

Media packet

Thank you for your interest in writing about Williams syndrome.

The media packet presented here is a subset of information readily available throughout our site, and on sites in our Links area. We know how valuable your time is so we have summarized key topics into a quick reference roadmap of links below. We have also compiled this same information in an Adobe Acrobat file for you to download and use or print offline for easy reference.

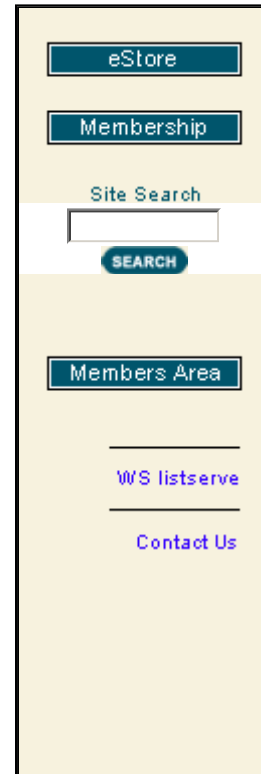
Note: our members are usually more than willing to share their stories and biographies with you. If you are interested in contacting families in your area, or with regard to a specific WS topic, please contact the WSA national office for additional information.

Media roadmap

- [What is Williams syndrome](#)
- [Music and Williams syndrome](#)
- [Diagnosing Williams syndrome](#)
- [Current research](#)
- [WSA administration](#)
- [WSA programs](#)
- [Contact the WSA](#)
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- [Articles of interest](#)

Compiled Acrobat file

- [Media packet \(pdf\)](#)



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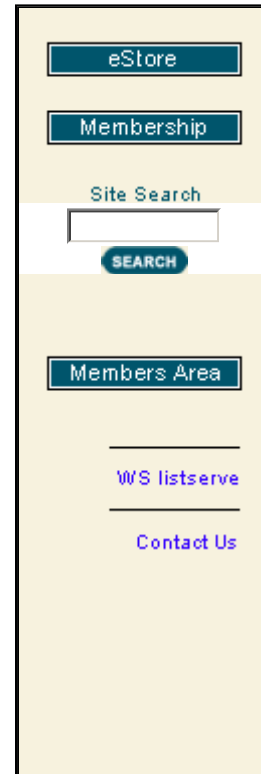
What is Williams syndrome

Williams syndrome is a rare genetic condition (estimated to occur in 1/20,000 births) which causes medical and developmental problems.

Williams syndrome was first recognized as a distinct entity in 1961. It is present at birth, and affects males and females equally. It can occur in all ethnic groups and has been identified in countries throughout the world.

What are the common features of Williams syndrome?

- [Characteristic facial appearance](#)
- [Heart and blood vessel problems](#)
- [Hypercalcemia \(elevated blood calcium levels\)](#)
- [Low birth-weight / low weight gain](#)
- [Feeding problems](#)
- [Irritability \(colic during infancy\)](#)
- [Dental abnormalities](#)
- [Kidney abnormalities](#)
- [Hernias](#)
- [Hyperacusis \(sensitive hearing\)](#)
- [Musculoskeletal problems](#)
- [Overly friendly \(excessively social\) personality](#)
- [Developmental delay, learning disabilities and attention deficit](#)
- [Further reading from the UK](#)



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Characteristic facial appearance [\[back to top\]](#)

Most young children with Williams syndrome are described as having similar facial features. These features which tend to be recognized by only a trained geneticist or birth defects specialist, include a small upturned nose, long philtrum (upper lip length), wide mouth, full lips, small chin, and puffiness around the eyes. Blue and green-eyed children with Williams syndrome can have a prominent "starburst" or white lacy pattern on their iris. Facial features become more apparent with age.

Heart and blood vessel problems [\[back to top\]](#)

The majority of individuals with Williams syndrome have some type of heart or blood vessel problem. Typically, there is narrowing in the aorta (producing supravalvular aortic stenosis is SVAS), or narrowing in the pulmonary arteries. There is a broad range in the degree of narrowing, ranging from trivial to severe (requiring surgical correction of the defect). Since there is an increased risk for development of blood vessel narrowing or high blood pressure over time, periodic monitoring of cardiac status is necessary.

Hypercalcemia (elevated blood calcium levels) [\[back to top\]](#)

Some young children with Williams syndrome have elevations in their blood calcium level. The true frequency and cause of this problem is unknown. When hypercalcemia is present, it can cause extreme irritability or "colic-like" symptoms. Occasionally, dietary or medical treatment is needed. In most cases, the problem resolves on its own during childhood, but lifelong abnormality in calcium or Vitamin D metabolism may exist and should be monitored.

Low birth-weight / low weight gain [\[back to top\]](#)

Most children with Williams syndrome have a slightly lower birth-weight than their brothers or sisters. Slow weight gain, especially during the first several years of life, is also a common problem and many children are diagnosed as "failure to thrive". Adult stature is slightly smaller than average.

Feeding problems [\[back to top\]](#)

Many infants and young children have feeding problems. These problems have been linked to low muscle tone, severe gag reflex, poor suck/swallow, tactile defensiveness etc. Feeding difficulties tend to resolve as the children get older.

Irritability (colic during infancy) [\[back to top\]](#)

Many infants with Williams syndrome have an extended period of colic or irritability. This typically lasts from 4 to 10 months of age, then resolves. It is sometimes attributed to hypercalcemia. Abnormal sleep patterns with delayed acquisition of sleeping through the night may be associated with the colic.

Dental abnormalities [\[back to top\]](#)

Slightly small, widely spaced teeth are common in children with Williams syndrome. They also may have a variety of abnormalities of occlusion (bite), tooth shape or appearance. Most of these dental changes are readily amenable to orthodontic correction.

