td>
<td><em>Jennifer Latson and Cindy Schiro</em></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Author, Jennifer Latson, and Cindy Schiro (aka “Gayle”) will talk</td>
<td></td>
</tr>
<tr>
<td></td>
<td>about their shared journey over three years of research and</td>
<td></td>
</tr>
<tr>
<td></td>
<td>the writing of the poignant story of “Gayle and Eli.”</td>
<td></td>
</tr>
<tr>
<td>3:00 - 4:15</td>
<td>Adults with WS: Obtaining Good Jobs and Benefits (16+)</td>
<td>Harborside D</td>
</tr>
<tr>
<td></td>
<td><em>Grace Francis, Ph.D.</em></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Educational and employment options for young adults. This session</td>
<td></td>
</tr>
<tr>
<td></td>
<td>will discuss ways to navigate the system and think outside the box</td>
<td></td>
</tr>
<tr>
<td></td>
<td>to achieve success.</td>
<td></td>
</tr>
<tr>
<td>3:00 - 4:15</td>
<td>Being Your Child’s Champion: Advocacy Tools and Legal Framework for</td>
<td>Harborside E</td>
</tr>
<tr>
<td></td>
<td>Your School-Age Child</td>
<td></td>
</tr>
<tr>
<td></td>
<td><em>Melissa Murphy, Esq. and Leslie Margolis, Esq.</em></td>
<td></td>
</tr>
<tr>
<td></td>
<td>This session will provide an overview of special education law</td>
<td></td>
</tr>
<tr>
<td></td>
<td>essentials. It will also include the top 10 tips and best practices</td>
<td></td>
</tr>
<tr>
<td></td>
<td>for successfully advocating for the placement, supports, and related</td>
<td></td>
</tr>
<tr>
<td></td>
<td>services your child needs (and is entitled to!)</td>
<td></td>
</tr>
<tr>
<td>3:00 - 4:15</td>
<td>General Overview of WS for Spanish-Speaking Families (All)</td>
<td>Falkland</td>
</tr>
<tr>
<td></td>
<td><em>Angela Becerra, Ph.D.</em></td>
<td></td>
</tr>
<tr>
<td></td>
<td>This session will be conducted in Spanish. There will be follow-up</td>
<td></td>
</tr>
<tr>
<td></td>
<td>round table discussions on specific topics as needed.</td>
<td></td>
</tr>
</tbody>
</table>
Wednesday July 11, 2018 (con’t)

I Don’t Know What I Don’t Know: How Can I Plan for the Future?  (All)  Harborside C
Barbara Pober, MD; Bonnie Klein-Tasman, Ph.D.; Meredith Greene, Esq.; Laura Chesser, BS
Moderator: Terry Monkaba, MBA
A facilitated conversation with medical, behavioral, transition and financial specialists will help you “be prepared” for the future.

Loosen Up: How to Prevent and Manage Joint Contractures in Teens and Adults using a PT Approach
Kristen Kouvel, PT  (13+)  Waterview CD
This interactive session will cover the who, what, where, when, why and how of joint contractures and teach you how to prevent and manage them.

Thursday, July 12, 2018

8:45 - 10:00 AM  Breakout Sessions

Common Endocrine Issues in Adults with Williams Syndrome  (18+)  Harborside E
Takara Stanley, MD
Many adults with WS have issues with obesity, bone health and glucose. This session will discuss the signs and treatments for each.

Building a Critical Support Network  (10 and under)  Harborside D
Laura Chesser, Jenny Knox, Griselda Polanco, Julia Uhll
Moderator: Melissa Murphy, Esq.
WSA moms will discuss the “whys” and the “hows” of building a support network in your community, which includes the special education director, school superintendent, ISD officials, etc.

Williams Syndrome Research Today and Tomorrow  (All)  Harborside C
Barbara Pober, MD; Tom Collins, MD; Carolyn Mervis, Ph.D.; Leslie Smoot, MD; Beth Kozel, MD, Ph.D.
Moderator: Jocelyn Krebs, Ph.D.
Members of WS Research community will talk about research trends today and what might be on the horizon for tomorrow.

Insights from Japan for Williams Syndrome: A Unique Challenge in Language Arts and Mathematics  Essex AB
Fusa Katada, Ph.D. and Cindy Utama  (Teens +)
Despite their strength in language performance and sociability, it is rare that individuals with WS pursue language-related jobs. In this session we analyze what should be supplemented to their linguistic and social intelligences, using Japanese traditional language arts and math instructional methods, demonstrating two attempts targeted for teens with WS: develop unique skills to play picture-story shows and learning how to count on an abacus (counting frame) using the thumb and index finger only. The attendees will have an opportunity to practice, assisted by the speakers.

Admission Granted: But Leave Your IDEA at the Door  (18+)  Harborside A
Marisa Fisher, Ph.D.
Before your son or daughter leaves for college it is important to understand the types of accommodations and supports that will be provided and how they differ from those provided in the K-12 system. Most importantly, parents must understand that the procedural rights and safeguards afforded to students through IDEA are not mandated in post-
secondary settings. This presentation will discuss some of the recent difficulties individuals with WS have experienced including issues with Title IX.

10:00 - 10:20 AM  Break                        Grand Ballroom 6

10:20 - 11:35 AM  Breakout Sessions

**Common Endocrine Issues in Youth with WS**  (12 and under)  Harborside E
*Takara Stanley, MD*
Thyroid problems, slow growth and puberty issues are common in Williams syndrome. Learn the signs, symptoms and treatments.

**Putting Fun in Functional Aquatics**  (6 and under)  Essex AB
*Jane Styer-Acevedo, PT, DPT, C/NDT*
Join us to learn how activities in the water can help your child's stamina, coordination and overall health.

**Current Research on WS**  (All)  Harborside C
*Bonnie Klein-Tasman, Ph.D.; Barbara Pober, MD; Tom Collins, MD; Carolyn Mervis, Ph.D.; Marisa Fisher, Ph.D.*
Current WS researchers will present mini-platform presentations on their current research studies.

**Improving Lives through Sports: Special Olympics and WS Community**  (6+)  Harborside D
*Special Olympics Coaches Maryland; Heather O'Connell (SO New Jersey)*
Learn about the integrated Special Olympics Young Athletes Program, Athlete Leadership Programs (ALPs), Unified Sports and other programs positively impacting athletes from two years of age to 88+, as well as their families. Attendees will meet Michael Heup and Delaney O’Connell, individuals with Williams syndrome, and hear their story about how Mike and Delaney’s involvement with Special Olympics and participation in ALPs has helped them develop the skills to prepare them for where they are on the world stage.

**Helping Justice System Professionals Understand Your Sons and Daughters**  (16+)  Harborside A
*Officer Laura Blankman, Montgomery County Police*
A presentation by one of the Montgomery County Department of Police, Autism/Intellectual, Developmental Outreach Program officers. Officer Blankman will provide an overview of their outreach program, which provides a “layered” approach to safety and awareness through education, outreach, follow up, empowerment and response. The goal in providing this presentation is to learn as much as they teach.

11:35 - 1:00 PM  Lunch Break & Lunch & Learn Conversations

1:00 - 2:15 PM  Breakout Sessions

**Helping the Adult with WS to “Balance Their Bodies”**  (16+)  Harborside E
*Jim Guimond*
Fitness expert Jim Guimond will present a proven fitness regimen for adults with cognitive challenges that is easy to do at home or with a fitness coach (this program will also be presented to the adults with WS and a video will be provided).
Thursday, July 12 (con’t)

Top 10 General Medical Issues in Children with Williams Syndrome (under 12) Harborside D
Barbara Pober, MD; Beth Kozel, MD, Ph.D.; Marty Levinson, MD
How much does your child’s doctor know about Williams syndrome? Members of the WSA’s medical advisory team will discuss the common issues and treatments that every doctor of a patient with WS should know.

Melodies for Growth: Music Therapy for Individuals with WS (under 12) Harborside A
Leanne Belasco, RMT
An interactive session including a music therapy overview, research and clinical applications in school, and practical tips and applications to use at home. Case examples, IEP success stories, demonstrations and experiential learning will be included.

Pulmonary Surgery in WS (under 12) Essex AB
Tom Collins, MD
Dr. Collins will be presenting the results of pulmonary artery reconstruction in patients with Williams syndrome. The session will detail the technique pioneered and used by Dr. Frank Hanley at Stanford, and the short and longer term follow-up results of the surgical approach will be discussed.

Post-Secondary Options for Individuals with Williams Syndrome (16+) Harborside C
Moderator: Cate Weir, M.Ed.
The growing number of post-high school program options for students with WS is wonderful… and complicated. Join us for a conversation with program representatives aimed at helping you understand the variety of programming types and cognitive profiles served. There is something out there for everyone.

2:15 - 2:45 PM Break Grand Ballroom 6-10
2:45 - 4:00 PM Breakout Sessions

Cardiovascular Research Advances in Williams Syndrome Harborside A
Beth Kozel, MD, Ph.D.
Dr. Kozel will discuss her current cardiovascular research at NIH and the findings that can change the way we treat cardio issues in WS.

What about Writing? Beyond Handwriting and on to Composition (School age) Harborside D
Robin Pegg, M.Ed., COTA/L, ATP
Our kids are natural story tellers, but that doesn’t often translate to good written composition. This session will discuss the need for students with WS to have ongoing instruction in writing composition. Best practices in instruction, instruction strategies that work, and accommodations, including AT- will be reviewed and discussed.

Behavior Concerns and Challenges (11 and under) Harborside E
Bonnie Klein-Tasman, Ph.D.; Karen Levine, Ph.D.
A Q & A session to provide ways to address common behavior issues in children 11 and older, including challenges associated with fears, phobias and anxiety in children and adolescents.

The Highs and Lows of Living with my Brother or Sister with Williams Syndrome (All) Harborside C
Simon Levinson, MA, TLLP and Katy Levinson, LMSW
Listen in as siblings of individuals with Williams syndrome discuss the challenges, joys, personal expectations and expectations of others--all things they confront on a daily basis.
Thursday, July 12 (con’t)

Your Classmate has WS: Interactive Guide to Creating a Classroom Presentation

Katie Roodvoets, MA
(School age)
Have you been thinking about creating a presentation to teach your son or daughter’s classmates and teachers about your child and Williams syndrome? Katie will walk you through the process.

