CLEAN BILL
Real People on the Quest for Health

A String of Miracles



When a 44-year-old mother was suddenly struck with a life-threatening disease, a series of serendipitous interventions, extraordinary doctors and the tefillos of klal Yisrael carried her through a desperate fight for her life

AS TOLD TO GOLDY SWIMER BY RALPH AND JEANNE



Two weeks before Pesach, I came down with a bad cold. I assumed that the nonstop business of Yom Tov preparation, combined with far too many late nights, had finally caught up with me. But even after Yom Tov was over, I was still feeling extremely fatigued. I began to wonder if perhaps I had long COVID.

I was 44 years old, young and fit, and loved playing tennis. There was no reason to think this wouldn't pass with some sleep and hydration.

Then, on Wednesday, I started feeling worse. I went to urgent care and had some blood drawn. The results showed some inflammation, but the doctor said we should keep an eye on it. I thought nothing of it.

By Friday night, I was so winded that I found it difficult to get in and out of bed. I was struggling to breathe.

Could this be what long COVID felt like?

Ralph, Jeanne's husband

Did Jeanne have long COVID, or was it some sort of walking pneumonia? Whatever it was, it didn't look too bad until Shabbat.

Shabbat morning found me at *Shacharit* in our *shul*. Toward the end of the prayers, I sensed that something wasn't right.

I have to check on Jeanne, I thought. Though prayers weren't quite over yet, I left and rushed home.

I found Jeanne on the couch, almost lethargic. She said she was out of breath simply from doing small things, even from just sitting there. I looked at her and knew she needed to go to the hospital, and she needed to go now.

I called her parents. They knew I wouldn't call on Shabbat unless it was an emergency, and they rushed right over. For a short while, we debated where to take her. I insisted Jeanne needed excellent doctors and a stellar institution.

We settled on NY Weill-Cornell. Jeanne and I felt comfortable with the choice.

The chain of miracles begins here. Weill-Cornell is not just a top tier institution but just the hospital Jeanne needed.

Our daughter, who'd gotten married just months earlier, lived a few blocks away. We'd been in the area a lot prior to the wedding, setting up her apartment and seeing her off. It somehow sounded familiar to us.

Jeanne's mother came along with us to the hospital, and her sister took our younger children while our older ones stayed home. We thought she might need some fluids, antibiotics perhaps.

"We'll probably be home tonight," I told my daughter. "We just need to get her some medicine."

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Jeanne

The ER took us in right away and began running some tests. It was the weekend, and it took a couple of hours for the doctors to identify the cause of my illness: myocarditis, or inflammation of the heart muscle. They wanted to admit me immediately and start a regimen of IV antibiotics.

"Wow," I said to Ralph. "They want to keep me overnight." Still, we weren't concerned. The doctors made it sound pretty run-of-the-mill.

Shabbat and Sunday passed slowly. On Sunday night, the doctors wanted to keep me another night for monitoring. I looked at Ralph. We shrugged.

"Okay, if that's what we need," he acquiesced. The team would be in on Monday morning to reassess.

Jack, Jeanne's father

"I knew Jeanne wasn't feeling well. Before I left for *shul* on Shabbat morning, my wife, Barbara, reminded me to ask Ralph how Jeanne was doing.

"I don't know," Ralph told me. "I just don't know."

When I returned home, Barbara told me Ralph had called. We ran right over.

After Shabbat, Barbara called me from the hospital. Jeanne had viral myocarditis, but she'd be fine.

For the first day, she was. On Sunday, I reached out to Nathan Hoffman of Lev Medical. Nathan's not only a family friend but also the go-to guy in our Sephardic community when anyone needs medical help.

Lev Medical would be Hashem's emissaries. Without them, the story likely would've ended very differently.

We gave him access to Jeanne's charts, and he began reaching out to medical professionals. I was worried, as any father would be if his daughter was hospitalized.

But when I arrived on Monday morning, I found Ralph sitting quietly, staring straight ahead. He barely spoke. And then I heard the words no father should have to hear.

My wife said, "Jeanne is very sick. She may need a heart transplant."



Ralph

We knew that Jeanne had been having some ventricular arrhythmias, irregular heartbeats that were a downstream effect of the myocarditis. While Jeanne wasn't feeling great, she was still able to get in and out of bed. We didn't know that the monitors, imaging and blood tests were telling a very different story. Jeanne's heart was floundering, struggling to pump blood through her body.