Kidney abnormalities [\[back to top\]](#)

There is a slightly increased frequency of problems with kidney structure and/or function.

Hernias [\[back to top\]](#)

Inguinal (groin) and umbilical hernias are more common in Williams syndrome than in the general population.

Hyperacusis (sensitive hearing) [\[back to top\]](#)

Children with Williams syndrome often have more sensitive hearing than other children; Certain frequencies or noise levels can be painful an/or startling to the individual. This condition often improves with age.

Musculoskeletal problems [\[back to top\]](#)

Young children with Williams syndrome often have low muscle tone and joint laxity. As the children get older, joint stiffness (contractures) may develop. Physical therapy is very helpful in improving muscle tone, strength and joint range of motion.

Overly friendly (excessively social) personality [\[back to top\]](#)

Individuals with Williams syndrome have a very endearing personality. They have a unique strength in their expressive language skills, and are extremely polite. They are typically unafraid of strangers and show a greater interest in contact with adults than with their peers.

Developmental delay, learning disabilities and attention deficit [\[back to top\]](#)

Most people with Williams syndrome have some degree of intellectual handicap. Young children with Williams syndrome often experience developmental delays; milestones such as walking, talking and toilet training are often achieved somewhat later than is considered normal. Distractibility is a common problem in mid-childhood, which appears to get better as the children get older.

Older children and adults with Williams syndrome often demonstrate intellectual "strengths and weaknesses." There are some intellectual areas (such as speech, long term memory, and social skills) in which performance is quite strong, while other intellectual areas (such as fine motor and spatial relations) are significantly deficient.

Further reading from the UK [\[back to top\]](#)

[Go here](#) to find additional information on this topic from the Williams Syndrome Foundation in the UK.

Music and Williams syndrome

There appears to be a unique link between children with Williams syndrome and their affinity to music. However, there are misconceptions about what this "link" to music really means - especially in an educational setting.

This section is intended to help educators understand the Williams syndrome musical link that has been documented through studies, documentaries, and special programs by experts in the fields of Cognitive Neuroscience, Educational Psychology, Developmental and Cell Biology, Special Education, and others.

What does it mean to have an "affinity" towards music? And how might this effect a child's general education?

The topics covered in this section include:

- [What is an "affinity to music"?](#)
 - [Will a child with WS be musically gifted?](#)
 - [Can the musicality of a child with WS be affected through education?](#)
 - [Should a child with Williams syndrome be assessed for Music Therapy treatment?](#)
 - [How will Music Therapy benefit a child with WS?](#)
 - [Related published articles](#)
 - [Related national broadcasts](#)
 - [Additional articles/resources](#)
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What is an "affinity to music"? [\[back to top\]](#)

The definition of the word affinity is: "A natural attraction, liking, or feeling of kinship." This definition fits well the relationship between Williams syndrome and music. People with Williams syndrome talk often about a natural feeling that music is part of their being.

People with Williams syndrome often appear drawn towards music and things musical. For some, music can help overcome obstacles they might not otherwise overcome. For example, some children with Williams syndrome have been known to overcome their acute sensitivity to loud noises in order to join others on a dance floor where music is playing at levels that would otherwise bring them to tears.

The same can sometimes be said for children with Williams syndrome in a classroom. They are often able to stay on task during a "musical" activity, for much longer times than would be possible during non-music activities. This can be an important piece of information for an educator who is working with a Williams child who has a limited attention span.

It is important to note, however, that "affinity" does not equal "ability" (although that is the case in some instances). The musical link with Williams syndrome refers to cognitive, emotional and psychological characteristics. Individuals with Williams syndrome usually enjoy participating in musical activities, whether or not, they show increased musical abilities.



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"Many children with WS have considerable aptitude for MUSIC AND RHYME. Teaching through music, songs and rhymes can speed up the learning process, and encouraging talents in playing musical instruments can boost self confidence"

Guidelines for Teachers
Dr. Orlee Udwin
Professor William Yule

Will a child with WS be musically gifted? [\[back to top\]](#)

Possibly....

Individuals with Williams syndrome (as a whole) seem to have a higher rate of musicality, and in some instances musical ability, than the general population. Among those who have increased levels of musicality there are people with Williams syndrome who are musically gifted. But many others who are not. It is the affinity and love of music, rather than musical "giftedness" that appears to be a common trait in individuals with Williams syndrome.

Additionally, recent research suggests that the percentage of individuals with Williams syndrome who have perfect pitch is higher than the percentage among individuals in the general population.

Can the musicality of a child with WS be affected through education?

[\[back to top\]](#)

Yes. Due to the wide range of early childhood delays and medical problems it is possible that many common Williams syndrome traits will only emerge after time. For example, a child with WS who appears to have little interest in music at age three may exhibit a high level of interest and/or ability at age 11.

A child's musicality can potentially be brought out by circumstances, and thus affected by their educational experiences.

Should a child with Williams syndrome be assessed for Music Therapy treatment? [\[back to top\]](#)

As a general rule, you will probably want a child with Williams syndrome assessed by a Music therapist. The published link between music and cognition in individuals with Williams syndrome indicates that this assessment is appropriate.

The following questions may help members of an IEP team determine the appropriateness of a music therapy assessment. Note: a "no" response to one or more questions does not necessarily mean that a child is inappropriate for a music therapy assessment. If disagreements or questions arise, a music therapist should be contacted.

