Williams Syndrome

TIPS AND RESOURCES FOR FAMILIES

What causes Williams syndrome?

Individuals with Williams syndrome usually are missing a small piece of chromosome 7. This rare genetic disorder occurs spontaneously in 1 out of every 7, 500 births. It is not a result of an inherited characteristic from the parents. First recognized in 1961, Williams syndrome affects males and females at equal rates and has been diagnosed in all ethnicities and socioeconomic backgrounds.

What are the effects of Williams syndrome?

While every individual is unique in how they look and act, people with Williams syndrome have some traits in common. They may have some or all of these characteristics, which include:

- Small, delicate bones and features—small teeth spaced far apart
- A white star shape in the iris of the eye
- High sensitivity to loud noises
- Trouble nursing as a child, slow weight gain, and colicky behavior as a baby
- Anxious or nervous behavior—including "picking" behavior
- Heart, blood vessel, and stomach problems
- High levels of calcium in the blood
- Learning or cognitive disabilities
- Preferring to spend time with adults instead of peers
- Musical talents and/or intense connection with music—ability to learn though music
- Large vocabulary, well spoken
- Extremely friendly, caring behavior—cannotidentify bad intentions in other people

Can Williams syndrome be treated?

Individuals with Williams syndrome benefit from early intervention and lifelong physical and psychological therapies. Any medical problems that develop should be monitored closely by doctors experienced in working with individuals with Williams syndrome. To help alleviate maladaptive and social-emotional challenges, try to:

- Keep distractions to a minimum—manage auditory and visual distracters.
- Manage sensitivity to sound—provide comfort and explain loud noises.
- Encourage positive thinking—teach skills for reframing negative thoughts.
- Alleviate anxieties—reassure and aid transition into other activities or topics.
- Monitor sadness—be aware that depression can hide under a cheerful exterior.
- Provide social skills training—practice interaction with others, taking turns, and how to be appropriately cautious of strangers.

Children with Williams syndrome probably will have special needs in their education. The best education programs will be collaborative team approaches, and those that build on and encourage a child's strengths. Children with Williams syndrome generally respond well—both cognitively and emotionally—to educational programs that use music as a tool. When writing is involved, allow extra time and support and recognize that using computers, calculators, and audiotape recorders may be beneficial.

Please see reverse for resources.

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RESOURCES

Who We Are and Who We Serve

The **Vanderbilt Kennedy Center** (VKC) works with and for people with disabilities and their family members, educators and service providers, researchers, students, and policy makers. Faculty and staff engage in interdisciplinary research, training, service, and information dissemination and work in collaboration with local, state and national networks and partners. (615) 322-8240, toll-free (866) 936-8852, **vkc.vumc.org**

ACM LIfting Lives Music Camp

This week-long summer residential camp is designed for people with Williams syndrome who are at least 18 years old. This fun, musical experience also focuses on social skills and independence. Campers celebrate music by participating in a songwriting workshop, recording session, songwriter's night, and a live performance on the stage of the Grand Ole Opry. Campers are invited to take part in research activities. See **vkc.vumc.org/acmll**

Sibling Programs

Support for siblings who have a brother or sister with a disability, chronic health care issue, or mental health concern. SibSaturdays, ages 5 to 12 and Tennessee Adult Brothers and Sisters (TABS), ages 18+. See **vkc.vumc.org/sib**

Tennessee Disability Pathfinder

Provides free information, referral sources, and help with navigating services via phone, email, and website. Assistance is available to individuals of all ages, all types of disabilities, and all languages spoken. Its website database has more than 3,000 agencies searchable by Tennessee county and service. Pathfinder is a project of the VKC and is partially funded by Tennessee Council on Developmental Disabilities and other state agencies. (615) 322-8529, toll-free (800) 640-4636, **DisabilityPathfinder.org**

Two Easy Ways to Take Part in Research

StudyFinder is a searchable database that lists current VKC studies. Studies seek people of all ages with and without developmental disabilities. See **vkc.vumc.org/studyfinder.** Research Match is a secure place for volunteers and researchers to connect. See **researchmatch.org**

Local and National Resources

- **The Arc Tennessee**
  www.thearctn.org
- **The Arc US**
  www.thearc.org
- **Family Health Library, Junior League Family Resource Center, Monroe Carrell Jr. Children's Hospital at Vanderbilt**
  www.childrenshospitalvanderbilt.org/information/junior-league-family-resource-center
- **National Heart, Lung, and Blood Institute (NHBLI)**
  www.nhlbi.nih.gov
- **Regional Intervention Program**
  www.ripnetwork.org
- **Tennessee's Early Intervention System (TEIS)**
  www.tn.gov/didd/for-consumers/tennessee-early-intervention-system-teis.html
- **Williams Syndrome Association**
  www.williams-syndrome.org
- **Williams Syndrome Foundation**
  www.williams-syndrome.org.uk

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