Monday morning, the team came by as promised. All eight of them filed into Jeanne's room to discuss the case. While they were treating her for viral myocarditis, and indeed, it looked like a classic case, some thought it would be wise to obtain a biopsy to rule out other issues.

The endomyocardial biopsy would be a minimally invasive procedure in which a tiny piece of Jeanne's heart muscle would be removed with a needle. Jeanne also needed a line in her neck to monitor her heart function and blood flow, and doing both procedures at the same time seemed to make sense.

We didn't know.

"They'll take a piece of my heart?" Jeanne shuddered. I agreed. At this point, wasn't that overkill?

The phalanx of doctors parted to allow Dr. Evelyn Horn in. She introduced herself and came straight to the point.



We were dumbfounded. How did we go from "she'll be home in a day or two" to "she might need a heart transplant"?



Dr. Horn, sent by Lev Medical, was the physician whose quick thinking ultimately saved Jeanne's life.

"I've been watching this case for 24 hours," she informed us. "I'll do anything for Pessy."

Pessy was Pessy Schlafrig of Lev Medical, and she'd been in touch with Dr. Horn since my father-in-law had called Nathan Hoffman.

She looked at Jeanne. She scanned the monitors and then turned to a doctor and said, "Get everyone in here."

Within moments, personnel poured into the room. "I want you all to see this," she instructed the crowd. "Because you might not see it ever again."

She pointed at the monitors, speaking rapidly to the arrayed doctors. "This might be giant cell myocarditis. You want to wait another day or two? She may not be here. If it's not giant cell myocarditis, I'll apologize to the family."

She turned to me and my mother-in-law. "You're the husband and mom? I don't mince words. She might need a heart transplant."

What? We were dumbfounded. How did we go from "she'll be home in a day or two" to "she might need a heart transplant"?

"I know according to the textbook this is pointing to viral myocarditis," she said. "But as I'm watching this, I'm noticing these arrhythmias," she pointed to the screen at Jeanne's bedside. Her heart was jumping about 40 beats every three minutes, impervious to any antiarrhythmic drugs. "That doesn't read viral, that reads giant cell."

Giant cell myocarditis is a rare, rapidly progressive form of myocarditis in which T cells launch an all-out attack on the heart muscle. It's an abnormal, aggressive immune response rather than a direct infection of the heart. Unlike viral myocarditis, which can resolve without major intervention, patients with giant cell myocarditis can deteriorate rapidly and descend into cardiogenic shock.

Patients with an ejection fraction—the percentage of blood pumped out of the heart's main pumping chamber with each beat—as low as Jeanne's need ECMO treatment, Dr. Horn explained. Her disease was progressing too quickly, and her heart was failing. In the most severe cases, when the heart muscle is so ravaged, a heart transplant is the only option.

"Even though the most likely outcome is that it's viral," she concluded, "we need to prepare in case it isn't."

Jack

Giant cell myocarditis is rare, fast moving, and lethal. And my daughter might have had it.



A Giant Cell myocarditis diagnosis so early in the game is unusual. And early diagnosis gives patients the best shot at survival.

We all kind of panicked. Nathan called me immediately.

"What do you mean, my daughter might need ECMO and a transplant? How did we get here?"

"Whatever Dr. Horn says, listen to her," Nathan advised. "She's the best we have; she's renowned for her diagnostic expertise."

Giant cell myocarditis is the ultimate zebra among the more common forms of myocarditis, with just 300 cases diagnosed each year in the US.

"Look, it's probably not it," Nathan conceded, "but we need to hedge our bets."

He explained that Dr. Horn was ordering treatment for both giant cell and viral myocarditis. If Jeanne didn't have giant cell myocarditis, no harm would be done. If she did, early treatment could save her life. We also spoke with Jennifer Jemal and Esty

Ausch of Lev Medical. In the days to come, both would prove utterly devoted to championing Jeanne's case.

Ralph and I hit the phones, making a zillion calls, and everyone seemed to agree. As Monday wore on, it did look like Jeanne was getting worse. Her labs were coming back wacky, and she was struggling to breathe. Her X-rays weren't looking pretty, either. There was fluid in her lungs, and her ejection fraction was declining.

It wasn't giant cell. It couldn't be. After the Swan-Ganz catheter was inserted and the biopsy was completed, Jeanne was wheeled into intensive care. The results would be in by morning. We held tight and prayed.