Q&A for Parents of Infants to Three Year Olds

Carolyn Mervis, Ph.D.
(0-3) Essex AB
Dr. Carolyn Mervis will discuss the developmental profile of infants and toddlers with Williams syndrome.

Friday, July 13, 2018

8:45 - 10:00 AM Breakout Sessions

Important New Findings from Cardiovascular Research at NIH
Beth Kozel, MD, Ph.D.
(All) Harborside A
Dr. Kozel will discuss her current cardiovascular research at National Institutes of Health (NIH) and the findings that can change the way we treat cardiovascular issues in WS.

Is Medication the Right Intervention for My Son or Daughter?
Christopher McDougle, MD, Ph.D.
(5+) Harborside B
Dr. McDougle will talk about the reasons for choosing medication and the medications that are most often “right” for those with WS.

Transition to Adulthood Starts in Kindergarten
Michelle Self-Bentley, Ph.D.
(4+) Harborside D
The transition process can start with simple tasks and become more concrete by middle school and high school. Guard against having your child “fall off  the cliff.” You will gain ideas for different visions and transition activities.

Sexual Nuance: Understanding the Concept
Beverly Frantz, Ph.D.
(18+) Harborside E
Does your child understand sexual nuance? Each year, an increasing number of students with WS are enrolling in university-based programs. Join us for a frank and important session addressing sexual issues on campus, and the critical importance for preparing your son or daughter to be appropriate in a college community.

Covering all the Angles of Estate Planning
Meredith Greene, Esq.; Pearl Hartley
Moderator: Tia Marsili, BA
(All) Harborside C
Representatives from all facets of the estate planning process will participate in a moderated discussion that will offer the when, where and how’s of creating a special needs trust, and how they intersect with your ABLE account.

10:00 - 10:20 AM Break

Grand Ballroom 6
Friday, July 13, 2018 (con’t)
10:20 - 11:35 AM

Behavior Issues in Young Children (Under 11) Harborside A
Bonnie Klein-Tasman, Ph.D. and Karen Levine, Ph.D.
Drs. Levine and Klein-Tasman will discuss (in a Q & A format) common behavior challenges in young children (under age 11) and successful interventions. Bring your personal questions.

Putting Together a Team to Include and Teach Your Child (School age) Essex AB
Beth Boylan, BCBA; Susan Chaplick, CCC-SLP, MS; Monica Fickenscher, BS
Hear from a team that currently supports children with WS who are fully included - learn the strategies they use, and how they communicate and work together to help each child with WS achieve their potential.

Realistic Expectations for Language, Cognition and Reading for Students with WS Harborside B
Carolyn Mervis, Ph.D. (School age)
Dr. Carolyn Mervis will provide a language, cognition and reading update.

IEPs in Action - Using the Power of Parental Input for Positive Change (School age) Harborside E
Robin Pegg, M.ED
The good, the bad and the ugly of IEPs: In this interactive session, we’ll show how to increase the positive outcomes and overcome the negative experiences by providing solid, evidence-based parental input to increase communication and collaboration. Please bring a printed copy of your child’s IEP/IFSP and a pen or highlighter to this session.

Anesthesia Concerns for Those With Williams Syndrome (All) Harborside C
Tom Collins, MD; Andy Matisoff, MD, Ph.D.; Leslie Smoot, MD; Morgan Brown, MD, Ph.D.
What we know, what you should know and how to prepare your child’s anesthesia team to take the precautions that can guard against adverse reactions to anesthesia.

Pathways to Justice - It Takes a Village (14+) Harborside D
Leigh Ann Davis, MSW, M.P.A.
A broad overview of the issue of people with I/DD in the criminal justice system. Lessons learned at the ARC National Center on Criminal Justice and Disability, and model programs will be included. Victim’s issues, and Pathways to Justice (ARC training program) will be described as well as up to date information on how to proactively get involved as a parent/advocate.

11:35 - 1:00 PM Lunch Break and Lunch & Learn Conversations Grand Ballroom 6-10

1:00 - 2:15 PM Breakout Sessions

Sleep Issues in Children (All) Harborside A
Melissa Moore, Ph.D.
Sleep issues in young children can be troubling. Melissa Moore will provide ideas to help.

Understanding the Educational Profile of students with WS (School age) Harborside C
Robin Pegg, M.Ed., COTA/L, ATP; Carolyn Mervis, Ph.D.; Karen Levine, Ph.D.
This session will review the educational profile of strengths and weaknesses for students with WS. Understanding this profile can provide teachers and school staff with a deeper understanding of the student with WS, and help guide instructional practices and routines. Parents who have a good understanding of the profile will be in a much better position to ensure their child receives the best possible education.
Friday, July 13, 2018 (con’t)

**Transition After High School: How to Prepare and When to Begin**   (18+)   Harborside E  
*Stella Beard and Donna Mooneyham*

Transition is a multi-step process. It is never too early to start.

**Meshing Employment Services**   (18+)   Harborside D  
*Nancy Mercer, John Kramer; Nicole Jorwik, JD; Jill Pierce; Kevin Walker; Moderator: Laura Chesser*

Working with vocational rehab, DDS, and community agencies to secure community employment with the supports you need for success!

**Expectations for the Future: How Self-Driving Vehicles, Virtual Reality and More Will Change the Future for Our Sons & Daughters**   Harborside B  
*Randy Cole and Abe Rafi*

This session will discuss how connected and self-driving vehicles can provide new independence for individuals with Williams syndrome, and new VR applications that are helping those with I/DD cope with anxiety, prepare for surgery, explore new work environments and more.

**Let’s Get Moving: A PT Perspective for Toddlers**   (0-3)   Essex AB  
*Helen Milligan, RPT*

Helen will discuss PT-based developmental milestones for 0-3 year olds with WS, followed by a hands-on class with the children for parents to practice activities for improving progress. (Bring your kids to class!)

2:15 - 2:45 PM   Break   Grand Ballroom 6-10

2:45 - 4:00 PM   Breakout Sessions

**Cardiovascular Concerns in WS**   (All)   Harborside A  
*Leslie Smoot, MD*

Seventy-five percent of our kids have mild to severe cardio issues. Learn all you need to know about the different issues and where you should take your kids when a problem arises.

**Behavior Supports in School**   (School age)   Harborside B  
*Beth Boylan, BCBA and Monica Fickenscher, MS*

How to develop and implement positive behavioral support plans in preschool/elementary school - from requesting a Functional Behavioral Analysis to working with a BCBA and paraprofessional.

**Speaking about Best Buddies - Positive Impacts for Everyone!**   (12+)   Essex AB  
*Amy Davies and Rachel Lipke*

Learn about the Best Buddies program - how to get involved and the positive impacts it can have on both the individual with WS and their Buddy!

**Charting the Life Course**   (All)   Harborside D  
*Celia Schloemer, MA*

Do you work best with structure? Do you find it hard to know where to begin when it comes to plotting a course for the future? Charting the Life Course is a curriculum that can add the structure you need.
Friday, July 13, 2018 (con’t)

Finding/Creating the Best Housing Opportunity Outside Your Own Home  (18+)  Harborside C
Jillian Copeland, MS; Nicole Jorwik, JD; Terry Monkaba, MBA; Julia Uhll, Desiree Kameka, MTS; Carol Patinkin, MSW; Moderator: Laura Chesser, BS
An independent life is the goal of a growing number of adults with WS, but finding the right opportunity for them is not always easy. Several parents who have located/created successful opportunities for their sons and daughters will be joined by housing professionals to discuss the when, where and how to find the right “fit”.

Warning Signs and Prevention of Adult Gastrointestinal Issues  (16+)  Harborside E
Barbara Pober, MD, Jenna Ottenheimer, PA
Diarrhea, constipation, diverticulosis, diverticulitis, IBS…the list of possible gastrointestinal issues for those with WS is long. Dr. Barbara Pober, along with WS parent and gastrointestinal PA Jenna Ottenheimer, will discuss the issues and possibilities for minimizing their impact over the lifespan.

Saturday, July 14, 2018

8:45 - 10:00 AM  Breakout Sessions

Sleep Issues in Adults with WS  (All)  Essex AB
Indira Gurubhagavatula, MD, MPH
Sleep Apnea and other sleep issues common to adults with Williams syndrome will be discussed as well as CPAP use.

Learning Experiences of an Excellent Reader with WS  (School age)  Atlantic
David Koppenhaver, Ph.D.; Sydney Shadrick and Clancy Hopper
This session will provide an in-depth reading profile of an accomplished young adult with Williams syndrome.

Growing Up with Williams Syndrome  (All)  Harborside D
Moderator, Laura Chesser, BS
Several young adults will share the life they have created and their dreams for the future. (this session repeats with other adults at 10:20 AM).

Making Math Meaningful  (School age)  Harborside B
Robin Pegg, M.Ed., COTA/L, ATP; Mary Ann Schmedlen
This session will focus on the best practices in math instruction featuring targeted instructional strategies for students with WS. Grades K-12 will be touched on, with the heaviest focus being on grades 3-9.

Considering Post-Secondary Options  (18+)  Harborside E
Moderator: Lisa Portune, MSW
Several parents of young adults who are currently in post-secondary programs or recent graduates will talk about the journey to finding the right program.

Future Financial and Public Benefits Planning - Do it Now  (All)  Harborside C
Tia Marsili, BA; Meredith Greene, Esq.
What can be done now to build a long-term solution? This session will provide information on all types of benefits - Medicaid, Medicare, SSI, SSDI, SNAP, energy assistance, etc. Legal authority and a comparison of trusts and ABLE accounts will also be included as well as a sample Letter of Intent which is a guidance document that every caregiver should write and update annually.
Saturday, July 14, 2018 (con’t)

10:00 - 10:20 AM Break

10:20 - 11:35 AM Breakout sessions

Anxiety and Depression in Adults with WS (16+)

_Dr. Barbara Pober, MD; Dr. Christopher McDougle, MD, Ph.D._

Drs. Pober and McDougle will discuss common issues of anxiety and depression, as well as triggers and treatments.

Reading Comprehension Profiles of Teens with WS (13+)

_Dr. David Koppenhaver Ph.D. and Dr. Sydney Shadrick_

Individuals with Williams syndrome (WS) can experience difficulties learning to read. In order to gather research that will provide appropriate instruction, we administered an informal, diagnostic reading battery to 11 adolescents in a camp environment in the summer of 2017. In this presentation we will share the informal diagnostic reading assessment process, results of our assessment, and instructional strategies that might be employed by educators, related services personnel, and families of individual with WS.

