

Insight

Hope: The legacy of death

By John DiNolfo
Guest contributor

"People with illnesses are the world's greatest healers," Dr. Bernie Siegel told a large Connecticut audience not long ago. "The secret of living one day at a time is being willing to give up life ... in order to give love," the author of *Love, Medicine and Miracles* added.

That prescription recalls my brother Jim exactly. Jim was 23 when he died of leukemia — cancer of the bone marrow and blood. He had wanted to do everything possible to defeat his disease — to give new hope to those fighting intolerable odds. He grew to care deeply about people and, in his last years, used his cancer to reach out to others in pain.

But then, Jim was by nature a peacemaker whose presence made people want to heal a dispute. Maybe he had that effect on people because he smiled so often. They immediately felt at ease with him. He liked to tell jokes and make others laugh. And he valued gentleness.

Although he took great pride in having played center for the Aquinas team that won the Catholic championship in 1971, he once admitted to me that he had grown to dislike contact sports. He feared that in a burst of strength he might unintentionally hurt someone.

To remember my brother now is to recall, especially, his determination. When, after days of fever and deep fatigue, Jim learned that he had leukemia rather than just a very bad flu or virus, he responded with characteristic pragmatism.

"OK," he said after a long pause. "What do we do about it?"

Jim soon determined that if he was meant to have the disease, it was for a reason. Something was expected of him, and he would discover what it was. A shy, and in many ways ordinary person, Jim was to discover the extraordinary in himself.

Shortly before his transplant, he visited the Trappist Abbey of the Genesee in Piffard, N.Y., where he spoke at length with Father Stephen Leahy. "I know in my heart that God is watching over me," Jim wrote after his visit. "I feel that my physical ailment will be eliminated. It is my obligation to take charge of the situation and to make myself a better person."

For Jim, that meant confronting the cancer head-on. He grew convinced that leukemia would someday be overcome, and that he was to participate in this victory. He would have been thrilled to know that today, thanks to advances in treatment and follow-up, adult patients who have a bone marrow transplant while their leukemia is in remission — in check due to therapy — have a 30- to 40-percent chance of surviving. Even better, the chances for survival may be as high as 50 percent or more for some children and teenagers in remission. Such success was unheard of just a few short years ago.

For patients who have the transplant after their leukemia has flared up again, however, the odds for living are still only about 20 percent. Those were the odds Jim faced in November, 1976, when he boarded a plane for Seattle and the world-renowned Fred Hutchinson Cancer Research Center. A long remission, produced by months of powerful drug therapy, had ended abruptly. Jim was told that the bone-marrow transplant was his only chance.

Despite the pain and side effects he could expect, Jim opted wholeheartedly for the transplant. "I want to live," he wrote in his journal.

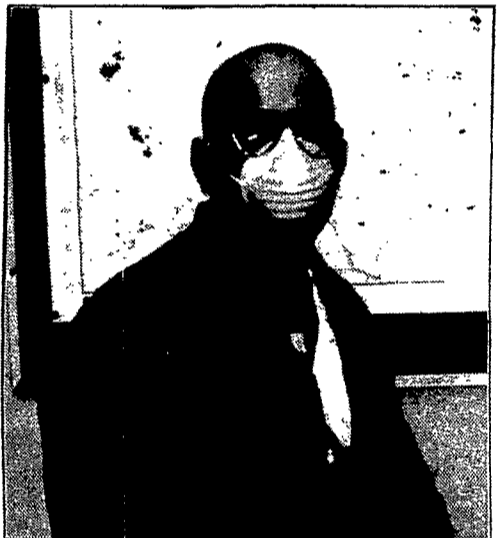
Jim traveled to the Pacific Northwest with our parents, John and Teresa, and our

brother, Dick, who was to be the bone-marrow donor. Shortly before Thanksgiving, the transplant occurred.

