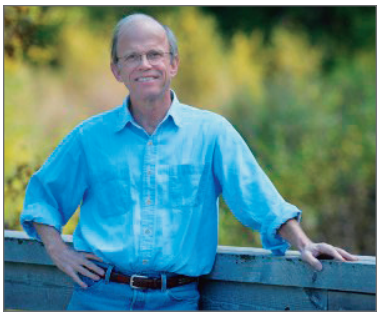
THALIDOMIDE AND ME

By Landon Jones



"Thalidomide?"

The four syllables did a macabre soft-shoe dance deep into my memory. My hematologist had just asked if I would be interested in a clinical trial combining my current drug, ruxolitinib, with thalidomide.

To anyone who remembers the early 1960s, thalidomide was at the center of a pharmaceutical scandal – and a worldwide tragedy. Marketed by the German company Chemie Grünenthal as a sleeping pill and promoted as an antidote for morning sickness in pregnant women, it instead produced a devastating array of birth defects, most prominently malformed arms and legs. The photos were heartbreaking. Of 10,000 cases reported worldwide, an estimated 5,000 of the children survived, most born in 1960-61, almost all of them now in their late 50s.

I swallowed hard. I also knew enough about thalidomide to know that it is something of a zombie drug. It has returned to the market as a treatment for multiple myeloma, leprosy, Crohn's disease, and multiple sclerosis.

Now two hospitals, Memorial Sloan-Kettering in New York and MD Anderson in Houston, were organizing a clinical trial for 25 patients with progressive myelofibrosis. This was a lottery I had never expected to enter.

My doctor outlined my situation by drawing a sketch on a sheet of notepaper. I had been diagnosed with primary myelofibrosis in 2011. I started taking ruxolitinib – or "rux," as they call it – soon after it was first approved by the FDA a little later. But rux loses efficacy for many patients after a couple of years, and my blood counts seemed to suggest that was happening. Moreover, I had two genetic mutations associated with rux losing its effectiveness.

As the doctor explained, I could consider getting into one of the ongoing drug trials at various hospitals around the country – if they would take me – or enter the one he and his colleagues had recently started with thalidomide.

"What's the best-case result?" I asked.

He paused. "It's not a cure," he said. "But it can buy you some time."

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That night, as my commuter train passed through Newark, N.J., I gazed at the shells of long-abandoned buildings standing near the railroad tracks. I had seen these brick ruins thousands of times on my daily trips to New York but now for the first time they reminded me of the photos I had seen of Dresden after it was bombed in World War II. It was as if I had found a grim outer symbol for the way I felt on the inside – hollowed out and afraid.

But my doctor's words stayed with me. Could I buy some time? Otherwise, the next step for me could be a stem-cell transplant, a much scarier prospect.

Two weeks after the conversation with my doctor, and after having read a list of theoretically possible side-effects that was longer than Martin Luther's 95 theses, I signed the consent form and took my first thalidomide pill at bedtime.

There had been some surprises for me. One is that I pay for the drug myself (or my insurance company will). The drug company which makes ruxolitinib, Incyte, pays for the costs of the clinical trial. Another is that the study could last up to 36 months, though I can leave anytime I choose, if I wish. And the list of risks included the disquieting information that the drugs could affect how certain parts of my body work – namely, my "liver, kidneys, heart, and blood."

After taking the pill, I slept like a baby. When I woke up the next morning, I felt a palpable sense of relief. I was rested and refreshed (thalidomide is a sleeping pill, after all) and full of optimism. Maybe it was the power of suggestion, or maybe I had finally exhaled. Or maybe it was because I had decided to let my body be my friend.

Patient Update

The four months since the trial began have been heartening. My doctor is enormously pleased that my blood counts have all either improved or stabilized. A package of thalidomide arrives by overnight delivery every four weeks, but only after I answer a stern questionnaire attesting to my responsible sexual habits. Otherwise, I have returned to my corrupt habits of tennis and fly fishing. May that always be the case. ■

Landon Jones is the co-translator of Pia de Jong's new memoir about the year she spent following her newborn daughter's diagnosis with what was thought to be a terminal leukemia. It is called Saving Charlotte: A Mother and the Power of Intuition, and was published by W.W. Norton.