



Student waits, hopes for life saving transplant

BY: Josie Luke

2/5/2007 - <http://www.theemerycountyreview.com/index.html#Student>

17-year-old Ryan Thompson's life has changed dramatically in the past four years. He has gone from an active lifestyle where he had perfect attendance in school, was on the honor roll, excelled in sports, and achieved the rank of Eagle Scout, to the point where life is a long period of waiting...and hoping.

Today Ryan can no longer attend school or leave his home in Huntington for more than a few hours because he becomes fatigued very easily. Ryan is now faced with needing a liver transplant to save his life.

Ryan's mother, Yolanda, explains that the doctors have said that "tomorrow wouldn't be too soon" for Ryan to have the transplant, but they have warned the family that "livers are a precious commodity and don't come easily." Ryan's most recent hospitalization was from Jan. 14-24 when he had a drain put into his liver between his ribs to drain bile

which wasn't able to escape because the liver duct had become completely closed off. "He's had more pain than anyone should ever experience in a lifetime. He was in pain for days," Yolanda relates.

During this stay at Primary Children's Ryan was placed on the liver transplant list. At this time Ryan's parents received a pager to keep with them at all times for when a liver becomes available. The rest of the families contact information was also recorded.

Ryan's problems began in 2004 when he was in 8th grade. He began to experience aching joints to the point he was unable to get out of bed in the morning. Over the next year this was followed by stomach pain and lack of energy. Ryan felt that the lack of energy meant he "wasn't in good enough shape and needed to work out more." After months of uncertainty as to what was making him sick, in April of 2005 Ryan was initially diagnosed with pneumonia. His mother wasn't convinced that the correct diagnosis had been made and insisted that he be transferred to Primary Children's Medical Center in Salt Lake City. During the two weeks of being hospitalized and undergoing tests, doctors discovered that Ryan had some serious medical issues.

What had been originally diagnosed as pneumonia was in fact Pulmonary Nodules, which were causing him to have difficulty breathing, combined with Ulcerative Colitis, a form of inflammatory bowel disease. More seriously, Ryan was diagnosed with a rare form of liver disease called Primary Sclerosing Cholangitis which, according to the National Liver Foundation, is a chronic disease that causes scarring and inflammation in the bile ducts of the liver. The ducts become permanently blocked and bile accumulates in the liver, damaging it and causing cirrhosis, which leads to the need for a transplant.

Since the diagnosis, Ryan has had periods where he feels well and periods when he is unable to function. "I would be OK for a couple of months and then I'd get another flare-up. It just puts me on the floor where I can't move for hours," he explains. He has slowly had to quit many of the activities he enjoyed. "In 9th grade I made the basketball team, I was on the wrestling team and on the football team, and I was planning on doing baseball in high school. I can't do any of it anymore." He has also lost a lot of weight, "I've lost 20 pounds in the last few weeks. When I was in junior high I weighed 155 and right now I weigh about 120," he said.

Since Thanksgiving Ryan hasn't been well enough to attend school. His mother said that "the school is trying to work with him, but they're having a hard time finding tutors. He's gone to school a couple of times but just for a couple hours and has his girlfriend bring his homework back and forth." He was especially disappointed to have to drop into a lower math class. "I liked math, I was on the math team, but I had to drop out," he says.

Because Ryan's father, Timothy, works for Geneva Rock near Salt Lake during the week, Ryan and his mother spend a lot of time together. Although Ryan loves his mother, he reports that his days are "boring". The first thing he wants to do when he is well again is "get out of the house and go for a run".

The situation is also taking a toll on his family. “We’ve spent a lot of time at Primary Children’s Medical Center. He’s probably been five times that he’s had to stay, but we’ve been up there a lot for just day trips,” says Yolanda. They have good days and bad days. “A bad day is when he’s in so much pain we’re on our way to Primary’s. A good day is when he does not have to take any pain medication and he’s feeling good,” she explains, “We try to keep each other happy.”

The family is also concerned about the associated costs. On average a liver transplant surgery costs about \$392,000. Yolanda explains, “We have insurance, but our insurance has a \$250,000 a year cap, and some of that has already been used. “If we have to end up selling our house, that’s what we’ll do, it’s only a house. We can replace everything but Ryan. We just need to have enough money to take care of Ryan to get him better.”

Asked what the perfect outcome would be, Yolanda pauses attempting to hold back tears. She explains, “It’s kind of hard. Somebody’s got to lose their life in order for Ryan to get a liver. There’s going to be a family out there that is going through a loss and we’re pretty much going to be rejoicing. It’s kind of messed up. I hope that people donate. It’s a hard thing. One person donating can save eight lives and make other lives better. I just pray that whoever it is, that they don’t suffer.”

Another fear is being faced with the possibility of having another one of their sons giving part of their liver if a deceased donor does not become available in time. Doctors have told the family that they prefer a full liver transplant, but if Ryan only had a few days left, they would consider a living donor. His mother says, “He has three brothers that have the same blood type. If they do that, they would take two-thirds of the donor’s liver, and the donor would be left with one-third.” Doctors have told them the donors’ liver would be back to a full sized liver in 5 to 8 weeks. Ryan’s liver would be full sized in approximately 3 months.

Ryan and his family are looking forward to a time when he can do all of the things his diseases are keeping him from. “We’ve always been pretty avid outdoors people. I’ll just be excited to see him do about anything. Climbing the rocks when we go to the desert, riding the four wheelers, or building a dam in the river when we’re up the mountain—anything he loves to do” says his mother.

Ryan’s brother has put together a web site to try to raise money for the transplant surgery at www.HELPRYANNOW.com A fund has also been set up to help the family to pay for the transplant at Wells Fargo under the Ryan Thompson Liver Fund.