

Williams syndrome shows gene-behavior links: Key to autism?

By **David W Freeman**

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(Credit: Terry Monkaba)

(CBS) Williams syndrome is a rare genetic disorder marked by learning difficulties, heart problems, and odd facial features, including a short, upturned nose and a small chin. But Williams has been in the news recently because people with it tend to be very, very sociable - and some scientists think research into the disorder may help explain the links between genes and behavior.

[PICTURES - Williams syndrome: One boy's inspiring story](#)

"We're on the brink of a whole new world," Dr. Ursula Bellugi, a long-time Williams researcher at the Salk Institute in La Jolla, Calif., told [msnbc.com](#). Speaking of a large-scale research project she's involved with - one supported by a new \$5.5.-million grant from the National Institute of Child Health and Human Development - she said, "We want to know: Are there links across the levels from the genes to behavior."

The research could benefit people with autism, said one researcher who has joined the project.

"Even though Williams' behavior is the opposite of autism, it may be influenced by gene activities that push it in a different way through a common process," Dr. Ralph J. Greenspan, associate director for the Kavli Institute for Brain and Mind at the University of California at San Diego, told msnbc.

Williams syndrome occurs in about one of every 8,000 births. There's no cure, but physical therapy, along with speech therapy, can be helpful. Some people with the syndrome are able to function independently, though most live with a caregiver.

The Williams Syndrome Association has [more on Williams syndrome](#). Want to know what it's like to raise a child with the disorder? [Click here](#).

Williams Syndrome: One boy's inspiring story

World's friendliest kids? Gene disorder means extreme sociability

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Credit: Terry Monkaba



Williams syndrome is a rare genetic disorder marked by extreme friendliness, learning difficulties, heart problems, and distinctive facial features. And it's in the spotlight as scientists say the disorder showcases the links between genes and behavior – and could even lead to new treatments for autism.

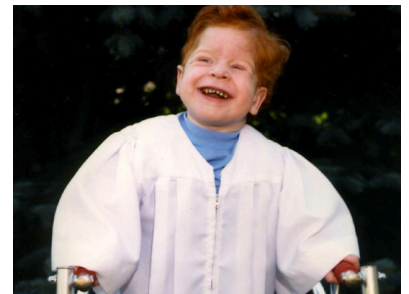
What's it like to have a kid with Williams syndrome? No better person to ask than Terry Monkaba. The Troy, Mich., woman is not only the executive director of the Williams Syndrome Association, but also the mother of someone with the disorder. Keep clicking as she tells the story of Ben Monkaba, now 25...

Ben was diagnosed with Williams syndrome at six weeks. Here he is at 16 months, weighing 15 pounds. By this time, he had undergone two major heart surgeries – but that didn't stop his sunny personality from shining through.



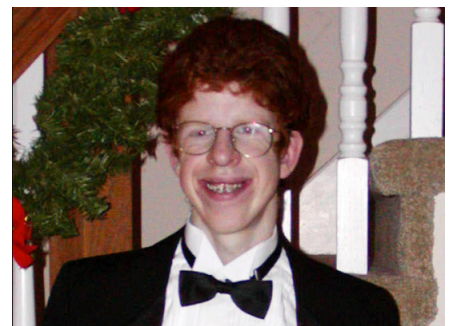
At age three, Ben's developmental delays were already evident. But "his smile could brighten any moment," says his mom. He loved life and enjoyed normal everyday experiences of a typical three-year-old – such as jumping in this pile of autumn leaves.

As soon as Ben was diagnosed with Williams syndrome, he began to receive treatment for heart and spinal problems. His surgeries and scoliosis delayed his ability to walk on his own. Here Ben stands at two and a half years old, a proud graduate of his early intervention program.



From a very early age, Ben exhibited the affinity for music that is very common in kids with Williams syndrome. Whether helping him through his many hospitalizations, as entertainment at every age or providing him with the opportunity to "shine" for his peers, music has always been very large part of Ben's life.

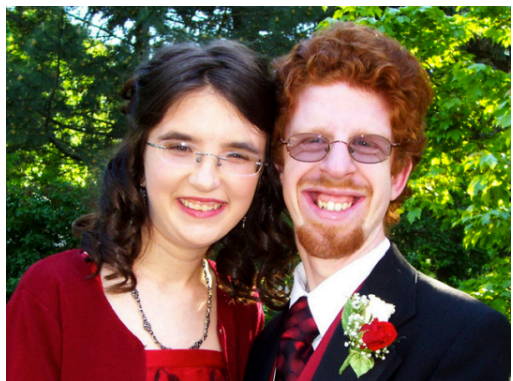
Beginning in fifth grade, Ben started playing drums in school bands. Many of his proudest moments were on the nights when he donned a tuxedo and performed side by side with his peers.





With such an outgoing personality, Ben loves clowning almost as much as he loves music. The community fair provides regular opportunities for Ben to become “Big Red” and to march in the parade.

While in high school, Ben traveled with his jazz band for competitions. Here, he poses with other members of the orchestra.



Like most people with Williams syndrome, Ben has a difficult time carrying on conversations and making lasting friendships with his peers. However, he has had a steady girl in his life periodically and attending the senior prom was a true high point in his high school experience.

This is Ben’s senior portrait from high school. Although some students with Williams syndrome graduate with regular high school diplomas, many – including Ben – graduate with special education diplomas or certificates of completion and qualify for federal services.



Ben was held back twice – in kindergarten and in first grade – to enable him to catch up a bit with his peers, and attend a mix of special education and regular education classes. He and his brother Adam graduated from high school together – here they pose at graduation. Adam is two years younger and one foot taller – not uncommon in individuals with Williams syndrome and their siblings.

Where’s Ben now? He attends a music academy in South Hadley, Massachusetts that caters to students with learning disabilities – and whose music-based curriculum aims to improve students’ life skills and independence as well as their musical abilities. Ben’s become quite an accomplished drummer and hopes eventually to put his talent to work – perhaps by playing in day-care or senior centers.

