

IN SICKNESS & IN HEALTH

Leukemia changes a young couple's life – and dreams

By LEE HILL KAVANAUGH
The Kansas City Star

Early September 1995. He wasn't expecting this telephone call. "Scott, your test results indicate your white blood count is elevated," the doctor says. Silence. Then, seconds later: "Possibly leukemia. We don't know for sure. We need you to come in right away for more tests." Days before, Scott Michelson had gone in for a routine medical exam. He was getting married soon, he told the doctor. Taking advantage of a free check-up. Yeah, he was a little tired. But he played a lot of golf in the summer heat, too.

Leukemia? I'm only 26. Last weekend I was camping and canoeing with friends down on the Niangua River. ... There must be a mistake. ... That's it; this is all a mistake.

He calls his fiancée, Carlyn Cygan, a sales trainer at Hallmark Cards Inc.

"It's probably wrong," he says slowly, "but the doctor just called. He thinks I have cancer. Maybe leukemia."

Carlyn, 25, feels her legs go weak. Her eyes tear up.

By afternoon Scott is in a hospital for more lab work. One test is a more intricate blood workup. His white blood cells are stained so a lab technician can look at them under a microscope.

The next morning he has a bone marrow biopsy. A core of his bone marrow is extracted with a pull from a large needle inserted into his hip bone. Marrow is where all blood cells are manufactured.

The first test reveals not only that his blood has a high number of white blood cells, but also that the cells are not developing. They're immature and cannot fight off infections. Their high numbers are crowding out Scott's other blood cells: his red blood cells, which carry oxygen throughout the body; and his platelets, the smaller cells that stop bleeding.

His marrow biopsy delivers the final decree: a genetic marker appears called the Philadelphia chromosome.

Scott has chronic myelogenous leukemia.



Scott Michelson and his fiancée, Carlyn Cygan, enjoyed a trip to Colorado in 1995. Just weeks later, however, Michelson's visit to the doctor's office would turn their world upside down.

Without treatment, he will probably die before his 30th birthday. And in 1995 his only chance for a cure is a bone marrow transplant.

In just 24 hours Scott and Carlyn have been thrown into a world revolving around blood tests, survival statistics, bone marrow transplants, chemotherapy and radiation treatments.

They cancel the wedding, the one they'd been planning for months. She calls her family. He calls his.

Scott swallows his first treatment against the disease – an oral chemotherapy pill that will slow the growth of his white blood cells.

In one instant, with the words "You have leukemia," this couple's dreams for the future – marriage, buying a house, having children, growing old together – seem insignificant.

Cancer is teaching them to have only one dream now – to live.

But there's another bombshell coming, too. What they don't know, what the doctor doesn't tell them, is that even if Scott beats the cancer, leukemia will leave its fingerprint forever on his life.

Treating the disease also means killing his fertility.

And by swallowing his first chemother-

apy dose, the process has already begun.

Seattle, mid-September 1995

For many families touched by leukemia, the journey back to a normal life begins with a step inside Conference Room 905 at the Fred Hutchinson Cancer Research Center.

Room 905 has blue industrial carpeting and fluorescent lighting. The conference table faces a white marker board hanging on the wall. The room has a businesslike feel.

And the business this day is the rest of Scott's life. Today he will learn exactly what medical science can do to kill the leukemic cells in his blood and how the new donated marrow can make him well again.

He sits in one of the chairs. Also in the room are his fiancée, Carlyn; his stepmother and father, Gary and Lennie Michelson, from Colorado; and his future in-laws, Andrea and Tom Cygan, who moved to Seattle three months earlier. These are the people who will see him through this, no matter what happens.

When Scott was diagnosed two weeks earlier, he knew right away where he wanted to go for treatment: the Hutchinson center.

The Hutch, as it's known, was the first hospital in the nation to perform bone marrow transplants, in the early '70s when a physician named E. Donnal Thomas developed the experimental procedure while working in a cramped basement.

Here is where that same doctor earned the 1990 Nobel Prize in medicine for his transplant research. Here is where more marrow transplants – 7,000 – have been done than anywhere else in the world.

