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HEADLINE: Walkers hope to raise awareness of genetic disease

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BODY:

When Naperville resident Linda Yoakam participated in the Angelman Syndrome Walkathon two years ago, she read the signs along the way describing the symptoms of the disorder.

"That sounds like Billy!" she thought as she went on block after block.

Armed with her new knowledge, Yoakam went to her son's pediatrician, who agreed it would be worthwhile to test Billy for AS.

Two weeks shy of his 17th birthday, Billy was diagnosed with the disability that had mystified his parents since he was under a year old.

Previous testing had proven Billy's delayed development, impaired motor skills and inability to speak were not due to autism, Down syndrome, nucleic acid abnormalities, fragile X syndrome or cerebral palsy.

Now Yoakam knew. When she and Billy participated in last year's walk, she did it as the mother of a child who had Angelman Syndrome.

"It meant more to me," she said. "People who knew how much it meant to me helped me raise more funds."

Yoakam said she also was able to talk to other people on the walk, specifically about the challenges they face in raising a child with Angelman Syndrome.

"Being a member of a community meant a lot to me, too," she said.

Yoakam and Billy will be part of this year's walk Saturday at Word of Life Lutheran Church, 879 Tudor Road, Naperville.

Registration is at 8 a.m. Ozzie the Cougar, the mascot of the Kane County Cougars, will lead walkers in stretches and warm-ups before Naperville Mayor George Pradel starts the walk at 9 a.m. Walkers can choose a 3- or 5-mile route before coming back for prizes, music and refreshments.

First steps

Now a national event, the first Angelman Syndrome Walkathon started at Word of Life seven years ago.

Church member Al Kelkhoff of Aurora proposed starting the walk to fellow church member and neighbor Eileen Braun, whose daughter, Kaitlin, had Angelman Syndrome.

Kelkhoff, who was then president of the church's branch of Aid Association for Lutherans, previously had been involved with walks for multiple sclerosis.

"Having Kaitlin as a neighbor, we wanted to see what we could do to help," said Kelkhoff, who continues to coordinate the Naperville walk.

Obtaining support from the Lutheran Aid Association, volunteers organized the first walk with a turnout of 348.

Braun now is executive director of the Aurora-based Angelman Syndrome Foundation, which will have walks in 13 cities across the nation this year.

The Naperville walk draws people from as far away as Minnesota, Wisconsin, Michigan and Indiana, Braun said. Most come because they have been invited by someone they know, she said.

"Last year we were over 450. We're expecting that many this year," Braun said.

About 30 families at the walk will have a member with Angelman Syndrome, Braun said. Because the condition is rare, the Angelman Syndrome Foundation knows of only 1,000 individuals around the country who have the chromosomal disorder.

"To have 30 of them in Naperville at one time is extraordinary," Braun said. "It's a wonderful opportunity for these families to network with each other."

Walkers pay no registration fee, but are asked to raise donations. Last year, the Naperville walk brought in \$68,000 for support of families, education and research.

Unraveling the causes

Often misdiagnosed, Angelman Syndrome once was thought to occur only in blond, blue-eyed children, Braun said. In actuality, it crosses gender and ethnic lines. The disorder first was recognized by Dr. Harry Angelman, who observed similarities in a group of children in an English institution in the 1960s. The children exhibited awkward movements, hand-flapping, developmental delays and lack of speech. But they were characterized by exceptionally happy, excited and affectionate behavior. By the 1980s, technology had advanced enough to reveal that the disorder was caused by the abnormality of a gene on chromosome 15.

Although many more people have been diagnosed with Angelman Syndrome since then, obtaining the testing still can be difficult, Braun said.

"It's fairly common for someone outside the medical community to recognize symptoms of Angelman Syndrome," she said. "Sometimes these families are pressing physicians pretty hard to test."

Braun's daughter, now 14, was diagnosed at the age of 21 months. Kaitlin, who attends a special class at Granger Middle School in Aurora, enjoys many typical teenage activities and speaks more than some children with Angelman Syndrome do, Braun said.

Yoakam got to know Kaitlin after she and her family joined Word of Life seven years ago. But because the symptoms of people with Angelman Syndrome are not all the same, Yoakam saw enough differences between her son and Kaitlin to initially dismiss the thought that Billy might have Angelman Syndrome, too.

Now that she knows, Yoakam said she can better plan for the future. She knows that Billy -now 18, a student at Aurora Education Center and an athlete in Special Olympics - will always need 24- hour care.

And, at some point, his parents will need to find him a home away from their home.

"In getting support, it's wonderful to have a diagnosis to put on forms," she said.

Angelman Syndrome

Common characteristics of Angelman Syndrome include the following. Some symptoms occur more frequently than others.

Consistent (100 percent)

- Developmental delay (evident by 6 to 12 months)
- Speech impairment, no or minimal use of words
- Movement or balance disorder
- Frequent laughter, happy demeanor, excitable personality, often with hand movements, short attention span

Frequent (more than 80 percent)

- Delayed, disproportionate growth in head circumference by age 2
- Seizures, onset usually under 3 years
- Abnormal EEG

Associated (20-80 percent)

- Squinting, crossed eyes
- Hypopigmented skin and eyes
- Tongue thrusting; sucking/swallowing disorders
- Hyperactive tendon reflexes
- Feeding problems during infancy
- Uplifted, flexed arms during walking
- Prominent lower jaw
- Increased sensitivity to heat
- Wide mouth, wide-spaced teeth
- Sleep disturbance
- Frequent drooling, protruding tongue
- Fascination with water
- Excessive chewing/mouthing behaviors
- Flat back of head

Source: Angelman Syndrome Foundation Web site