- Can the child be motivated to attempt tasks through the use of music?
- Can the child be motivated to complete tasks through the use of music?
- Could the child benefit from the use of additional communication modalities?
- Does the child initiate interaction with music in the classroom or at home?
- Does the child retain information conveyed in songs more easily than information conveyed in spoken interchanges?

An assessment for music therapy as a related service should, at minimum, include a review of the child's current IEP, interviews with key IEP team members, and an assessment process/instrument that provides specific data as to whether or not music therapy makes a significant difference in a child's ability to benefit from his or her IEP.

How will Music Therapy benefit a child with WS? [\[back to top\]](#)

There is good likelihood that children with WS will benefit from music therapy. Music therapy uses an interactive musical setting to achieve specific educational goals. The affinity toward music of a child with Williams syndrome will often allow them to be more engaged and have a higher retention of success, when difficult tasks are reinforced with music.

However, as with any type of therapy, not all children respond in the same way. For this reason, it is very important to have a thorough Music therapy assessment performed on the child with Williams syndrome. This assessment should be performed by a licensed Music Therapist. It is also helpful when the evaluation includes time with

the child in the current classroom. The assessment should take place prior to the IEP meeting.

If Music therapy is deemed appropriate for a child with Williams syndrome, the Music therapist should become a part of the child's IEP team. As with all therapies, whether or not music therapy is appropriate at the time of initial assessment, periodic reassessment is recommended.

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Related published articles [\[back to top\]](#)

The following articles regarding Williams syndrome deal primarily with the relationship between cognition and music in children with Williams syndrome.

Music, the Brain, and Williams syndrome (2001)

[Article transcript](#) (free registration required)

This article appeared in *The Scientist* magazine and is primarily a discussion of new research into Williams syndrome and general cognitive ability. It also provides a glimpse of the musical affinity of children with Williams syndrome.

To quote:

"Music encourages something of normalcy and fulfillment," says Don (Morris). Morris speaks of counseling families to use music to instruct and for its calming effect.

Williams Syndrome and the Brain (1997)

[Article transcript \(pdf file\)](#)

by: H. Lenhoff, P Wang, F Greenberg and U. Bellugi

This article appeared in *Scientific American* magazine, This is an excellent explanation of Williams Syndrome and a summary of research at the time.

Music Lights A Fire (1997)

[Article transcript](#)

by: David Scheiber, St. Petersburg Times

This article discusses the musicality and passion for music displayed by campers at the WSA's Music and Arts Camp.

Different Minds (1991)

[Article transcript](#)

by: Robert Finn

This article appeared in *Discover Magazine* and presents an interesting look at the beginning research into Williams syndrome. Note: This article was written prior to the discovery of the actual genetic problem, and prior to much of the music research. However, it outlines specifically some of the educational obstacles observed when trying to teach children with Williams syndrome.

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Related national broadcasts [\[back to top\]](#)

The following programs regarding Williams syndrome were broadcast nationally. Links are provided to transcripts where available.

Growing up Different (Friendly Genes segment - 2001)

[Online video and transcript](#)

This PBS television broadcast appeared as a Scientific American Frontiers special hosted by Alan Alda. The broadcast also featured remarks by Dr. Ursula Bellugi, Director of the Laboratory for Cognitive Neuroscience at the Salk Institute.

Gray Matters: Music and the Brain (1998)

[Program transcript](#)

This radio broadcast appeared on National Public Radio and was hosted by Mandy Patinkin. (Note: Only a segment of the broadcast referred to Williams syndrome.)

To quote:

'A child with William's syndrome once said, "Music is my favorite way of thinking..." As we've heard in this past hour, music has become a favorite way of thinking for an expanding group of neuroscientists.'

A Very Special Brain (1997/1998)

Copies available by request from the WSA

CBS *60 Minutes* segment on Williams syndrome. This Peabody Award winning segment aired in both October 1997 and July 1998.

Additional articles/resources [\[back to top\]](#)

There are dozens of reference articles and/or videos relating Williams syndrome and music that have been printed over the past several years. Not all are presented here because they do not specifically reference general education through music. However, they are important in emphasizing the distinct and overwhelming connection between music and Williams syndrome.

You can see all related articles in the [Literature/Video](#) section of the website.

Diagnosing Williams syndrome

The diagnosis of Williams syndrome generally has two parts:

- Clinical diagnosis based on a variety of characteristics. See the [Facts about Williams syndrome](#) article for details.
- Medical/genetic test confirmation through a blood test: the FISH test.

The FISH test

You can obtain a blood test to confirm the clinical diagnosis of Williams syndrome. A laboratory can use the technique known as *fluorescent in situ hybridization* (FISH).

FISH is a type of specialized chromosome analysis utilizing specially prepared elastin probes. If a patient has 2 copies of the elastin gene (one on each of their chromosomes #7), they probably do not have WS. If the individual only has one copy, the diagnosis of WS will be confirmed.

Virtually all (98-99%) persons with typical features of WS will have a deletion of the elastin gene.

In more technical terms:

Williams syndrome is the result of a deletion of the 7q11.23 region of chromosome #7 containing the elastin gene and is believed to be a contiguous gene syndrome. Diagnosis of Williams syndrome is confirmed by dual colour FISH using a specific probe and a control probe.

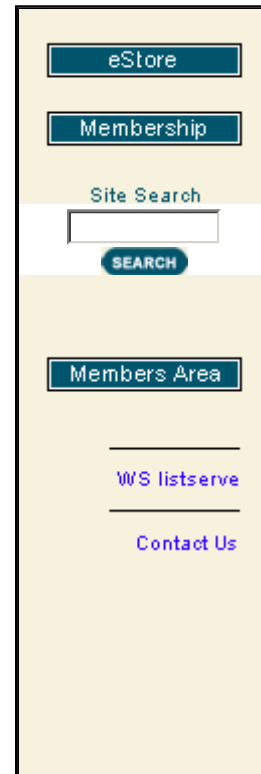
The laboratory will need 5 ml of blood drawn in a Sodium heparin tube. The sample should arrive in the lab the same day it was drawn or on the following day. Results are usually available in 2-4 weeks.

