

2022 CONVENTION SCHEDULE

Please indicate the session you would like to attend by placing a check mark in the box to the left of the session title. If both adults plan to attend the same session please put a "2" in the box.

Tuesday – July 12

10:00-12:00 PM **Registration - Families of Young Children**

1:00-4:00 PM **Registration for Everyone**

2:30 PM-3:45 PM **New Family Welcome & Networking for first time attendees with younger children**
If you are a first-time convention attendee with a young child (under 12), join us for a special welcome reception. Meet other "first-time" families and learn the "tips and tricks" that will help you get the most out of your convention experience.

4:00 PM-6:00 PM **Exhibits Open**
Exhibitors and Resource providers will be on hand in the ballroom foyer to provide you with valuable resources and answer your questions.

6:00 PM-9:00 PM **Opening Night Festival**
Join us on the hotel's "grassy knoll" for a casual opening night celebration complete with music, activities for the kids, food trucks and more!

Wednesday - July 13

8:45 AM-10:00 AM **KEYNOTE**

 Raised Expectations for Self-Determination, Productivity, Inclusion and Community Belonging for All Children and Adults with Williams Syndrome and ID/DD is The Law: "Suit the Actions to the Words" is Our Advocacy Allan Bergman

This session will provide exact language and guidance to see the amazing consistency and alignment of core values from the Developmental Disabilities Assistance and Bill of Rights Act, the Individuals with Disabilities Education Act (IDEA), Rehabilitation Act, the Americans with Disabilities Act (ADA) and Medicaid Home and Community-Based Services Waivers. They demonstrate the elimination of the "deficit/medical model" of disability and labels into the individualized, person-centered approach based on each person's strengths, preferences and interests.

10:15 AM-11:30 AM **Breakout Sessions**

 Be Your Child's Champion: Advocacy Tools and Legal Framework Melissa Murphy, Esq

This session will focus on tools and strategies for families to become effective advocates for their children. An overview of special education law essentials, programs for family engagement, and top tips for successfully advocating for the placement, supports, and related services your child needs (and is entitled to!) will be provided. Perfect for newly diagnosed families or families with children elementary age and younger.

7/13 10:15 AM - 11:30 AM (con't)

Renal Issues in Williams syndrome Mark Joseph, MD

The prevalence of significant renal abnormalities in patients with Williams syndrome is high. Kidney abnormalities, missing kidneys, renal artery stenosis, hypertension and more can occur. Learn about the screening and prospective follow-up for renal abnormalities.

Supporting an Older Adult with Williams Syndrome Barbara Pober, MD, Martin Levinson, M.D., Robyn Thom, MD

As we get to know many older adults with Williams syndrome, we are learning more about new challenges (medical and neuro-developmental) that are part of the aging process for those with WS. Join Drs. Pober and Levinson, and parents of aging adults for an informative and important session!

Social Relevancy + Executive Functioning=Autonomy Robin Pegg, M.Ed. and Carolyn Mervis, Ph.D

Worried about your child being a part of their classroom and school community? Not sure what to do to help them fit in? This session will discuss how being able to follow the routines of the classroom and be involved with your peers helps kids feel relevant and a part of their school community. We will also discuss how these same skills support can support your child's ability to live a life of their own choosing as they get older.

What is Music Therapy? An introduction on the benefits of music therapy for child development and at-home music tools to support your child Alyssa Stone, MT-BC

Join Alyssa to learn about the evidence-based practice of music therapy for individuals with disabilities, communication needs, and more. If you've always been curious about what music therapy is and how it might best support your child, this is the workshop for you! Alyssa will give you take home tips and tricks to use music for communication, regulation, social engagement, and more.

FSN-NETWORKING GROUPS Parent of Adults

7/13 1:00 PM - 2:15 PM Breakout Sessions

Success in the Early Elementary School Years: Strategies to use both at home and in the classroom Robin Pegg, M.Ed.

Robin Pegg will discuss things you can do/make both at home and in the classroom to help your student with WS access grade level curriculum, overcome learning challenges and succeed

First Steps for Parents of Young Children Marty Levinson, MD

An informative overview of what you can do to help ensure your child's good health throughout their early years, periodic wellness exams and what they should include; signs of issues that require medical intervention; developmental milestones, all of the steps that can help ensure that your child's early development creates a solid foundation for their growth and success.

Black, Brown and Extra Special: raising children of color with WS Jennifer Walton, MD, Jalan Burton, MD moderators

Parent representatives from several culturally diverse communities will discuss the challenges they face every day in this interactive panel presentation.

Understanding the Maze of Government Benefits Barbara Bush

Do you have questions about the difference between SSI and SSDI, or how to maximize your SSI benefits with the use of an ABLE trust account? What happens to your child's benefits when they work? These questions and many more will be discussed in this presentation.

