

# Duluth News Tribune

## Minnesota girl in the fight of her young life against rare form of cancer

12-year-old Megan Wegge faces a cancer so rare that her case is known nationwide. But doctors say the 'strong, sweet girl' from Moose Lake has the faith to beat it.

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By: [John Lundy](#), Duluth News Tribune

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When Megan Wegge twice donated her long, blond hair to "Locks of Love" last year, she didn't know that when she was 12 she would lose all of her own hair to the effects of chemotherapy.

When she laid the groundwork for her own business, "Chocolate for Children," to raise money for pediatric cancer research, Megan didn't know she would be diagnosed with a rare form of cancer herself.

When Megan was playing in the state tournament with her Moose Lake U12B hockey team in March, she had no idea that by the end of May she and her mom would be temporary residents of Bloomington, Ind., preparing for a form of radiation treatment that's available in only nine places in the country.

Megan, mom Jodi, dad Dan, older sister Lindsey and her triplet brother and sister Nicholas and Brooke moved to Moose Lake less than five years ago from Arlington, Minn. Before that, they lived in Cummings, N.D., where they were close friends of Jim and Denise Murphy and their son, Johnny. When Johnny lost his battle with cancer in 2005 at age 11, it had a profound effect on the Wegge children, especially Megan.

"She had wanted to do something in honor of Johnny, so she's donated her hair to Locks of Love two times," Jodi Wegge said on Thursday from a hotel room in Bloomington, where she and Megan are beginning a seven-week stay. "She came up with an idea to make chocolates, and she named her little company Chocolate for Children."

Megan talked to her youth minister about using the church kitchen to make chocolate. She talked to her school's principal about selling chocolate in the hallway during parent-teacher conferences. She planned to set up a table in downtown Moose Lake on Friday afternoons.

## **'Something's not right'**

Life went on, and for Megan, a lot of that revolved around hockey. She and best friend Asia Gobel were on that U12B hockey team that competed in Grand Rapids on March 18-20. The Friday game went into triple-overtime.

Megan hadn't been feeling well for a while, especially not that week. She had stayed home from school every day, but her mother told her she would have to go to school on Thursday or not compete in the state tourney. She went to school on Thursday.

"Come to find out here she's skating at the state tournament with this ruptured malignant tumor," Jodi Wegge said. "Never complained. Gave it her all. Pretty amazing."

Megan had been sick off and on for weeks. Tests administered during clinic and emergency room visits revealed nothing. "And she just kept getting worse, and I felt like I was just watching her wither away in our bed," Jodi Wegge said. She called her husband, a contractor who is building houses in North Dakota.

"I said, 'Dan, something's not right.' He said, 'Well, take her back in.'"

The clinic scheduled a CAT scan for the morning of April 14. An hour after they got home, Jodi got a call. They should go to Children's St. Paul hospital right away; doctors were waiting for them. A softball-sized mass was in Megan's liver.

About 10 that night, a doctor walked into Megan's room and said he was going to be her primary oncologist. "And that was the first we'd heard the cancer word," Jodi Wegge said.

## **Still beautiful**

The cancer was diagnosed as undifferentiated embryonal sarcoma of the liver — "undifferentiated" meaning highly malignant. The good news was that doctors removed all of the tumor, along with half of Megan's liver. The bad news was that the tumor had ruptured, or "spilled," into her abdomen. Because of that, "she's a lot higher risk of a relapse or this cancer starting somewhere else," Jodi Wegge said. "Because there's so few people (with this form of cancer) there isn't any clear data on how to treat it. It's just not very good."

Chemotherapy and radiation were prescribed. Megan's hair started to fall out, and on May 10 Jodi shaved Megan's head. Family friend Cathleen Nummela said losing her hair didn't faze Megan.

"She went to the school last week and talked about how everybody tells her she's beautiful even without hair," Nummela said. "And she told her mom that being beautiful is what's inside of you, not how you look."

When a child is seriously ill, her parents become experts in that disease, sometimes learning things even the doctors don't know. Jodi Wegge, concerned about the effects of radiation, read about something called proton therapy.

She and Megan's radiation oncologist, Dr. Patsa Sullivan, started calling proton therapy centers. Houston; Loma Linda, Calif.; Boston ... they couldn't fit Megan in soon enough. On the evening of May 20, Sullivan reached Dr. Jeff Buchsbaum of the Indiana University Proton Therapy Center by cell phone. Buchsbaum had the day off and was shopping with in-laws. In a telephone interview on Friday, he said it was the fourth referral he'd gotten that day.

"We are committed to not making a child wait," Buchsbaum said. "We're committed to not making anybody wait. ... I told Dr. Sullivan, just send her, I'll figure it out."

One of the IU center's focuses is treating children, and Buchsbaum is passionate about the work. "I am extremely busy; right now I am excruciatingly busy," Buchsbaum said. "The other doctor who does children with me — we will do whatever it takes to help the kids. That's our calling."