Growing up with Williams Syndrome (All)

_Moderator: Julia Uhll_

Several young adults will share the life they have created and their dreams for the future.

Implementing Effective Behavioral Principles in Learning for Children Diagnosed with WS (Under 8)

_Elizabeth Walsh, BCBA_

Basic principles of Applied Behavior Analysis (ABA); promoting independence with schedules and token economies; functional communication training and naturalistic teaching methods will be discussed.

---

 BERKSHIRE HILLS MUSIC ACADEMY

**LIFE SKILLS**

**MUSIC**

**VOCATION**

We use music to help individuals with intellectual disabilities develop skills for communication, independence, and employment.

For more information, visit www.berkshirehills.org or contact admissions at 413.540.9720 ext. 202

---

Special needs require Special Care.

When you’re ready, we’re here to help. MassMutual’s Special Care program provides access to information, specialists and financial products and services to help families facing the financial responsibilities of raising a child with a disability or other special needs. To learn more about how a financial professional can help your family, visit MassMutual.com/SpecialCare

Insurance. Retirement. Investments.
A Special Thank you to Our Convention Sponsors

Program Sponsors

UNITEDHEALTH GROUP

Strong
Everly’s Therapy Initiative

Boss Family

Silver Sponsors

Bernon Family
Vollbrecht Foundation

Wheeler Family

Bronze Sponsors

Maryland Developmental Disabilities Council

EMPOWERMENT • OPPORTUNITY • INCLUSION

Ronald Delanois, MD
The Bernon Family thanks WSA and Terry Monkaba for continued support to the families.

Our lives are better because of the tireless energy of the leadership and those who care so deeply for our children with Williams syndrome.
Hotel Floor Plans - Session & Program Locations

4TH FLOOR

Convention Registration
Infant Program Kent ABC
Toddler Program Laurel ABCD
Parent Sessions Harborside - All sections Essex AB
Exhibits, Cont. B-Fast, Breaks, Lunch & Learn
Grand Ballroom Salons 6-10
Volunteer registration
Elevator to Waterview

3RD FLOOR

Research Boardroom
WSA GANG Dover ABC
Parent Sessions Atantic
IEP-Advocacy Bristol
Research M. Greenfield

LOBBY LEVEL

Young Adults Waterview CD
Teens Waterview AB
Waterview Rooms accessible by elevator from 3rd & 4th floors
Dream Team Raven

Entrance to Raven is at the left end of the lobby level restaurant
Infant and Toddler/Preschool Programs - Infant to Age 5

Infant Program Leader: Erica Diffenderfer  
Location - Kent AB  
Toddler Program Leader - Julie Oglesbee  
Location - Laurel ABCD

Entertainment by musicians, magician, puppeteer and others will be provided throughout each day, as well as many supervised play activities. Programs are directed by experienced day-care providers who know Williams syndrome. They will be assisted by volunteers to ensure a ratio of 1 volunteer for every 3 children.

Additional information:
- Parents MUST provide all personal necessities for their child such as diapers, formula, and extra clothes.
- Morning and afternoon snacks will be provided.
- ALL children must be picked up for lunch.
- If your child requires a special diet for snacks you must provide clearly marked personal snacks.
- Naps will be provided for all children in the infant program and for children in the toddler program per parental request. Portacribs will be available for infants. Toddlers will utilize floor mats.
- Children with behavior issues that endanger the safety of other children or prevent others from enjoying the children's programming will be removed from the program. Parents will then be responsible for caring for their children outside of the structured programs.
- Toddlers/pre-school children are required to wear a WSA t-shirt and wrist band/name tag (provided) each day.
- The childcare program is staffed by volunteers. Although they will be briefed on the characteristics of Williams syndrome and told what to expect, most of them will not have had direct experience with children who have Williams syndrome. If you are not comfortable with a 1 - 3 ratio or if your child has severe behavior issues, we highly recommend that you provide an additional volunteer (relative, older sib, family babysitter, etc.) to accompany your child. Your caregiver will then be SOLELY responsible for your child while in the program.
School-age Program - Ages 6-12

WSA Program Leader
Robin Pegg
On-site Co-leaders - Alex Carrico & Bill Bentley
Location - Living Classrooms East Harbor Campus

The day-camp program* is hosted by RVR Outpost Camp at the Living Classroom’s East Harbor campus just 1/2 mile from the Marriott. Children will travel to and from the camp by privately reserved Water Taxi. Parents will escort children to dock area at prescribed time. Camp will start each morning at 9 AM (Water taxis will be leaving at 8:15 and 8:35) and campers will return at approximately 4:20.

Children will be divided into groups to facilitate age-appropriate activities at camp. Anticipated age groups are:
- Yellow: Ages 6 - 7
- Lime: Ages 8 - 9
- Turquoise: Ages 10-12

Daily activities include outdoor games, bounce houses, gaga ball, climbing wall, music, arts & crafts. There will be a sibshop for siblings ages 8 and older on Thursday morning.

*Children who have difficulty in a very active camp program may participate in a small, hotel-based program designed for school age children who need more adult support than a 1:4 ratio will provide.
Teen Program - Ages 13 to 17

Program Leader - Emma Thomas
Program Location - Waterview AB

Teens with Williams syndrome and their siblings will enjoy excursions in and around Baltimore’s Inner Harbor area, and entertainment brought to them at the Marriott. Registration each morning will begin at 8:15 AM and teens will be ready for pick up at 4:00 PM. Daily activities include:

**Wednesday 7/11**
Day in the Bay – group will depart at 9 AM. Activities include exploring the Aquarium, lunch at UNO grill and a trip to Ripley’s Believe or not

**Thursday 7/12**
Musical entertainment
Urban Pirates
Swiss Ball Fitness

**Friday 7/13**
A Full day at Terrapin Adventures

**Saturday 7/14**
Travel by water taxi to the Baltimore Museum of Industry
Program ends at Noon on Saturday
Young Adults - Ages 18 - 25

Program Leaders - Alyssa Bauman & Kaitlin VanWyk
Program Location - Waterview CD

Young adults will participate in a combination of programs on site at the Marriott as well as visits to local attractions and Washington DC. Optional early morning exercise class with Jim Guimond on the pool deck! (we will be creating an exercise video during this class. Pre-registration required - first come, first serve for 30 participants each morning.)

Check in each morning beginning at 8:30 AM and programs will end at 4:00 PM. (Note early start on Thursday!)

Wednesday, July 11
Welcome and introductions
Urban Pirates - Shipboard show
National Aquarium

Thursday, July 12
Busses depart at 8:30 AM for Penn Station
Travel to Washington DC by Train
Tour Washington DC by double decker bus

Friday, July 13
Learn about criminal justice - Officer Laura Blankman
Tour Pier 5 Lighthouse
Cruise the Inner Harbor - lunch and karaoke on board!
Session Choice:
  • Sexuality - Beverly Franz
  • Tips for Reducing Anxiety - Bonnie Klein-Tasman
  • Self-Advocacy (write a civil rights song) - Nancy Mercer

Saturday, July 14
Travel by Water Taxi to Fort McHenry for guided tour and exploration
Program ends at noon
WSA GANG - Ages 26 - 37

Program Leaders - Ashley Johnson, Eleni Norskey & Nancy Hanson
Program Location - Dover A thru C

WS GANG participants will enjoy a combination of programs on site at the Marriott as well as visits to local attractions and Washington DC. Optional early morning exercise class with Jim Guimond on the pool deck! (we will be creating an exercise video during this class. Pre-registration required - first come, first serve for 30 participants each morning.)

Check in each morning beginning at 8:30 AM and programs will end at 4:00 PM. (note early start on Wednesday!)

**Wednesday, July 11**
Busses depart at 8:30 AM for Penn Station
Travel to Washington DC by Train
Tour Washington DC by double decker bus

**Thursday, July 12**
Session on Safety in the Community with Officer
Water Taxi to Inner Harbor Attractions
Lunch at Hard Rock Cafe

**Friday, July 13**
Criminal Justice Session with Leigh Ann Davies
Cruise the Inner Harbor - lunch and karaoke on board!
Caricatures and Crafts
Educational Session Choices:
- Sexuality - Beverly Franz
- Tips for Reducing Anxiety - Bonnie Klein-Tasman
- Self-Advocacy (write a civil rights song) - Nancy Mercer

**Saturday, July 14**
Private Movie Showing at local theater
Program ends at Noon
WSA Dream Team - Age 38 and Older

Program Leaders - Pam Blevins & Jan Beard
Program Location - Raven

Young adults will participate in a combination of programs on site at the Marriott as well as visits to local attractions and Washington DC. Optional early morning exercise class with Jim Guimond on the pool deck! (we will be creating an excercise video during this class. Pre-registration required - first come, first serve for 30 participants each morning.)

Check in each morning beginning at 8:30 AM and programs will end at 4:00 PM. (Note early start on Thursday!)

Wednesday, July 11
Welcome and Guest Presentation
Water Taxi to Inner harbor
Lunch at Hard Rock Cafe
Choose an Option
• Ripleys Believe it or Not
• Historic Ships tour
• Maryland Science Center

Thursday, July 12
Busses depart at 8:30 AM for Penn Station
Travel to Washington DC by Train
Tour Washington DC by double decker bus

Friday, July 13
McFadden Art Glass
Cruise the Inner Harbor - lunch and karaoke on board!
Session Choice:
• Sexuality - Beverly Franz
• Tips for Reducing Anxiety - Bonnie Klein-Tasman
• Self-Advocacy (write a civil rights song) - Nancy Mercer

Saturday, July 14
B & O Railroad Museum - tour and train ride
Program ends at 12:30 PM
Welcome Reception for New Families - Wednesday, July 11    10:00 AM  
Harborside DE

The convention experience is awesome, but it can also be overwhelming. If this is your first convention please join us for a special welcome designed just for you and your family. We will have “seasoned” convention goers on hand to provide you with the tips and tricks that will help make your first convention experience a lot MORE awesome, and a lot LESS overwhelming.

Opening Reception - Wednesday, July 11    6:30 PM - 9:30 PM  
All are welcome  
Grand 6-10

Join us for a convention grand opening celebration. Speak to vendors from many resource providers, meet your RCs, re-unite with friends and enjoy great entertainment!