Jim entered a concrete-block room isolated in the basement of the hospital. He reclined on a special bed, where, for nearly four hours, radiation bathed his body, extinguishing his bone marrow and its cancer-causing cells. Dizzy, nauseated and shivering, Jim left the irradiation couch and, with the help of a nurse, made his way back to his room.

Meanwhile, in a procedure that left fierce pain once the anesthesia wore off, long needles were inserted repeatedly into Dick's hip bones to extract his marrow. Shortly thereafter, those healthy cells began flowing through an intravenous line into Jim's arm to rebuild his marrow.

To ward off infections, Jim received frequent transfusions of Dick's white-blood cells, and continued to receive potent cancer drugs. Both therapies were designed to avoid another relapse and to prevent Graft vs. Host Disease, a condition in which the donor's bone marrow suddenly attacks the patient's



Jim jokingly called himself "The Bandit" because he had to wear a surgical mask to avoid infection.

immune system, leaving it helpless against a deadly onslaught of viral and bacterial diseases.

Jim felt totally depleted. For days, little things became great annoyances — the sudden appearance of someone in his room, unwanted conversation, the lack of privacy. Jim wanted to be left alone, but that was impossible.

He endured mouth sores, headaches, frequent nausea and painful spinal taps. My brother's body became a map of needle marks. His face and neck bloated from the drugs, and his hair fell out.

Typically, Jim chose to make the best of his new look. "My appearance isn't very becoming," he liked to say of his Kojak-style look, "though it does have a certain charm."

For weeks he had to wear a surgeon's mask almost constantly in order to avoid germs. After a bone marrow transplant, even the flu can kill. Jim often joked about his mask, especially with his nurses, whom he respected greatly. He referred to himself as "the bandit."

In Seattle, one, or more often both, of my parents accompanied Jim during the many tests and medical procedures. With my father, Jim took short walks, played cards or board games, watched football on TV. When Jim sought private moments to write in his journal or rest, my father sat silent, reflecting.

My mother fed and bathed Jim, massaged his swollen back and repaired the leaky places in his chest where a drug-bearing tube had been inserted. She told jokes and sang familiar melodies. The keeper of

family stories, she shared memories and anecdotes that kept the family connected.

Had the leukemia been a person attacking their youngest son, my parents would have risked their lives defending him. What could they do against malignant cells ravaging his bone marrow and blood? They prayed.

Jim never complained or grew bitter about his pain. Outwardly, he denied the possibility of death — perhaps at first to encourage himself, but more likely to boost the spirits of his family and friends.

Inwardly, it was different. He wrestled with doubts. "I have fears that I will not ... do this thing well," he wrote of his recovery.

My brother was a novice photographer with an artist's sensibility. He used his art to wrestle with his fears. Among photos Jim took a few months before the transplant, while he was a student at the University of Dayton, are scores of angry images: the blackened, bloated limbs of trees ... desolate, gutted buildings ... battered trash cans turned upside down, waiting.

One picture simply reveals the dark image of a man's shadow thrown starkly against a wall.

Among his photos are many healing images, too. Water. A tree in winter, lithe branches curving in embrace. A snowy, untrod passage through a trellised archway, its barren vines waiting for spring.

One photo, filled with sunlight, shows a beckoning white-brick funeral home. It looks like a Victorian mansion. Large pillars guard the entrance, and nine concrete steps lead up to the shaded, canopied doorway.

Another reveals a sculpture of a young man, the torso thick and muscular, the legs strong. Vandals had decapitated the statue, and cut off one hand, as well. The abused sculpture, still bearing its unflinching dignity, appears to rest in the middle of an Ohio cemetery. And in Jim's soul.

My brother's art had become his prayer. Perhaps Jim had so much hope and optimism because inwardly he was coming to terms with himself. "Will I ever be able to accept death if it comes?" he asked in his journal. "I would fight, fight until the end ... God, please give me the strength."

The youngest of five brothers, he had become older than any of us. He endured trauma none of us knew, confronted a stark loneliness we could only guess at.