7/13 1:00 PM - 2:15 PM (con't)

Employment First means "Employment for All" Persons with Williams Syndrome and ID/DD in 2022 and the Future Allan Bergman

This session will provide an overview of the research and best practice and cost data in understandable language on the benefits of "real jobs for real pay" beginning with school transition plans, supported employment, customized employment, self-employment and employer feedback in comparison with the outmoded sub-minimum wages paid in many segregated facilities (work centers/sheltered workshops).

FSN NETWORKING GROUPS Adult - topic driven

2:30 PM - 3:45 PM Breakout Sessions

Pediatric Geneticists - Why they are an Important Team member for parents Joshua Baker, MD

The session will be a brief overview of the benefits of a medical home model using the pediatric genetics team to help follow and direct care using the published guidelines.

Behavior Concerns for those 11 and younger - Q & A Karen Levine, Ph.D, Bonnie Klein-Tasman, Ph.D

By answering questions from those attending, this session will provide strategies to address common behavior concerns in children 11 and under, including challenges associated with phobias and anxiety.

Coping in the Midst of a Chaotic Life: Taking Care of You! Kit Sluder, RN

When our children are diagnosed with Williams syndrome, we tend to switch into high gear and work really hard to accomplish way too many things and we often do it without taking the time to personally relax and rejuvenate. That's a bad idea! Join us to learn the coping strategies you need and get ideas for healthy rejuvenation!

Housing Options, like Classroom Options Must be Carefully Chosen for Success PANEL - Ed McManus Moderator

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. Learn how to start the conversation with your adult, where to start the search and what questions to ask.

Let's Get Moving - Youth Physical Therapy Issues Kristen Kouvel, RPT

Learn about the common PT issues for youth with WS - stair climbing, playground navigation and much more.

The things our Parents Just Can't see About our brothers/sisters PANEL

Brothers and sisters of all ages, as they discuss the challenges, joys and lessons they have learned (and are still learning!) in their journey as the sibling of an individual with Williams syndrome.

FSN NETWORKING GROUPS Parents of Teens

7/14 8:45 AM - 10:00 AM KEYNOTE

40 and Counting... The Journey of a Lifetime - KEYNOTE

Terry Monkaba will talk about 40 years of our growing knowledge of Williams syndrome and the growth for the WSA. What's Next?

10:15 AM-11:30 AM Breakout Sessions

Anxiety in Adolescents and Adults with Williams Syndrome Robyn Thom, MD

Anxiety disorders affect approximately half of individuals with Williams syndrome and can affect social, educational, and occupational functioning. This session will cover how symptoms of anxiety in Williams syndrome manifest across the lifespan, with an emphasis on symptoms that develop during adolescence and adulthood. Treatments for anxiety will also be discussed.

Therapies for Early Development PANEL

Specialists in OT, PT, Speech and AT will discuss the importance of therapeutic intervention

How to Avoid Parenting on Empty Susan Millner, LCSW

Marriage can get left behind when a child in the family has complex needs - Don't let that happen!

Breaking the Math Myth for Students with Williams Syndrome: Algebra IS an option! Robin Pegg, M.Ed.

For years we have all heard that our kids can't do math. We now know that the experts were wrong. The key is in the approach, and with the right one, advanced concepts are achievable. This session will present recent research in math abilities for students with WS and provide guidance in instructional strategies to support skill development.

Customized Employment: The Future for Individuals with WS is NOW Steven Hunt, PhD

FSN NETWORKING GROUPS Parents of School aged Children

7/14 1:00 PM - 2:15 PM Breakout Sessions

What to do if your Son or Daughter is a Victim or a Suspect of a Crime Beverly Frantz, PhD, Leigh Ann Davis
Individuals with WS are achieving greater levels of independence and community inclusion every year. And with that, comes new opportunities for relationships and new vulnerabilities that must be confronted. Join us for a frank and important session addressing sexual issues and safety concerns for adults with Williams syndrome.

The College Search: Tips and Tools for Parents and Students Cate Weir
This presentation is a demonstration of the College Search resource on www.thinkcollege.net, and provides a walk-through of critical features families need to know when using this database.

Transition...An Important Step into the Future for Every Individual with WS TBA
Transition has many stages. We as parents often ask ourselves questions about our child's future: What does the young person want to do with his or her life? What are his or her dreams, aspirations, or goals? What are their needs, abilities, and skills? This session will help families understand the importance of "letting go" and how to help find their wings. We will help families begin to think outside of the box and imagine what a desirable future for their child can look like.