Block Party in Little Italy - Thursday, July 12    4:30 - 8:30 PM  
S. High St.  
Pre-registration required. $10pp  
ages 3 and under - free

Baltimore’s famous Little Italy is famous for its amazing Italian restaurants. On July 12, the WSA will take over 2 blocks of the neighborhood for a fabulous evening of fun! Four bands, stilt walkers, street painters, face painting, crafts and bocce ball will provide the fun. Families can eat before they come or enjoy fabulous food and outdoor seating at 4 great restaurants. Each of the restaurants will be adding special menu items for our kids that evening in addition to all their great food offerings. Little Italy is a short 3 block walk from the hotel!

DJ, Dance & Dessert! - Friday, July 13    7-10 PM  
Grand 5  
Pre-registration required. $10 pp  
ages 3 and under - free

We’re bringing in a great DJ to “Rock the House”. Join us for 3 hours of non-stop music, dancing and sweet treats!
Research Studies

Prominent Williams syndrome research teams will be conducting research throughout the national convention. Each of these studies help us to further our understanding of the characteristics of Williams syndrome. If you have not already signed up to participate, you may do so at the researchers’ exhibit tables at the opening reception on Wednesday. Study participation is voluntary and scheduled at your convenience. Children in the infant and toddler programs will be picked up and returned to childcare by a research team member. School-age participants must be picked up and returned by to the program by parents.

How Do Individuals with WS Understand Their Physical & Social Environments?  
Daniel Dilks, Ph.D.  
Emory University  
Ages 18 and older
We study how adults with Williams syndrome understand their physical environment (i.e., recognize and navigate places), and their social environment (e.g., whether another person might be considered a friend or foe). The studies we will be carrying out at the convention involve looking at a series of pictures of places, and asking simple questions such as, “Is this a kitchen, living room, or bedroom?” , “Which door could you use to exit this room?” , or reading (or hearing) a series of short stories about people, and answering basic questions about the people in the stories. We would ask you or your son/daughter to participate in several short studies, and anticipate that the entire session will last a maximum of one hour. We have short breaks between studies.

The “SHAAPE Study: Strength, Hormones, Activity/Adiposity, DNA Programming and Eating”  
Barbara Pober, MD  
Massachusetts General Hospital  
Ages 18-70  
ESSEX C
People with Williams syndrome can be thin, heavy or in-between. Heavy persons with Williams syndrome often store extra fat in their legs and arms. What causes these differences in size and shape? A new study run by Drs. Barbara Pober and Takara Stanley tries to answer these questions. If you take part you’ll be asked to get a short checkup and provide a small amount of saliva for DNA, and your parents/caregiver will be asked to complete a questionnaire. You will receive a $25 gift card as a thank you! We’ll be at the 2018 Convention but there are several ways to take part in this study.

“What do people remember about what they see and what they do?”  
Katrina Ferrara, Ph.D.  
Johns Hopkins University Language and Cognition Lab  
Ages 8 and older  
JAMES
We study what people know about the world and how people learn about space. In our study, we will show you pictures of different scenes and objects on a computer. For example, you might see a picture of a beach, a tennis ball, a leaf, etc. We want to learn what stands out the most about these pictures. We also have a study where we will search for hidden objects around the room. We want to learn what type of information is helpful in remembering various aspects of an event, such as what, where, and when an object was hidden. Each study will take about 45 minutes, and people will be paid for their participation.

Reducing Fears and Anxieties in Children with Williams Syndrome  
Bonnie Klein-Tasman, Ph.D.  
University of Wisconsin-Milwaukee  
Ages 4-10  
Suite TBD
Help us develop guidance for therapists working with children with Williams syndrome to reduce anxiety and fear. This research is open to families of children with Williams syndrome who get very anxious or afraid in particular situations (e.g., brushing hair, haircuts, flushing toilets, birthday parties). Dr. Karen Levine and Dr. Bonnie Klein-Tasman are working together to develop an online web portal to help guide therapists to use a play-based approach to reducing fear and anxiety.
• Parents will be interviewed either in person or via video chat about their child’s anxiety, and will be asked to complete some questionnaires about their child’s behavior, anxiety, and fears. They will track their child’s anxiety/fear for 2-4 weeks before and after the intervention sessions. Families will travel to the University of Wisconsin-Milwaukee for the sessions with the children. Children will complete a measure of cognitive abilities and participate in 2-3 play sessions (depending on availability and individual needs) aimed at reducing anxiety and fear.

The classification function of the visual spatial index of the Wechsler Intelligence Scale for Children with Williams syndrome  
Melissa Greenfield, M.S.  
The Chicago School of Professional Psychology  
Ages 6-16  
CHASSEUR
Individuals with Williams syndrome can experience difficulties in processing visual information and coordinating hand and body movements. This study will examine the use of two popular assessments with the goal of improving interventions targeted to develop these skills. Each participant will be given the two assessments, and a demographic questionnaire.
WHAT is the Registry
An online tool designed to promote research on Williams syndrome.

The Registry:
☐ Helps everyone learn about Williams syndrome; collects and organizes information about individuals with Williams syndrome.
☐ Makes research easier; connects persons with Williams syndrome & their families to those currently researching the condition.

WHY Join the Registry
By encouraging research, knowledge can grow even faster and lead to better care for persons with Williams syndrome.

The Registry takes advantage of:
☐ Power in Numbers: the more people who join the easier it is to answer research questions
☐ Group “at the Ready”: when new studies/treatments become available there is a group “at the ready” to consider participation.

WHO Can Join the Registry
The Registry is for families of individuals with Williams syndrome:
☐ A parent or legal guardian may join the Registry on behalf of a family member with Williams syndrome.
☐ Any family can join, even those who are not members of the WSA (FYI- being a member of the WSA does not automatically make you a member of the Registry.).

The Registry:
☐ Helps everyone learn about Williams syndrome: collects and organizes information about individuals with Williams syndrome.
☐ Makes research easier: connects persons with Williams syndrome & their families to those currently researching the condition.

HOW to Join the Registry
Visit www.williams-syndrome.org/registry-families

To Learn More or Become a Member Today!

If you have questions, do not hesitate to contact Registry Staff by email at WSRегistry@partners.org or by phone at 617-643-3190 or 617-726-5318
2018 Speakers

KEYNOTE SPEAKER

Michael Porath, The Mighty
Mike Porath is the founder and CEO of The Mighty, the leading digital health community that reaches more than 20 million people a month. He discovered the importance of community as the father of a girl with a rare disease, Dup15q syndrome, and created The Mighty to empower and connect people facing diseases, disabilities and other health conditions. Mike spent most of his career as a journalist, where he won multiple awards and held a variety of reporting, editing, producing and executive roles at ABC News, NBC News, The New York Times and AOL. He is on the board of directors and fundraising chair of Dup15q Alliance, the nonprofit organization that helps people with his daughter’s disorder, and a member of the Global Commission to End the Diagnostic Odyssey for Children with a Rare Disease.

Stella Beard - is the education and outreach coordinator for KYSPIN and has been involved in special education and advocacy work for many years. She and her husband Ryan have 4 children – JB (24), Clayton (22, WS), Taylor (16) and Cole (15) and she is currently serving on the WSA board of trustees. She has worked in special education in different school systems as a parent resource coordinator, special education liaison and special education program assistant, assisting families in locating resources in their local area and helping them become better advocates for their children. She has facilitated admission and release committee meetings for middle and high school students in a school district and has also worked for an agency for those with intellectual and developmental disabilities as the staff development director. She has trained around the state on many subjects including transition and medicaid waivers, and was the executive director for The Arc of Kentucky and was the parent enrichment coordinator for The Arc of Kentucky for many years. She has served on many statewide committees including: State Advisory Panel for Exceptional Children (Governor Appointed); Commonwealth Council for Developmental Disabilities (Governor Appointed); Kentucky Post School Outcomes (KyPSO); The Arc of Kentucky (Past Board Member); Kentucky TASH Board of Directors; Kentucky Interagency Transition Council; Kentucky Alternate Assessment Advisory Council (Past Parent Representative) as a parent representative on the College and Career Readiness/Kentucky State Personnel Improvement Grant. In 2009, she received the Betty Triplett Award sponsored by the Kentucky Partnership for Families and Children. This award is given each year to an outstanding professional who excels in working with families and children with disabilities.

Angela Becerra, Ph.D. - graduated from the Universidad de Los Andes in Bogota, Colombia with a degree in Psychology. She received her doctorate from the Department of Psychological and Brain Sciences at the University of Louisville, and is currently a senior research associate, working with Dr. Carolyn Mervis. Dr. Becerra's interests as a developmental psychologist include early language and gestural development in children with neurodevelopmental disorders. She is currently studying the developmental trajectory of gestural, lexical and grammatical abilities and how these trajectories affect later cognitive and behavioral characteristics in children with Williams syndrome.

Leanne Belasco, MS, MT-BC - is the Director of Music Therapy at Levine Music, a community music school in Washington, DC (www.levinemusic.org). Leanne has worked with individuals of all ages and abilities, including extensive work with individuals with Williams syndrome in the public school setting. She has presented at numerous conferences, in-services, and parent workshops in the metropolitan DC area and on a national level. Leanne earned her degree in music therapy from Duquesne University and her master's degree in special education, with an emphasis on autism and severe to profound disabilities, from Johns Hopkins University.

Officer Laura Blankman - is a Montgomery County Department of Police, Autism/Intellectual, Developmental Outreach Program officer, working to help police officers understand how to approach and communicate respectfully and effectively with community members with autism, and other intellectual and developmental conditions.

Beth Boylan, M.Ed., BCBA - received both undergraduate and graduate training through Penn State University. She was an autistic support teacher for 7 years before becoming a board certified behavior analyst (BCBA) in 2012. Beth has experience working in residential, private and public schools as well as home settings. She has a special interest in working with children and families to develop and train collaborative home, school and community teams to ensure all children achieve success and reach their potential.
Best Buddies mission.

