Cancer at 23: a diary

Last December, <u>Glamour</u> profiled women battling a potentially deadly form of leukemia. Now one of our staffers, **Erin Zammett**, has been diagnosed with the same rare disease. Follow her progress, starting this month, as she deals with a host of unthinkables, from side effects to survival stats.



Last summer, totally Carefree with my boyfriend, Nick. Did I have cancer then?

NTIL VERY RECENTLY, my biggest health fear—my only health fear—was accidentally getting pregnant. At 23, that was the worst thing I could imagine happening. I guess I'd been spoiled by good luck: I had a great job at *Glamour*, an awesome apartment in New York City, a supportive family only an hour away and an amazing boyfriend. I met Nick at college in Tennessee, and he'd transferred up to New York to be closer to me. He took an internship with my father's company and was crashing at my parents' house while he finished school. In my family, this wasn't weird at all. We were at their house in Huntington, Long Island, all the time anyway—celebrating the tiniest occasion with one of my father's famous four-hour, seven-course meals.

Not that I was totally content. I used to suffocate myself with thoughts of the future, worrying that I needed to hurry up and write my book, travel, paint, be a better person, read more, think more. I've been an athlete all my life (I played volleyball at the University of Tennessee), so I was used to achieving goals, constantly pushing myself to improve. I liked to be in control, and if things didn't go as planned, I freaked.

My parents encouraged me to be less compulsive, to put things in perspective. When I complained to my mom, who works in a hospital, she'd tell me about someone who'd lost a limb, or a loved one. "It's not cancer, Erin," she'd say. It annoyed me to think that just because I had two arms and two legs I wasn't allowed to get upset. But they were right to give me occasional reality checks.



Taking a deep breath for Dr. Mauro -

Suddenly even simple procedures in the exam nom ure norve - racking.

**OHN BRENNAN** 



First day of second grade (like my Kneesocks and jelly shoes?)

Three weeks after my diagnosis. Nick is the one I





I'm praying that one of mysisters, Meghan (left) or Melissa (center), will be a bone marrow match and that the Mets make it to the World Series.

Then last November, I got the last reality check I may ever need. After a routine physical, I was diagnosed with chronic myelogenous leukemia. CML *is* cancer, and until very recently it proved fatal in the vast majority of cases, unless you were lucky enough to find a match for a bone marrow transplant. In May 2001, the Food and Drug Administration approved a new drug called Gleevec, which is getting great results and may even lead to a cure. That's what I'm pinning my hopes on now.

In the meantime, I'm a lot less frantic about writing my book or cramming in my morning workout. I realize that I used to sweat all the small stuff because I had no big stuff to worry about. Since November, all that remains is big stuff. It's like those cheesy T-shirts the high school jocks used to wear: Life is football, the rest is just details. Only now mine would say Life is cancer, the rest is just details.

To help me stay focused on what matters, I've been keeping a diary. What follows is a moment-by-moment, jolt-by-jolt journal of my life with cancer—*my* details.

# TUESDAY, NOVEMBER 13 Learning to say "leukemia"

I had just returned from a nice, long salmon lunch to find a voice-mail message from Dr. Lutsky. Could I call back? Something had come up in my blood-work report. Maybe it was a sixth sense, maybe it was my post–September 11 nerves, maybe it's that I like to be prepared for the worst, but when he came to the phone, I had adrenaline pumping through me like never before. Dr. Lutsky said he was concerned about one of my blood levels but that he didn't want to make a "statement" until he ran the tests again to make sure it wasn't a mistake. Make a statement? That sounded so doctorly and serious. Then he said, "Erin, I don't think this should wait. Can you come down right away?" I hopped in a cab and tried to think nice things about the people we passed as we lurched across town. I hoped that would somehow affect my prognosis—a last-minute kiss-up to God.

