



# What is Williams Syndrome?

Williams syndrome is a genetic condition that is present at birth and can affect anyone. It is characterized by medical and cognitive problems, including cardiovascular disease, developmental delays, and learning disabilities, which often occur side by side with striking verbal abilities, highly social personalities and an affinity for music.

Williams syndrome affects 1 in 10,000 people worldwide – an estimated 25,000 to 30,000 people in the United States. It is known to occur equally in both males and females and in every culture.

Unlike disorders that can make connecting with your child difficult, children with Williams syndrome tend to be social, friendly and endearing. Parents sometimes say they could not have imagined the joy and perspective their child with Williams syndrome has brought into their lives. Nearly everyone with Williams syndrome loves music, and for some, there is a musicality and eventual talent for music that is far greater than would be expected based on general functioning levels.

There are major struggles as well. Many babies have life-threatening cardiovascular problems. Children with WS may need costly and ongoing medical care, and early interventions (such as speech or occupational therapy) that may not be covered by insurance or state funding. As they grow, they struggle with things like spatial relations, numbers and abstract reasoning, which can make daily tasks a challenge. And as adults, most people with WS need supportive housing to live independently. Opportunities for social interaction are extremely important. Without social interaction, adults with Williams syndrome often experience intense isolation which can lead to depression. They are extremely sociable and experience the normal need to connect with others; however people with Williams syndrome often don't process nuanced social cues and this makes it difficult to form lasting relationships. Other characteristics common to Williams syndrome are:

Hypercalcemia (elevated blood calcium levels)  
Low birth-weight / slow weight gain  
Feeding problems  
Dental abnormalities

Kidney abnormalities  
Hernias  
Hyperacusis (sensitive hearing)  
Musculoskeletal problems





**williamssyndrome**  
ASSOCIATION

# The Williams Syndrome Association

The Williams Syndrome Association (WSA) is the most comprehensive resource for people and families living with WS as well as doctors, researchers and educators. The WSA provides the resources and referrals that families need, and a strong and supportive community with which to connect throughout that child's life.

We create a roadmap to help families navigate challenges – providing answers to common questions, a step-by-step guide, information about WS clinics across the country and best practices for age-appropriate interventions.

Your support of the WSA community can provide vital, day-to-day programs. The WSA is a volunteer driven organization. We are parents, grandparents, relatives and legal guardians of people with Williams syndrome. We know first-hand the challenges of raising and caring for an individual with special needs. Among the programs and initiatives provided by the WSA are:

**Family Support.** Information, specialist referrals, a research library and best practice guidelines for every phase of life – from diagnosis and early intervention, to planning for life beyond school.

**Patient and Medical Registry.** A connection between families and the research community. This is the single most valuable tool for improving understanding of Williams syndrome and discovering new ways to help children, plan research needs and distill best practices for families and doctors to use.

**Cutting-edge Research.** Funding for initiatives at leading facilities like Yale University, Johns Hopkins University, Massachusetts General Hospital and Stanford University.

**National Conventions.** An educational opportunity for parents and caregivers with special programs for children with WS and their siblings.

**International Research Symposiums.** The bi-annual meeting provides a forum for scientists and doctors to discuss new research findings in Williams syndrome, plan research needs and distill best practices for families and doctors to use.

**Enrichment Opportunities and Scholarships for Individuals with WS.** Workshops and camp programs provide life-changing enrichment experiences. Scholarships for summer and post-secondary programs enable families in need to participate.

**Nineteen Regions Nationwide.** Volunteers host social events and other opportunities for individuals with WS and their families to connect.

Since its inception, the WSA has helped thousands of families affected by Williams syndrome. But there are thousands more who need our support, and there's much more to be done. By supporting the WSA, you will help create opportunities for people with Williams syndrome and help accelerate research that could have far broader implications.