Jeanne

I was very tired. My chest ached. I was out of breath. I didn't know it at the time, but I was in heart failure.

The kids came by on Sunday, and we didn't tell them much other than that I'd be home soon. The younger ones were staying with my parents while the older ones were sleeping at home. After two days in the hospital, I thought I'd be discharged. But instead of feeling better, I was plainly getting worse.

After the biopsy, the doctors were worried. Under almost unbearable strain, my heart had swollen to the point that my upper valves were having trouble closing, causing blood to flow back into my lungs. My ejection fraction continued to decline as my heart struggled to function in its compromised state.

Slowly, the world grew fuzzy around me as my body preserved energy for its most basic functions, keeping blood and oxygen circulating through my body. I remember Dr. Maria Karas, one of the physicians on the team, coming in to see me again later that Monday. My heart needed a break to recover, she told me. I'd need ECMO.

Once they connected me to ECMO, I would need to stay still in bed, my legs immobile. The thought of remaining immobilized for an indeterminate amount of time was panic-inducing, but Dr. Karas calmed me, explaining that it was a necessary but temporary intervention to give my heart a break

For the next two days, all I did was sleep as my family and community went into overdrive around me.



All I knew about heart transplants was that they were frightening, life-altering events. I thought the end of the world had come.

Ralph

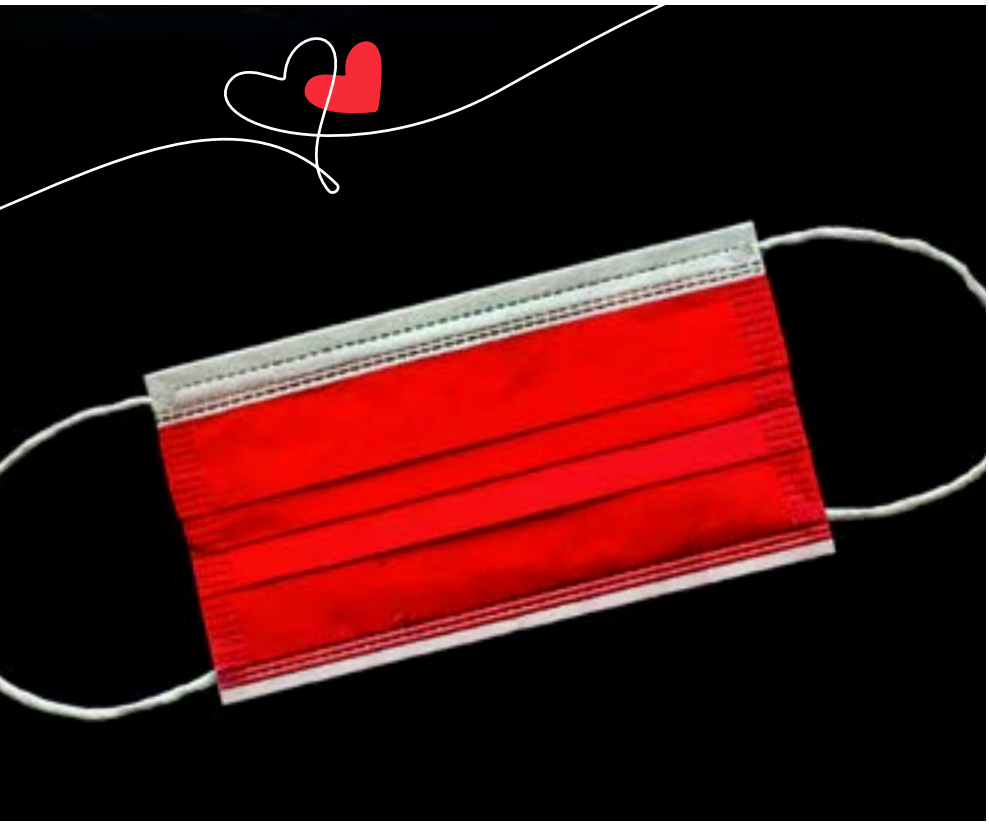
Late Monday afternoon, Jeanne was placed on ECMO. While she wasn't sedated, she was out of it, and it was hard for me to see her that way. But we still held out hope that this wasn't giant cell. Perhaps this was just a very severe case of viral myocarditis. After all, hadn't we been told that the chances of it being giant cell were slim?