When we got into the exam room, Dr. Lutsky asked if I'd been tired lately. Had I lost a lot of weight? (I wish.) Fever? No, I still felt as healthy as the day before. The nurse took more blood, and we made an appointment to discuss the new test results. Dr. Lutsky thought my parents should come too, if I didn't mind. That was it—I had to know what he suspected, so I kept him talking, forcing him to be more specific. Eventually he admitted that he thought it was some kind of blood abnormality. I told him I'd had an infection of the blood, idiopathic thrombocytopenic purpura (ITP), back when I was eight. Could that be it? "This isn't ITP," he said flatly, with an expression that read, "You wish this was ITP, honey." That's when I knew. Before I'd been diagnosed with ITP, the doctors were initially worried that I had leukemia, and I vaguely remember them asking my parents the same questions: Fatigue? Weight loss? So I looked at Dr. Lutsky and said, "What then? Leukemia?"

He nodded. "Yes, leukemia." I'd gotten it out of him, but now all I wanted was to put it back. He told me to try to relax—he'd see me on Thursday.

Minutes later, I was at a pay phone, dialing my mom. She answered right away, but then I stumbled over the news, unable to say the word, just like Dr. Lutsky. She got impatient. "How bad, Erin?" "He thinks it might be...leukemia, Mom."

"What!" she shrieked. "Holy shit! Give me the doctor's number." She sounded angry, as though it were his fault, but I knew she was just scared, like the time she yelled at me for getting lost on our Brownies trip to Radio City Music Hall. We decided that I would come home to Huntington for the night so we could tell my older sister, Melissa, who lived nearby with her fiancé, Israel. My dad was in Las Vegas on business and would have to wait-he would have a heart attack if we told him about this when he was halfway across the country. My younger sister, Meghan, was at college, studying for finals. She could wait too. But Nick needed to know right away.

Back at the office, I explained what was going on to Alison, my boss, and we shared a box of tissues. But the big cry came later that night. I couldn't let Nick think I had come home just to hang out with him for the night, so I gave him the basic info over the phone. Forty minutes later, I heard him running up the stairs of my parents' home. We just hugged. His whole body was shaking, and I realized he was sobbing, and then I was too. It was totally unlike us to show so



With a volleyball pal. As an athlete, it feels strange to have lost control of my body.

much emotion. In the two and a half years we'd been dating, I'd only seen him cry once before-when I left Tennessee after my graduation. And we thought dealing with long distance would be hard....

### WEDNESDAY, NOVEMBER 14 A name for my cancer

Dr. Lutsky confirmed it: I have chronic myelogenous leukemia. As soon as I got off the phone with him, I grabbed the latest issue of Glamour. I was right: We'd just done a story on CML: "These Women Knew They Were Dying...Then a New Drug Saved Their Lives." From that point on, the office was a leukemia command station. Within an hour, I had the names and numbers of the doctors who had developed the miracle drug. Everyone seemed sure it could help me, too.

### THURSDAY, NOVEMBER 15 Numbers and needles

In the age of managed care, people at doctor's offices are supposed to shove a clipboard at you without looking up and tell you to take a seat. But when my parents, Nick and I got to the fourth floor of Memorial Sloan-Kettering Cancer Center, everyone was much too sweet. Before we were two feet out of the elevator, they all smiled and asked if we needed anything. I immediately felt worse. These people are so nice because they know their patients are dying. Not a good sign.

I filled out some paperwork and went into an exam room to meet Kathleen Cath-

Hearing the facts from Dr. Druker. This is when my Cancer began to feel real.





Drug trials, mortality rates, side effects Thank God for my mom.

cart, my oncologist (I have an oncologist!). She is pretty and young, and she got down to business with zero chitchat. With five of us crammed into that tiny room, it was like a total-immersion cancer class. Four pieces of information stuck in my head: 1. The only known cure to date for CML is a bone marrow transplant, a grueling procedure that kills 10 to 15 percent of patients who have

it and usually requires a genetically matched donor. 2. Without a transplant or successful drug treatment, CML patients typically survive four to seven years from diagnosis. Oh, my God, I'd be 27.3. If I'm lucky enough to find a match, the transplant would probably zap my fertility, not to mention cause dozens of other major side effects. 4. Then came the news about Gleevec: Thirty to 40 percent of patients were achieving complete or "cytogenetic"

remission on it, with minimal side effects.

