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Innovating cancer research

Tuesday, December 23, 2008

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By HARVY LIPMAN
RECORD COLUMNIST



Norman Scherzer has two basic goals for the non-profit he heads:



DON SMITH/STAFF PHOTOGRAPHER

Norman Scherzer, executive director of the Life Raft Group, has pooled the non-profit's research efforts.

wife, Anita, was diagnosed in the mid-90s, and by 2000, after nine surgeries and numerous rounds of radiation treatments, her condition seemed hopeless.

"We finally had run out of options," Scherzer recalled. "We gathered our family for our 39th wedding anniversary. We decided to re-exchange our wedding vows and give our grandchildren Jewish names, which we'd never done, because she was not going to be here for our 40th."

Shortly thereafter, they found out about a trial for a new drug called Gleevec, and his wife was signed up.

"Twenty-eight days later, she went for her first CAT scan, and the radiologist says to me, 'Fifty percent of her tumors are gone, and the other half are dissolving into liquid.'"

In 2002, Scherzer and others touched by the disease formed the Life Raft Group as an educational non-profit, to spread information about the disease and its treatment and to do advocacy on behalf of patients.

"The first year we raised \$50,000 to \$75,000, mostly from our members," he said. The organization also got some small grants from foundations and the pharmaceutical industry.

But problems were arising with the miracle drug: In about half the GIST patients treated with it, the cancer developed resistance and began growing again. Three years ago, Scherzer brought some prominent cancer researchers to the group's conference, who explained what was happening.

Jerry Knapp, a retired California businessman on Life Raft's board, told Scherzer the group should fund research into the resistance problem. Knapp donated \$750,000 from a small family foundation to get the work off the ground, said Scherzer, whose background is in public-health administration, having worked at the Centers for Disease Control and the New York City health commissioner's office.

Life Raft shifted its focus. It would still provide education and advocacy, but its primary mission became funding research that would lead to eliminating GIST.

"Most cancer research is done by individual scientists who investigate whatever idea interests them," Scherzer added. "They work on their own, and they don't discuss what they're doing with other researchers until they publish their findings."

Life Raft's board developed a different strategy: Instead of sitting back and waiting for

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individual scientists around the world to come up with research proposals that touched on some aspect of GIST, they would fund their own research program.

It would put together a committee of top cancer investigators to design a coordinated approach to solving two problems: Figuring out how the cancer was developing resistance and come up with techniques to overcome that resistance. Then they would focus on killing off the cancer cells entirely.

"When we had raised \$2 million, I brought four of these guys together at the Holiday Inn in Totowa," Scherzer said. "I told them, 'We want you to create a strategy and agree to cooperate.' And then I turned to the institutions where they worked, places like Stanford University and Memorial Sloan Kettering, and told them, 'You can only charge us 10 percent of our grants for overhead.' Typically those charges are as much as 75 percent. You know what? Not one of them argued with us."

Today, 10 internationally renowned scientists participate in Life Raft's research team, each receiving annual grants of about \$90,000.

Dr. Brian Rubin, director of soft-tissue pathology at the Cleveland Clinic, said the approach is very different from typical cancer research.

"Generally, people get funded and they're out on their own, without so much collaboration," Rubin explained. "Here we assemble a team and carve up the duties. It fosters interaction. It's not a model a lot of us have used before, but it's a very good idea, especially because it's a rare disease."

Rubin added that researchers appreciate the fact that their funding is coming from an organization made up mainly of people touched by the disease, many of whom have made donations to help keep Life Raft's efforts going.

"It's gratifying for all of us to work with the patients and the families," he said. "It's very neat to be connected directly to the patients, who are essentially funding research into their own disease. They know it may not help them, but it may help people in the future."

Scherzer said he's unsure who would own the rights to any new drugs developed through the research Life Raft is funding.

"In some cases the compounds are owned by pharmaceutical companies, in some cases by universities," he said. "In some cases, somebody has to make a new drug from a discovery. We're just starting to learn more about intellectual property — who owns what."

He emphasized that the money raised and distributed by the organization doesn't give any donor — including pharmaceutical companies — ownership of the research. "When we raise money, it is no-strings attached," Scherzer said.

Raising enough to keep the research going is his main preoccupation at this point.

"We make two-year commitments in our grants, and we have enough money on hand to honor those," he said. "That gives us two years to catch up and raise more money. Where we're going to find that money, I don't know. We can sustain the laboratory part for a long time, but in order to run the clinical trials, that's where money is needed."

Spending on programs: Life Raft has one of the highest program spending rates of any non-profit in the state: 94 cents of every \$1 it spends. Plus

Spending on fund raising: The group spends little on fund raising, relying on its members along with a few regular corporate and foundation backers. Thus, it generates nearly \$100 in donations for every \$1 spent on fund raising. Plus

Executive compensation: Scherzer's total compensation, including benefits, is about \$96,000, in the middle third of executive pay for North Jersey non-profits. Neutral

Financial stability: For the past two years, Life Raft has eaten about \$1 million into its cash reserves to fund its research projects. Minus

Outcomes: The group's research team says it has made significant progress in developing compounds to overcome the cancer's resistance to treatment, and is getting ready to begin clinical trials. Plus

Demand for services: Between 5,000 and 10,000 people in the U.S. develop GIST annually. Plus

Transparency: The organization readily provided all financial and other relevant documents. Plus

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