All leukemia patients at The Hutch advance the study of cancer, even if they die. Scott knows this because his mother died here in 1988 of a different kind of cancer.

Claudio Anasetti enters. He shakes hands. Anasetti is the medical director at The Hutch. He also will be Scott's primary care physician. He sits next to the white marker board and begins scribbling as he talks, outlining what Scott's treatment will entail. He sounds almost like a football coach explaining plays.

Anasetti divides the course of treatment into three sections: conditioning for the pre-transplant; the transplant; and the post-transplant. His voice drones on, explaining in steady, nonemotional words what might happen to Scott's body.

Massive doses of radiation and chemotherapy will kill the diseased marrow to make room for the healthy donated marrow, Anasetti says. A dramatic cure, but the best that 20th century medicine can offer.

But the transplant could kill Scott if the new marrow is rejected or he is infected with a virus or bacteria before the new marrow begins making healthy blood cells.

"The entire treatment from beginning to end will take at least one year," Anasetti tells Scott. "You will be hospitalized for four weeks and need daily outpatient care probably for another three months. As part of the conditioning, the radiation will affect your fast-growing cells first. ... Your hair will fall out. Your tongue will swell. Your esophagus and stomach lining will slough off. You'll probably throw up a lot. Your appetite will disappear, so we'll feed you intravenously. ..."

Scott knows most of this already from reading the leukemia literature his Kansas City doctor gave him. He watches Carlyn, who is hearing the grim details for the first time.

Carlyn is his college sweetheart from the University of Kansas. She has brown hair, a dazzling smile and light blue eyes. Scott met her July 16, 1991, a date burned into his memory, the date he first lost himself in Carlyn's eyes.

Friends describe both Carlyn and Scott as passionate people – passionate in

work, in friendships and in love.

Six months ago Scott asked Carlyn to marry him by hiding her ring in a lavender porcelain Easter egg, planting clues around a friend's house and inviting their closest friends over for a contrived egg hunt.

He remembers how her eyes opened wide when she found the ring inside the egg. How he asked her to marry him, with all their friends watching. How her blue eyes melted his heart then, and do still.

Now, those eyes are welling up with tears.

Scott wrestles with his fears, too. What kind of future does he offer his wife-to-be? What future does he have?

The doctor's voice interrupts his thoughts.

"... And, 95 percent of leukemia patients become irreversibly sterile from the treatments."

Carlyn begins to sob.

Her father cries.

Even Scott tries to swallow the growing lump in his throat. It isn't the chance of death that daunts him now; he's betting on himself to beat leukemia.

What never occurred to Scott, never entered his mind, was that the leukemia would steal his dreams even after the disease was beaten. A dream that includes not only marrying Carlyn, but also having children with her. Anasetti mentioned sterility as if it were an unfortunate battle scar of survival.

Anasetti thought they already knew.

Emotions erupt inside Conference Room 905 as people struggle with yet another loss from this disease.

"This can't be! It's not fair!"

"No grandchildren? No babies?"

Questions fly out, born of fear and grief and pain.

Scott ignores everyone, but one. Watching Carlyn, he rises from the table.

Silence now, except for Carlyn's quiet sobs. Scott wraps her in his arms. Processing all the information – first the diagnosis two weeks ago, then the cancellation of their wedding and now the news that even their dream of having babies likely will be snatched away – it's too much for Carlyn to bear.

She can't stop crying.

"It's OK," Scott whispers to her. "Everything will turn out OK. We'll beat it. There's a reason for all this."

Carlyn nods through her tears.

Later that night, he asks her the question. The question that he never wanted to ask.

"Carlyn, I'm too young to die," he says, his voice penetrating the darkness. "... Am I going to live?"

"Yes," she says quickly. "I won't let anything happen to you."

He knows Carlyn can't stop anything terrible from happening. But in the night,

in the dark, her words make him feel better somehow.

Kansas City, the next week

Life is moving fast for Scott.

A national search is under way for preliminary marrow matches. His health insurance company, an HMO, has not yet agreed to pay for his transplant in Seattle. His insurance is pushing him for treatment in Omaha, Neb., or St. Louis, medical facilities that don't have as much experience doing bone marrow transplants as The Hutch.