The FISH test is readily available at major hospitals and Cytogenetics laboratories around the country, but it is not a routine test. Therefore not all labs will do FISH-based diagnosis. Families or their physicians should call the lab in advance to make sure they can perform the test.

If you have any doubts that a child may have Williams syndrome, the FISH test will give you a clear cut answer in most cases.

It may be possible, however, that an individual has most of the characteristics of Williams syndrome yet does not show that an elastin gene is missing. In such cases, only an experienced medical geneticist will be able to assess whether or not the questioned individual may have Williams syndrome.

NOTE: It is extremely unlikely that any other family member also has Williams syndrome. On the other hand, if the individual with Williams syndrome plans to become a parent, there is a 50/50 chance that his or her child will have Williams syndrome. If such a situation should arise, consult an obstetrician about using the FISH test for prenatal testing of the embryonic cells.



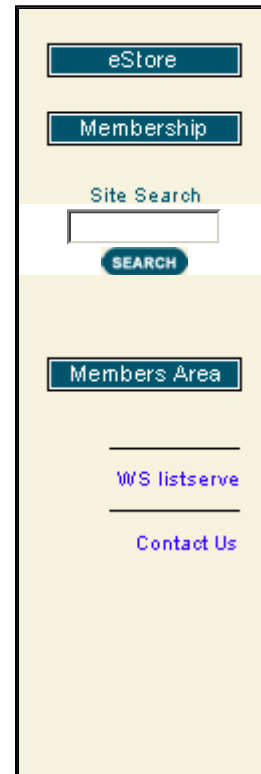
Current research

Williams syndrome is gaining wider popularity in the research field due to its unique characteristics and to the wealth of information it is providing to the Human Genome project.

Research projects concerning Williams syndrome specifically (or chromosome 7 generically) fluctuate rapidly. Because of this fluctuation, it is impossible to provide an exact list of active research projects. However, there are many research centers who are specializing in areas concerning Williams syndrome. These centers are listed here.

For more information, contact any of the researchers below, or contact the [National WSA office](#) with inquiries on specific research topics that may not be listed here.

- [University of Nevada, Las Vegas \(UNLV\)](#)
- [University of Louisville](#)
- [Boston University](#)
- [Yale School of Medicine](#)
- [Johns Hopkins University](#)
- [Laboratory of Cognitive Neuroscience, Salk Institute](#)
- [University of California, Los Angeles \(UCLA\)](#)
- [The Hospital for Sick Children, Ontario, Canada](#)



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- Site Search section with an input field and a [SEARCH](#) button
- [Members Area](#) (button)
- [WS listserve](#) (text link)
- [Contact Us](#) (text link)

University of Nevada, Las Vegas (UNLV) [\[back to top\]](#)

Dr. Colleen Morris
conducts studies relating to the "genetics" of WS. Dr. Morris and her team are responsible for the initial discovery of the elastin deletion in WS and continue to work to define the possible other causes of WS (gene inversions) as well as determining the roles of the approximately 20 additional genes in the WS critical area on chromosome #7.

University of Louisville [\[back to top\]](#)

Dr. Carolyn Mervis
conducts clinical research studies primarily devoted to the cognitive processes in WS. Her team is conducting longitudinal studies of Language and Cognition in WS, as well as studies of language in very young children and the relationships between language, cognition and adaptive behavior in Williams syndrome.

Boston University [\[back to top\]](#)

Dr. Helen Tage-Flusberg
is conducting clinical research studies of the sociability of individuals with Williams syndrome. Dr. Flusberg's primary studies in this area are with teens and adults with WS.

Yale School of Medicine [\[back to top\]](#)

Dr. Robert Schultz

conducts clinical research into the facial recognition skills of children and adults with WS.

Dr. Barbara Pober

is conducting studies which will help describe the characteristics (medical and cognitive) of WS in adults.

Johns Hopkins University [\[back to top\]](#)

Dr. Barbara Landau

conducts studies into the cognitive processes of adults with WS. Present studies focus on spatial language, and object/motion perception.

Laboratory of Cognitive Neuroscience, Salk Institute [\[back to top\]](#)

Dr. Ursula Bellugi

conducts research with children and adults with WS. Primary focus area is communication. The Salk team studies facial perception in very young children, differences between language and spatial skills in children of ages 7-12, behavior, and visuospatial and social ability in teens and adults. They also study the musicality of individuals with WS in collaboration with Dr. Dan Levitin at McGill University, and a comprehensive study of WS across all disciplines in collaborations with geneticists and Sinai Hospital in Los Angeles and neurologists at Harvard University.

University of California, Los Angeles (UCLA) [\[back to top\]](#)

Dr. Elizabeth Dykens

has conducted extensive studies into anxiety in teens and adults with Williams syndrome and is currently looking at Behavioral concerns and the use of music to see how they might interact.

The Hospital for Sick Children, Ontario, Canada [\[back to top\]](#)

The Chromosome 7 Project

is part of the Human Genome project and is currently underway at The Centre for Applied Genomics at the Hospital for Sick Children in Toronto, Canada. More information can be found at the Chromosome 7 Project [website](#).