But on Tuesday morning, the results came in. Under the microscope, the pathologist had detected giant cells, clumps of immune cells in the tiny tissue sample taken from Jeanne's heart. Without Dr. Horn's timely diagnosis, it's doubtful that Jeanne would have pulled through.

We needed to get Jeanne listed with UNOS, the United Network for Organ Sharing. Now that giant cell was confirmed, we knew she'd need a transplant to recover.

I'm a partner in a childrenswear company, about as far removed from medicine as you can get. Importing children's clothes has nothing in common with procuring a new heart, and all I knew about heart transplants was that they were frightening, life-altering events. I thought the end of the world had come.

The transplant team came by, and they walked me through the process. I was amazed by how far medicine has advanced, and that while Jeanne would need a lifetime of medication to protect her new heart, with the help of Hashem, she'd be able to live a full life as a mother to our children and future grandchildren, *b'ezrat Hashem*.



"She'll be playing tennis again," a doctor promised. "We've got heart transplant patients running marathons and playing pro soccer. She's fit, young and in great shape. She'll do just fine."

But before we were able to get Jeanne listed, her condition worsened. We feared she might not make it onto the list. The ECMO wasn't doing enough. Jeanne's heart was so enlarged, so swollen from the inflammation, that the backflow of blood from the upper chambers of her heart into her lungs had increased from a drip to a torrent. ECMO assists the heart in doing its job, but Jeanne's heart had been badly hit, going from an effective muscle with a steady beat to a swollen, inflamed organ contracting ineffectively, erratic and unstable.

She was slowly drowning in her own fluids.

Jack

Tuesday was a hard night. Jeanne's case was severe enough to warrant a conference call between four different hospitals. Doctors from NYU, Cornell, Columbia and Mount Sinai came together to determine the best way to save my daughter's life. It was a Cornell doctor, originally from Jerusalem, who devised a daring plan. He proposed repositioning the ECMO cannulas to redirect blood flow through the lower chambers and relieve some of the pressure on the upper portions of her heart. Perhaps Jeanne's condition would stabilize.

At 3 p.m., the doctor rushed into the room, his face tight. "Where's Ralph?"

Ralph had stepped out and would be back in five minutes, I explained.

Not five minutes later, the doctor returned. "Where's Ralph?"

Still no Ralph. "You're the father?" he asked me. I nodded.

"I don't have time to explain," he told me, his words tumbling out. "But we need your consent to save her life."

Of course, I agreed. He turned to leave, and I followed him out of the room.

"What's going on?" I asked, bewildered. "What are you doing?"

"Your daughter is very critical, and we're about to do something we've never done before," he replied. "This has to work."

I asked him what our other options were. He stopped short and looked me in the eye, and I knew there were none.

It had to work.

Several hours later, Jeanne came back into the room. The doctor explained what he'd done, and said she was already doing better.

This procedure had never been done before. But Jeanne was able to receive this lifesaving treatment. By the right doctor. In the right hospital. Another miracle.

Ralph

What were the chances that my wife would get a new heart? According to the team at Cornell, Jeanne stood a very good chance of receiving one. She was eligible to be listed as Status 1A, the highest priority level. While that was good news, it hammered home the fact that Jeanne was desperately sick, so ill that she needed mechanical circulatory support and, without a new heart, would not last much longer.

"She stands a good chance of getting a new heart within a month or

Ultimately, the insurance company agreed to cover Jeanne's transplant at Cornell. This ended up helping other patients.



less," the doctors reassured me.

A month? Thirty sunrises and sunsets, four weekends and a full 720 hours? The doctors told us that Jeanne could remain on ECMO for as long as she needed it, though they were worried. She needed a new heart soon, before an infection could set in. In her weakened state, they didn't know if her body would be able to fight it.

When we chose Cornell that Shabbat morning, it was certainly Hashem guiding our hands. What else could explain how we landed in a hospital with a top-notch transplant team? We kept being told that Dr. Yoshifumi Naka, the surgical director of the heart failure and transplant team, was the absolute best. And we didn't need to travel the country to see him. He practiced right in the very hospital we'd brought Jeanne to on the day she first felt ill.

We were seeing miracle after miracle. At some point, after I counted three, I was certain Hashem would not forsake us. He'd sent us to the right hospital, with the right doctor and the right diagnosis. After four days of everything going downhill, the tide was slowly turning in our favor. I prayed that the good news would continue.

