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## Friends have party to raise money for girl with incurable disease

BY KEVIN COLE  
WORLD-HERALD STAFF WRITER

A bright smile spread across Sarah Inks' face Sunday as her wheelchair rolled into a Bellevue skating rink and a chorus of 150 voices greeted her.



Sarah Inks, 13, is the center of attention at a fundraiser in her honor Sunday at Skate City in Bellevue. The Logan Fontenelle Middle School student is flanked by teacher's aide Terry Mack, left, and teacher Reed Keenan. Behind Sara is her grandmother Jean Schaefer. Sarah has a degenerative disease that has taken her sight.

"Surprise!" shouted friends and family members.

A rare disease has stolen the 13-year-old girl's sight and her ability to walk. Eventually, it will take her life.

But on Sunday, at a fundraiser on her behalf, Sarah showed she could still listen and have fun.

As her mother, Sue, pushed Sarah's wheelchair through the crowd, Sarah tilted her red-haired head back and soaked up the cacophony of well-wishers.

"Hi, Sarah! Hi, Sarah!"

Sarah quickly picked out the voice of her grandmother Jean Schaefer. She returned each greeting with an imperial "Hello-o-o!"

"And," she would say, sounding not unlike a royal princess deigning to talk to a stranger, "who are you?"

For four years, Sarah has fought juvenile Batten disease, an inherited neurodegenerative disorder that strikes in childhood and is fatal, typically by the late teens or early 20s. The disease is very rare, occurring in just two to four of 100,000 live births.

Symptoms of this disorder typically appear in children between ages 5 and 10 and include vision problems, seizures, personality and behavior changes, slow learning and clumsiness. Over time, affected children suffer mental impairment, worsening seizures and progressive loss of sight and motor skills.

Sarah, unaware of the deadly nature of the disease, enjoys life. She attends movies, listens to music and plays games.

Trish Davis, a neighbor who joined forces with Sara McCormick to organize the fundraiser for the Inks family, summed up the teenager's personality in one word: spunky.

"She loves music and she loves being with other kids," Davis said. "I have never once heard her complain about losing her sight or her ability to walk."

The Inks family struggled to pay for medical costs even when there were two incomes. Then Sarah's dad, John Inks, developed lung cancer and died two years ago, at age 38.

Sarah, Sue Inks and three other children have moved into an apartment.

Tears welled in Sue Inks' eyes as she described support they receive from family and friends.

"I have four kids that really depend on me, so I have to keep going," Sue Inks said. "I feel like I want to give Sarah and the rest of the kids a good life — no matter what."

Out on the floor at Skate City, Sue Inks pushed her daughter around and around as other children came alongside to squeeze Sarah's hand and shout a hello.

Suddenly, the whole group formed a circle for the "Chicken Dance." Sarah hardly missed a clap or a cluck.

"She and her dad loved to go to (Omaha) Royals games," Inks said. "She still remembers all the moves and words to that song from dancing along at the games."

Sarah attends Logan Fontenelle Middle School, where she is one of 12 disabled students taught by Reed Keenan and her aide, Terry Mack.

Both women attended Sunday's party. Keenan said Sarah is "definitely the most vocal" of her students.

"Sarah has a great sense of humor and likes to be very social with the other kids," Keenan said.

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"She's gone through some rough times, but her spirits are always high."

As the disease progresses, Sarah will one day be confined to bed. Eventually, she will receive..... nourishment through a feeding tube.

Sue Inks and Sarah will travel to the University of Rochester (N.Y.) Medical Center this month to learn how far the disease has progressed.

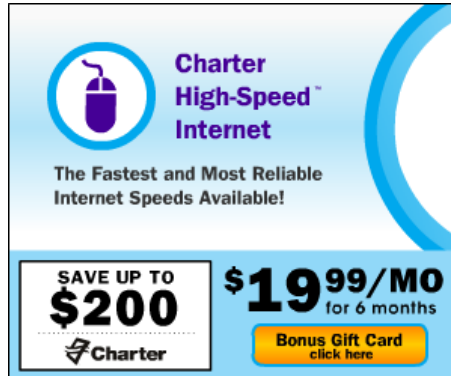
Schaefer said the family gives the spunky redhead only enough information about her condition as they feel is necessary. The subject of the girl's death has not been discussed.

"I don't even know how to describe it because it really is devastating for the whole family," Sarah's grandmother said. "To watch a child who is like a perfect flower . . . and little by little to see them die . . . it's heartbreaking."

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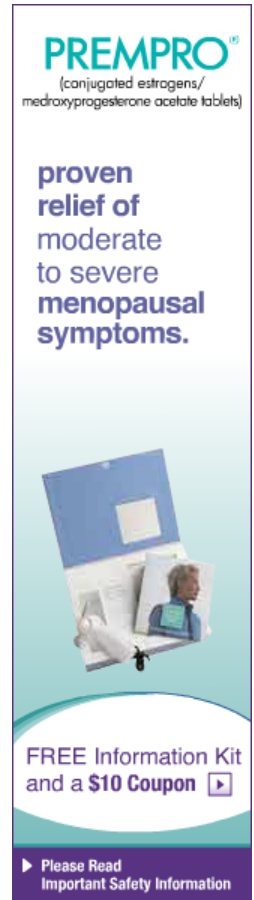
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