[HOME](#) : [About WSA](#) : WSA structure and administration

WSA structure and administration

The Williams Syndrome Association is people: individuals with Williams syndrome and Williams syndrome-like characteristics, their families, and interested medical professionals and educators.

Founded by a handful of families in San Diego, CA, the WSA is a volunteer driven 501 (c)(3) non-profit organization divided into 11 regions across the US and Puerto Rico. Each region works to provide social and educational opportunities for its members. The WSA also has affiliation with similar international groups.

The WSA has about 4000 families on its membership list.

The WSA is administered at four levels:

- [National Board of Trustees](#)
- [Executive Director](#)
- [Regional Directors](#)

Board of Trustees [\[back to top\]](#)

The Williams Syndrome Association is governed by a volunteer Board of Trustees. Board members are elected by the membership for 2 year terms, and may seek re-election. The Board establishes the direction of the association and works closely with the Executive Director and regional volunteers to carry out its goals.

The current Board is:

Officers:

President

John Catizone
Columbia, MD

Vice President

William Palmer
Lyons, CO

Secretary

Jane Stephenson
Wichita, KS

Board Members at Large:

Doug Betz
Bellbrook, OH



Frank Catalanotto
Plainview, NY

William Cotts
Hinsdale, IL

Chris Grejtak
Los Altos, CA

Robert Scheiber
Rockville, MD

JoAnne Starkman
Smyrna, GA

Julie Uhl
San Diego, CA

Mark Walker
Gainesville, FL

For complete contact information for the Board members, please [contact](#) the WSA national office.

Executive Director [\[back to top\]](#)

A full-time Executive Director handles all daily administration decisions, supports board programs and projects, actively seeks funding sources for those programs, and is the primary spokesperson for the Association.

The current Executive Director is:

Terry Monkaba
WSA Office
PO Box 297
Clawson, MI 48017-0297
Phone: 248-244-2229
Fax: 248-244-2230

Regional Directors [\[back to top\]](#)

Eleven volunteer regional directors and over 60 regional representatives provide local support to families. All members of the WSA *Administration* have children or relatives with Williams syndrome, and all members are available to provide support and answer questions regarding WS and the WSA to families, professionals and the public.

The current Regional Directors are listed in the [WS Community](#) area.

WSA programs

The programs of the Williams Syndrome Association are designed to support individuals with WS, their parents, and the professionals working with our children.

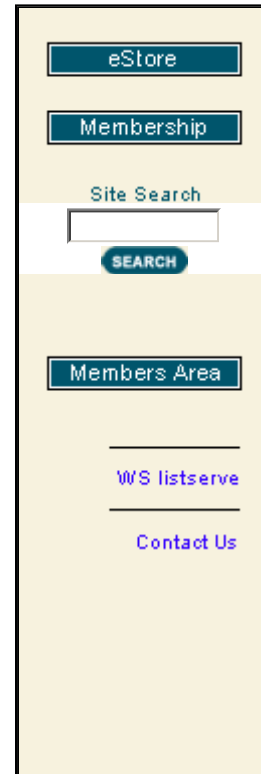
Programs are provided at both the national and regional level.

At the national level, the WSA provides:

- [Bi-annual national convention](#)
- [International professional conference](#)
- [Adult committee and yearly workshop](#)
- [Music camps](#)
- [Scholarship programs](#)
- [Research grants](#)
- [Resource libraries](#)
- [Member benefits](#)

At the regional level, programs include:

- [One day regional conferences](#)



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Bi-annual national convention [\[back to top\]](#)

The WSA sponsors a national convention every two years. The 5 day convention is held at varying locations around the country, and includes an exhibit fair, general sessions, daily workshops, child care and excursions for children, special programs for teens and adults, opportunities to participate in ongoing research and evening programs. In 2002, more than 1000 professionals, parents and children gathered in Long Beach, CA for our *Lighting the Way to Brighter Futures* convention.

Our next National Convention will be held in Grand Rapids, MI in July 2004.

International professional conference [\[back to top\]](#)

The WSA sponsors a professional conference in conjunction with the family convention. The WSA works with its medical advisors to gather scientists from around the globe who are conducting research on Williams syndrome. The event includes a poster session, keynote presentations and research discussions.

Adult committee and workshop [\[back to top\]](#)

Recognizing the need for separate programming for adults with WS, the WSA created the WS Adult committee to raise the awareness of adult needs. We also sponsor a workshop for adults with Williams syndrome and their parents.

Music camps [\[back to top\]](#)

The WSA co-sponsors two music camps, one for small children ages 4-11 and one for older children and adults with Williams syndrome.

- The Blue Lake music camp in Twin Lake, MI provides a 4 day music therapy program specifically for young children with Williams syndrome and their families. It is currently held each year in early fall.
- The Williams Syndrome Music and Arts Camp is held for one week each Summer. The special one-week session is limited to children and adults with WS. Campers can participate in voice, musical instrument and dance lessons as well as swimming, art, basketball and team-building sessions.

For more information on either camp contact the [WSA National Office](#). Camp applications will be available online soon, or through the National office in January.

Scholarship programs [\[back to top\]](#)

Limited scholarship funding is available through funds set up by parents and maintained by the WSA. Scholarships are currently available for:

- post secondary/independent living programs for adults with WS
- conferences
- music camp
- music lessons and musical instruments

Research grants [\[back to top\]](#)

Each year the WSA awards up to \$20,000 in small grants to professionals conducting research on WS. Grants are awarded for clinical research that will directly affect the lives of individuals with WS.

For more information on submitting grant requests and research abstracts to the WSA contact the [WSA national office](#).