Best Buddies, Rachel and Amy have both found friendship, employment, and leadership opportunities – the three pillars of the Citizens Program for more than two years and have both been involved individually in the program for over ten years. Through Davies, and Rachel Lipke, Global Ambassador for Best Buddies International, have been matched in the Best Buddies Maryland integrated employment, and leadership development for people with intellectual and developmental disabilities (IDD). Amy organization dedicated to establishing a global volunteer movement that creates opportunities for one-to-one friendships, Therapy. Emily received her master's degree in music therapy at Florida State University where she also received her certification as a NICU music therapist. www.levinemusic.com

Crystal Casmirri PT, DPT, C/NDT - graduated from Widener University in 2010 with her doctorate in Physical Therapy. She spent a brief part of her career working in adult inpatient trauma and rehabilitation centers before completely moving to pediatrics. She now specializes in early Intervention and solely treats children from birth to age 5. She is also one of the founders, owners and President of Sequoia Seeds Inc. Sequoia Seeds Inc provides early intervention services for children from birth to age 5. Crystal started this company to ensure all children receive high quality early Intervention. Crystal has advanced training in pediatrics and received her NDT certification this past year.

Susan Chaplick, CCC-SLP, M.S. - is a speech-language pathologist who helped establish early intervention programs at Bryn Mawr College. Currently she teachers four specialized preschool language groups and also provides individual speech and language services to the community. She is an ASHA certified speech-language pathologist with over 25 years of experience.

Laura Chesser, BS - holds a degree in Elementary Education and is currently working toward an M.A. in “Educational Leadership: Organizational and Global Leadership.” Laura is the Regional Coordinator for the WSA, and a member of the web-based educational advocacy team for the WSA. She is the former Executive Director of the ARC of Allegan County and a long-time advocacy specialist. Laura is a Phoenix Perth Partners in Policymaking graduate. She established a chapter of PRAISE (Parents Raising Awareness in Special Education) in Illinois and is a former educator of parents and professionals at “Family Matters.”

Randy Cole - is the executive director of the Ohio Turnpike. In 2013, Government Technology magazine named Randy as one of the nation’s Top 25 Doers, Dreamers & Drivers. He currently serves on the Advisory Board of “Drive Ohio” which is focused on bringing Smart mobility to Ohio, particularly for the benefit of populations currently limited by independent mobility options. He and his wife, Cyndra reside in Aurora, Ohio, with their five children, one of whom is a 9 year old daughter diagnosed with Williams syndrome.

Tom Collins II, MD - is an Assistant Professor of Pediatrics and Internal Medicine in the Division of Pediatric Cardiology at Stanford University and Lucille Packard Children's Hospital as well as coordinator of the Williams Syndrome Clinic. Dr. Collins graduated from the University of Tennessee College of Medicine, and completed a combined residency program in Internal Medicine and Pediatrics at the University of Tennessee Health Sciences Center in Memphis. Upon completion of his residency, he went on to complete his pediatric cardiology fellowship at the Children's Hospital of Philadelphia. He finished his subspecialty training with an advanced fellowship in adult congenital heart disease and non-invasive imaging. Dr. Collins has a special interest and expertise in the cardiovascular abnormalities associated with Williams syndrome. He has published multiple papers and has presented his research at national and international medical meetings and several WSA conventions and professional conferences.

Jilian Copeland - is the co-founder of Main Street - the first inclusive living opportunity and gathering space for adults with needs in the Washington DC region. The Main Street Vision: Main Street will provide an inclusive living opportunity and a gathering space with social, educational and therapeutic programming for ALL adults! Main Street will be a bustling hub of positive energy, a home away from home, where adults come to learn, live, socialize and play together!

Amy Davies - is Deputy Director of Programs for Best Buddies International. Best Buddies International is a nonprofit 501(c)(3) organization dedicated to establishing a global volunteer movement that creates opportunities for one-to-one friendships, integrated employment, and leadership development for people with intellectual and developmental disabilities (IDD). Amy Davies, and Rachel Lipke, Global Ambassador for Best Buddies International, have been matched in the Best Buddies Maryland Citizens Program for more than two years and have both been involved individually in the program for over ten years. Through Best Buddies, Rachel and Amy have both found friendship, employment, and leadership opportunities – the three pillars of the Best Buddies mission.
Leigh Ann Davis, MSW, MPA - is Director of Criminal Justice Initiatives at The Arc of the United States and directs The Arc’s National Center on Criminal Justice and Disability® (NCCJD®). With over 20 years of experience working at the intersection of intellectual/developmental disability (I/DD) and criminal justice, Ms. Davis strives to build stronger lines of open communication, understanding and respect between these two worlds. She authored The Arc’s first training curriculum for law enforcement on I/DD, The Arc’s first publication on sexual assault of people with I/DD, and presents nationally and internationally on a broad array of criminal justice and disability topics that involve both victim and defendant issues.

Tovah Feehan, MS, CCC-SLP CEIM - currently works in outpatient therapy at Nemours Al DuPont Hospital for Children, with a special interest in early communication as well as feeding and swallowing difficulties. Tovah helps develop interdisciplinary clinics and hospital processes to streamline care. Her clinical practice is driven by a passion to empower families and bridge the gaps that often exist in care.

Monica Fickenscher, BS - is a graduate of Cabrini University, receiving a BS in Special Education, with a minor concentration in elementary education. Upon graduation, Monica worked as a teacher of neuro-typical education and exceptional students for more than 10 years. After teaching for three years in a team approach method to teaching inclusion, Monica decided to work privately to provide services which would support inclusion in private school settings. Her vision and passion over the past 8 years has been to provide successful inclusion support within a regular classroom setting. Through collaboration, goal setting, formal planning, evidence-based practices, social skills language and training, behavior modifications as well as academic modifications and adaptations, she has witnessed amazing growth academically and socially with each and every student with whom she has worked. Monica lives outside of Philadelphia with her husband Chris, son Christian (14), and daughter Maggie (11).

Marisa Fisher, Ph.D. - is an assistant professor of special education at Michigan State University, a Board Certified Behavior Analyst-Doctoral (BCBA-D), the co-director of Spartan Project SEARCH, and the younger sister to a brother with WS. She conducts research examining the social behaviors of individuals with WS, and how those social behaviors are related to increased risk of victimization. She then uses these findings to develop safety training specifically for individuals with WS. Her current work examines how the social behaviors of individuals with WS are manifested through online platforms (e.g., social media) and how we can teach internet safety to young adults with WS. She is also developing a social skills intervention specifically for adults with WS.

Grace L. Francis, Ph.D. - is an Assistant Professor of Special Education at George Mason University. Her research interests include transition to adulthood and family-professional partnerships policies and practices that result in a high quality of life for individuals with significant support needs.

Beverly Frantz, Ph.D. - is an adjunct professor and project director of the criminal justice and sexual health programs at the Institute on Disabilities at Temple University. Dr. Frantz specializes in working with individuals with intellectual disabilities and autism and the intersection of healthy sexuality, sexual violence, and the criminal justice system to ensure all survivors have access to equal justice. Dr. Frantz is an expert in working with victim services, law enforcement, the disability community, and the judiciary to develop sustainable and proactive strategies and resources to reduce the risk of sexual and domestic violence, especially for individuals with complex communication needs.

Meredith Greene, Esq. - is an attorney specializing in Special-Needs Planning, Estate Planning, Guardianship & Conservatorship, Elder Law and Government Benefits Advocacy. She contributes extensive work in the area of in-service training with families, special educators, social workers, attorneys and other professionals and presents numerous workshops and seminars on special-needs planning and advocacy. She is a member of numerous professional organizations including the Council of Parent Attorney and Advocates, Inc., Special Needs Advocacy Network, Inc. and National Academy of Elder Law Attorneys. She is a Board Member of the Minute Man ARC.

Meredith received her law degree, cum laude, from Suffolk University Law School and her BA in political science from the College of the Holy Cross, where she captained the women's soccer team. She lives in Sudbury, Massachusetts with her husband, Tom, and their four children. Her eldest son, Connor (15) has Williams syndrome and will be skipping around the convention with her!

Jim Guimond - is a life coach, fitness technology consultant, personal trainer, and triathlete in addition to serving as Camp Director for Camp Bule Skies. He owns Live Well Charlotte LLC, and he is part owner of Kinetic Heights. His certifications include the American College of Sports Medicine, National Exercise & Sports Trainers Association, and Certified Group Fitness Instruction. Along with leadership development and fitness training, he works one-on-one and with groups of individuals with developmental disabilities. He's worked and volunteered with Special Olympics, Camp SOAR, The Exceptional Foundation of Charlotte and Autism After 18.
Indira Gurubhagavatula, MD, MPH - is Associate Professor at the Division of Sleep Medicine at the University of Pennsylvania's Perelman School of Medicine. She went to medical school at Johns Hopkins, completed her residency training in internal medicine at Washington University in St. Louis, and specialty training in Pulmonary, Critical Care and Sleep Medicine at the University of Pennsylvania in Philadelphia. She also has a Master's Degree in Public Health from Harvard University in Boston, MA. She is board-certified in sleep medicine. She practices at Penn and also at the VA Medical Center in Philadelphia. She has conducted extensive research and published many manuscripts, review articles and book chapters about obstructive sleep apnea, focusing specifically on screening for the sleep apnea in high-risk populations, including commercial vehicle operators. Her research has been funded by the National Institutes of Health, by the Veterans Administration, and by the American Heart Association. She is currently chair of the American Academy of Sleep Medicine's Public Safety Committee, Director of the VA Sleep Clinic and Sleep Laboratory, and Director of Penn's Occupational Sleep Medicine program. She has more than 25 years of experience in managing sleep disorders, including obstructive sleep apnea.

Griselda Guzman - lives in Paterson, NJ. She has been an advocate for more than 15 years. In 2015, her daughter, Ariana was diagnosed with WS and her passion for advocacy grew stronger. Griselda has completed the Partners in Policymaking program, is a committee member for the NJ Democratic Disability Caucus, a volunteer at New Jersey Coalition for Inclusive Education and a founder of the Special Education Parent Advocacy Council in Paterson, NJ (the third largest school district in NJ). She is a passionate advocate for inclusion and her goal is to establish a visible presence in the community by providing information, education, services and support to the underserved populations.

Pearl Hartley, Esq. - is a native of Pennsylvania. She is a Financial Advisor and member of The Washington Group Special Care Planning Team. Working in the financial industry for 35 years, Pearl's practice consists of individuals, families and businesses, with an emphasis on working with families with a special-needs situation and helping them meet their financial goals. She is actively involved with The Brain Foundation, a non-profit that provides housing to mentally ill adults. Pearl served on the board as treasurer from 2010 to 2014 and now manages one of their nine houses. She also enjoys spending time with her family, the beach and traveling. Pearl is securities and insurance licensed in several states including MD and VA and works with a variety of companies to find the best solution for her clients.