The next step was getting approval from the insurance company to cover the transplant. There was some red tape and paperwork to get through, but with the help of Lev Medical and the team at Cornell, we were able to get approval within a day or so.

Dr. David Majure, a physician on the heart failure team, personally called the insurance company and advocated for Jeanne in a way that went far beyond the usual bounds of his role. The rest of the Cornell heart failure team advocated for her as well. Ultimately, the insurance company agreed to cover Jeanne's transplant at Cornell. This ended up helping other patients down the line, too.



Getting insurance to cover the trasplant was no minor neis!

Nathan Hoffman helped us scale the mountain of paperwork. We were interviewed to determine whether we were suitable candidates to receive such a valuable organ. Again and again, the transplant team reviewed the entire process with us, including the risks, recovery and possible complications.

Listing a patient can take weeks. But by Thursday afternoon, in no small part due to the efforts of the Cornell team, Lev Medical, and the prayers of our family and friends, Jeanne was listed.

Jack

We met Dr. Jonathan Weinsaft, the chief of Cornell's heart failure team.

"I don't know why you passed over so many hospitals on your way here," he told me. "Only Dr. Horn could catch a diagnosis so early."

Five minutes later, Dr. Weinsaft returned with another doctor in tow and introduced us.

"Meet Dr. Shmuel Chen," he said. "He saved your daughter's life."

"Oh, another one," I said playfully. Dr. Weinsaft wasn't joking. It was Dr. Chen who had figured out how to reposition Jeanne's ECMO cannula that night. His ingenuity and quick thinking had been there when Jeanne needed them most.

Seeing my daughter's heart fail broke my own. I've heard countless medical stories, and each one has touched me, but nothing prepares you for seeing your own loved one in a hospital bed, her legs strapped down to prevent her from moving, a machine keeping her alive.

One day during that interminable



week after Jeanne was listed, she turned to me.

"Daddy," she began. All of a sudden she seemed like she was five years old again. "Daddy, I want to live. Let them know I will do whatever I need to do to live. I want to see my kids grow up and get married. I want to meet my grandkids. Promise you will help make it happen?"

I promised, but I was distraught. I had made a promise I wasn't sure I could keep.

Then I dialed Nathan. "Promise me that she'll be okay," I pleaded.

Nathan told me that he and his team were doing everything they could to keep Jeanne alive. After that, he said, it was up to Hashem. We had so many people praying for us, it had to turn out okay.

I couldn't think of a more appropriate response. It gave me the strength to continue.

Jeanne

By Wednesday, I was more cognizant of my surroundings. I was pretty much immobile from the waist down. My blood flowed through the ECMO machine, which was doing the work my heart could no longer do.

It's difficult to explain, but throughout my illness, I sensed I was in Hashem's hands. In this sterile hospital, surrounded by beeping machines and covered with a thin hospital-issue sheet, I felt His Presence keenly.

Until very recently, I really had no idea how ill I actually was. I didn't know much about that terrible night when my family thought they were going to lose me. I just wanted to be home, surrounded by my husband and children and the life I loved. And if a transplant was the route that would get me there, then so be it.

In general, throughout our ordeal, both Ralph and I, along with the rest of our family, adopted a positive attitude. If this is where we were, we said, then this is where we needed to be. I consciously kept the atmosphere around my bedside light. I wanted to ease the burden my family and friends were carrying in any way I could. I marshaled every bit of strength and resilience I had to get back home healthy.

If mindset is half the battle, then the other half is certainly support. We had an army of family and friends around us all day, every day. Knowing they were praying for us, worrying about us and advocating for us meant so much.

Once I was listed, we began the wait. Though I was still on ECMO, the head of my bed was raised and I was able to eat, an unusual occurrence for which I was grateful. I wasn't in pain, and I was alert enough to be involved in my own care. My ejection fraction was improving, though without a transplant, my damaged heart did not stand a chance of functioning without mechanical assistance.

I was at the top of the list because I was so critical, but no one could skip ahead. It wasn't just a matter of waiting for a heart but waiting for the right heart for me. The wait was anxiety-provoking. Ralph picked up lots of spam calls because he couldn't afford to let an unknown number ring through!

It was Wednesday night when my phone rang. I'd been trying to get some sleep, and while my phone was on silent, it vibrated.

"This is the Cornell heart transplant team," a voice told me. "We have a heart for you. Please stop eating in preparation for surgery."