Resource libraries [\[back to top\]](#)

Print Library:

The WSA maintains a resource library nearly 1000 articles on Williams syndrome and related subjects. WSA publications include *Fulfilling Dreams*, *Handbook for Parents*; pamphlets on Educational strategies; *Ben's Big Decision*, a storybook for children with WS; *The Promenade*, a story for adolescents with WS; compilations of past Convention reprints; professional abstracts, etc.

Print publications and videotapes are available through the WSA [estore](#), by downloading and completing the [Fax order form](#), or by contacting the [WSA national office](#) directly.

Videotape library:

The WSA maintains a videotape library of informational videotapes on Williams syndrome. Tapes include:

- *For The Love of Music* - A short tape which follows a young man through the suzuki method of learning to play the piano.
- *Bravo Gloria* - A tape produced for public television which highlights the life of Gloria Lenhoff, a musically gifted adult with Williams syndrome.
- *Williams syndrome - A Highly Musical Species* - Filmed primarily at the WS Music Camp in 1995, the tape features WS individuals, and includes interviews with Drs. Oliver Sacks, Colleen Morris and Ursula Bellugi. Parental anecdotes

help to provide a look at the special characteristics of Williams syndrome and the impact these individuals have on their families and those around them.

- *Growing Up Different* - PBS Special from the Scientific American Frontiers series. Hosted by Alan Alda, this film provides insight into Williams syndrome and current research. Interview with Dr. Ursula Bellugi.

Member benefits [\[back to top\]](#)

In addition to the generally available programs listed here, the WSA provides many additional benefits to its members. See the [Membership benefits](#) page for more information.

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One day regional conferences [\[back to top\]](#)

One day events held throughout the country each year to help parents and educators learn more about Williams syndrome. Our 11 regional directors strive to hold these conferences in varying locations within their region each year so that many families can benefit. A typical conference includes information on the latest medical findings, educational strategies, work, education and residence options for adults, and parent networking opportunities.

Contact the WSA

There are many ways to reach the national WSA office:

By phone:

- 1-248-244-2229
- 1-800-806-1871 (toll-free)

By fax:

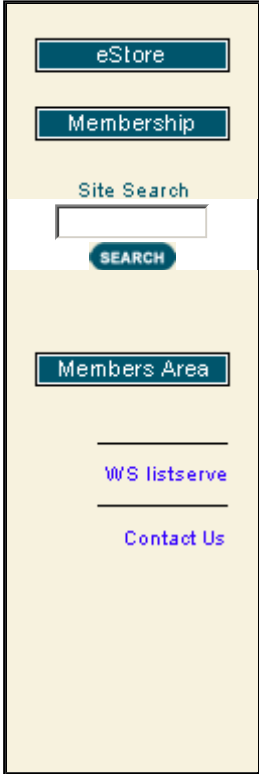
- 1-248-244-2230

By email:

- info@williams-syndrome.org

By postal mail:

Williams Syndrome Association
PO Box 297
Clawson, MI
48017-0297



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Note: for regional contact information, go to the [WS Community](#) area.

[HOME](#) : Resources outside the WSA

Resources outside the WSA



There are many resources on the internet that contain useful information relevant to Williams syndrome or related topics.

Hundreds of sites contain information pertinent to individuals with Williams syndrome. While we cannot list every site, the list provided here is a good starting point for further research in the appropriate areas.

NOTE: Sites that have direct relevance to the treatment or support of individuals with Williams syndrome were referenced in the appropriate places throughout our website and are *not* duplicated here.

Sites are categorized as:

- [Other US Williams syndrome organizations](#)
- [Support and advocacy organizations and resources](#)
- [Special educational organizations and resources](#)
- [International Williams syndrome organizations](#)

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Other US Williams syndrome organizations [\[back to top\]](#)

- [The Williams Syndrome Foundation](#)
The Williams Syndrome Foundation is dedicated to establishing music academies and residential villages for adults with WS and similar disabilities.
- [The Lili Claire Foundation](#)
The Lili Claire Foundation was formed in memory of Lili Claire Resnick, an infant with WS who passed away in 1998. The Lili Claire Foundation is dedicated to making a positive difference in the lives of people living with neurogenetic birth defects.

Current projects include:

- The LiliClaire [Open Heart Surgery Program](#).
- The [Lili Claire Diagnostic Clinic at UCLA](#): For the diagnosis and treatment of WS and other neurogenetic conditions

Future Projects include:

- *The Lili Claire Family Center* - a "nexus for community resources, and emotional and psychological support"
- *The Lili Claire Performing Arts Center* - will provide vocational education, primarily in the performance arts vocations, for young adults

with neurogenetic conditions.

- *The Lili Claire Housing Campus* - will provide short-term and long-term housing for people living with Williams syndrome in an environment specifically designed to understand and assist with their special needs.

- [Berkshire Hills Music Academy](#)

The BHMA is a post-secondary/transition program established to provide comprehensive training in music, essential academics, social, vocational, and independent living skills. Find information on the BHMA [here](#).

Support and advocacy organizations and resources [\[back to top\]](#)

- [The ARC \(Association for Retarded Citizens\)](#)

The Arc is the national organization of and for people with mental retardation and related developmental disabilities and their families.

- [National Association for Music Therapy](#)

The mission of the American Music Therapy Association is to advance public awareness of the benefits of music therapy and increase access to quality music therapy services in a rapidly changing world.

- [Wright's Law](#)

Parents, advocates, educators, and attorneys come to Wrightslaw for accurate, up-to-date information about advocacy for children with disabilities.

- [The National Organization for Rare Disorders - NORD](#)

NORD is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and service.

- [Genetic/Rare conditions - national resources](#)

Organizations, support groups and information on genetic and rare conditions.