But today Scott won't worry about that. On this day his goal is to tell the news to his colleagues at Koch Supplies, a restaurant equipment business.

One of the first people he tells is his good friend Mike Collings. "You won't believe this, but I found out I have leukemia," Scott says. "And soon I'll be sterile, too, from the treatments."

Collings, 39, knows about cancer: His sister died of breast cancer. And he knows how much Scott wants to have children. Collings has watched his friend hold other people's babies. Even his own two daughters nicknamed Scott "Popo."

Collings feels a sting of tears as Scott tells him. The air feels thick, hard to breathe. As the news spreads about Scott, Collings won't be alone. Scott is bright, athletic and well-liked at the office.

"My sperm banking appointment is at noon," Scott tells Collings. He has to begin today, he explains, before the chemotherapy drugs damage his reproductive system further.

The radiation and intensive chemotherapy treatment will almost certainly leave Scott sterile. Even the daily oral therapy he has taken since his diagnosis may have already damaged his sperm.

For male cancer patients, reproduction is possible – through artificial insemination or in vitro fertilization – if sperm is collected before any treatment begins. But Scott was already three weeks into his oral chemotherapy when he learned this.

A urologist gave Scott hope. A man's sperm regenerates every 86 days, he told Scott in a phone call. Scott has been on the drug for 21.

For some men, dealing with the subject of sperm banking would be difficult. But Scott is quick with a joke and a grin. He's most loved for his humor – one of his greatest personal weapons against cancer.

Oblivious to the two men's conversation, several work associates gather nearby organizing a group for lunch. It's a noon ritual.

"Hey Scott, you coming with us?" one asks.

"No, I've, uh, got to go to the bank," he says, with a wink to Collings, "and make a

deposit.”

“Scott, we can loan you some cash for lunch,” says a well-meaning but uninformed female friend.

“No,” Scott says, hiding a smile. “I’m not going to that kind of bank.”

As the group walks past, Collings and Scott burst out laughing. Laughter helps them both today.

Sperm banking isn’t a normal topic in polite conversation.

But then, neither is cancer. When cancer pushes itself into a person’s world, society’s taboos change. Real life isn’t modest.

Cancer isn’t going to beat me, Scott thinks. He vows to make his life as normal as possible, even if it does sometimes feel like a “Seinfeld” episode.

And this is definitely one of those moments, he thinks later, as he tries to discreetly tell the receptionist at the University of Kansas Medical Center why he’s there.

He’s told to go to the second floor. There, a lab technician hands him a plastic cup and a tag for privacy to place over the doorknob of an examination room. There are no locks on the doors.

“Do you need the magazines?” the technician asks Scott.

“Excuse me?” Scott says. Then, trying to sound nonchalant and avoiding his gaze at the same time: “Yes. Yes, I do.”

He is led down a hallway, past other rooms with tags hanging from door-knobs, until one room is empty.

For the next month and a half, until the chemotherapy damages the chromosomes in Scott’s sperm, he will make regular visits to the medical center’s urology department.

This is the one thing he can do to control his out-of-control life. Medical science is giving him back hope for a future – a future that might yet include fatherhood.

Kansas City, February 1996

Scott sees himself as a survivor. He pictures his leukemia fight as climbing a mountain. Each step, even a baby step, takes him closer to the top, the mountain’s summit, where he can see beyond the disease to his normal life again.

His goal each day is simple: to laugh, to eat well and to notice as many sunrises and sunsets as he can – even as he works a 40-hour-a-week job.

Leukemia is teaching him.

“Every time there’s a crisis in our lives, there’s a reason,” he tells friends. “God didn’t give the disease to us. God gives us the strength to deal with it. ... Don’t focus on the negatives.

“And surround yourself with a core group of good friends.”

He’s trying his best to savor each moment in the now, and to imagine a

bright future. But the disease still mocks him.

“Why does this have to be so hard?” he says one night, after opening mail from his HMO, a letter explaining again why it refuses to pay for his treatment at The Hutch.

Scott can’t forget he has leukemia. Every day brings another doctor appointment, another round with the insurance company or another day that passes without finding that perfect bone marrow match.

Carlyn describes Scott’s leukemia to friends as “a cancer that spreads everywhere because it’s in the blood. You can’t cut it out. It has to be killed.”

Fighting leukemia is a battle. In the year 2000, the Leukemia & Lymphoma Society estimates, 30,200 new cases of leukemia in the United States will be diagnosed; 22,100 people will die of the disease.

Carlyn struggles with anger, out of Scott’s view. Sitting at her kitchen table, she explodes into a tantrum.

“I feel so much rage,” she tells a friend on the phone. “Why is all this happening? Why us? Why now?”

She has told only a few close friends about the disease. She doesn’t want to give in to her feelings of anger. She doesn’t tell too many others, because she doesn’t want her personal life to affect her work.

She doesn’t want people to feel sorry for them, she tells a friend, because “I don’t want to feel sorry for myself.

“The really bizarre thing about having a disease like leukemia is that the entire world goes on like normal. You still have to pay bills. You still have to go to work. You still pay rent and the news comes on every night and the sun rises every morning. But you have this drama happening in your life, like a bad nightmare, except it’s real.”

On Valentine’s Day 1996, five months after learning Scott has leukemia, the couple’s phone rings. The National Marrow Donor Program tells Scott that a match has been found, and the prospective bone marrow donor has agreed to the operation.

“Yes,” Scott says, almost in a whisper. Carlyn cries at the news. This is the best Valentine’s Day present ever, she tells him.

But Carlyn doesn’t share with Scott her worst fears. Only a friend the next day hears about them.

“How can we be happy about finding the donor when we don’t know what’s happening with the insurance?” she says. “What if Scott gets sicker before they approve him? What if all this doesn’t really matter?”

Carlyn is on edge. The waiting is hard. She tells her parents she fears the insurance is going to refuse.

Carlyn’s parents jump in to help. Her

father, Tom Cygan, is president of a steel distribution company, a man who has learned how to negotiate.

Writing letters, calling, seeking the advice of an attorney, he begins a weekly, sometimes daily campaign, urging the HMO to pay for Scott’s treatment at The Hutch. His strongest argument is that Andrea Cygan, Carlyn’s mother, has volunteered to be Scott’s main caregiver during the outpatient phase. Scott can live with them, Tom Cygan says, pointing out how that will save the company additional money.

On April 22 the HMO approves Scott’s choice. Two days later Scott turns 27.

In less than four weeks Scott will have a bone marrow transplant. If the transplant takes, the new marrow will manufacture healthy blood again. If it doesn’t take, Scott will die.

The night before he leaves for Seattle, his friends at Koch give him a going away party, wish him luck, present him with the airplane ticket they bought for him and a phone card with 1,500 minutes of long-distance calls.

The next morning Carlyn drives Scott to Kansas City International Airport. She will join him in a week, after he has completed his preliminary tests.

They wait at the Delta Air Lines gate, pretending life is normal.

He jokes. She laughs. They sit next to each other on the plastic seats, facing a window. Spring sunshine streams in, leaving little pieces of lint drifting in beams of light. People rush past, going places, coming home.

Scott and Carlyn linger together until the very last call for boarding. Saying goodbye is too hard. Scott stands up. Carlyn hugs Scott tight, not wanting to let him go. She isn’t sure he’ll ever come back.

Scott tears himself from her arms and waves goodbye. Carlyn breaks down. She can’t stop crying. Her shoulders shake with each sob. She doesn’t have a crystal ball telling her everything will be OK; only a tiny inner voice repeating it like a mantra.

People gawk at Carlyn and Scott. At 6 feet 2 inches tall and his pre-transplant weight gain to 240 pounds, Scott looks like a linebacker. Carlyn looks like a model.

He turns once more to wave to her, before disappearing down the ramp. Scott doesn’t cry. Not yet. Not in front of Carlyn.

Not until he’s in his seat, and he’s buckled in, and the roar of the plane drowns out conversations around him. Not until he sees the gauzy wisps of clouds slowly blurring the view.

As the ground shrinks away, he leans back, sighs. The view is really blurry now. But not because of clouds.