Clancey Hopper - has Williams syndrome, and lives in Nashville, Tennessee with her family, where she is a tour guide for the Grand Ole Opry. She is a motivational speaker and her goal is to change perspectives about persons with disabilities. Another goal she has is to help persons with disabilities find their voice and to effectively advocate for themselves. She loves God, family friends, traveling and country music! She is 29 years old and she tells us that she thanks God for giving her Williams syndrome because without it she would not be who she is today.

Nicole Jorwic, JD - is the Director, Rights Policy for ARC of the United States. She is committed to working toward systems change that will create equal access, improve supports, and provide full lives for all individuals with disabilities. Nicole has served in various roles to this end, including her appointment as a Senior Policy Advisor and Manager of the Employment First Initiative in Illinois, where she collaborated to draft a statewide strategic plan to make Employment First the reality in Illinois. Prior to that appointment, Nicole served as the CEO/President of the Institute on Public Policy for People with Disabilities where she continued the Institute's mission to improve the lives of people with disabilities and assisted the leadership of the state of Illinois in developing public policy driven best practices.

Nicole is also an accomplished special education attorney and an advocate for students with disabilities. She has written several articles and developed trainings in areas such as transition services for individuals with disabilities, early intervention, special education law and policy, and first responder training for police officers responding to individuals with disabilities in crisis situations.

Desiree Kameka, MTS - is the project lead for the Autism Housing Network. Her work for the Madison House Autism Foundation focuses on researching housing issues, advocating on issues of autism in adulthood, and presenting her work at local and national gatherings. She visits residential communities and social enterprises across the USA and highlights their unique victories and learning curves while sharing stories of individuals on the spectrum or who have other developmental disabilities. Her passion is empowering autistic adults and parents to create a future that is exciting and life affirming by offering small group consultations for forming projects.

Fusa Katada, Ph.D. - is a linguistics specialist. She received her Ph.D. from the University of Southern California, and a BA in Math Education from Tokyo Gakugei University, Japan. She is currently a professor at Waseda University in Tokyo, Japan. Dr. Katada volunteered at WSA's Whispering Trails Camp from 2009-2011. She has been a researcher on language and cognition in WS since 2008; and was an international participant at WSA National Conventions and International Professional Conferences 2010, 12 & 14. Dr. Katada is a frequent speaker at conventions and congresses including the 2014 WSA National Convention, 2015 World Congress of Modern Languages in Canada, and 2015 Cognitive Modeling in Science, Culture, and Education in Bulgaria.
Bonnie Klein-Tasman, Ph.D. - is Associate Professor in the Department of Psychology at the University of Wisconsin – Milwaukee, and Director of the Child Neurodevelopment Research Lab conducting studies on WS and Autism. Dr. Klein-Tasman completed her Ph.D. in Psychology at Emory University, with specializations in Clinical Psychology and Cognition & Development, and completed an internship in Child Clinical Psychology as well as post-doctoral training in Pediatric Neuropsychology at the University of Chicago, Department of Psychiatry. As director of the UWM Child Neurodevelopment Research Lab, her research focuses on the cognitive, emotional, and behavioral characteristics of children with neurodevelopmental disorders. She has published research about the cognitive, adaptive, and personality characteristics of children with Williams syndrome. Current research projects include examination of the socio-communicative difficulties of young children with WS that overlap with the autism spectrum.

Jenny Knox, BA - attended Wittenberg University, receiving a bachelor's degree in Communications. Upon graduation, Jenny moved to the Philadelphia region where she began her professional career with Liberty Property Trust, serving on their marketing team. Jenny is the mother of three beautiful children: Palmer (2), Everly (5) and Jackson (7), who happens to have Williams syndrome. As the mother of a child with unique needs, her journey of motherhood has been a whirlwind of doctors, therapists, specialists and tutors, all with the goal of helping her children live their lives to the best of their abilities.

Armed with knowledge, compassion and a desire to help others, Jenny now gives her time and energy to a variety of committees and causes that improve the lives of children. Her focus and passion is in helping families of children with special needs on the journey to advocacy and understanding. Jenny is an active volunteer at her children's schools and on the parent-run Committee for Special Education in her district. She donates her time to many local advocacy and support groups and is the co-founder of the Philadelphia Walk for Williams syndrome.

David Koppenhaver, Ph.D. - is a professor in the Department of Reading Education and Special Education (RESE) at Appalachian State University (ASU). He holds a Ph.D. in curriculum and instruction and a Masters in reading from the University of North Carolina at Chapel Hill (UNC). In 1998 he co-founded the Center for Literacy and Disability Studies at UNC and in 2002 was a Fulbright Scholar at the University of Queensland in Australia. His research focuses on literacy in children with significant disabilities including autism spectrum disorders, intellectual disabilities, complex communication needs, and multiple disabilities. His current projects include a study of visual attention to print in young children with Rett syndrome, an examination of reading skills in children and adolescents with Williams syndrome, and the development of a universal theory of learning for children with the most significant intellectual disabilities.

Kristen Kouvel, PT, DPT, PCS, CPMT - received her Doctor of Physical Therapy degree in 2009 from the University of the Sciences in Philadelphia. She is a physical therapist at the Children's Hospital of Philadelphia where she is the lead in their Connective Tissue Disorders Clinic. Kristen has a special interest in working with children with Williams syndrome. She is an exceptionally driven therapist who aspires to advance the field with her innovative treatment techniques, research efforts and through creating resources for the community.

Beth Kozel, MD, Ph.D. - is the Lasker Clinical Research Scholar at the Laboratory of Vascular and Matrix Genetics at the National Institutes of Health (NIH). Prior to joining NIH, Dr. Kozel was an assistant professor of pediatrics in genetics and genomic medicine at Washington University and Director of the Williams Clinic at St. Louis Children’s Hospital. Dr. Kozel has authored or coauthored more than 20 publications and three book chapters. The majority of Dr. Kozel’s work in research is focused on the study of Williams syndrome (WS) and isolated supravalvular aortic stenosis (SVAS). In 2015, she received the Williams Syndrome Association’s Heart Award for her work families at the Williams Clinic at St. Louis Children’s Hospital.

Jocelyn Krebs, Ph.D. - is a researcher of molecular and cell biology and Professor of Biological Sciences at the University of Alaska, Anchorage. Jocelyn is a cell and molecular biologist with expertise in the field of epigenetics, the realm of biology that explores how we actually use our genetic material. In 2007, Jocelyn received a grant from the Whitehall Foundation to study the role of Williams Syndrome Transcription Factor (WSTF). Jocelyn became fascinated with WS, training graduate and medical students to increase their understanding and awareness of Williams syndrome, and even meeting a handful of families affected by WS. In 2009, her son Rhys was born. Rhys was small and frail, had “truly impressive” colic for 9 months, and began to miss developmental milestones. Neither his pediatrician or his geneticist could venture a guess at a diagnosis, and then at 18 months, testing revealed that Rhys has Williams syndrome.

Jennifer Latson, MFA - is the author of “The Boy Who Loved Too Much,” a narrative nonfiction book about Williams syndrome that was one of LitHub's top 10 science books of 2017. Jennie is a former newspaper reporter, most recently at the Houston Chronicle. Her work has appeared in the Wall Street Journal, the Boston Globe, Time, Psychology Today, and other publications. She has an MFA in creative nonfiction writing from the University of New Hampshire and a BA in English from Yale University. In 2013, she was a recipient of the Norman Mailer Fellowship for nonfiction. jenniferlatson.net.
Karen Levine, Ph.D. - is a psychologist in private practice in Lexington, Massachusetts, and a lecturer at Harvard Medical School. She has treated children with developmental challenges including Williams syndrome for over 25 years. She was co-director of the Boston Children’s Hospital Williams Syndrome Program, with Barbara Pober, MD, in the late 90s, and co-founder of the Boston Children’s Hospital Autism Program. Dr. Levine is the recipient of the 2012 Lesley University Autism Hero Award, and the 2010 Federation for Children with Special Needs Founders Award. She has authored numerous articles and book chapters as well as co-authored 3 books. Her most recent book is Attacking Anxiety (Jessica Kingsley pub, 2015).

Katy Levinson, LMSW - is a school social worker at a high school in Metro Detroit. She works with students with a wide range of abilities. Her passion lies in inclusion and she has spent the last four years growing the Peer to Peer program in her building, working with students to create a community that celebrates diverse strengths and needs.

Marty Levinson, MD - is a pediatrician in the Detroit area who has been active with the WSA since its inception. He is the father of four adult sons, the oldest of whom, Josh, has Williams syndrome, diagnosed in 1980. Dr. Marty has lectured extensively on WS topics and participated in several publications, including the Healthcare Guidelines by the American Academy of Pediatrics.

Simon Levinson, TLLP - is a clinical therapist with a heart for play. His clients range in age from 6 to 76, and he works hard to integrate experiential and play-based interventions with solution-focused and depth-oriented treatment. Simon grew up in Huntington Woods, Michigan with his three brothers. Josh, his oldest brother, has Williams Syndrome.

Rachel Lipke - is a Global Ambassador for Best Buddies International, an organization she has been involved with (first in the Chicago area and now in the MD area for more than 10 years. Rachel and Amy Davies have been matched in the Best Buddies Maryland Citizens Program for more than two years, and they have both found friendship, employment and leadership opportunities – the three pillars of the Best Buddies mission.

Amanda A. Litt, DrOT, OTR/L - is an occupational therapist at The Children's Hospital of Philadelphia on the outpatient team. She has been a therapist at CHOP since 2016 and a pediatric occupational therapist since 2010. She provides outpatient-based therapy services for children with a wide range of diagnoses. She also provides interdisciplinary specialty clinic evaluations with the following programs: Adaptive Seating and Positioning Clinic, Cerebral Palsy Clinic, and the Connective Tissue Disorders Clinic, which includes children with Williams syndrome.