After the transplant, Jim slowly grew stronger, bolstered by Dick's marrow, the ongoing drug therapy and family support. An accountant, Dick had taken an indefinite leave from his job with the state to remain with Jim after the transplant. Another brother, Dave, an educator, flew in from Geneva to spend a few weeks. The three friends spent many hours together, while our mother was joined by a loving sister from California.

When his doctors reported 14 days after the transplant that Jim's early results were among the best they'd seen to date, Jim's spirits soared.

The good news was followed by a phone call from Dr. James Brennan, a brilliant and compassionate University of Rochester oncologist whom Jim greatly admired. In charge of my brother's care in Rochester, Brennan called to compliment and encourage Jim.

Feeling much stronger, Jim visited other transplant recipients at the Fred Hutchinson Center to cheer them up with a smile, a wave, and words of support. It seemed like he knew everyone on the floor. He gave and received many embraces. On Christmas Eve, he enjoyed playing Santa Claus for a child recovering from a bone marrow transplant.

Jim began to take driving tours with the family. He visited snow-capped Mt. Ranier, its volcanic beauty spread across the Seattle skyline. He delighted in a ferry boat ride on Puget Sound.

One hundred days after the transplant, Jim returned to Rochester. For weeks, he seemed fine. He traveled to Connecticut to spend warm days with family there. A new godfather, he proudly helped baptize his niece, Julie. He often walked the Long Island shoreline alone, pausing to sit in the afternoon sun.

The cancer therapy had left him permanently sterile. Very happy with the relationship he was establishing with his nieces and nephews, Jim increasingly spoke of adopting a child someday.

He also talked about creating a slide-tape discussion of bone-marrow transplantation, its side-effects and benefits. He hoped, above all, that such a discussion might enable future patients to undergo the procedure successfully.

"I feel that God has chosen me for a special purpose," he wrote in his journal. "... to somehow help others with my sickness." He planned to apply to graduate programs in health-care administration.

But new skin rashes developed, and fever and exhaustion set in. Worse, Jim seemed confused, disoriented. It was becoming clear that the bone marrow graft was collapsing. He developed pneumonia. Within days, the leukemia reappeared.

In early April, 1977, shortly after his 23rd birthday, Jim entered Strong Memorial Hospital. For 11 days, my brother struggled to survive, but his immune system had gone haywire. The cancer, with nothing to stop it now, invaded his central nervous system and brain. Mercifully, the disease and a blood clot in his brain cut off his ability to feel pain.

The leukemia also short-circuited Jim's ability to speak. Yet he could hear everything being said to him. Jim spoke with his eyes and an occasional attempt to lift his hand. He often turned his head to note someone's entrance into his room. Family members from Rochester and Connecticut shared a constant bedside vigil. Many of Jim's friends from high school and college were there too.

From the Abbey of the Genesee, Father Leahy asked that the "Jesus Prayer" be whispered in Jim's ear whenever this seemed right. Jim listened intently to the sound of the Lord's name,

and to the Psalms in the hospital room. ... surrender and ... him.

At night, my Jim's room on ... A big man and p ... the closest of the ... kept a steady vig

On a cold Satu ... mother and fathe ... home for a much- ... dawn on Sunday ... fitful, sweaty sl ... struggled desper ... chest rose and fel

Dick lay on ... moment he first r ... had felt a profou ... Jim realized he v ... breathing relaxed

"It's OK to go ... stay," Dick said, ... family had reach ... sensed that Jim w ... himself, but for u ... needed to stay, b ... We had to let go,

Dick forced b ... much — his bor ... courage. "We lov

Not long after, ... and began to cry. ... fist into the hosp ... again.

Seemingly w ... reached by phone ... held Jim for a ve

"Don't let go ... you've had a mor ... Siegel has said. ... moment, and wh ... all right." Jim ... moments of beau ... was, indeed, righ

At the wake, ... friends lingered ... in the crowded ... memories of a ... friend.

Bish ... R

