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## Wellness/organ transplant

Wednesday, April 19, 2006

KATY MULDOON

### FACTBOX

- Organ and tissue donation: the facts

The highlights of a young man's life flash across an auditorium's wide screen in a series of happy photographs.

Rob Ayers, tucked into his kayak, shooting through a fast river's froth.

Rob, tuxedoed, marrying his beautiful Jennifer.

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Rob cradling their sweet-faced newborn, Lauren Elizabeth.

As the teen-agers in the audience ooh and aah over the cute baby snapshots, Rob hits them with this:

"I want to hang out with this little girl. I want to teach her how to tie her shoes, to ride a bike, and when she gets to be your age, to talk her out of that tattoo."

The tattoo bit gets a laugh from the group of Sandy High School students visiting Oregon Health & Science University on an April morning. But they quickly fall quiet again as Rob shares his story.

The 30-year-old manufacturing engineer and avid outdoorsman has primary sclerosing cholangitis, the same rare, incurable disease that struck football great Walter Payton and Olympic snowboarder Chris Klug. The bile ducts in and around Ayers' liver are inflamed and scarred. In time, the liver will fail, or cancer will grow in the ducts.

He needs a transplant. But on any given day, about 160 others in Oregon and Southwest Washington need new livers, too, and Rob's name is not at the top of the list.

"Waiting," he says, "is hard."

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So he has found a way to channel his anxiety and his hope. When he's feeling well enough, Rob spends hours each week volunteering for the Oregon Donor Program, either speaking publicly or using his technological skills on various projects. Recently, he helped the program customize new electronic readerboards designed to encourage those doing business in 15 busy Oregon DMV offices to make organ and tissue donation a priority.

After two miscarriages, Jennifer and Rob Ayers, who'd met as engineering students at Oregon State University, decided their chances of conceiving and carrying a healthy child to term might be better if they found jobs less stressful than the ones they held.

In fall 2004, Rob applied at Welch Allyn, a Beaverton company that makes medical products. In a pre-employment health screening, a blood test showed elevated liver enzymes, the first hint that something was wrong.

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Rob wasn't a drinker or a smoker. He'd grown up a studious Eagle Scout in Bend and took to outdoor pursuits like any good Central Oregonian. When he learned he was gravely ill, Rob remembers, he felt as healthy and vigorous as a 29-year-old should.

A doctor prescribed medication to thin Rob's bile. He underwent a balloon dilation, similar to angioplasty, to stretch his bile ducts. And he was still symptom-free in January 2005, when his wife learned she was pregnant.

The couple chose to make the most of the months before their baby was born. That summer they backpacked 60 miles through the Enchantments in Washington's Cascades, and circumnavigated Mount Hood on Timberline Trail.

In September, Rob's health deteriorated. He grew so tired he'd go to his car in the middle of a workday and nap in the parking lot. Jaundice colored him a sickly yellow, and his skin itched so mercilessly he'd scratch until he bled.

Five days before his wife was due to deliver, doctors installed a stent in an effort to keep Rob's bile ducts open; the ducts act like drain pipes, carrying a stew of cholesterol, acids, salts and waste products out of the liver.

His condition improved enough for him to be at Jennifer's side for their child's birth on Oct. 18.

But just hours after they brought Lauren home from the hospital on Oct. 21, searing pain shot through Rob's gut. He was bleeding internally and landed in OHSU's intensive-care unit.

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On Oct. 28, 10 days after he welcomed his newborn into the world, doctors put Rob on the waiting list for a liver transplant.

The Ayers were enjoying a family dinner at their home in Sherwood on Feb. 9 when the phone rang. Rob remembers a rush of excitement when a transplant coordinator told him to be at OHSU at 7 a.m. the next day.

A liver was available.

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Another patient who was sicker than he was would be first in line. But if surgeons opened that patient and found cancer outside the liver, he or she wouldn't be eligible for a transplant.

Rob would be the backup recipient.

He hardly slept.

At 5:40 the next morning, his phone rang again. The donated liver was no good.

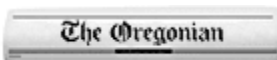
Instead of getting prepped for surgery, Rob went to work.

The next call came two days later, at 8 a.m. He was to fast all day and check into the hospital at 5 p.m. Again, if the donated liver was transplantable, he'd be the backup recipient.

Hospital staffers drew 10 vials of Rob's blood, took a chest X-ray, measured his heart activity with an electrocardiogram and performed other tests. He took a pre-surgery antibacterial shower and started on a high dose of antibiotics. And he heard the transplant team arrive carrying a cooler containing a human liver.

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Around midnight Rob and Jennifer learned the other patient, a man more desperately ill than Rob, got the transplant.

On the drive home, the powerful antibiotics coursing through Rob's system made him vomit.

A week later, between 2 and 3 a.m., the Ayers' phone rang again. They went straight to the hospital and Rob repeated the pre-op routine, knowing, again, he was the backup. As he and Jennifer waited, they watched the rising sun paint a brilliant backdrop for Mount Hood, Mount Adams and Mount St. Helens. At 8 a.m., a surgeon told them that something was wrong with the donated liver.

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Bend Oregon Visitor & Convention Bureau advertisement featuring a mountain scene and a photo of the Tower Hotel at night.

Rob recalls purposely hiding his emotions as his spirits plunged. He wanted the transplant team to know that no matter how deep the disappointment, he could handle it. He doesn't want them to hesitate calling him again.

"It's like the Academy Awards," he says. "It's an honor to be nominated."

Last year, Oregon Donor Program volunteers spoke to 15,000 high-school students about the lives people can save when they choose to donate organs and tissue. This year, they aim to reach 30,000 young people, plus thousands of adults.

Some of the program's 400 to 500 volunteers are fortunate enough to have received donated organs or tissue. Others come from families that chose to donate when their loved ones died. Fewer are like Rob Ayers; many people waiting for transplants are too sick to be able to help.

"Rob sees the need, obviously," says Mary Jane Hunt, the Oregon Donor Program's executive director. "He knows that he has a very long wait for a transplant. While he feels up to volunteering, he wants to do his part."

And so, on an April morning, a slide show brightens a dim auditorium at OHSU and the highlights of a young man's life flash across the screen. As they do, Rob talks about the wife he feels so lucky to have found and about the daughter he'd like to watch grow.

As he speaks, he hopes for a ripple effect: The students in this audience might code their drivers licenses with a "D" for donor. They might go home and talk about their wishes with their families. They might persuade their parents, siblings or friends to consider organ donation, too.

So Rob talks.

"This," he tells those listening, "is my therapy."

Katy Muldoon: 503-221-8526; katymuldoon@news.oregonian.com