Good for the heart

Given months to live, a native Minnesotan comes back home and finds a new care team—and a more positive outlook

Nearly three years ago, Ray Hunke’s cardiologist gave him six months to live.

“The doc walked in and said, ‘Ray, I’ve got bad news for you. We can’t do anything for you anymore,’” recalls the Minnesota native, who has advanced heart failure and was living in Texas at the time, in spring 2014. “He said, ‘If we put you on the operating table, you’ll die there. You’ve got six months. But we can make you comfortable.’

“I went home and told Marietta, ‘We gotta sell everything and move back to Minnesota,’” Hunke says. So he and his wife started packing and prepared to spend their remaining days together up north.

As the Hunkes were getting settled in Minnesota, a neighbor urged Ray to call University of Minnesota Health, convinced that its heart failure clinic would not share his previous doctors’ defeatist perspective.

That neighbor was right. Today Hunke lights up when he talks about his cardiologist, Cindy Martin, M.D. “Dr. Martin says to me, ‘The heart you have left is doing great.’ And she tells me to walk every day, which I do.

Ray and Marietta Hunke are thankful for the caring University of Minnesota Health cardiology team that looked for ways to improve Ray’s condition when other doctors had “given up” on him.
I just appreciate the way she takes care of me, talks with me, listens to me,” he says. “I would tell anyone, if you’ve got serious heart problems, the U is the only place to go. They care.”

Making adjustments

Hunke had a heart attack and bypass surgery in 1989 and got his first pacemaker/defibrillator in 2001. He says his health began to seriously decline in 2012, and by 2014 his doctors in Texas had essentially “given up” on him.

Fortunately, he found himself in good hands at University of Minnesota Health. The University has been a pioneer in heart failure research and treatment over the past seven decades, including through its work more recently on the left ventricular assist device (LVAD), which helps an ailing heart pump blood to the rest of the body. That was one option Hunke’s cardiac care team discussed with him.

But following a routine probe of his stent grafts, Hunke began to feel markedly better, and the LVAD option was shelved for the time being.

Then Hunke’s team gradually weaned him off of palliative inotrope, a medication he’d been taking since before he moved back north.

“We see a lot of these patients come in who are older, they’ve had their heart disease for many years, and oral medication therapy doesn’t seem to be maintaining a good quality of life anymore. They’re declining and they’re just kind of told there’s nothing else,” Martin says.

“Sometimes they’re referred for advanced therapy [like transplantation or the LVAD]; sometimes we’re able to find areas within their [existing] medical regimen to intensify. And we can adjust their medical therapy. Ray would be an example of this.”

Inspired to give back

Hunke’s gratitude to his team at the University—not only to his physicians, but nurse practitioners, nurses, and others—inspired him to donate to the Lillehei Heart Institute in each of the past two years.

Coincidentally, Martin, an associate professor in the Medical School’s Department of Medicine, is a Lillehei Endowed Scholar and has received research funding through the Lillehei Heart Institute. She says support like that of the Hunkes is critical to physician-scientists working with patients in the clinic and in the laboratory to translate basic science discoveries into lifesaving therapies.

In her newest project, Martin is exploring right ventricular development with an eye toward improving treatment for right ventricular failure. “I’ve been a developmental biologist basically my whole research career. Now I want to translate that kind of knowledge to hopefully apply some of that in clinical arenas,” Martin explains. “That’s what a physician-scientist does.”

Since summer 2014, Hunke, a recovering alcoholic of 40 years, has felt good enough to volunteer every Sunday night in the inpatient detoxification program at Fairview Recovery Services in Minneapolis. It’s good for his heart, he says.

So is the relationship he has developed with Martin. “We’re a team,” Martin says.
Desperate to improve his son’s prognosis, a New Jersey father seeks out the best in muscular dystrophy research—and finds the University of Minnesota

When Jamesy Raffone was diagnosed with Duchenne muscular dystrophy (DMD) in 2013, his parents, Jim and Karen Raffone, were devastated. They felt helpless.

