

With two new lungs, Schafer savors renewed life

Written by Darci Tomky



“I now have renewed hope. Renewed life.”

Randy Schafer celebrated a new birthday when he received a double lung transplant—a second chance at life. He and his wife Joy describe it as a tremendous gift, a gift only because of the goodness of God. It is a journey that has only just begun.

The Schafers’ wild roller coaster adventure started last April when Randy’s doctor recommended he get evaluated for a lung transplant.

Randy had immotile cilia syndrome—a condition in which cilia, the hairlike processes of epithelial cells in the lungs, fail to function normally. As a result, Randy had difficulty filtering dust and other airborne debris from his respiratory system. He also faced bronchiectasis, which Randy said essentially meant there was irreparable lung damage.

Breathing at only 40 percent lung capacity for many years, Randy said the function had gone down quite a bit in the last two years, causing him to breathe with only 25 percent lung capacity.

“You can do the transplant and have good quality of life, or not do it and continue to deteriorate,” the doctor told Randy.

The Schafers scheduled an evaluation for June. “Our lives would go one way or another,” said

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Joy. "It would be a turning point."

Doctors conducted a three-day evaluation at the University of Colorado Hospital in Denver. To be eligible for a transplant, Randy could not have any other outstanding health issues.

Also at the evaluation, they asked Randy if he would have a caregiver that could help him through the transplant. He said yes. A skeptical Joy asked Randy in the car on the way home, "So who is your caregiver?" Randy simply answered, "YOU!"

The entire process would be a team effort. "You couldn't do it on your own," said Randy.

Evaluators approved Randy as a suitable candidate for a double lung transplant, now he just needed to find a new set of lungs.

***"It's overwhelming that someone gave up life and I have a better life because of it."
—Randy Schafer***

Randy and Joy decided to hold off going on the waiting list until their daughter Naomi was done with school in Roswell, N.M.

Two months later, Randy went on the list in August. Those waiting for transplants are evaluated

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based on need, and Randy went straight to the top of the list.

He explained he could have opted to go on more than one list around the country, but he chose to just try the regional list that included Colorado. If the Schafers got the call that a donor had been found, they needed to get to Denver within four hours. It simply would not have been possible to get to a hospital halfway across the country, even if they had found a donor that matched there.

Some even suggested to move to California for a while since they generally have more donors in that part of the country, but the Schafers chose to stay put in Holyoke.

Joy started sleeping with the cell phone by the bed, which was stressful for the first couple weeks. Finally they told themselves the house phone would be sufficient to wake them up in the night, so they started sleeping much better.

Strong in their faith, prayer played a huge role in the whole process. Not only were they praying for Randy and his health, the Schafers also began praying for the donor.

“It’s giving a life,” said Joy. “It feels predatory—waiting for someone to die.”

The primary focus for a lung transplant match is blood type and size of the lungs. Something like an auto accident probably would have injured the lungs, so the donor most likely would have a head wound because both lungs needed to be in good condition.

“It’s overwhelming that someone gave up life and I have a better life because of it,” said Randy.

During the waiting period, Joy spoke with Damon and Pam Struckmeyer who lost their son Westyn. Joy learned about how they donated Westyn’s organs, and it was important to her to see how supportive the Struckmeyers were from the donor’s point of view.

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Randy also began corresponding with four men who had received lung transplants. They began emailing back and forth about their different experiences so Randy could know better what to expect.

After two months on the waiting list, Randy and Joy began making more preparations for the transplant. They looked for a place to stay in Denver and found the Lung Connection TLC, which has condos for people who have had lung transplants.

Randy, who works as an administrator with the Phillips County Commissioners, was hoping work on the Event Center would be far enough along before the transplant. Joy, who was working at the Phillips County Extension office, was praying to get through October to finish up 4-H events for the year.

It seemed as though things were falling into place.

Monday, Nov. 2, 2009 was a day that would change their lives. Randy answered the phone at 3:23 a.m.

Joy said it was out of the ordinary because Randy didn't usually answer the phone at night. She could hear him telling the person on the phone that he felt fine.

Randy said they wanted to make sure he was feeling okay, and they told him they thought they found a match for his lung transplant.

The two packed up and began the long drive to Denver. They said it was right after the long time change weekend, so they were both finally caught up on sleep. With a moon that was one day shy of being a full moon, they drove with a bright light leading the way. They said it was like God put it out there as a light to guide them.

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“I felt like this was God’s plan the whole way,” said Randy. “Each step was being put in place as necessary.”

“People all over the world were praying.” —Joy Schafer

Arriving at the University of Colorado Hospital in Denver, Joy said around 8 a.m. the doctors said they were going to “harvest the organs.”

Not knowing if the lungs would be a match, they still began preparing Randy for surgery. The Schafers had heard numerous stories of “false calls” where a patient is notified there is a donor, they prepare for the transplant, but then the donor doesn’t end up being a match. Even with that fear in the back of their minds, Randy said with confidence, “We felt like God didn’t plan a false call.”

With a final determination that the lungs were ready to use, Randy was ready for surgery at 3:15 p.m. Seeing the surgeon only once right before the procedure, Randy would have a new set of lungs after 10 1/2 hours of surgery.

Some complications made the surgery last longer than expected. They anticipated one lung would be able to carry the body while the other lung was being put in. This didn’t happen so they used a heart bypass machine which takes over for the heart and lungs during surgery. Randy also had to have 9.5 units of blood before the transplant was complete.

