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An Update from Friends

BY LAMBETH HOCHWALD

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Rachel Baumgartner

Rachel Baumgartner, the vibrant spinal cord tumor survivor whose essay about her “fairy godmother nurse” Tish Mullen appeared in the Summer 2007 issue, is now a full-time interior design student who dreams of becoming an art therapist. She’s also gotten engaged since she first told her story in our pages, and Tish, who remains a dear friend, is helping her alter her wedding dress.

The last time **Tamika Felder** was interviewed for CURE—her story appeared in the Winter 2005 issue—her friends were on her case about finding time for a personal life. Today, her girlfriends still hound this cancer advocate about meeting a guy.

“Just this week, one of my girlfriends had a long conversation with me about dating,” says Felder, a 32-year-old television producer. “Part of it is that I haven’t met the right person,” she says. “But I know that when I do, they’ll accept my advocacy work.”

This is key for Felder, who founded Tamika & Friends (www.tamikaandfriends.org) in response to what she felt was a dearth of information about cervical cancer when she was diagnosed in May 2001 (her diagnosis was followed by a radical hysterectomy, chemotherapy, and radiation).

“When I was out there looking for websites, they were all gray and blue,” she says. “I wanted something warm that would make me feel comforted and good. Our site is like a virtual hug. There might be clouds, but you come here for sunshine.” Last October, she shared her story with 700 survivor delegates as a speaker at the LIVESTRONG Summit in Austin, Texas, in hopes of helping them develop their own action plan.

Felder receives nearly 40 e-mails daily, including notes from women who update her after their surgery and treatment. In turn, the team behind the site—made up entirely of volunteers—gives women gift cards for groceries and any other help they need. “When I was diagnosed, I had a great job and it still got hard to pay my mortgage,” Felder says. “I said, ‘If I beat this cancer, this is the way to give back. If a mother needs a day away, we’ll pay for a babysitter.’ ”

To pay for these initiatives, Felder and her team recently held their first-ever cervical cancer walk in Washington, D.C. Nearly 420 walkers showed up garnering \$19,000 in donations, all of which will go to help women in need.

Jasmine Brenneman is some kind of special sister. Featured in the Fall 2006 issue, Brenneman spent most of her senior year in turmoil after her younger brother, Josh, now 7, was diagnosed with Ewing's sarcoma. She was thrust into mini-mom mode, caring for her younger sisters (today, Joy is 18, Jubilee is 15, and Jordan is 13). Regular teenage life seemed to be permanently on hold.

Now, three years since Josh's diagnosis and treatment, she's starting to feel like things have settled into a routine. Brenneman, 20, is a junior at Simpson University and Josh is full of energy and spunk, despite a tracheotomy, continued complications with his esophagus, and being fed through a tube. "It was devastating to see what happened to Josh," she recalls. "People have said, 'Isn't it time for you to move on from this?' And I tell them that I try not to dwell on the hard times, but what happened to him has shaped who I am as a person."

Still, when she thinks back to her life three years ago, she's sometimes surprised she was able to do it all. "It's one of those things where you never know how you're going to react until you're put into that situation," she says. "You take it moment by moment, and you take it in little chunks."

What really has helped, she says, is SuperSibs!, an organization that raises awareness of the problems facing siblings of children with cancer. "It's an amazing organization," she says. "They send me a care package each month with a newsletter filled with writing from other siblings of cancer patients. Sometimes they'll send a journal to write down thoughts. It was a lifesaver. I don't know what I would have done without it."

Triathlete **Allan Goldberg**, 40, knows what it's like to be a childhood cancer survivor. He had rhabdomyosarcoma when he was a teenager and, in August 2006, battled a secondary tumor caused by the high-dose radiation he received decades ago.

Firsthand experience made him the ideal candidate to be executive director of First Descents (www.firstdescents.org), a nonprofit that provides outdoor adventures for young cancer patients. Since Goldberg wrote about his experience in CURE's Survivors Issue in 2006, he left his position at the Lance Armstrong Foundation and moved to Vail, Colorado, where First Descents is based. "I was very lucky," he says. "There were days when I ran home after chemo."

His goal: To practice what he preaches. Goldberg and Heidi Adams, the founder of Planet Cancer, set up the first young adult track at CURE's Patient and Survivor Forum this past September in Chicago. "I feel that life is hard, but we have no control over our situations," he says. "Whether you have cancer or not, you're going to deal with something sometimes that's life or death—it's just a matter of when. The hardest part is not knowing."

His job is in keeping with his personal mission. First Descents instills confidence and fun for young adults with cancer. The adventures begin on flat water, and by the end, most participants are paddling Class III rapids, Goldberg says. “We have people on treatment, out of treatment, and amputees on our trips. It’s about making them realize they’re not as fragile as they think. Cancer is a part of their identity, but it doesn’t have to define them. It’s kind of the way I try to live my life.”

Arlene Pannullo always loved riding, and owning a horse was a dream of hers. So when the 67-year-old chronic lymphocytic leukemia survivor locked eyes on Clover, an Irish hunter, she knew she had found the horse for her.

Since she was profiled in the Winter 2006 issue, she has visited him every day. She grooms and brushes him, cleans his feet, and spends time with him. And then there are the lessons—she’s working up to doing some jumping with him. “He’s very kind, and he has a puppy dog personality—he just doesn’t know how big he is,” she says.

For Pannullo, riding fills her with an intense feeling of freedom. “These animals are so beautiful,” she says. “They have a grace in movement that’s just an incredible thing to watch.”

As for her health, she feels good. She goes for checkups every two months and was just told she can extend those visits to every three months. She also goes in for immune boosters every four weeks, something she has done for six years. Other than that, she’s medication-free. “The leukemia is back because I only experienced a partial remission this time, but it’s quiet,” says Pannullo, who was first diagnosed in 1980. “We know from my history that I can go for long periods and it remains quiet.”

For now, horses provide all the healing she needs. “I go to the stables and I don’t think of anything else,” she says. “I feel lucky I have Clover in my life!”

Fran Robinson, RD, and Nellie Sandoval, are determined to build breast cancer awareness within the Navajo community. Since they were profiled in the Winter 2005 issue, they’ve stayed focused on a critical mission: early detection in a population that has the poorest five-year survival rate of any ethnic group in the United States. To put this mission into motion, the two are about to release their third Navajo-language video with English subtitles. This one focuses on lymphedema.

“Some women will never develop lymphedema, but we don’t want them to be surprised if they have a problem,” says Robinson (at right in photo). The video—done in partnership with the Northern Navajo Health Promotions Department—includes preventive teaching, such as exercises, massage, and compression wrapping of the arm.

And Sandoval is busier than ever. The breast cancer survivor is in her second year of a three-year term on the Susan G. Komen American Indian/Alaska Native

National Advisory Council. “Our primary function is to advise the Komen organization on how to work with Native American women who are dealing with breast cancer issues,” she says. Her biggest challenge right now is finding more native Navajo volunteers for Reach to Recovery, an American Cancer Society breast cancer support program she has worked with since 1993.

“At one point, we were down to two volunteers and I couldn’t handle the referrals,” she says. “We now have seven and I have requests from more women to be trained. Still, I need more volunteers from the community. I had a woman six months ago who was in the hospital. The doctor was trying to talk to her about chemo and she didn’t understand what he was saying. I explained it to her in Navajo and the doctor was grateful I was there. If we can put a light in someone’s eye about why treatment or surgery is important, it will save their life. That’s a big thing for me.”