

# Internet provides connections during cancer battle

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## A parent's nightmare

When Allie's two-week fever didn't fade, Jenny Scott took her to the doctor. She thought it was teething problems. The blood work told a different story.

"We think your baby has leukemia," the doctors said.

Scott could do nothing but write.

Her husband had set up their website, scotthousehold.com, to showcase pictures of the chubby, giggly 4-month-old to their family. After Allie's diagnosis, Jenny Scott blogged about Allie's condition to vent her frustration. Eventually, she referred her loved ones to the blog and asked them to stop calling.

"I could not tell the story 12 times a day," Scott says today. "It was physically and emotionally draining."

News of Allie's struggle spread. Scott, of Allen, was a member of babycenter.com, a discussion board for mothers, and the members sent out e-mail blasts asking for prayers. The traffic to the blog exploded, and she began communicating with other mothers whose children had cancer.

Strangers began showing up with meals at the hospital. Others arrived to pray over Allie. The hospital didn't know what to do, Scott says.

## Seeking answers

While Jenny Scott found that writing online built a real-life community, another woman found an online community that led to treatment for her son.



**Ann Podeszwa** is convinced that resources she discovered online saved the life of her son, Alex, who was diagnosed with neuroblastoma, a cancer that affects the nervous system.

About a year after Allie's illness was diagnosed, 5-year-old Alex Podeszwa complained about his leg on a walk home from school. Tests at Texas Scottish Rite Hospital for Children led to a diagnosis of Stage IV neuroblastoma, a type of cancer that affects the nervous system.

It was the beginning of a five-year fight by his mother, Ann Podeszwa of Dallas.

From the time Alex's illness was diagnosed, Podeszwa lived on her laptop. She searched high and low to find a child whose story matched Alex's.

She searched for hope.

"You have a box of Kleenex, a glass of wine, and you're sitting there bawling, trying to figure out what child is your child," she says. "Problem is, no disease for any child is the same. That's a tough pill to swallow."

Podeszwa started exchanging e-mails with other parents whose children had



Photos by BEN TORRES/Special Contributor

cancer. This led her to acor.org (Association of Cancer Online Resources), a site that allows people across the globe to share information about cancer. Podeszwa signed up for the neuroblastoma group and found treatment options for Alex that weren't available in Texas. After talking to her doctor, she flew Alex to the University of Michigan.

"I'm convinced he's alive today because of it," Podeszwa says. "If we would have stayed until the treatment came here, he would not be here."

## Finding inspiration

While Podeszwa scrambled to save her son's life by combing through studies and websites, Melinda Wells searched the Internet for inspiration.

Wells, 38, of Coppell, began having seizures in 2007. She saw a neurologist and was driving to work when she got

the call.

"You have a growth in your brain," she remembers the doctor saying. Within four months, what she was told was "nothing serious" transformed into radiation and brain surgery.

Wells has had surgery two more times because of cancer recurrences. The past three years, she has relied on e-mails and CaringBridge.org to keep her family and friends updated. About a half-million people have Web pages through the nonprofit organization's site.

Wells has had a similar experience to Podeszwa. She follows one child in Arizona through CaringBridge. She tracks a man in Highland Village with cancer who does weekly video updates.

"I feel like I can pray for them in ways that other people who haven't been through this can't," she says. "You kind of start feeling like you know

them."

## Lasting connections

For all three women, the connections found online have become vital parts of their lives — even if they aren't dealing with cancer today.

Podeszwa still researches for treatment options for her son. Alex is 10 now and his cancer is stable. But just as she did in the early days of his illness, she has continued to reach out and make connections online.

She and her family recently visited a woman in Hawaii she met on acor.org. Her child also has neuroblastoma. And Podeszwa and her husband spent an entire evening in June on the phone with another woman whose child is taking chemotherapy.

She still seeks advice on treatments from a woman in Minnesota whose son died of neuroblastoma. The

connections give her hope.

"You have today," she says. "And you're feeling good today."

Melinda Wells' last surgery was in January. Scans show she is cancer-free. She still blogs on CaringBridge.

"The second I hit 'post,' I have a peace come over me because I know so many people are praying for me," she says.

Allie Scott died on Sept. 13, 2004. Jenny Scott's website was flooded with messages from strangers around the world. Some became friends, and today she and five other women she met online are known as "the posse" and take vacations together each year. Others are now employees and business partners.

Her nonprofit organization, Heroes for Children, helps families with cancer-stricken children pay for expenses. She and Larissa Linton, whose child also died of cancer, have provided about \$2 million to families.

And she writes. On June 11, she blogged about the 100 things that make her happy: No. 14 — "My Allie Necklace."

## HELPFUL SITES

[caringbridge.org](http://caringbridge.org) — gives people with serious illnesses a free Web page to blog, post photos and share their stories.

[lotsahelpinghands.com](http://lotsahelpinghands.com) — organizes family and friends to manage volunteers and activities to help the ill. Provides a group calendar to coordinate visits to the doctor, meal times, etc.

[upopolis.com](http://upopolis.com) — a social network for young hospital patients to connect with family members and friends and blog about their journey — a type of Facebook for the sick.



Photos by COURTNEY PERRY/Staff Photographer



**Melinda Wells**, a brain cancer survivor, found support on the Internet, receiving scores of cards and e-mails. She still blogs on CaringBridge.org. "The second I hit 'post,' I have a peace come over me because I know so many people are praying for me," she says.

## HEALTH CALENDAR

### Safety first

The National Council on Aging hosts "A Look Within: What to Know, What to Do, What to Ask" from 9 to 11:30 a.m. Wednesday. The free educational event on medical imaging and electronic implantable devices will be at the West Dallas Senior Center, 2828 Fish Trap Road, and includes heart rhythm, blood pressure and edema screenings. For reservations, call Virginia Smith at 214-670-6350.

**CONCUSSION DISCUSSION:** Former Dallas Cowboy Daryl "Moose" Johnston and scientists with the Center for BrainHealth at the University of Texas at Dallas will address the causes, treatment and effects of concussions and traumatic brain injury at a lecture. "Rebound and Recovery: Concussion Discussion" will be from 6:15 to 8:15 p.m. Aug. 31 at the Center for BrainHealth, 2200 W. Mockingbird Lane, Dallas. Tickets are \$45. To purchase, visit [www.concussiondiscussion.com](http://www.concussiondiscussion.com).

**NEW MOMS MEETING:** Mingle with new moms and learn how to be prepared with your little one in an emergency. The free New Mom's Tea is at 2 p.m. Sunday. Dr. Jason Buttles will explain the nuances of navigating through an

emergency-room medical crisis at Medical Center of Plano, 4001 W. 15th St., Suite 315. A Mommy & Me Yoga instructor will share moves and relaxation tips. For reservations, call 972-519-1209.

**CELEBRATE SURVIVAL:** The Virginia R. Cvetko Patient Education Center will hold its annual celebration for prostate cancer survivors from 11 a.m. to 1 p.m. Sept. 7 on the 17th floor of Roberts Hospital, Baylor University Medical Center at Dallas, 3500 Gaston Ave.

Keynote speaker Joel Allison, president and chief executive of Baylor Health Care System in Dallas, will discuss "The Future of Health Care in America." Space is limited, and registration is required. To register or for more information, call 214-820-2608.

Helen Bond

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