Miracle drug? Thirty percent didn't sound

miraculous to me, but Gleevec was clearly

my best option. Nonetheless, we decided to

get my sisters tested to see if they were

bone marrow matches (each had a one in

four chance). If the Gleevec were to fail,

having a good match would be like money in

Next came the bone marrow biopsy

and aspirate, an excruciating procedure in

the bank, Dr. Cathcart said.

marrow transplant would zap my fertility, **but Nick** says nothing matters except that I aet better.

which Dr. Cathcart cranked a five-inch needle through my hipbone to suck out marrow. It was the realest pain I'd ever felt. I sweated right through my black turtleneck and onto the paper lining the table, and I had to be reminded to breathe. The whole thing lasted an eternal 15 minutes, after which I was sent home, sore and shaky. Day one down, lots more to go.

## FRIDAY, NOVEMBER 16 My first cancer present

Retail therapy works: I bought a \$300 Coach bag today, and it actually made me feel better. Since I have to get a bone marrow aspirate every three months, I plan to reward myself after each one with something indulgent. Eventually I'll be the best-accessorized cancer patient that Sloan-Kettering has ever seen. The final molecular evi-

dence came in, confirming 100 percent that I have CML. I was actually relieved and said to Dr. Cathcart, "That's good news, right? At least we know it's not something worse." She responded that she wouldn't exactly say it was good news. I'm not sure how much I really like her.

Meanwhile. Melissa got her blood drawn to see if she's a bone marrow match. We won't get results for more than a month, but I'm already (continued on page 303)

A bone

## Erin's Diary Continued from page 303

little too eager to please him, though. When he ran down a list of symptomsnight sweats, chills, headaches-I got cocky with my answers. Nope! Hmm ... nope! Never! I was on a roll with my nos, but afterward, I realized I hadn't been truthful: I do have occasional shooting pains in my chest. Maybe I was hoping he would say, "Well, there seems to be some kind of mistake. You don't have leukemia at all. So sorry to make you come all the way out to Oregon just to send you home. Merry Christmas." When I got back to the hotel. I e-mailed him about the chest pain. He told me to make sure I tell him those kinds of details from now on. Nothing is nothing anymore.

When I quizzed Dr. Mauro about the various trial options, his response was, "Well, I can't tell you what to do. It's really your choice." Then we met Dr. Druker, who came right out and told me that if he were in my shoes, he'd do the trial that combined Gleevec with a drug called Interferon. Bam! An opinion. It was all I needed; my decision is made. I will join that trial as soon as it starts and spend the next 12 months in it. There will be side effects—flulike symptoms, exhaustion, depression—but I think I can live with those. Strangely enough, feeling awful makes more sense to me than feeling fine, the way I do now.

## MONDAY, DECEMBER 31 In the land of What If...

New Year's Eve. After September 11, the whole world is saying, "Wow, 2001 was so tragic; what a relief it is to start fresh in 2002." But this will probably be the hardest year of my life. I'm beginning to drive myself nuts with the "what if" game. What if neither of my sisters is a bone marrow match? What if I'm one of the 70 percent for whom Gleevec doesn't completely work? What if I grow a third arm as a side effect? What if I start feeling too sick to come to work? What if I can't freeze my eggs? What if I start taking out all my anxiety and frustration on Nick and drive him away? I know there's no point in asking these kinds of questions, except for one: What if *I actually am cured of CML?* When my mind gets staticky, I try to focus on how wonderful it would be to come through this whole ordeal as a cancer survivor. "Hi, my name is Erin. I like reading, sports and spending time with my family, and I used to have leukemia, but now I don't." You can't really top that, can you?

The next installment of Erin Zammett's diary will appear in July.

## Experienced Continued from page 291

Men can be taught. You just have to know how. Jennifer, 30, used humor to make her point. "Connor had this one move he did while performing oral sex, this one thing I could not stand," she says. "But I could never quite figure out how to tell him." While visiting Jennifer's mom in Oregon, Connor and Jennifer took a walk with Misty, the neighbors' big black Lab (this story is not as alarming as it sounds). Suddenly, Misty, who was ordinarily a dawdler, took off, crashing through the underbrush.

