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An Update From Friends

BY LAMBETH HOCHWALD

Since we wrote about **Phillip Berman** in the Winter 2005 issue, the California radiologist who created RedToeNail.org has inspired thousands of bloggers to join the online community for people with cancer.

After his diagnosis of stage 4 non-small cell lung cancer in January 2004, Berman created the blog site not only to help cancer patients update family and friends on their progress, but to also provide a way for individuals to express their emotions. Best of all, the site—named for Berman’s goal of painting one of his toenails red for every year he lives post-diagnosis—just began a partnership with the American Cancer Society that will enlarge the site’s exposure and appeal.

As for Berman, he’s continuously challenged by his own health. “I’ve been pretty much staying alive,” he says. “It’s sometimes difficult and sometimes easy for long stretches.” He spends his days exercising, reading, helping his kids with their studies, being a father and husband, and, of course, nurturing the site.

“Our biggest aspiration for the site is for the community to continue to grow as a warm, loving, and helpful site for people to support and help one another with information and experience in the field of cancer,” he says. “We’re so happy that a great ethos exists on the site, uniquely its own, and hope it continues to flower as the next several thousand bloggers join and strengthen the voice of cancer patients and cancer advocacy.”

And he’s excited to paint his fifth toenail in January.

This summer, when we wrote about [Callie Caylor](#), who was diagnosed at 15 with Ewing’s sarcoma, she was waiting to see if she could take part in a phase I clinical trial testing an IGF-1 (insulin growth factor 1) inhibitor to keep the cancer at bay. She was enrolled in the study and for months, she was doing well. Then, just recently, her doctors discovered the tumor had grown slightly. Caylor worried she would be taken off the study and have to begin radiation.



Callie Caylor with her father, Byron, at homecoming. Photo courtesy
Donna Caylor

“It’s scary,” says Caylor, 18. “I only have one lung and messing with it with radiation makes me a little scared.” (Her initial treatment regimen included

surgery to remove one of her lungs.) Luckily, her doctors determined that she could remain in the study for two more months before getting scanned again.

For Caylor, life on the clinical trial has been fairly routine. “I was able to go about my life, including tennis, working after school, and studying,” she says. “I’d go to school every Monday and leave at lunchtime for my sessions.” Now a senior, Caylor has applied to two public colleges in Texas—both are close to Children’s Medical Center Dallas, where she receives treatment—and she can’t wait to start college. “I’m in the top ten in my class,” she says. “They have to accept me!”

[Edith Joyner](#) has tirelessly committed herself to spreading the word about breast cancer screening to the African-American community, specifically through the Sister Study. Joyner, who was profiled in the Spring 2008 issue, does it to honor her two sisters, one who survived and the other, Carrie Noland, who died of the disease at age 51.

Since our story, Joyner, of Nashville, has appeared on local TV and radio programs, including two Spanish-language radio shows.

“I don’t even speak Spanish, but I feel so strongly that Latina women need to know about this study,” says Joyner, 62, who has sarcoidosis, an inflammatory disease that affects her breathing and mobility. But it doesn’t get in the way of her mission—to inform all women, but especially women of color, about the importance of breast cancer research.

“When you’re dealing with women of color, it’s a little more work to get them involved in research,” she says. “When I’m hustling around a health fair, I’m sometimes asked if I get paid for what I do. At first, I did it to express how proud I was of my baby sister who died of breast cancer and my other sister who survived.

“Later on, I realized that the Sister Study gave me a vehicle to grieve. I talk to my [deceased] sister and ask her how I’m doing.”

[Joyce Neifert](#), whom you met in the Fall 2007 issue, is slowly adjusting to life without her husband, Steve, her high school sweetheart who died three years ago at age 52 of lung cancer after fighting it for 26 months. It hasn’t been easy for Neifert and her two sons, now 19 and 21. “Their dad was their best buddy, and he was gone at a very crucial point in their lives,” she says. “They hit the most important parts of adolescence without their father.”

Her mission of advancing knowledge—and funding—for lung cancer has kept her going. “As a family dealing with lung cancer, our grief experience is different from families with other cancers because of the stigma surrounding it.” Although she recently stepped down as co-chair for the California chapter of the Lung Cancer Alliance, she hasn’t slowed down on the work she does for the organization, something she began while Steve, a non-smoker, was alive.

“Right now, we’re working on an initiative on a tobacco tax that will address lung cancer,” she says. “It will provide money for lung cancer research.” Neifert balances her work for the Alliance with her job as a sign-language interpreter, taking care of her mother-in-law who just moved in with the family, and being a mom.

Editor's note: Phillip Berman passed away at his home in Coronado, California, on February 8, 2009. CURE is proud to honor his memory.