Not All Classroom Placements are Created Equal: Finding the right placement for your child with WS
PANEL- Robin Pegg Moderator
Classroom settings are not "one size fits all". Parent panelists with children who are successful in a variety of different programs will tell you how they made the right choice, and what they've done to ensure their children are accessing grade-level curriculum regardless of classroom placement.

7/14 1:00 PM - 2:15 PM (con't)

Moving from Group Homes to Supported Living and "Home Ownership" for All Persons with Williams syndrome and ID/DD Allan Bergman

This session will provide an overview of the research on community integrated living and the consistent data that the best quality of life outcomes and community belonging occur when three or fewer individuals with disabilities, regardless of complexity or intensity of supports, choose their own home (based on affordability and accessibility) share a "home" with housemates of their choice and choose their providers - as well as funding strategies to pay for them.

Behaviors Q&A - Ages 6 – 17 Bonnie Klein-Tasman, PhD

This session will provide strategies to address common behavior concerns in children 6 through 17, including challenges associated with phobias and anxiety.

FSN NETWORKING GROUPS Parents of Infants/Toddler Optional

7/14 2:30 PM – 3:45 PM Breakout Sessions

College Program Options PANEL, Rebecca Lazo, Moderator

Program representatives from several college programs will talk about qualifications, applications, student profiles and more.

Intro to WS deletion - interactive session!! Jocelyn Krebs, PhD

This session is a basic introduction to how the WS deletion occurs and to the known roles of the genes in the WS deletion. You will also have the unique opportunity to become a part of chromosome 7 in this interactive and informative session.

Loosen Up: Prevent and Manage Joint Contractures in Teens and Adults using a PT approach Kristen Kouvel

An interactive session covering the who, what, where, when, how and why of joint contractures, as well as how to prevent and manage them.

The Heart of WS: Lessons from the National Institutes of Health (NIH) Mark Levin, MD

With such a wide range of aortic and pulmonary disease within WS, how diligent should we be? Dr. Levin will review the major cardiac abnormalities seen in Williams syndrome as well as the generalized vascular disease and how that relates to recommending fluids and exercise... and much more.

Anxiety in Youth Bonnie Klein Tasman, PhD

Anxiety can be a factor at any age. Session will discuss common manifestations of anxiety in youth with WS and strategies for dealing with and overcoming the challenges they present.

FSN NETWORKING GROUPS Parents of adults with dual diagnosis or adults beginning the journey to find housing options

7/15 8:45 AM - 10:00 AM KEYNOTE

Williams Syndrome in the Media

On the Brink of a New World of Awareness for Williams Syndrome - Producers/Writers of Current Projects on WS will introduce us to their "stars" and talk about their projects Susan & Matt Dunnigan, Phil Viardo & Trueloves et al, Jake Jacobowski & Josh Bloom, Tommy & Mariella Elm

10:15 AM -11:30 AM Breakout Sessions

What our genes tell us about health in WS: Lessons from the NIH Beth Kozel, MD

This presentation will focus how changes in DNA (both within and at a distance from the WS deletion) impact the severity of vascular and developmental features of WS. We will also talk about the work we are doing at the NIH to take the lessons learned from patients' DNA and cells to guide us toward new therapies for vascular disease in WS.

Introducing the Social Skills Training Program for Adults with WS Marisa Fisher, Ph.D

Presentation will describe a Social Skills Training Program for Adults with WS, including the topics the program currently covers, findings from the pilot program, and ideas for next steps. We would enjoy discussion with the audience on additional topics that could be included in future trainings.

Psychopharmacology of Williams syndrome Chris McDougle, MD

This session will review how psychopharmacology can be used for the treatment of psychiatric conditions which commonly co-occur with Williams syndrome, including attention-deficit/hyperactivity disorder (ADHD), anxiety disorders, mood disorders, and psychosis.

Gynecological Issues for Girls and Young Women with WS Carrie Terrell, MD

This session will discuss the special concerns of early puberty, hygiene issues, GYN exams, birth control for girls/women with WS

The Nuts and Bolts of Special Education for a Student with Williams syndrome Michelle Self, PhD

Special Education can be daunting. This session will review the basic components of an IEP with specific focus on eligibility, parental input; FAPE, and LRE.

FSN NETWORKING GROUPS Infant/Toddler Topics Optional

7/15 1:00 PM - 2:15 PM Breakout Sessions

College is a Blast! Perspectives from College Students with WS PANEL

An interactive session with current & recently graduated college students. Hear their perspectives on what they are doing, their challenges and what is working well, plus what they expect to do in the future.