- [Family Village Home Page](#)

This site also contains a Williams syndrome discussion board. Go to the discussion board [here](#).

Special educational organizations and resources [\[back to top\]](#)

- [TASH - Equity, Diversity, Social Justice and Inclusion](#)

TASH is an international association of people with disabilities, their family members, other advocates, and professionals fighting for a society in which inclusion of all people in all aspects of society is the norm.

- [Family and Advocates Partnership \(FAPE\)](#)

The FAPE project is a partnership that aims to improve the educational outcomes for children with disabilities.

- [Council for Exceptional Children](#)

The Council for Exceptional Children (CEC) is the largest international professional organization dedicated to improving educational outcomes for individuals with exceptionalities, students with disabilities, and/or the gifted.

- [Institute of Community Integration](#)

Working to improve the community services and social supports available to individuals with developmental and other disabilities, and their families.

- [Learning Disabilities Association](#)

The Learning Disabilities Association of America is a national, non-profit organization committed to advancing the education and general welfare of children and adults of normal or potentially normal intelligence who manifest disabilities of a perceptual, conceptual, or coordinative nature.

- [Learning Disabilities Online](#)
LD Online is a service of The Learning Project at WETA, Washington, D.C., in association with The Coordinated Campaign for Learning Disabilities.
- [Inclusion Press](#)

International Williams syndrome organizations [\[back to top\]](#)

- [Argentina](#)
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- [Portugal](#)
- [Slovak Republic](#)
- [South Africa](#)
- [Spain](#)
- [Sweden](#)
- [Switzerland](#)
- [United Kingdom](#)

Argentina

- [Asociación Argentina de Síndrome de Williams \(aAsW\)](#)

Australia

- Williams Syndrome Association of South Australia Inc.
102 Amsterdam Crescent
Salisbury Downs
Adelaide 5108
Australia
Tel: 8258 3867
Email: amarob@chariot.net.au
- Williams Syndrome (IHC) Association of New South Wales

32 Selwyn Street
Paddington
New South Wales 2021
Australia
Tel: 02 9332 1361

Belgium

- [Afrham Syndrome de Williams](#)
- French speaking group
- [Williams-Beuren Syndroom v.z.w.](#)
- Flemish speaking group

Canada

- [Canadian Association for Williams Syndrome](#)

Denmark

- Williams Syndrome Association of Denmark
V/gitte Petgersen Kildemarken 44
4622 Havdrup
Denmark

Finland

- Kettutie 4 A 14
FIN-00800
Helsinki
Finland
Tel: 358-9-19140926
Email: jari-matti.vuorio@helsinki.fi

France

- [Le Syndrome de Williams et Beuren](#)
- [ASW du Nord de la France](#)
- ASW Ile de France (Paris and suburb)
BP 50
78362 MONTESSON CEDEX
Tel: +33 (0) 1 39 52 06 75
- ASW Normandie
209 Rue du Commandant Abadie
76600 LA HAVRE
Tel: +33 (0)2 35 45 71 28
- ASW Sud-Est (covering Lyon-Toulouse-Nice)
16, rue Teresa Maxence Chaix
13200 Aries
France
Tel: 04 90 85 18 99
Email: helene.monti@wanadoo.fr

Germany

- [Bundesverband William-Beuren Syndrom](#)

- [Regionalgruppe Bayern-Süd im Williams-Beuren-Syndrom Bundesverband](#)

Hungary

- Hernad u 27
H-1078 Budapest
Hungary
Email: pogany@korb1.sote.hu
Tel: 36 1 326 7492 (English/French speaking)
Tel: 36 1 266 1639/2890 (English/Spanish speaking)

Ireland

- [Williams Syndrome Association of Ireland](#)

Israel

- Williams Syndrome of Israel
Louis Pasteur 5
Tel Aviv
Jaffo
68036
Israel
Tel: 03683 0538

Italy

- Associazione Italiana Sindrome di Williams
c/o Sovrano Militare Ordine di Malta
Piazza dei Cavalieri di Malta 4
00153 Roma
Italy
Tel/Fax: 06.574.1342
Email: aisw.rm@mclink.it

Japan

- Williams Syndrome Association of Japan
2-27-21 Nokata
Nakano-ku Tokyo 165
JAPAN
Tel: 03-3388-7488
Additional WS information in Japanese: <http://www003.upp-so-net.ne.jp/Williams/>

Netherlands

- Postbus 85276
3508AG Utrecht
Netherlands
Email: M.vanLeeuwen@fvo.nl

New Zealand

- [WSA of New Zealand](#)

Norway

- Norsk Forening for WS
Lisen Julie Mohr Norsk Forening for WS Bernhard Herresvel 17
0376 Oslo

Norway
Email: lisen.mohr@frambu.no

Portugal

- [Associação Portuguesa de Portadores de Síndrome de Williams](#)

Slovak Republic

- Spolocnost Williamsovho Sydrom
MUDr. Vladimir Bzduch
I.detska klinika DRNsPLimbova c.1
833 40 bRATISLAVA-Kramare
Slovenska Republika
Email: v.bzduch@pobox.sk

South Africa

- The WSASA
Contact: Mike Kabat
P O Box 24003
Claremont 7735
Republic of South Africa
E-mail: kingscol@mweb.co.za

