Orphans No More

Robert Rosen '66: Diagnosed with a rare blood disease, a businessman makes an eye-opening discovery.

By William Bunch '81

Seven years ago Robert Rosen saw a doctor about tingling and discomfort he'd been feeling in his feet and fingers. When, after conducting a blood test, Rosen's physician advised him to see a hematologist, the Chicago real estate executive could think of only one thing: he must have leukemia.

"It was a scary time," recalls Rosen. A six-foot, five-inch star basketball player in over-fifty competitions, he'd been in perfect health until then. When further tests revealed that Rosen in fact suffered not from leukemia but from a non-lethal blood disease, he was relieved.

Rosen's illness was one he'd never heard of: polycythemia vera, a condition in which the bone marrow produces too many red blood cells. It is one of several types of blood cancers known collectively as myeloproliferative disorders, or MPDs. Although not as deadly as leukemia—in which white blood cells are overproduced—MPDs can cause a range of symptoms, from numbness and dizziness to a greatly increased risk for fatal blood clots.

But when Rosen tried to learn more about them, he learned that his was one of many conditions so rare that research into them is just not cost-effective. The National Institutes of Health considers MPDs and other such illnesses "orphan diseases," conditions that affect fewer than 200,000 Americans at any one time and thus get little research funding or attention from drug companies. "I couldn't even find an advocacy group," Rosen says. "That blew me away."

His diagnosis had come at a time when Rosen was already at a crossroads. His successful real estate career was winding down, and his daughter, Molly '99, was graduating. After he read stories about advances in the study of the human genome, an idea struck Rosen: if anyone were to find the money to study MPDs, it would have to be him.

"I felt that all the business lessons I'd learned so painfully over the years became easily transferable," he says. He learned by chance that a business associate, Chicago real-estate magnate Robert Pritzker, was also undergoing treatment for polycythemia vera. Rosen asked Pritzker and another MPD patient he'd discovered, David Ricci '80, to become directors of a new nonprofit group, the MPD Foundation.

A neighbor from the Chicago suburbs, Ron Hoffman, a researcher from the University of Illinois–Chicago Medical Center, became a valuable adviser. "I've been working with him extensively," Hoffman says, referring to Rosen. "He's done an amazing job increasing the visibility of a disorder that was not on the radar screen." So far the MPD Foundation has raised about $3 million while jawboning for research money and federal grants and forging alliances with the major leukemia foundations.

Meanwhile, about seven or eight times a year Rosen receives a treatment that he equates to the medieval treatment of blood-letting. And he says he's feeling fine. If you don't believe him, just try taking the sixty-year-old to the hoop for a lay-up sometime.

For more information about the MPD Foundation, go to http://mpcfoundation.org.