

# WILLIAMS SYNDROME

## TIPS AND RESOURCES

### 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 information about Vanderbilt Kennedy Center programs.



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## HOW WE CAN HELP

### Who We Are and Who We Serve

The Vanderbilt Kennedy Center works with and for people with disabilities and family members, service providers and advocates, researchers and policy makers. It is among only a few centers nationwide to be both a University Center for Excellence in Developmental Disabilities Education, Research and Service and a national Developmental Disabilities Research Center. The Center also is a site for the Rare Diseases Clinical Research Network's Angelman and Prader-Willi Syndromes Consortium.

### Two Ways to Take Part in Research

The Vanderbilt Kennedy Center serves families of people with Williams syndrome through research studies. **StudyFinder** is a searchable database that lists current studies. Studies seek people of all ages with and without developmental disabilities. See [www.kc.vanderbilt.edu/studyfinder](http://www.kc.vanderbilt.edu/studyfinder), (615) 936-0448. **Research Family Partners** allows families with and without disabilities to register with the Center and to be contacted when a study begins for which the family might be eligible. See [www.kc.vanderbilt.edu/rfp](http://www.kc.vanderbilt.edu/rfp), (615) 936-0448.

### 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 Elizabeth Roof, (615) 343-3330.

### Music Camp for Youth With Williams Syndrome

This weeklong summer residential camp is held on the Vanderbilt campus in conjunction with the Blair School of Music and the National Williams Syndrome Association. 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 [kccamps@vanderbilt.edu](mailto:kccamps@vanderbilt.edu), (615) 322-8529 x3.

### SibSaturdays

This program provides siblings who have a brother or sister with a disability the opportunity to play games, meet friends, and participate in group discussions. Contact (615) 936-5188, [familyoutreach@vanderbilt.edu](mailto:familyoutreach@vanderbilt.edu).

### Tennessee Disability Pathfinder

This resource and referral service provides free phone, web, and print resources in English and Spanish. It is a project of the Vanderbilt Kennedy Center and the Tennessee Council on Developmental Disabilities. See [www.familypathfinder.org](http://www.familypathfinder.org), (615) 322-8529, (800) 640-4636.

### Family Outreach Center

This center provides families with a single point of entry into the many services and supports of the Vanderbilt Kennedy Center, Vanderbilt University, and the community, including research projects, clinics, social work services, and recreational and arts programs. Contact [familyoutreach@vanderbilt.edu](mailto:familyoutreach@vanderbilt.edu), (615) 936-5118.

### Behavior Analysis Clinic

This clinic provides in-depth assessments of the causes of behavioral problems and develops family oriented person-centered interventions. The clinic serves children ages 5 and up. Contact [n.houchins-juarez@vanderbilt.edu](mailto:n.houchins-juarez@vanderbilt.edu), (615) 322-9007.

### Reading Clinic

This clinic provides intensive, individualized, one-to-one tutoring using assessment and instructional methods proven by research to promote reading. The clinic serves children in early elementary grades. Contact [caresa.l.young@vanderbilt.edu](mailto:caresa.l.young@vanderbilt.edu), (615) 936-5123.

### Other Local and National 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), (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 (NHLBI)

[www.nhlbi.nih.gov](http://www.nhlbi.nih.gov)

Please see reverse for facts about Williams syndrome.

### Contact the Vanderbilt Kennedy Center

Nashville (615) 322-8240

Toll-Free (866) 936-VUKC [8852]

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FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES