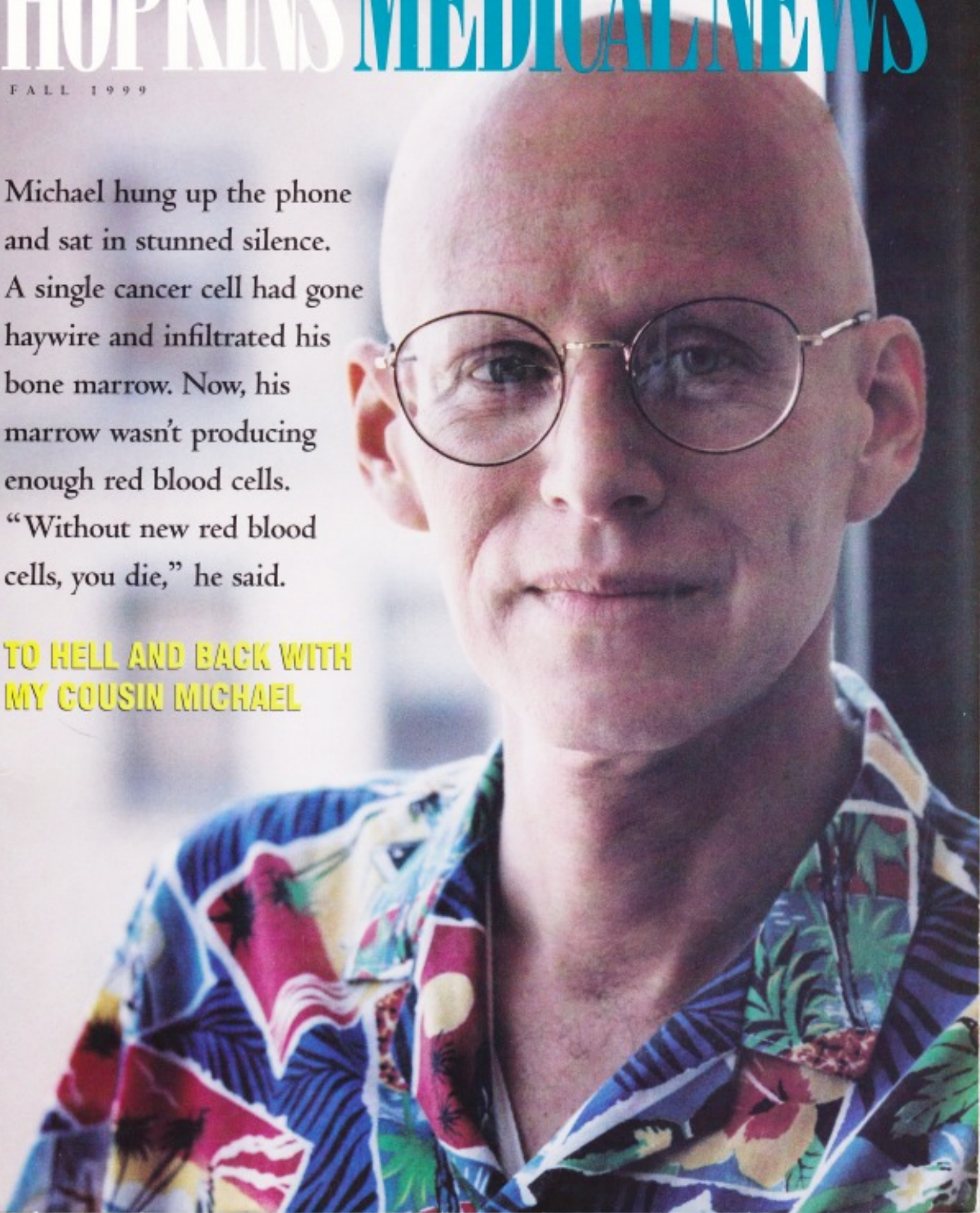


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Michael hung up the phone and sat in stunned silence. A single cancer cell had gone haywire and infiltrated his bone marrow. Now, his marrow wasn't producing enough red blood cells. "Without new red blood cells, you die," he said.

**TO HELL AND BACK WITH
MY COUSIN MICHAEL**



TO HELL

By Bill Glovin • Photographs by Keith Weller

AND

with My Cousin Michael

Michael Billig was a conditioned runner and popular college professor when he was stricken with an aggressive form of leukemia. This is the story of his journey back: the medical procedure that saved his life and the people who stood by him.

As I board an almost empty train in New Jersey, I'm more convinced than ever that Sunday mornings are the best time to travel. It's mid-May and I'm off to visit my first cousin, Michael Billig, who is undergoing a stem-cell transplant at Johns Hopkins Hospital. Michael has been battling chronic lymphocytic leukemia for almost a year. Now, after months filled with tests, wrenching decisions and battering chemotherapy, his oncologist is ready to reinfuse his blood with healthy stem cells, the biological building blocks that produce all the red cells, white cells and platelets a person needs. What the physician and Michael hope is that this transplant will rebuild his immune system and cure him from this dreadful cancer.

On the phone a few days before, Michael referred to the first days of this procedure as "Hell Week." But without undergoing the potentially

risky transplant he'd likely die. I stare out the train window, wondering if he can beat this thing.

In Baltimore, I pay the cab driver and follow Michael's directions through the Hospital to an elevator and head for the Oncology Center's IPOP (inpatient/outpatient) unit. This program [box] for stem-cell transplantation patients is allowing Michael to spend a good part of the time it takes to complete this complex procedure living with his wife in an apartment outside the Hospital. A receptionist directs me to a back room where Michael, seated on a cardiac recliner, looks up from his crossword puzzle and smiles. Before he's finished gauging my reaction to his shaved head, I ask him how it feels to finally resemble the other follicle-challenged members of our family.

Bill Glovin is senior editor at Rutgers Magazine. This is his first story for HMN.

BACK





Jane Rossetti cleans the catheter in her husband's chest, a ritual that took an hour every day and helped Michael stay germ-free during his transplant.

When this dreaded disease was diagnosed last summer, Michael, a 43-year-old associate professor of anthropology at Franklin & Marshall College in Lancaster, Pennsylvania, was completing a book about the Philippine sugar industry. His wife of four months, Jane Rossetti, an economics professor at F&M for six years, had left teaching a few months before and was contemplating a career change.

Life was now on serious hold for both. Jane had put her squeamishness aside to

for shopping, chauffeuring, cheerleading and, most importantly, keeping their apartment germ-free during the frightening stretch when Michael's body, awaiting the redevelopment of his bone marrow, is virtually defenseless against infections.

When I ask how she is holding up, Jane hesitates for a moment, smiles, and says: "This is certainly a lot better than someone calling to tell you that your husband just got hit by a truck."

Michael and I had been kindred spirits, growing up close in age. As kids, it didn't matter that I lived in New Jersey and he lived 90 minutes away by car. My parents made the trek almost every Sunday to visit his family and my grandmother in Rockaway, N.Y. Michael and I seemed to have everything in common: baseball, guitar, Phil Ochs, English-muffin pizza competitions, a disdain for our grandmother's chicken salad. Time off from school often meant extended sleep-overs at one another's house, and when Michael's family took a three-week summer driving trip to Canada, I was included.

In high school, we both got summer jobs

"This is certainly a lot better than someone calling to tell you that your husband just

meet IPOP's requirement that transplant patients have a full-time caregiver while they're living at the apartment. Michael and Jane both see IPOP as something of a silver lining in their ordeal. Without it, transplantation patients would have to stay alone in the hospital in relative isolation for the duration of their treatment. With IPOP, Michael and Jane can leave the hospital every evening for the refuge and togetherness of a place of their own. Clucking over the two of them every step of the way, like mother hens guarding fragile chicks, have been the nurses from IPOP.

Kindred Spirits

IPOP makes Jane an equal partner in the all-consuming struggle. She's been trained to care for Michael's surgically implanted catheter, give injections, track her husband's pill-taking, and record his daily medical regimen in a journal. She's also responsible

at a Catskill Mountains camp for mentally challenged and autistic teenagers. By the time we were college students, Michael—smart and mature—was made camp director. As adults, I served as his best man in his first marriage, held his daughters days after they were born, and helped him bury his father.

For the past 16 years, part of Michael's identity had been tied to running, a one-hour ritual he performed every other day. On that rare occasion when I was inspired to try to run with him, I labored along while he barely broke a sweat. His exceptional conditioning, in fact, had tipped him off last year that something was wrong when he suffered the ultimate indignity of having to walk his rail-thin body home.

At first, he thought he was just over training. But as his running became increasingly labored, he visited a doctor, thinking he had come down with the flu, a virus or, at worst, Lyme disease. Blood tests showed that he

had leukemia. Later, his doctor phoned and tried to put a positive spin on the diagnosis. It was the most common form of adult leukemia in the United States, she said, and the least likely to be a death sentence. Michael hung up, dragged himself out of bed and down the stairs, collapsed in a chair, and sat in stunned silence: "I thought of my daughters, my wife of four months, all the things I had yet to do in life," he said.

He called me later that day and explained how a single cancer cell had gone haywire, proliferated and infiltrated his bone marrow. Now his marrow wasn't producing a normal supply of red blood cells. "Without new red blood cells, you die," he said.

Michael had been the kind of kid who threw himself completely into some new passion every few months. So it was no surprise that he obsessively began learning all he could about chronic lymphocytic leukemia. As an academic with a B.A. and M.A. from Columbia and a Ph.D. from Harvard, he knew where to find information. He interrogated his doctors and scoured the Internet. In a week's time, he knew as much about cell structure as he did about his precious Philadelphia Phillies. As a new participant on a CLL list serve, he became familiar with standard treatment methods, ongoing clinical trials and new drug therapies.

got hit by a truck.

Michael learned that his form of leukemia is monitored closely and often left untreated. Sometimes, years go by before chemotherapy is necessary. But the first of what would be many painful biopsies revealed that his marrow was heavily infiltrated with malignant cells, and the marrow's failure to produce red blood cells had made him dangerously anemic. His doctor explained that he had an unusually aggressive form of the disease and advised immediate chemotherapy.

From the Web, Michael discovered that the administration of chemotherapy held many subtleties. So, with Johns Hopkins just an hour and a half away he decided to look there for a leukemia specialist. A few phone calls later, he had an appointment with Ian Flinn, M.D., a 35-year-

old hematologist and oncologist.

At first, Michael was skeptical about leaving his fate in the hands of someone so young. But the more they talked, the more Flinn's knowledge and conviction impressed him. Flinn told him that the best he could hope for with chemo alone was a complete remission, in which he would have the impression that the disease had disappeared, even though malignant cells still lurked within his blood. But by having a bone-marrow transplant, the odds that the CLL wouldn't flare up again would improve. He suggested that Michael's two older sisters be tested to see if they had matching bone marrow to his. Flinn then candidly laid out the risks of the transplant: a 5 to 20 percent mortality rate, the possibility of death from infection, and no absolute guarantee that it would work.

Michael and Jane debated whether to go ahead. Michael also solicited opinions from his friends on the list serve. Some argued that in five years some magic bullet drug could come along and eliminate the need for his undergoing the horrendous procedure. Others believed that if Michael could attain a complete remission he should go for the transplant, since chemo wouldn't work as well the second time around when the disease reappeared. Michael also sought the opinion of his Lancaster doctor. If this were his son, the

doctor said, she'd want him to do it. That way, he wouldn't have a Sword of Damocles hanging over his head.

Gearing Up for a Fight

But round after round of chemotherapy to kill off the malignant cells in his blood lay ahead before Michael could even consider a transplant. And so it began: five straight afternoons every month when he'd show up at an oncologist's office in Lancaster to receive a new combination of two familiar drugs, Fludarabine and cyclophosphamide (cytotoxin), that Flinn had prescribed. The potent new regimen had been developed at Hopkins and was now being tested internationally, with Flinn acting as the principal investigator.

Mixed with these treatment sessions were "off" weeks filled with constant blood drawing, antibacterial and antiviral medication, and injections of a drug that stimulates the growth of white blood cells. One Sunday afternoon, in late September, a few days after Michael's second round of chemo he suddenly lost consciousness. Both his white and red cell counts had dropped so dramatically that he'd become anemic.

Through it all, Michael continued to teach his courses. At one point, he even held office hours while getting a blood transfusion in a local hospital, and seven students appeared. But aware of his extreme vulnerability to infections, he pleaded with the undergraduates to keep their colds and other germs out of the classroom. Once a month he returned to Baltimore for tests and consultations with Flinn.

Michael's sights were set on the transplant. His sisters—each with a 25 percent chance of having matching bone marrow to his—were tested to see whether their stem cells could be introduced into his system. Flinn, an expert on the subtleties of the procedure, suspected what turned out to be the case—that neither would match.

The oncologist, however, offered Michael a second option: an unusual "autologous" stem-cell transplant. Rather than using donor cells, he would receive healthy stem cells taken from his own body. The process would work like this: First, through



Oncologist Ian Flinn, M.D., offered Billig the chance to join a clinical trial of two new drugs aiming to purge his leukemia cells.

Billig and IPOP charge nurse Linda Paulaitis, R.N., share a moment of levity during a routine exam.

chemotherapy, Michael would achieve a near-complete remission of the leukemia. His body would regain its vigor and once more begin producing healthy stem cells. Those cells would then be taken from him (harvested) to use later. At that point, Michael would receive more high doses of chemotherapy and radiation to wipe out any residual disease. And then, finally, his harvested stem cells would be transfused back through his blood.

The catch was that it wasn't going to be easy for Michael to achieve the near-complete remission necessary for the transplant. The leukemia had infiltrated more than 90 percent of his marrow. Flinn, however, hoped the new chemotherapy regime would help. He also offered another potential boost. In just a few months he would be acting as the principal investigator in a second protocol testing two more new drugs, Rituxan and GM-CSF, that could help purge the leukemia from Michael's blood. The Rituxan would be given both before the transplant and afterward, so as to wipe out any lingering malignant cells.

Through the next several months, Michael underwent round after round of chemotherapy to put his disease in remission. The potent drugs left him with all the familiar setbacks: nausea, low-grade fever, swollen gums, loss of appetite, fatigue. But little by little his counts improved—and so did his health. As the Lancaster winter faded, he began race walking and put on some much-needed weight. With a complete remission in sight, he arranged to take



a medical leave of absence from Franklin and Marshall for the spring semester and have his stem-cell transplant.

Waging the Battle

The first (preparation) stage for the transplant officially began in late March with a two-day screening that required 17 tubes of blood; a heart scan; a pulmonary function test; CAT scans of the sinuses, thorax and abdomen; chest X-rays; an EKG; another bone-marrow biopsy; a complete physical; two medical history interviews; a radiology consultation, measurements and fittings for irradiation; and a class and tour. Michael spent his birthday, April 7, signing consent forms and going through transplant orientation.

The following day a catheter was surgically implanted in his chest. This access to Michael's body through a large vessel would make it easier for nurses and doctors to administer the multitude of medications he'd be receiving over the crucial weeks that followed. Every drug and transfusion from that point on would go through the catheter. "The catheter was the moment the transplant became a reality," Michael said. "The day it's removed will be the day this will truly be over." An IV connector that was restrictive and uncomfort-

Michael Billig before leukemia interrupted his fitness regimen and chemotherapy cost him his hair.

able made him feel helpless and unattractive. Infections related to the catheter were a danger, so for the next three months, Jane would take an hour every day to flush it with solutions and change the dressing.

Next, the procedure called for him to spend two weeks at Hopkins going through a "mobilization" process. Over two days he received his first doses of Rituxan and Cytoxan to stimulate his bone marrow to over-produce stem cells. Then, he returned to Lancaster, visited his lawyer to complete a will and a Living Will. Jane continued to give him his daily injections of the trial drug GM-CSF to stimulate stem-cell production.

Five days after he'd left, Michael was back in Baltimore for the second two-week stint to complete his mobilization and harvest his stem cells. Then, unexpectedly, he came down with a fever. For three days, he lay in the Hospital, watched closely by the IPOP team. On the morning of the third day, the attending physician looked at his blood counts and announced that the window of opportunity had suddenly opened for the leukapheresis, the six-hour harvesting procedure that had been scheduled for later that week. After months of waiting, Michael's healthy stem cells were retrieved from his blood. If all went well, in a few weeks those cells would give him back his life.

And now, the countdown to transplant



day began. In Lancaster, he visited his barber to have his head shaved, because his hair was falling out from the chemotherapy; he went through 11 straight days of diarrhea and weight loss from the antibiotics, ending his hopes to exercise and drink some wine with dinner before returning to Hopkins; and he sent me this e-mail: "Feeling as terrific as I do, I want to give in to the fantasy that this beast within me is vanquished."

"I'll Hit the Wall"

On the May day I arrived in Baltimore, I watched as Michael received his last dose of chemo. He flinched as two long tubes silently snaked their way out of two clear bags of liquid and disappeared beneath a bandaged hole on his chest. He teased nurses Amy Vance and Carol Judkins about the hospital food and chatted easily with fellow patients and caregivers who

The next day, the three of us gathered in a Thai restaurant. No one would have guessed that the guy in the "Pinky and the Brain" baseball cap had just had four straight days of intensive chemo and a day of total-body irradiation to wipe out his bone marrow. "In a few days, I'll hit the wall and fun things like going out to restaurants will end," Michael told me. "First, these high doses of chemo and irradiation

Why can't the way I feel right now last at least until I'm 80?"

Why can't it all just be over? Why can't the way I feel right now be made to last at least until I'm 80? I know I should enjoy it while it lasts. But, when one knows that it is just the high point on a long roller coaster ride, one's enjoyment must always be tentative."

wandered into the IPOPOP clinic. During a break, he and his portable IV stand took their daily walk through the corridors and lobbies that connect the hospital buildings. When he felt fatigued we sat on a bench near Hopkins' well-known Christ statue.

destroy all my cells and practically kill me. Then, they re-infuse my stem cells and bring my bone marrow back to life."

The next day—Friday, May 21—the actual procedure felt rather anticlimactic, Michael said, like a typical transfusion. This

Bone Marrow Transplant with Heart

Starting four years ago with a simple question—What can we do better?—nurse managers Gina Szymanski and Jane Shivan transformed the way patients with leukemias, lymphomas and several other types of cancer who receive transplants from the bone marrow and peripheral blood are cared for at Johns Hopkins.

With managed care nipping at their heels, the pair knew costs for the pricey BMT program needed trimming. Furthermore, patients were dissatisfied—not with Hopkins' medical treatment, which they rated superb, but with the lack of continuity among their medical team during a prolonged, two-month hospitalization (which in itself seemed unbearable). Finally, a new Cancer Center was on the drawing board, so an updated model of care was in order.

Today, the revamped program the nurses conceived is recognized as a national model. Called IPOPOP (Inpatient/Outpatient), it not only improves the patient experience, but trims 20 days off the average 45-day hospital stay and \$20,000 off the \$100,000 to \$200,000 cost of bone-marrow transplantation.

Jane Shivan and Gina Szymanski, who transformed care.

The key to the approach is allowing patients to move back and forth between the inpatient unit in the Hospital and nearby homelike apartments as their medical condition warrants. Yet, despite the fact that they are in the midst of a body-battering treatment patients never feel fearful. Always with them in their apartment is their own personal caregiver—a family member or close friend who has been trained by the IPOPOP nurses. The apartments also are staffed around the clock, and patients know how to make immediate contact with their medical caregivers in IPOPOP.

In coming up with alternative living arrangements for these desperately ill patients, the nurses, working with oncologist Georgia Vogelsang, M.D., examined issues from every angle. Would they be placing too much stress on the friend

or family caregiver who must learn to monitor temperatures and medications? How could the Hospital avoid shifting higher out-of-pocket costs for outpatient treatment to patients with families? And would the staff, already working with critically ill inpatients, accept yet another level of responsibility?

Meanwhile, as the two nurses worked to provide seamless transitions from one phase of BMT care to the next, Shivan acknowledges, "we knew we were turning the program upside down. We weren't just looking at cost and length of stay. We wanted to make sure we were really improving things."

"There were billing issues, home-care issues, medical record issues, legal issues," Szymanski adds. "Being bedside nurses was essential to understanding what could be tweaked, fixed, changed. I don't think

this is an idea that could have come from a higher administrative level."

In the end, Szymanski admits that revamping care was economically essential to the very survival of the bone marrow transplant program. But the fact that IPOPOP cuts costs is by no means what she finds most gratifying. "The cost piece is gravy," she says. "This is better care. This is something you can really feel good about."

—Mary Ellen Miller



transplant, however, was anything but routine. The healthy stem cells that slipped so easily back into his body were the key to my cousin's future. In the days that followed, "the preservative used on stem cells made me smell like garlic. Poor Jane," Michael recounted. He waited for his counts to crash as the IPOP nurses circled him with attention. Whenever the numbers dropped too far, he received a blood transfusion.

By May 26, Michael's white count was zero. Feeling weaker than usual and running a slight temperature after a day of transfusions, he was allowed to leave the IPOP unit for his Baltimore apartment on the condition that he call in to talk to the attending physician, Georgia Vogelsang, M.D., later that evening. When

a systemic infection and not wake up at all.

This time three days of transfusions, antibiotics and fluids followed before Michael's fever dropped and he and Jane could leave the Hospital. But after that things started to get better. The mask that Michael had been wearing in public came off; he and Jane got permission to go out to restaurants; and on one of his best days in weeks his sister brought his two teenage daughters to visit. All together, the group picnicked at Fort McHenry.

On one of Michael's last days with IPOP, he learned that as part of the clinical trial his stem-cell sample had been cultured to see if any tumor cells would grow. None did. In mid-June, 34 days after he and Jane had

Soldiers Returning from War

Michael and Jane didn't adjust to their old routines easily; Michael compares their re-entry to soldiers returning home from war. They found that they actually missed the daily camaraderie among the IPOP patients and the nurturing nursing staff. Jane was so inspired by the IPOP nurses, in fact, that she is considering nursing as her new career.

Since Michael will need to steer clear of germs and toxins for many months, he is no longer permitted to take out garbage, pump gas, garden, and mow the lawn. Jane, who will pick up the slack, says this burden is a small price to pay to have her husband's health back.

"The day the catheter is removed is the day this will truly be over."

he reported to her that his temperature was still above normal, Vogelsang's response was, "Come in to the Hospital immediately." Michael pleaded to be allowed to wait until morning, promising he'd go right to bed. But Vogelsang told him bluntly that he might have

moved into their tiny Baltimore apartment, Michael received another infusion of Rituxan and he and Jane headed home. On July 2, almost a year to the day after his leukemia had first been diagnosed, he returned to Hopkins to have his catheter removed.

Michael is still weak. He has no idea whether he will ever run again. He's now sterile. But he considers himself incredibly fortunate. Some of the transplant patients he and Jane met through IPOP have been inpatients for months; others have regressed or died. His disease has changed his life forever, he says. It taught him the hard way the full meaning of such clichés as "don't take anything for granted" and "make the most out of every day."

The day before I call Ian Flinn about this article, I ask Michael if there is any particular question he wants me to put to him. "Ask him if I'm cured," Michael says. "I've asked him myself, but I'd like to hear whether he responds the same way."

The next day I put the question to Flinn. "I believe with all my heart that he is," the oncologist answers. "But we won't have enough data to have a definitive answer for 10 years. We are one of the few hospitals in the world that attempts this additional purging approach with Rituxan, and Michael is only the 35th patient here who has had the procedure." Later, as I relate Flinn's response, Michael seems satisfied. We wind up our conversation by talking about our families. Then Michael puts the portable phone back in the cradle and goes back to living the rest of his life. ■

As the weeks-long transplant process drew to a close, Michael's spirits lifted, thanks in no small part to a visit from his daughters Shira, left, and Monica.