Was I hallucinating again? Some of the medications I was taking had made me hallucinate in the past. Was this happening again? And besides, they were supposed to call Ralph, not me! But what if? I told them to hold and woke up my son Eli, who was sleeping near me.

"Call Daddy!" I whisper-yelled. I don't think Eli quite understood.

"Just call Daddy!" I repeated. Ralph picked up.

Once Ralph was on the line, I asked them to please start all over again.

A one-week wait for a heart is unheard of. And yet, Hashem heard the tefillos.

Ralph

In the days leading up to that phone call, I called Nathan Hoffman probably six times a day to ask if he had any news about Jeanne's heart. Each time my phone buzzed, I jumped. And when the phone call finally did come, they called Jeanne!

I was sleeping in an apartment that Habayit had provided for us. Habayit provides apartments near hospitals, and in our case, Eli and I switched off, one of us sleeping at the hospital while the other slept in the apartment. I pretty much didn't go home from the day Jeanne was admitted.

After the call, none of us were able to fall back asleep. There were tears, celebration and, yes, lots of fear. We had a group chat with all the Lev Medical caseworkers assisting us, and I posted the news that we'd received the phone call we'd been waiting for. I assumed the first reaction would come around 7 a.m. After all, it was well past midnight.

Within minutes, team members responded, their joy warming us. One replied that she'd just had a dream where our entire family was having a meal together, saying that Jeanne had gotten a heart. Immediately after the dream faded away, she awoke to my message. These caseworkers were even dreaming about our salvation!

Jeanne asked her parents to keep the news under wraps until our kids came home from school so we would have a chance to tell them. It was a long day for all of us.

It took forever to complete all the testing. They had to recertify Jeanne's condition. Jen and Nathan sat with us



They pointed to my youth and fitness, but I knew it was the prayers and advocacy of my community that had carried me aloft.

for a full hour, reviewing once again what we could expect. We were all nervous wrecks, but deep down, we knew it would be okay. They wheeled Jeanne into the OR at 6 p.m.

Throughout the interminable wait, I kept telling myself that we'd seen Hashem's hand, and He would see it through. Eight hours later, the surgeon came out, tired and happy. It had gone very well, and the heart had been a good fit.

I'd never seen so many bags hanging from IV poles at once, most of the machines merrily beeping along. The first few days after the transplant were difficult, with both the host and the new organ straining to find equilibrium. The nurses were exceptional during this difficult period.

Jeanne

"Don't worry, I'm a rule follower," I joked to a nurse. I was determined to get better and get back home. Still in the ICU, I began walking with a physical therapist. A few days after the transplant, I was downgraded to the step-down unit.

The doctors were very happy with my progress. They pointed to my youth and fitness as points very much in my favor, but I knew it was the prayers and advocacy of my community that had carried me aloft.

I left the hospital exactly a month after I was admitted. Breathing fresh air and going home was surreal, but acclimating was difficult. The stairs were challenging. Moving around the house gradually became easier. Little by little, I got stronger. Each activity I was able to do was a meaningful step toward normal life. Showering on my own, cooking a simple meal and managing my household were each reasons to celebrate.

Both Ralph and I view our family through very different eyes these days. It's special to see how each of our children would do anything for us and how much they love us. As parents, we know we would move mountains for our children. It's what we do. But when the roles are reversed and we need them, it's wonderful to see that they are there, moving mountains for us. It's just very special, and I'm very proud of each one of them.

I'm enjoying the fact that I was forced to slow down. It makes family life more mindful, more meaningful. I'm the luckiest person in the world.

Ralph

Jeanne's story connected us so deeply with our wonderful community. Of course, I always considered us blessed to be part of our Sephardic community and the Jewish nation. But seeing their devotion up close made it very personal.

Family and friends stepped in, showing up in every way. I'll never forget when rabbis and fellow congregants filled the waiting room near Jeanne's room, simply to come together to recite *Tehillim*.

Jen texted multiple times each day, not just to ask how Jeanne was doing but how we were doing. Five minutes after a doctor left the room, we'd get a call breaking down the medical jargon in plain English. I couldn't be prouder to be part of the great brotherhood that is *klal Yisrael*, and to know these messengers from Hashem who helped save my wife's life.

In the end, Jeanne received more than a new heart. Along the way, she had been carried by an extraordinary chain of people who had devoted their own hearts to saving hers. ●

MEDICAL EXCHANGE

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