

Bill Bartholome introduced himself to Midwest Bioethics Center in early 1986, a fortuitous moment in the history of the Center.

Living in the Chicago area at the time, Bill wrote to Karen Ritchie, one of the Center's founders, and said he would be moving to Kansas City shortly thereafter. He knew of Midwest Bioethics Center, and wanted to discuss with us how he might be involved in the Center's work.

Karen and I met Bill at a restaurant in the Country Club Plaza. He was young, tall, nice looking, but my original impression of this man was that I wasn't sure his ego would fit in Kansas City, nor could I understand why he would be interested in our fledgling organization. But initial impressions aside, it was impossible to ignore the intense interest and offer of help from this pediatrician who was already well known by all of us who had studied the history of the bioethics movement.

Bill's introduction to the bioethics movement began years before, and it was truly a baptism of fire. While a pediatric resident at Johns Hopkins University, Bill encountered a situation that changed his life. It involved an infant born with Downs Syndrome, and the decision by the infant's parents to forgo a simple surgical procedure that would allow the baby to thrive. Further, the parents decided not to feed the baby, and to allow him to die in the hospital.

Foreword

*by Myra J.
Christopher*

Against the objections of the parents and the attending physician, Bill and the chief resident, Norman Fost, went to the mat on the child's behalf. In the end, the court decided with the family.

The baby was placed in the back of the hospital nursery where he lived for seventeen days, then finally died. At the time of the baby's death, Bill was on a plane with a legal document in hand, hoping to solicit support from the state court of appeals. Afterwards, disillusioned by the process, Bill went to Harvard University where he received a master's degree in theological studies.

While in Cambridge, Bill became acquainted with the Kennedy family. With their support, he went on to the Kennedy Institute as a fellow. But

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he hadn't forgotten his experience at Johns Hopkins. While at the Institute, Bill produced a compelling video that vividly and dramatically portrayed the ethical situation he had encountered during his residency. At the time of its production, the video of the Johns Hopkins "Baby Doe" case was so compelling that Walter Cronkite once showed it in its entirety on the *CBS Evening News*. It is still used today for teaching purposes. And Bill Bartholome became a nationally known name in bioethics.

Thus did Bill's work in bioethics begin. While still a young physician, he was largely responsible for shifting the way we view the rights of parents to make treatment decisions for their children, and his legacy of promoting the rights of children in healthcare decision making continues to this day.

By the time we met Bill, he had been at two prestigious ethics institutes – The Center for Medical Humanities at the University of Texas at Galveston, and the Parkridge Center in Chicago, Illinois. He and his family had recently decided it was time to return to their home town, to Kansas City. Bill had taken a position at his alma mater, the University of Kansas School of Medicine, to work with the Department of the History and Philosophy of Medicine and to do clinical ethics in the University's hospital.

At lunch that day, Bill became clearly energized as we discussed the Center's vision of a health care delivery environment anchored in respect for the dignity of patients and informed by ethical discourse. He became even more excited about the notion of "doing ethics in community." And that was the beginning of a relationship that became vital to the direction and growth of Midwest Bioethics Center. I could never have imagined that day, fourteen years ago, how important Bill would be to the Center, nor how close a colleague and how dear a friend he would become to me.

Even before moving to Kansas City, Bill joined the Center's board of directors. He was looking for a community of people, he said, with whom he could share ideas and engage in dialogue. And once he and his family were settled in Kansas City, Bill began to live his words.

Bill threw himself into the Center's work. Immediately he demonstrated that, in addition to his board duties, he was willing to do virtually anything necessary to help the organization grow. He and other founders of the Center became "volunteer staff." As such, Bill presented programs, led the ethics committee consortium, participated in ethics committee education, headed up task forces, and regularly wrote articles

for the Center's publication, now known as *Bioethics Forum*. He participated in planning programs for the community, and was always available to me as a sounding board.

In June 1994, Bill called me to tell me that he had been diagnosed with esophageal cancer. The prognosis was grim — a fifty percent chance to live six months. We were devastated; I was not sure that we would be able to survive Bill's loss. And I couldn't imagine Midwest Bioethics Center without him.

Following the diagnosis, Bill had a major operation that nearly killed him in and of itself. The day he was discharged from the hospital, I met him as he was leaving for home. He explained the "disease model" to me and told me that he would not undergo further treatment. In the time he had left, he said, he would tend to family and to relationships. He assured me that we had to go on with or without him — and that we could. And he left us all with the feeling that before we even had time to deal with this dire prognosis, a dear, valued friend would be gone from us.

Fortunately, and much to the surprise of his physicians, Bill rebounded. In the months that followed, we all began to muster hope that he would be with us for a while longer. I remember desperately wanting to imagine that his prognosis was mistaken, and that things would return to the way they had been before.

But, to his credit, Bill never let us entertain that idea for very long. Even when he attended meetings that he had led for many years, he would not take his rightful leadership place. Rather, he would sit among participants, refusing the head table. Bill's message to us was clear: "You'll be okay when I am gone; you can do this without me. It's time to start."

During the first year following his diagnosis, Bill made a presentation he called "Living in the Light of Death," which we published in our monthly newsletter. And when the next year came around, he wrote another meditation, with a new one each subsequent year. This theme — that to

have a terminal diagnosis, to be named among the dying, is a liberating gift unlike any other — became Bill's recurring message.

For more than four years, we all benefited from Bill's insights and wisdom as a dying person. He shared that wisdom with us in the form of these yearly meditations, published here in the Center's journal, *Bioethics Forum*.

And with each new meditation we began again to believe that Bill had beaten the odds. He was cured. He would outlive us all, we said jokingly.

Just before the end of 1998, Bill's cancer returned. This time it had metastasized to his brain and there were now tumors in his lungs and throat. His beautiful voice — a voice that years before a conference participant had described as a "blend of Carl Sagen and Mister Rodgers" — was in jeopardy. Surgery would be required to

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preserve his speaking voice, and it appeared that his lecturing voice would be gone forever. We were all devastated.

At Christmas, I received a copy of the prayer that Bill had written for his family in a greeting card from Bill and his wife Pam. Overwhelmed by its beauty, I made copies and forwarded it to many friends and colleagues, a gesture that surprised Bill, who often underestimated the power of his words.

Here then are the meditations that Bill wrote in the years following his cancer diagnosis and the prayer he originally wrote for his family. He gave them to us freely as a gift. It is our hope that

they will be circulated widely — to our members and friends and to generations to come — so that we too may learn the kindness of Bill's angel and the freedom of living in the light of death.

This collection is our way of saying how very much we loved this man, how great his contributions have been to our work, and how tremendously we will miss him for all our days to come.

Myra J. Christopher
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