Leslie Seid Margolis, Esq. - is a managing attorney at the Maryland Disability Law Center (MDLC), Maryland’s protection and advocacy agency, where she has worked since 1985. In her practice at MDLC she handles individual special education cases and engages in special education policy work at the local, state and national levels, and has extensive experience with systemic urban school reform litigation, having co-counseled the 28 year Baltimore City Vaughn G. case for many years. Ms. Margolis is a frequent presenter at local, state and national trainings and conferences, and has published technical assistance documents, manuals, and articles. She has been a member of several national boards, including TASH, the Epilepsy Foundation and COPAA, and currently sits on several Maryland-based boards. In 2014, Ms. Margolis was the co-recipient of COPAA’s Diane Lipton Award for Outstanding Advocacy. She received the Outstanding Advocate of the Year award from The Arc Maryland in 2017.

Tia Marsili, BA - is the Director of Trusts, oversees the Special Needs Trust program at The Arc of Northern Virginia. September 6, 2015, marks the start of Tia's tenth year at The Arc. Tia meets with families, agencies, individuals, and attorneys throughout Virginia, Maryland, and Washington, DC. She specializes in educating the community about comprehensive Futures Planning and Special Needs Trust (SNT) services. Tia provides clients with over 23 years of experience in the world of disabilities. As a professional, as well as the mother of two daughters with disabilities, Tia personally works with families to establish a Special Needs Trust at The Arc of Northern Virginia.

Andrew Matisoff, MD - is an anesthesiologist at Children’s National Health System. As a member of the cardiac anesthesia team, Dr. Matisoff cares for all children with congenital heart disease undergoing various procedures. Dr. Matisoff has a special interest in caring for children with Williams syndrome and he is working on ways to make anesthesia safer for patients with WS.

Christopher McDougle, MD - is the Director of the Lurie Center for Autism, a multidisciplinary program that treats children, adolescents and adults with autism spectrum and other neurodevelopmental disorders. Dr. McDougle has received many awards of distinction and special recognition for his work in both psychopharmacology and psychiatry throughout his career. He also has a special interest in Williams syndrome and treats several clients, both pediatric and adult, with the disorder.

Nancy Mercer, LCSW - has more than thirty years of experiences putting the “continuum” in the idea of a continuum of services, in the housing, healthcare, disability, policy development and advocacy worlds. She is a champion of the belief that the key to calling
a place “home” is based on an individual’s ability to develop and maintain successful well-integrated support systems, for one’s lifetime. Ms. Mercer provides services to both individuals and communities as they vision and develop long-term care solutions that are reflective of their “unique” needs and goals; encourages broad-based stakeholder “buy in”; and creates sustainable “models” that will be able to support the long and very long-term needs of our increasingly diverse and aging communities. In 2015, she worked for Virginia’s Department of Behavioral Health and Developmental Services as a Community Integration Manager. In this role she provided the leadership required to transition the 137 men, women, families, staff and stakeholders from a lifetime of institutional care to homes of his/her own in the community. Ms. Mercer, founder of Inclusion Consultants, is committed to helping the people she works with find the answers that work for them, on both a micro and macro level. This type of advocacy and management requires the ability to understand, balance and maximize the many different ideas, resources and “challenges” that communities bring to the collective table.

Carolyn Mervis, Ph.D. - is a Distinguished University Scholar and Professor of Psychological and Brain Sciences, and Associate in Pediatrics, University of Louisville, Louisville, KY. Dr. Mervis has been conducting research on Williams syndrome for 18 years. Her primary interests are in language and cognitive development; temperament and personality; the longitudinal course of development of individuals who have Williams syndrome; and genotype/phenotype relations. Her research spans all age levels, from infancy through adulthood. Dr. Mervis first described the cognitive profile for WS that is commonly accepted today.

Helen Milligan, PT, MPT - has been the physical therapist in the Trisomy 21 clinic at The Children's Hospital of Philadelphia for the past 15 years. She has also worked as a PT in early intervention, in school systems and in private practice. She is also an adjunct professor at Arcadia University and Widener University in the physical therapy departments. Helen is a member of the Down Syndrome Medical Interest Group.

Terry Monkaba, MBA - holds a Master's Degree in Business Administration from Oakland University. She and her husband joined the Williams Syndrome Association when their oldest son Ben was diagnosed with WS in 1986. She has been involved with the administration of the WSA since 1990, serving as regional director, board member, board president, and since 1995, Executive Director of the WSA. During that time she has had the privilege of helping to grow the association from a small - parent support group operated out of the board president’s kitchen to a thriving non-profit with a million-dollar endowment, operating several annual programs for individuals with Williams syndrome.

Terry is on the professional advisory board and development and marketing committee of the Berkshire Hills Music Academy, a transition and life-skills program in Massachusetts, and is working with families in several countries to create better programs for families of individuals with WS worldwide.

donna Mooneyham, LRT/CTRS - has worked as a licensed recreational therapist, educator and trainer for 34 years. She presently teaches high school special education, aquatic therapy and rehabilitation courses for two universities and provides a number of other aquatic training programs. She has coached Special Olympics for 36 years and twice coached aquatics athletes in World Games, most recently in the 2015 World Special Olympics in Los Angeles. donna runs a private practice in Aquatic Therapy in Brunswick County, North Carolina serving individuals that are transitioning from rehab to community based participation. In her spare time, she enjoys kayaking, fly fishing and anything near the water.

Melisa Moore, Ph.D. - is a clinical psychologist in the Sleep Center at The Children's Hospital of Philadelphia and is board certified in behavioral sleep medicine. She received her Ph.D. from Case Western Reserve University with a specialization in pediatric psychology, and completed her predoctoral internship at The Children's Hospital of Philadelphia. She also completed a postdoctoral fellowship in Behavioral Sleep Medicine at The University of Pennsylvania.

Dr. Moore sees patients from ages 0-21 for a variety of behavioral sleep issues. She also regularly lectures and has taught courses on sleep at universities in the Philadelphia area. She conducts research on sleep in children and adolescents including the relationship between sleep and psychological functioning and interventions to improve sleep. Dr. Moore is also a sleep expert on the Pediatric Sleep Council. www.babysleep.com.

Melissa Murphy, Esq. - is a career federal government attorney, handling a range of complex appellate cases, regulatory matters, and policy issues under the Fair Labor Standards Act. Melissa is active within the special-needs community, particularly around issues concerning family engagement and inclusion practices. A graduate of Temple University Institute on Disabilities’ Partners in Policymaking program, she has served on the work group for the newly revised Early Learning Program Partnership Standards in Pennsylvania, as Parent Co-Chair of the Montgomery County Interagency Coordinating Council, and on the planning team for the annual statewide Family Engagement Summit in Pennsylvania. Melissa has been on the Board of Trustees for the WSA since 2015 and is currently the Board President. Melissa lives outside of Philadelphia with her husband Ben, a pediatrician, daughter Rose (7, WS), son Charlie (5), and Hope (6 months).
Heather O’Connell - is the Special Olympic Coordinator at the Hopewell Valley YMCA in Pennington, NJ. She oversees competition and development of athletes ages 6 and up currently in eight Special Olympic sports, and head coaches four - Strider Bike, soccer, basketball, and track and field. She manages the Special Olympics side of the Mercer County Equestrian Team’s competitive program. Heather is also the Director of In-House ice hockey at IceLand Skating Center in Hamilton, NJ and holds her Level 3 USA Hockey coaching certification. Heather believes in the importance of developing athletic skills for all athletes at their level and ability. Utilizing sport to improve gross motor, fine motor, social, and overall health of a person is at the core of her philosophy of programming and coaching. Heather is also mom to teenage daughter Delaney (WS), a regional chair for the WSA, and recently joined the board of the ARC of Mercer, and will be working with their recreation department and TV Production/Drama department.

Robin Pegg, M.Ed., COTA/L, ATP - is a Certified Occupational Therapy Assistant and Assistive Technology Specialist, working in the public schools for the last 13 years. Robin has extensive experience using all types of technology (low tech-high tech) to support learning and literacy development in children of all ages and ability levels. She also consults with various educational institutions to promote the implementation of Universal Design for Learning. Robin is the Recreation Director for the WSA Camp Programs.

Barbara Pober, MD - is a clinical geneticist who has provided care for persons with Williams syndrome for nearly 30 years. She started and then directed one of the first interdisciplinary Williams syndrome programs in the United States at Boston Children’s Hospital, and she continues to evaluate individuals of all ages with Williams syndrome at the Massachusetts General Hospital in Boston, MA.

Dr. Pober has published numerous articles about the medical status of those with Williams syndrome, and has lectured on Williams syndrome to both families and medical professionals. Increasingly, her interests are turning toward identifying issues across the lifespan and toward finding ways to improve the health and well-being of individuals with Williams syndrome. Dr. Pober is a long-standing member of the WSA Medical Advisory Board. Her current professional appointments in Boston, MA are: Geneticist at the Massachusetts General Hospital and Professor of Pediatrics (Emeritus) at Harvard Medical School.

Helen Pokrovsky, OTR - is a Pediatric Occupational Therapist providing therapy services in Philadelphia area. She graduated from Temple University with a Bachelor's degree in Psychology, minoring in Neuroscience in 2003, and received a Master's degree in Occupational Therapy in 2006. Helen has been in practice for 12 years working with children birth to 5 - addressing fine motor and gross motor skills, self-care skills and sensory processing difficulties.

Lisa Portune, MSW - is a licensed independent social worker with a passion to ensure all individuals, regardless of disability, age or mental health, have options to live as independently as possible with the proper supports and to have meaningful employment. She is married to Ned and they have three children; Grant (20) Erin (WS and 16) and Jack (14). As a parent advocate, Lisa has worked with parents to ensure children receive needed educational services, modifications and accommodations in the IEP and 504 Plan, within the least restrictive environment, and in accordance with IDEA law.

Abe Rafi - is Director of Digital Strategy and Online Services at the Arc of the United States. He is charged with enabling The Arc to achieve the digital dimensions of its goals. He leads the organization’s Technology Programs and Online Communications teams. He is responsible for managing relationships with technology-focused partners in corporate and government settings. He has organized and led product development teams to create online communities, mobile applications, websites and business intelligence tools for social change organizations such as Ashoka, Disability Rights International, The Bazelon Center for Mental Health Law, and for various clients as the founder of a web design firm. Abe is a long-time advocate for the rights of people with disabilities, having reported on human rights abuses in institutions for people with disabilities and trained human rights activists in Serbia, Turkey, and Russia. He is a graduate of the University of Michigan.

