

# Once

Category: Stories

written by David Goldblatt | August 1, 2008

## **David Goldblatt**

Movement disorders can be horrifying. Afflicted persons are solidified or contorted. They may flail so violently that a fork endangers their lives. As a beginning neurologist, I assumed that all such patients curse their fate. Once I got to know Brian, though, I realized that I could be wrong.

Brian and one of his brothers had inherited Wilson's disease, a rare, genetic movement disorder that had spared their eight siblings.

People who have Wilson's disease can't handle dietary copper properly. It accumulates in—and poisons—the kidneys, liver and brain. Avoiding foods rich in copper does not halt the progression of the disease, but it helps. If patients are also treated early and consistently with a drug such as penicillamine, which binds copper and aids in its excretion, they can expect to live a normal lifespan. If not treated, they die young.

Oscar, Brian's younger brother, was less affected than Brian in his movements and speech. He looked out for Brian in an unusual way: he punched, pushed and made fun of him. (Psychiatric disorders are common in the disease.) Oscar died in his twenties in a car accident. His spleen, swollen because of Wilson's-related liver disease, ruptured, and he bled to death internally.

After Oscar died, Brian spent some months in the county hospital, where a homeless man with a chronic illness could find care. Always, it seemed, he had a pretty student nurse at his side, and she was usually laughing. With his long, straight black hair, aquiline nose and lean, well-muscled body, he looked like—perhaps was—a Native American. Instead of showing the grace one might expect from someone with his looks, however, he moved stiffly. The harder he tried, the harder his anaconda muscles wrenched him back. Only sleep brought relief.

Speaking was especially difficult for Brian. It took him many seconds to begin to vocalize, and he often resorted to a letter board. Even then, his contrary musculature presented a challenge: his arm might snake toward the letter he wanted to touch but jerk away just as he was about to reach his goal. When he did try to speak, his tongue might protrude grotesquely. With great deliberateness, he would extend his index finger and thrust his tongue back into his mouth, then slowly and indistinctly articulate what he wanted to say. It was an exhausting experience, both for him and for the listener.

I was a member of an investigative team trying to treat the symptoms of Wilson's with various drugs used for Parkinson's disease. My assignment was to record Brian's status on videotape at regular intervals. Although treatment helped him, he was not always a compliant patient.

A tape we made in the eighth year of our association shows me pulling a blue packet of cigarette papers from Brian's shirt pocket and asking, "What's this?"

"Pay . . . pers," he says, with a slow, mischievous grin.

"What do you do with them?"

"They're for mari . . ." He haltingly continues: " . . . WAH . . . na."

"How often do you smoke it?"

The words come more freely: "Whenever I can get my hands on some."

Later in the session, I ask Brian about his favorite foods. He says that he loves Reese's Peanut Butter Cups.

"What's in them?" I ask.

"Peanut butter and chocolate"—two high-copper foodstuffs he knows he's not supposed to eat.

"Why would you eat something like that?"

"Because . . . I en . . . joy it!"

"But if you know it's bad for you . . .?"

Struggling to produce the words, but smiling serenely, he reminds me, "We . . . only . . . live . . . once."

#### **Editor's note:**

In January 2007, while *Pulse's* launch was still a year away, we were contacted by David Goldblatt, a neurologist living in Penn Yan, in the Finger Lakes region of New York State, who'd written a story about a patient with Wilson's Disease. We liked his piece, agreed to run it, and made a few editorial suggestions. In a return e-mail he noted, somewhat wryly, "When you see the attachment about me, you'll realize that I have a certain urgency about getting things done these days."

The attachment carried a brief chronology of his fight with cancer. Among the entries: "**3/3/05:** Operation to remove left kidney and ureter for urothelial cancer, regionally advanced: 3 of 19 nodes positive. **2006:** a great year until mid-December, when metastasis was detected...Only 20-30% of patients respond to the treatment I am taking...I'm shoveling snow when I get the chance. The quality of my life is as high as I could wish for-and then some."

In September 2007, eight months after David had first contacted us, his wife Ann wrote the following:

"You have all lost a friend. David died early Saturday morning here at home. His three sons and I were with him. He had had visits from family and several close friends all week long, a very busy week for a man as debilitated as he

was. It was also very exciting for him: he was on an emotional high for his last two days . . .

“I want you to know that David remained himself right to the end. He was clear-headed, talkative, caring, and even humorous straight through. Unfortunately he was also terribly thin, weak, and in great pain at times.”

On the surface, we at *Pulse* were connected to David by one story, a half-dozen e-mails and a couple of phone conversations. In another way, we were linked by his journey through the last stages of life, a journey that we too will make one day.

We're grateful to have known David and appreciate that he reached out to us even as time was running short. And we're grateful to Ann for following through on David's wish to publish "Once" in *Pulse*.

#### **About the author:**

David Goldblatt MD was a neurologist, writer, editor, potter, gentleman and avid slo-pitch softball player. A native of Cleveland, Ohio, he completed his medical degree at Case Western Reserve University in 1955 and his neurology residency at the New York Neurological Institute. After becoming chief of the neurology branch at the National Naval Medical Center in Bethesda, he conducted research at Johns Hopkins University, then spent thirty-one years at the University of Rochester as a professor of neurology and, later, as a professor of the medical humanities. His main medical interests were ALS, medical ethics, compassionate patient care and traumatic brain injury. David died of cancer at age 77 on September 1, 2007.