

## Area boys share their stories of living with rare syndrome

Written by Jan Rahn, Grant Tribune-Sentinel

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There's more to the saying, "health and happiness in the coming year," than many people realize. If only it were that simple.

For two area families, good health would be gift enough for Christmas. Having a normal, healthy child to celebrate the holidays with would be an overwhelming blessing.

"Angelman" syndrome, a rare syndrome that afflicts approximately one in 15,000 births, has been diagnosed in two little boys with Perkins County, Neb. ties—Brandon Talich and Cylas Bickford.

Talich, two-and-a-half, and Bickford, four, are among children with the syndrome that has several traits. Some of the "angels," as they are called, also have autism. Another trait of "angels" is that their need for sleep is much lower than normal children and adults, according to Lance and Shannon Talich of Holyoke, Brandon's parents.

They might sleep for a couple of hours a night, yet there are others who sleep on a fairly regular pattern.

### **Brandon Talich**

Talich, whose ties to Perkins County are his grandparents and aunt and uncle, was diagnosed with Angelman syndrome when he was 17 months old.

Born May 20, 2007, he suffered a delay in global development, low muscle tone, seizures, lack of speech, but an extremely happy personality.

Although limited in things he can communicate and accomplish, the happy little guy can now

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walk independently and attends preschool four days a week.

He is learning his colors, animals and other related areas of development. He is a very social individual who loves to be around other kids, say his parents.

Brandon has a pull-behind walker that he uses for long distances and uneven surfaces. Recordable switches are used for individual items that he pushes when we wants something.

Although he can communicate well by using simple hand gestures and body language, the Taliches are currently working on getting him a communication device so he can communicate verbally.

“He has progressed very well with his switches and we are excited to see how he does with his new communication device,” said his parents.

The Taliches have other family members in the region who can help support them in the challenges they face with Brandon. Lance has a grandmother, uncle and aunt who live in Sidney, Neb. Shannon has several immediate family members who live in Sterling, and her parents live in northwest Kansas.

The family had made several trips from Oklahoma to the Children’s Hospital in Denver. The Taliches made the move to Holyoke in July 2009 after deciding to expose Brandon to a better school system that offered better services than were available in the Oklahoma panhandle.

Fortunately, Shannon was able to transfer in her job with Seaboard Foods, a company she has served as farm manager for at various sites in the Oklahoma panhandle and now in Holyoke for six years.

Lance has been working for Seaboard for the past eight months in the environmental and resource management department.

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The couple planned to host Christmas at their home in Holyoke for Lance's family from Grant, Neb.

### Cylas Bickford

Four-year-old Cylas, who can make excellent use of an iPad, could excel if he had a communication device, according to his mother, Holly Trumbull of Grant.

Unfortunately, the communication device, which has more memory capability, also comes with a price tag out of the single mom's reach.

"You see a child that can't speak—I see miracles happen every day. To me, that doesn't need words," said Cylas' mother who is trying to eke out an income for Cylas and his two siblings, 8-year-old Deija and Isis, 3.

### About Angelman Syndrome

Angelman syndrome (AS) is a neuro-genetic disorder characterized by intellectual and developmental delay, sleep disturbance, seizures, jerky movements (especially hand-flapping), frequent laughter or smiling, and usually a happy demeanor.

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Angelman syndrome is a classic example of genomic imprinting in that it is usually caused by deletion or inactivation of genes on the maternally inherited chromosome 15 while the paternal copy, which may be of normal sequence, is imprinted and therefore silenced.

The syndrome is named after a British pediatrician, Dr. Harry Angelman, who first described the syndrome in 1965. People with Angelman syndrome are sometimes known as “angels,” both because of the syndrome’s name and because of their youthful, happy appearance.

The sooner the diagnosis is made, the better it is for the child and the family involved.

Those with the syndrome are generally happy and contented people who like human contact and play.

People with Angelman exhibit a profound desire for personal interaction with others. Communication can be difficult at first, but as a child with the syndrome develops, there is a definite character and ability to make themselves understood.

People with Angelman tend to develop strong non-verbal skills to compensate for their limited use of speech.

Many Angelman syndrome children and adults will require lifelong occupational, speech and physical therapy to help them become active members of their communities.