### **'Tough little cookie'**

Megan and Jodi reached Bloomington late on Monday. On Tuesday, they met Buchsbaum. A mold was made of Megan's body so that metal rings could be designed to introduce radiation where it's needed. Buchsbaum showed them the proton therapy unit. One of only nine such units in the country, it's housed in a room that's three stories high and it weighs 90 tons.

Megan made a strong impression on Buchsbaum, 43, a radiation oncologist for about 10 years.

"She's funny," Buchsbaum said in a telephone interview on Friday. "She has a very good smile. She is, as are most children who have these kinds of problems, she is wise beyond her years. ... I think Megan is a very strong and very sweet girl. And I think that she's got the right constitution to survive this and get through it.

"The question is going to be ultimately, is it going to work or not? She's got what it takes to get through this, and you can tell that she's a really tough little cookie."

The targeted beams of proton therapy will spare many of Megan's organs, but her right kidney won't survive. So on Friday, mother and daughter made the 90-minute drive to Riley Hospital for Children in Indianapolis for a blood test to find out how much of the load that kidney is bearing. If it's more than 50 percent, some kind of kidney surgery will be needed before radiation can begin. Riley is also where Megan will continue to receive chemotherapy while she's in Indiana.

While at Riley, Megan became feverish and her blood pressure dropped. She was admitted with a low white blood-cell count. Buchsbaum said that's a common side-effect of chemo, and she couldn't be in a better place than Riley to be treated.

In the meantime, Jodi and Megan are making the most of their time in Indiana. They toured a cave system in Bedford, Ind., on Wednesday until another violent storm system came in that afternoon. Storms persisted, and as tornado warning sirens sounded during the night, Jodi put Megan in the safest place, the bathtub, and covered her with blankets and pillows.

At home, relatives and family friends are taking turns staying with the children, because Dan Wegge still has to spend most of his time in North Dakota. Nummela said more people have volunteered to stay with the family than have been needed.

Stacia Heaton, Asia Gobel's mom, talked about being in the Wegge home when Megan was undergoing physical therapy.

"They'd tell her what to do, and you could just see the determination," Heaton said. "She's got the faith, she's just smiling, and she's just got that positive attitude. I just have to believe that ... she's going to make it through with that attitude. I just have to believe that."

### **How to help**

A benefit for Megan Wegge and her family is planned for 2-6 p.m. June 12 at Doc's Sports Bar in Sturgeon Lake, just off the Interstate 35 exit.

The event will include a kids' carnival, spaghetti dinner, silent auctions and raffles every half-hour.

Family friend Cathleen Nummela said donated auction items include a U.S. Olympic hockey jersey autographed by Cloquet native Jamie Langenbrunner, a trip for two to the Bahamas and an hourlong flight for three courtesy of Cirrus.

Jodi and Megan Wegge are planning to fly back from Indiana for the benefit.

On the Internet, visit <http://2crewgear.com> to purchase T-shirts with the 2crewgear logo. Money raised from sales will go toward Megan's "Chocolate for Children" business, which she plans to introduce online.

More information is available on an online Caring Bridge page for Megan.

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## Girl's treatment less invasive than traditional method

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As compared to the typically used dynamic rapid arc therapy, the use of proton targets the treatment at the enemy cells. No radiation hits organs in healthy parts of the body, and because the radiation is targeted, lesser amounts can be used.

"It's a game-changer," said Dr. Jeff Buchsbaum of the proton center, one of 67 radiation oncologists in the country. "The physics of the proton beam means the total amount of person that has to get dosed is less — maybe a third of what would get it if you had regular treatment. Might be less than that."

Not-yet-published studies from Harvard indicate patients treated with proton therapy get a third as many secondary malignancies later as those treated with traditional radiation.

In Megan Wegge's case, she would have been treated with 55.8 "grays," the unit of measure used in radiation. Jodi Wegge said she learned that there's "a percentage of patients that don't tolerate any more" than 45 grays, but with traditional radiation it would take more than that to kill the sarcoma.

The result, while it might save Megan's life, would be massive damage.

"It would be affecting her heart, it would be affecting her breast tissues, it would be affecting all of her female organs, both ovaries, both kidneys, everything would be getting it if we did the rapid arc," Jodi Wegge said.

Proton therapy will use the equivalent of 45 grays, and all of those organs — except the right kidney — will be spared, she said.

It's the right treatment for Megan's case, said Buchsbaum, who has consulted with colleagues at Harvard and Stanford.

“There’s no such thing as perfect treatment, no matter what you do as a physician,” he said. “But within the limits of what’s practical, this is the least toxic of the various

external-beam options that are out there, by a long shot. I’m really proud to be part of it. It’s exciting. This is the cutting edge of our field.”

The IU proton therapy center, which opened in 2004, was the third in the country and the first in the Midwest, Burnham said.

Buchsbaum praised the team that cared for Megan at Children’s in St. Paul, saying the tumor had been removed with “amazingly good surgery.”

“Megan has found a really good group of people,” Buchsbaum said. “The care that she’s gotten to date has been state-of-the-art. The radiation therapy I can deliver with proton beams is as good as you can get. So the next step is just to see where all the treatment leads. You can take people all the way you can, and then some of it we doctors can’t control.”