“I was told by seven different doctors in three weeks—because I got that many second opinions—that there was nothing they could do for my son. ‘Go home and love him,’” Jim Raffone recalls. “That didn’t sit well with me.”

DMD is a progressive genetic disease that breaks down muscle tissue over time, including that of one very important muscle: the heart. It affects boys almost exclusively and cuts their lifespan short. Historically, those with DMD didn’t live much past age 20, but medical advances have helped to extend their lives into their 30s or even 40s.

That’s tough for the Raffones to swallow. So within two months of Jamesy’s diagnosis, Jim Raffone had created an organization to raise money for research and named it JAR of Hope in his son’s honor.

One of his first fundraising efforts was a “10 pushups for $10” campaign at a local gym chain near his home in Manalapan, New Jersey. “I tried to tie the muscle wasting disease to the gym environment, where everybody goes to build muscle tissue,” he says.

The effort was so well received that he followed it up with a world-record attempt for the largest group of people doing pushups at one time. “From there, it just caught on fire,” he says.

Meanwhile, the Raffones had found a doctor for Jamesy who suggested that oxygen therapy might be beneficial. So they built an approximately 3-by-7-foot hyperbaric chamber inside their home, and they say it appears to be helping.

But there isn’t much science behind it—yet. “We needed to study this because I’m spending ... eight hours a day in this chamber with my son,” Raffone says. “Am I spending my son’s life now in the right way?”

Raffone started a nationwide search to find people doing research on oxygen therapy’s effects on cardiac, pulmonary, and motor function. That’s how he found University of Minnesota assistant professor DeWayne Townsend, D.V.M., Ph.D., who had shown that mice bred to model muscular dystrophy that spent time in a low-oxygen environment suffered a surprising amount of heart damage.

Today JAR of Hope has given more than $220,000 for a new University study to thoroughly measure skeletal muscle, respiratory, and cardiac function in mice exposed to “normobaric oxygen-rich” (meant to simulate what a person would get through an oxygen mask) and hyperbaric environments.

“We hypothesize that by increasing the oxygen available,” Townsend says, “it’s possible to slow the progression of heart muscle degeneration in patients afflicted with DMD.”

If there appears to be a benefit at the end of the two-year mouse study, he adds, it would be relatively easy to move into a clinical trial involving people who have DMD, because oxygen therapy is already used in the medical field and no additional approval would be required by the U.S. Food and Drug Administration.

Until then, Jim and Jamesy Raffone will continue with their own hyperbaric chamber experiment at home, watching movies, playing Minecraft, and building Legos together.

“I’m just a desperate father trying to save my son.”
In a groundbreaking University of Minnesota study, researchers found that artificial blood vessels bioengineered in the lab can grow with a recipient. The study was published in the prestigious journal Nature Communications in September.

If the results of this study can be replicated in humans, the grafts could prevent the need for repeated surgeries in some children who have congenital heart defects.

Distinguished McKnight University Professor Robert Tranquillo, Ph.D., and colleague Zeeshan Syedain, Ph.D. (above), generated vessel-like tubes in the lab from a donor’s skin cells and then removed the cells to minimize the chance of rejection. When implanted in lambs, the tubes were then repopulated by the lambs’ own cells, allowing the vessels to grow.

“This is the perfect marriage between tissue engineering and regenerative medicine,” says Tranquillo, “where tissue is grown in the lab and then, after implanting the decellularized tissue, the natural processes of the recipient’s body make it a living tissue again.”

The team is now developing tissue-engineered heart valves that could grow with children who need valve replacements. Tranquillo, whose work is supported in part by the John and Nancy Lindahl Children’s Heart Research Innovators Fund, won a grant from the National Institutes of Health to create this enormously complicated and sought-after product.

“In the future, this could potentially mean one surgery instead of five or more surgeries that some children with heart defects have before adulthood,” Tranquillo says.