

## My Clinical Study Experience with Multiple Myeloma

By Philip Falkowitz

Cancer tried to change my life.

Once I find something I like doing, I keep doing it. I've lived in a small town, Langhorne, outside Philadelphia, with Barbara, my wife of 44 years, since 1979. We have three grown children: two girls and a boy. I've been driving the same green 1967 Corvette since 1991. Until I retired in 2012, when the company I worked for closed, I worked 39 years as a distributor's rep selling disposable paper products in the food service industry. Nothing fancy, but I enjoyed the work. I've always been someone people could count on. That's important to me. Being sick meant someone else had to do my job. Basically, I was my own boss. I spent nine hours a day on the phone talking with customers. I had a nice routine going.



Phil and his wife, Barbara, in Rome

In 1995, I was diagnosed with a plasmacytoma on my spine. My neurological surgeon removed it, but the disease came back in 1997 as multiple myeloma, which means it was in more than one place, so a second surgery alone wouldn't work. They tried an autologous stem cell transplant in 1998 and some other immune approaches, but they didn't help much.

In 2001, I talked to Dr. Philip Greipp at the Mayo Clinic. He told me about clinical studies for two new drugs: Revlimid (a derivative of Thalidomide) and Velcade. There was no way to know which one was more likely to help, so I picked Celgene's Revlimid because it would create fewer problems for my family and co-workers. I looked into the places with studies closest to Philadelphia. Whereas the Velcade study involved two infusions per week in New York City, Revlimid required only a monthly trip to Boston to see the doctor, have my blood drawn, and pick up the capsules. I like to be in control of my life, so I liked how I could take the capsules myself.

In Boston, I went to the Dana Farber Cancer Institute. Dr. Paul Richardson screened me for the CC 5013 study. Dr. Robert Schlossman was the point man. He started out all business but we eventually got to know each other pretty well. Debra Ross, the Nurse Practitioner, was very friendly and forthcoming.

It was a 24-hour round trip. I always went with a friend for company and to help with the driving. Before each trip, I worked a full day Monday. We would leave after dinner, stay Monday night in Hartford, Connecticut, and then go to Boston in the morning. After lunch at Legal Seafood, we drove five hours to be home by Tuesday night. I was back at work Wednesday morning. The seven friends that went with me were glad to see the trips end.

I started in the Phase 1 study. The study rolled right into Phase 2. It was an open-label study. If there had been a choice, I would not have done a blinded study.

They started me on 50 mg, but that gave me rashes, so they dropped the dose to 25 mg. The other problems I ran into were low red and white blood counts, and intestinal issues. I told Dr. Schlossman I thought the intestinal issues were caused by the pills, but he said, "I don't think so" because he didn't see the connection. But I was right — when Revlimed got approved in 2006, the label warned about abdominal pain, diarrhea, constipation, and nausea. Fortunately, they had pills for that.

I'm still taking Revlimed, but at a 10 mg maintenance dose. I've been on it since 2001, the second longest of anyone in the world.

In 1995, I co-founded the Philadelphia Multiple Myeloma Networking Group. One thing I never understood was how I was doing so well but other people in the group still wouldn't look into clinical trials. Some of them died. That sort of gave me survivor's guilt. Of course, the later studies were blinded, so it was a different story. That's a horrible situation to put people into. I went into full remission in 2004 but it was another two years before the FDA approved Revlimed. A lot of friends died.

So, did cancer change my life? Yes, it sure messed with my routine along the way, but no, I'm still married to Barbara, I worked at the same company until it closed, and I'm still driving that green 1967 Corvette. However, I do have to admit that it gave me a new purpose and a lot of new friends at the Philadelphia Multiple Myeloma Networking Group.

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