

# 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 through music
- Large vocabulary, well spoken
- Extremely friendly, caring behavior—cannot identify 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, service providers and advocates, researchers and policy makers. It is among only a few centers nationwide to be a University Center for Excellence in Developmental Disabilities, a *Eunice Kennedy Shriver* Intellectual and Developmental Disabilities Research Center, and a Leadership Education in Neurodevelopmental and Related Disabilities Training Program. The following are some of the ways the Center's programs and staff can assist families, educators, and other service providers.

### Two Easy Ways to Take Part in Research

The Vanderbilt Kennedy Center serves families through research studies. StudyFinder is a searchable database that lists current VKC studies, including ASD research. Studies seek people of all ages with and without developmental disabilities. See [kc.vanderbilt.edu/studyfinder](http://kc.vanderbilt.edu/studyfinder), (615) 936-0448. Research Match is a secure place for volunteers and researchers to connect. Once you sign up and get added to the registry, a researcher will contact you if you're a possible match for the research study. See [www.researchmatch.org](http://www.researchmatch.org).

### Forming a Community

The Vanderbilt Kennedy Center can assist in creating a support community for individuals and parents who have a child with Williams syndrome. Staff members and researchers can help parents focus on their children's potential and positive qualities while keeping realistic goals. Workshops and other programs enable parents to be resources to one another. Contact (615) 343-3330.

### ACM Lifting Lives Music Camp

This weeklong summer residential camp is held on the Vanderbilt campus. Youth and young adults come together to explore and celebrate their musical abilities by participating in a songwriting workshop, recording session, songwriter's night, and a live performance on the stage of the Grand Ole Opry. The camp focuses on fostering social skills and independence, as well. Campers are invited to take part in research activities. Contact (615) 343-5322.

### Sibling Programs

Support for siblings who have a brother or sister with a disability, chronic health care issue, or mental health

concern. Tennessee Adult Brothers and Sisters (TABS), ages 18+. Contact (615) 936-8852.

### Tennessee Disability Pathfinder

Tennessee Disability Pathfinder is a free statewide phone, web, and print referral service in English and Spanish. It connects the Tennessee disability community with service providers and resources. Its website database has over 3,000 agencies searchable by Tennessee county and service. Pathfinder is a project of the VKC, TN Council on Developmental Disabilities, TN Department of Health, and the TN Department of Intellectual and Developmental Disabilities. Contact [www.familypathfinder.org](http://www.familypathfinder.org), (615) 322-8529, toll-free (800) 640-4636.

### VKC Reading Clinic

This clinic provides intensive, evidence-based instruction and assessment for students in kindergarten through middle school. Contact [readingclinic@vumc.org](mailto:readingclinic@vumc.org) or (615) 936-5123.

### Other Resources

- The Arc US  
[www.thearc.org](http://www.thearc.org), (301) 565-3842
- The Arc of Tennessee  
[www.thearctn.org](http://www.thearctn.org), (800) 835-7077, (615) 248-5878
- Tennessee Developmental Disabilities Network  
[www.tennddnetwork.org](http://www.tennddnetwork.org)
- Tennessee's Early Intervention System (TEIS)  
[tn.gov/education/teis](http://tn.gov/education/teis), (800) 852-7157
- Regional Intervention Program  
[www.ripnetwork.org](http://www.ripnetwork.org), (615) 963-1177
- Health Library, Jr. League family Resource Center, Monroe Carrell Jr. Children's Hospital at Vanderbilt  
[www.vanderbiltchildrens.com/healthlibrary](http://www.vanderbiltchildrens.com/healthlibrary)
- Williams Syndrome Association  
[www.williams-syndrome.org](http://www.williams-syndrome.org)
- Williams Syndrome Foundation  
[www.williams-syndrome.org/uk](http://www.williams-syndrome.org/uk)
- National Heart, Lung, and Blood Institute (NHBLI)  
[www.nhlbi.nih.gov](http://www.nhlbi.nih.gov)

**Contact the Vanderbilt Kennedy Center  
Nashville (615) 322-8240  
Toll-Free (866) 936-VUKC [8852]  
[vkc.vumc.org](http://vkc.vumc.org)  
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