Officer Laurie Reyes - has been a police officer with Montgomery County since 1997. In 2004 she created and implemented the Project Lifesaver tracking program in Montgomery County, an outreach program dedicated to educating law enforcement and community members on the dynamics of interacting with those who have Autism/IDD. She was honored in 2015 at the Champions of Change ceremony at the White House. She has helped countless families implement safety protocols in case their child attempts to wander away from home.

Katie Roodvoets, MA - began her teaching career as an AmeriCorp volunteer tutoring inner-city youth who exhibited a multitude of needs. Since receiving her MA in Education and ESL from Aquinas College, she has taught English learners who represent languages and cultures from around the globe. The most rewarding aspect of her job is teaching and building lasting relationships with a small refugee population in her district. Katie’s teaching experience has prepared her to be an advocate for her own child and others. She and her husband Jonathan have three children ages 2, 6 and 8. Their first child was diagnosed with WS at five months old, and it has been a journey of prayer, perseverance and praise. When she is not working or busy with kids, Katie enjoys the relaxation of watercolor painting and frisbee golf. She also leads Wonderfully Made: A Ministry for Families of Children with Special Needs at her church and is a WSA Regional Committee Member.
David Roth - is a singer, songwriter, recording artist, keynote speaker, workshop leader, and instructor. David has earned top honors at premier songwriter competitions – Kerrville (TX) and Falcon Ridge (NY) – and taken his music, experience, and expertise to a wide variety of venues in this and other countries full-time for three decades. David has also taught singing, songwriting, and performance at the Augusta Heritage workshops, SummerSongs (NY – where he currently serves as Executive Director), Common Ground on the Hill (MD), the Woods Dance & Music Camp (Canada), WUMB's Summer Acoustic Music Week (NH), Moab Folk Camp (UT), Rowe Center (MA), Pendle Hill (PA), Lamb's Retreat (MI), the Swannanoa Gathering (NC), the National Wellness Institute (WI), and for many other songwriting groups and associations around the country. David is also founder/director of the Cape Cod Songwriters Retreat and creator/host of Cape Cod's “Full Moon Open Mic” which, for the past 12 years has provided a forum for musicians to connect and be heard while at the same time collecting donations ($14,000 to date) for local non-profits to help neighbors in need.

Celia Schloemer, MA - is the Family Support Coordinator at the University of Cincinnati-University Center for Excellence in Developmental Disabilities, (UC-UCEDD). She comes to this position with more than 14 years’ experience working directly with families of children with disabilities as an educational advocate. In her present position, Celia supports individuals with disability and their families across the life span by connecting them to resources, assisting them in accessing information and offering trainings that improve outcomes. Celia is a Charting the LifeCourse Ambassador and a member of the National Community of Practice Supporting Individuals with Developmental and Intellectual Disabilities. She proudly brings to her work the perspective of being a sister-in-law, an aunt, a sibling and a mom to individuals with intellectual and developmental disabilities.

Cindy Schiro - has an 18-year-old son with Williams syndrome; the story of how she navigated her son's coming of age was documented in the 2017 book “The Boy Who Loved Too Much.”

Mary Ann Schmedlen, MA - is a math consultant at Eaton Regional Education Service Agency in Michigan. She has been in the education field for 17 years, 15 of those as a math and language arts teacher in the middle grades. Mary Ann has a Bachelor of Science in Education degree from Central Michigan University and a Master in the Art of Teaching degree from Marygrove College.

Michelle Self, Ph.D. - is an adjunct professor in special education at Bowling Green State University in Ohio. She teaches courses ranging from early childhood assessment to transitioning out of high school. She also is an advocate for the inclusion of students with Williams syndrome and this was her dissertation work. She is an educational consultant/owner of Partners for Educational Success LLC where she helps families get the supports their child needs to participate in the least restrictive environment. Michelle is a past WSA board member and also serves on the education committee. She is the proud parent of Bill (WSA counselor) and Alex (18 years old) with Williams syndrome.

Cheri Settanni, M.Ed. - received a B.S. in Special Education from the University of Florida and an M.Ed. in Special Education from Temple University. She was a special education teacher in Lower Merion School District, Pennsylvania, for thirty-five years where she worked with children with a wide range of exceptionalities. She currently works as an Academic Specialist. In this role she acts as a liaison between home and school and both develops and facilitates academic components for home programs that support the schools goals.

Sydney Shadrick - is a Wilson Scholar at Appalachian State University. She collaborated with Dr. David Koppenhaver throughout this past academic year on a pair of studies examining literacy in people with Williams syndrome. Sydney is on track to graduate as a special education major with a minor in Spanish.

Leslie Smoot, MD - received her MD from the University of Minnesota School of Medicine, followed by a Pediatric Cardiology Fellowship at Boston Children's Hospital where she has developed a long-standing career. Dr. Smoot's principal specialties are cardiomyopathy, heart failure, heart transplant and Williams syndrome. She has been the coordinator of the Williams Syndrome Clinic at Boston Children's Hospital since the late 90's.

Takara Stanley, MD - is a clinician in the Massachusetts General Hospital for Children's Pediatric Endocrine Unit and a clinical investigator in the Pediatric Endocrine Unit and MGH Program in Nutritional Metabolism. Her research interests include nonalcoholic fatty liver disease, hormonal perturbations associated with obesity, and metabolic effects of growth hormone. She directs the pediatric endocrine training program at MGHFC. Dr Stanley works closely with Dr. Barbara Pober at Mass General Hospital to oversee the endocrine issues in patients with Williams syndrome.

Jane Styer-Acevedo PT, DPT, C/NDT - is Senior Adjunct Faculty at Arcadia University, teaching in the Physical Therapy Department, and maintains a clinical practice, treating individuals through the lifespan with neurological challenges. She is a master clinician in the areas of pediatrics, neurology, and therapeutic aquatics and has been teaching continuing education workshops,
nationally and internationally since 1983. Jane’s scope of teaching includes aquatic and “land-based” courses in Australia, Europe, Asia, India, Africa, and North, Central, and South America. She is currently Chair of the Neuro-Developmental Treatment Association (NDTA) Instructor Group and an Active Pediatric Coordinator Instructor for the NDTA, teaching continuing education courses of varying lengths related to the NDT Practice Model. Jane excels in the problem-based approach to promoting functional shifts for an individual through therapeutic intervention from the acute phase, through rehabilitation, and community entry or re-entry towards life-long participation, health and fitness.

**Julia Uhll** - is on a mission to impact and improve the lives of others. She is a Realtor with Realty ONE Group, practicing for over 15 years. Previously she has been a professional ice skater, worked in television, owned a restaurant and worked in IT. She speaks Spanish and French... Julia is married to Ossie Arciniega, her partner in life and business. Their son, AJ, age 25, has Williams syndrome and is very proud of it! Julia is heavily involved with the local seniors and special-needs community in San Diego: advocating for individuals and families, working on adult programs and an independent apartment community. Super exciting stuff!

**Cindy Utama, M.Ed.** - is a licensed special educator. She currently works as a case manager at the University of Massachusetts Amherst Disability Services and has years of experience working as Learning Specialist at both UMass Amherst and Lawrence University of Wisconsin. She has a master's degree in Special Education from UMass Amherst and a bachelor’s degree from Tokyo Zokei University, Japan. Cindy's only sibling, Samantha, was diagnosed with Williams syndrome as an adult in 2012 following their participation in the WSA Convention in Boston that year. Cindy is passionate about helping students of all abilities and their families. Her vision is to promote accessibility and inclusion in Indonesia, where she was born, and Asia.

**Elizabeth Walsh, BCBA** - has been a Board Certified Behavior Analyst since February 2014. Elizabeth earned a Bachelors of Science in Psychology from Jacksonville State University (Jacksonville, Alabama) in 2008 and a Masters of Science in Psychology specializing in Applied Behavior Analysis from Jacksonville State University (Jacksonville, Alabama) in 2012. She has been providing ABA therapy and working in the field of Applied Behavior Analysis for 11 years on both in-home and school-based cases ranging from ages 2-21, specializing in treating maladaptive behaviors including elopement, toileting, and using the Verbal Behavior Approach to teach language to children with Autism and other developmental disabilities.

Elizabeth was introduced into the world of Williams syndrome in May of 2016 when her 6-month-old son, Brodie, was diagnosed. She is currently a WSA Regional Committee Member in the Gulf Coast Region and looks forward to continuing her future work with the WSA.

**Kevin Walker, BS** - is Director of Employment & Consulting Services for Penn-Mar Human Services in Freeland, MD. Kevin graduated from York College in 1995 with a Bachelor's of Science degree in Psychology. He has been employed with Penn-Mar Human Services since 1993 working in the day program as a Production Trainer, Rehabilitation Specialist, and presently serves as Penn-Mar’s Director of Employment and Consulting Services. Kevin has been a certified Behavioral Principles and Strategies instructor since 2002.

**Catherine (Cate) Weir, M.Ed.** - is the program director for the Think College National Coordinating Center. Previously, she served as a project coordinator for higher education-related projects at the Institute on Disability at the University of New Hampshire. Cate also has worked as a disability support coordinator and a faculty member for the Community College System of New Hampshire. Her expertise includes the provision of individual supports for postsecondary education, person-centered planning, and strategic planning for organizations.
UnitedHealth Group is honored to support the Williams Syndrome Association and its mission to improve the lives of people living with Williams syndrome.
Lipedema is a poorly understood chronic condition that occurs almost exclusively in women. It manifests as a symmetrical buildup of painful fat and swelling in the arms and legs, sparing the hands and feet.

Our mission is to define, diagnose, and develop treatments for lipedema.
Lucidus Solutions Welcomes the 2018 Williams Syndrome Association Convention to Baltimore!

Proud Sponsor of the PM Minority Scholarship for the 2018 WSA convention

About Lucidus

Lucidus Solutions ("Lucidus") is a Baltimore based consulting services company dedicated to the management and support of its clients as a trusted partner and advisor with the resources and expertise to meet their needs.

Domains

- Cloud Computing
- Health IT
- Grant Management Systems
- Financial Management
- Government Systems

Services

- Software Development & Technical Expertise
- Architecture & Design
- Program and Project Management
- Database Design and Administration
- Staffing

Contact Us

@ www.lucidus.com  info@lucidus.com  410-205-4500  Pikesville, Maryland
Thank You for Joining Us