Spain

- Asociación Síndrome Williams A.S.W.
C/Las Fabricas 3
Poligono Industrial Urtinsa
CP 28925 Alcorcon
Madrid
Spain
Tel: 91 486 0172
Fax: 91 556 7780
Email: elegary@teleline.es
- Asociación Síndrome de Williams en Soria
C/Sagunto 14 - 4B
42001 Soria
Spain
Tel: 975 22 2167
Fax: 975 22 5929
- Asociación Valenciana Síndrome de Williams
Plaza Alqueria Nova, 18, 49a,
46014 Valencia
Spain
Tel: +34 963 83 3547
Email: avsw@jet.es
- [Asociación Síndrome de Williams en Barcelona](#)

Sweden

- [Williams Syndromföreningen i Sverige](#)

Switzerland

- Sous La Rochetta
1566 St Aubin/Fr

Switzerland
Tel: (26) 677 17 17
Email: meroni@bluewin.ch

United Kingdom

- [Williams Syndrome Foundation - UK](#)

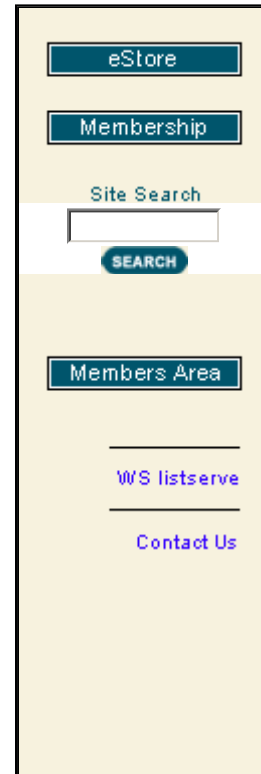
News and research articles

Many articles have been published by professionals (correct typo in professionals) in the research community regarding Williams syndrome. Most of these articles have been published in scientific journals and/or the New York Times.

The following is a list containing many of the most recent articles regarding Williams syndrome. Links are provided to those articles that exist online, and those available through the WSA are noted. For other articles, contact the author or publication for more information.

Article list

- [Music Lights A Fire](#)
- [Music, the Brain, and Williams syndrome](#)
- [Williams Syndrome and the Brain](#)
- [Different Minds](#)
- [With a Song in Her Heart](#)
- [WS Kids Can Be Musical Virtuosos](#)
- [Music in Her Soul](#)
- [Rare Genetic Disorder May Provide Musical Talent Along with Problems](#)
- [An Exceptional Performance](#)
- [Excerpts by composer Dalit Warshaw, the Juilliard School](#)
- [Brain and Cognition](#)
- [Williams Syndrome: From Cognition to Gene](#)
- [Presentation Accentuates the Positive](#)
- [WSA Professional Conference abstracts](#)



A vertical sidebar containing several navigation elements. At the top is a blue button labeled 'eStore'. Below it is another blue button labeled 'Membership'. Underneath is a 'Site Search' section with a text input field and a blue button labeled 'SEARCH'. Further down is a blue button labeled 'Members Area'. Below that is a horizontal line, followed by the text 'WS listserv' in blue. Another horizontal line follows, and at the bottom is the text 'Contact Us' in blue.

Music Lights A Fire [\[back to top\]](#)

[Article transcript](#)

by: David Scheiber

Publication: St. Petersburg Times

Summary: Feature article about WS Music Camp and musicality in Williams syndrome.

Music, the Brain, and Williams syndrome [\[back to top\]](#)

[Article transcript](#)

by: Brendan A. Maher

Publication: The Scientist magazine

Summary: This article is primarily a discussion of new research into Williams syndrome and general cognitive ability. It also provides a glimpse of the musical affinity of children with Williams syndrome.

Williams Syndrome and the Brain [\[back to top\]](#)

[Article transcript \(pdf file\)](#)

by: H. Lenhoff, P Wang, F Greenberg and U. Bellugi

Publication: Scientific American magazine

Summary: This is an excellent explanation of Williams syndrome and a summary of research at the time.

Different Minds [\[back to top\]](#)

[Article transcript](#)

by: Robert Finn

Publication: Discover Magazine

Summary: This article presents an interesting look at the beginning research into Williams syndrome. Note: This article was written prior to the discovery of the actual genetic problem, and prior to much of the music research. However, it outlines specifically some of the educational obstacles observed when trying to teach children with Williams syndrome.

With a Song in Her Heart [\[back to top\]](#)

Publication: San Diego Union Tribune, June 24, 1999

WS Kids Can Be Musical Virtuosos [\[back to top\]](#)

Publication: Toronto Star

Music in Her Soul [\[back to top\]](#)

Publication: Los Angeles Times, July 4, 1999

Rare Genetic Disorder May Provide Musical Talent Along with Problems

[\[back to top\]](#)

Publication: Minneapolis-St. Paul Star Tribune, July 16, 1998

An Exceptional Performance [\[back to top\]](#)

Publication: St. Petersburg Times, April 29, 2000

Excerpts by composer Dalit Warshaw, the Juilliard School [\[back to top\]](#)

Publication: The Juilliard Journal (Nov. 1996, pp. 10-11)

Summary: Deals with the musical gifts of Williams people

Brain and Cognition [\[back to top\]](#)

by: Ursula Bellugi and Paul P. Wang, Laboratory for Cognitive Neuroscience, The Salk Institute for Biological Studies, La Jolla, CA

Publication: Encyclopedia of Neuroscience, Elsevier Science Publishers, Amsterdam, The Netherlands (1996)

Williams Syndrome: From Cognition to Gene [\[back to top\]](#)

by: Bellugi, U. & Morris, C.A. (Eds.)

Publication: Williams Syndrome Association Professional Conference. Special Issue.

Presentation Accentuates the Positive [\[back to top\]](#)

Publication: Baltimore Sun, April 14, 1999

WSA Professional Conference abstracts [\[back to top\]](#)

Note: These materials are available directly from the WSA