Smart but Scattered: Helping Children Strengthen Executive Functioning Skills and Reach Potential

Peg Dawson, PhD

Executive skills are critical to the acquisition of academic skills, but, more importantly, they are the skills students need to get things done. They are brain-based skills such as task initiation, sustained attention, working memory, planning, organization, and goal-directed persistence that are absolutely critical to school success. Some students seem to acquire them naturally, but many students struggle with them. Dr. Peg Dawson, co-author of the books *Smart but Scattered* and *Smart but Scattered Teens*, will describe how these skills develop throughout childhood and suggest strategies parents can use to help children acquire the critical skills they need to be successful students.

Turning Eighteen - the Legal Options for Guardianship and Alternatives Meredith Greene

Learn about the different legal options families should consider when their child becomes an adult at the age of 18. Become familiar with the steps of the guardianship process, shared decision making and much more. Participants will learn how they can stay involved in decision-making with schools, doctors and other professionals.

7/15 1:00 PM - 2:15 PM (con't)

Acute ICU Care Claudia Algaze-Yojay, MD

Results from several studies at Stanford

Common Endocrine Issues in Williams Syndrome Takara Stanley, MD

Individuals with WS of all ages can have issues with obesity, bone health, glucose and more. This session will discuss the signs and treatments for each.

FSN NETWORKING GROUPS Parents of School-age children with WS

7/15 2:30 PM - 3:45 PM Breakout Sessions

Health Issues and Transition to Adult Medical Providers Barbara Pober, MD

Dr. Pober will address the new medical concerns which can affect adults with WS and the challenge of finding adult medical providers who understand WS.

Anxiety Issues in Youth with Williams Syndrome Bonnie Klein-Tasman, PhD

Anxiety is very real for many with Williams syndrome - and it can be a factor at any age. Dr. Klein-Tasman will discuss the common manifestations of anxiety in youth with WS and strategies for dealing with, and overcoming the challenges they present.

Estate Planning and Special Needs Trusts Meredith Greene

The when, where and how's of creating a special needs trust, and how they intersect with your ABLE account

What to Tell/Ask the Anesthesiologist Before a Procedure Morgan Brown, MD & Mark Levin, MD

Specialists from BCH and NIH will provide the latest information on anesthesia concerns in WS, what you should tell your child's anesthesiologist about these issues, and what you need to ask (and he/she should answer) to ensure your child is in the right hands during a procedure.

Finding the Right Employment: Agencies Can Help PANEL, Ed McManus, Moderator

Employment Opportunities are not easy to find - Agencies can help!

7/16 8:45 AM – 3:00 PM

Sessions for Spanish Speaking Families Angela Becerra, PhD

7/16 10:15 AM -11:30 AM Breakout Sessions

Cardiac Arrhythmia Tom Collins, MD

Dr Collins will present results from a recent study at Stanford

Gastrointestinal Issues in Children and Adults with WS TBA

Diarrhea, constipation, rectal prolapse, diverticulosis, diverticulitis, IBS...the list of possible gastrointestinal issues for those with WS is long. This session will provide an overview of common issues, treatments and strategies for prevention.

Common Dental Issues Missy Collins, DMD, Andrew Hoch, DDS

Common dental and orthodontia issues will be discussed.

7/16 10:15 AM -11:30 AM (con't)

Literacy & Communication for Children with Significant Needs – Virtual David Koppenhaver

What can we do to support children with WS who aren't yet speaking? How can we help fill in the communication gaps as our children grow? This session will explore the use of AAC (augmentative/alternative communication) to support language development. Children can learn vocabulary and have functional communication skills BEFORE their speech is clearly developed. Learn how AAC serves as a bridge to conventional communication and literacy skills.

7/16 1:00 PM - 2:15 PM Breakout Sessions

General Ability and Language (Virtual Presentation) Robin Pegg, M.Ed., COTA/L, ATP; Carolyn Mervis, PhD

This session will describe the sections of the WS Educational Profile related to General Ability & Language; review the supporting research; and provide examples of educational strategies & interventions to support skill development & curriculum access.

Designing Language Arts Instruction (Virtual Presentation) Robin Pegg, M.Ed., COTA/L, ATP; Carolyn Mervis, PhD

This session will focus on how to design instructional experiences to support optimal success for the student with Williams syndrome. We will specifically address the following: learning needs regarding language arts (reading & writing) instruction, important instructional supports and scaffolds, and common accommodations.

LGBTQ (Virtual Presentation) Arc of MA

Learn about the importance of supporting the integration of people with Williams syndrome who identify as LGBTQ into the broader LGBTQ community, to prevent their isolation.

Math: Research, Connecting to Ed. Profile & Examples of Ed. Strategies & Solutions (Virtual Presentation)

Robin Pegg, M.Ed., COTA/L, ATP; Carolyn Mervis, PhD

This session will describe the sections of the WS Educational Profile related to mathematics; review the supporting research; and provide examples of educational strategies and interventions to support skill development and curriculum access.

Networking Sessions for Everyone – Rooms to be assigned