"Before we had a chance to say, '*Misty*, *no!*' she'd grabbed a groundhog by the neck and shaken it vigorously from side to side. It was killed instantly," Jennifer recalls. "But when I saw Misty make that vigorous, side-to-side insta-groundhogkilling maneuver, I thought, Ack! That's what Connor does!" Later, during a tender, nonsexual moment, Jennifer explained to Connor how she loved having sex with him, except for the one move that reminded her of Misty killing the groundhog. The two had a good laugh, and Connor stopped doing it. "But time would pass and he'd forget," Jennifer says. "A few times a year, I have to call out, 'Misty, no!'"

If "*Misty*, *no*!" isn't an option for you, there are other strategies. Your man isn't a child—you wouldn't be dating him if he were (right?)—but it can be useful to think of him as one, just for this exercise. "If you want a child to stop jumping on the bed," Balinth says, "you say, 'Hey, let's read a book now' or 'Let's make fudge.' You don't focus on the negative behavior—you distract him." The adult equivalent of "Let's make fudge"? "Ooh, kiss me there."

Balinth recommends sandwiching each negative comment between two positive ones. And when your guy stops doing his version of the Misty move, respond immediately to the change. "The jargony term for what you're doing is 'differential reinforcement,'" says Balinth. "Reward what you want more of." Express yourself clearly with humor and at the right time—and you might be surprised at how receptive he is.

Basically, sexual adulthood is about knowing enough to take responsibility for your own bliss. A healthy attitude toward sex is easygoing but adventurous, selfprotective but optimistic, pleasure-seeking as well as pleasure-giving. And these six sexual steps will help you get that attitude. But don't take our word for it—get out there and experience them for yourself. ©

Marjorie Ingall lives in New York City and is the mother of a newborn. She dimly remembers sex.

### Bosnia Continued from page 297

sexual assault, domestic abuse and sex trafficking investigations, but "trafficking was so huge," she says, "that it became 75 percent of the workload." At first, Bolkovac applied the same determination she had used in her first assignment to her new job. "Right away, though, I sensed problems," she says. Bolkovac was responsible for reading reports filed by her field officers, and she soon uncovered an ugly pattern: Many U.N.-affiliated internationals-and some IPTF personnel from a variety of divisions-were allegedly patronizing the brothels. The reports she read made serious allegations about specific U.N. workers and IPTF officers, accusing them of forging documents to aid the trafficking of women, assisting in the transportation of women across borders, patronizing brothels while on duty and tipping off brothel owners about raids.

When Bolkovac learned that IPTF officers were involved with the sex trade, she followed protocol and personally delivered the files to IPTF's Internal Affairs office. "Part of me felt bad about turning them in, but I was a police officer, and you don't put up with illegal activity—especially when you're trying to set an example," she says. But every time she relayed such a report, Bolkovac says, "it would get quashed." She followed up on the progress of these cases but says her investigations of U.N.related workers went nowhere.

"The U.N.'s attitude seemed to be that if the problem isn't rearing its ugly head, then why deal with it?" says David Lamb, a former Philadelphia transit authority police officer who served as an IPTF human rights investigator in Bosnia from April 1999 to April 2001.

Jacques Paul Klein, special representative of the U.N. Secretary-General in Bosnia, says this is not true. "We had [independent] U.N. investigators" in Bosnia, he says. "They looked at the files [related to sex trafficking] and found that every single lead had been investigated."

Still, Lamb says, "the Bosnian police officers know that the same IPTF workers who tell them how to do their jobs by day are using sex slaves at night. This alone destroyed our credibility in Bosnia."

#### U.N. Cops and Sex Slaves

When Bolkovac filed her first reports about IPTF members visiting brothels, she chose to give her colleagues the benefit of the doubt. "At first, I assumed that [my IPTF coworkers] didn't realize these women had been trafficked," she says. "So I began educating them. During training,