Meanwhile, Joy sat in the waiting room. In the months leading up to the transplant, Joy had horrible visions, picturing herself all alone in the waiting room. How much support did she and Randy really have?

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Luckily Joy was wrong. Randy's brother Hal was there with her the whole time. She also had her son Joshua, two friends and Pastor Gordon Penfold who came to sit with her.

Joy said she had a sense during surgery that they were being carried. On the way to Denver they called family and friends. Several people also sent out mass emails about the exciting news. "People all over the world were praying," said Joy.

While in the waiting room, Joy noticed another family was there too. After talking with them, she found out a woman from Fleming was getting a heart transplant. Could it be that the 26-year-old man that gave up his life for Randy to have lungs also gave this lady a new heart? Joy just knew it had to be the same donor.

With surgery lasting until 1:45 a.m., the tired surgeon came to see Joy. She said he just shook his head and said, "He's not out of the woods yet." Joy finally got to see him in ICU at 3:30 a.m.—24 hours after they got the phone call.

The transplant was successful, but Randy's blood was very thin. In terrible condition, he spent the next three days getting his blood thicker.

Joy was staying with her friend Susan in Denver. She said it was good to be able to go there and simply "unload" all the emotions of the day.

Randy was in the hospital for 11 days. They said it was like a promotion when he was released from ICU, but the downside was there was no nurse at his side all the time. He was actually on the transplant floor of the hospital, and his new "sister," the woman who received a heart transplant, was just down the hall.

When a patient gets a transplant, the new organ is sealed off, so to speak, from the outside world. Lungs are the exception because the body still breathes in the air around it, and the lungs are more susceptible to outside influences. Because of this, Randy had to be very careful.

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He did not have to wear a mask when he was in his room, but any visitors did. When he stepped out of his room, he had to wear a mask, but Joy could take hers off.

Joy took a very active role as Randy's caregiver. She wrote down everything so she could keep up with what was happening to Randy. She regrets that she didn't have the doctors take a photo of one of his old lungs (which he donated to research) and one of his new lungs side by side, so later on she asked if she could take some pictures. The doctor said he would just take some pictures for her. They now have four color pictures of inside Randy's body—one of his voice box and three of his lungs.

The Schafers said they were overwhelmed by people's continued support. One of the hospital staff told Randy, "You must be the most popular man in the hospital," due to the massive pile of cards and letters. Beyond that, the Schafers were still being supported in prayer and then also supported financially. "It's beyond the realm of what we can take in," said Joy.

Texting was one thing Joy learned how to do in the hospital so she could keep everyone at home updated.

While Joshua was close by, just 10 minutes away from the hospital at Buckley Air Force Base, Naomi was holding down the fort in Holyoke. "She was our go-to person," said Randy, as Naomi could do things like get the mail. The community was very supportive of Naomi too—she could really lean on them during the tough times. Thanksgiving was the first time Naomi got to see her dad with new lungs.

Randy was certainly on his way to recovery. When he walked for the first time, his oxygen level was at 94 percent—compared to just 25 percent before the transplant! He was excited because he was actually ahead of Joy who was at 93 percent.

The Schafers eventually moved into their condo at the Lung Connection where they stayed for several weeks.

While staying at the Lung Connection, the Schafers got connected with a small church in

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Denver called Peace Mennonite. They also pointed out that while staying in Denver they had a lot more time together as a couple than they expected. They learned to encourage each other and find humor in all kinds of situations.

Randy did have a setback when he had to return to the hospital for five days. They asked him if he was having trouble breathing, but he wasn't sure if he was or not, because his lung capacity now was so much better than it was before the transplant.

Randy said it may take months or even a year for him to get to 100 percent health. He doesn't really know what that will look like.

"The theme here is God's grace." —Joy Schafer

Doctors told Randy that in exchange for a lung transplant he will continually face several risks. Randy must take immunosuppressant drugs for the rest of his life, causing his body to lose some ability to respond to things like colds and the flu. However, the drugs are used to prevent the body from rejecting the transplanted lungs.

Randy explained they expect transplant patients will go through periods of rejection. He already went through one and will probably face others in the future. "There's always that fear to deal with," said Joy.

Since returning home, Randy has had to give himself IVs on a daily basis. Even though it was a traumatic experience the first time they tried it by themselves, the Schafers seem to have the hang of it now.

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Joy said the technology is very fascinating, allowing them to do things like that at their home. The IV is a sort of pump ball that deflates during the process.

Randy has been going to Denver once a week and will now be promoted to going every other week to have blood tests and make sure his drugs are all balanced.

He is on a three-year drug trial for cyclosporine—an inhaled version of a drug he needs to take anyway. By inhaling the drug, it can go straight to his lungs and bypass other organs in his body.

Even though they gave him a 25-inch scar across his chest, Randy owes everything to the surgical/transplant team at the University of Colorado Hospital. He commended their wonderful expertise and quality of service. Those involved included Marty Zamora who is the head of lung transplants, Dr. Denny Liu and Dr. Crossno who called Randy in the middle of the night. Of course Randy can always call his lung transplant coordinator, Heidi, if he has any issues now.

In addition to the hospital staff, Randy and Joy depended on the support of the communities in Phillips County. They appreciate the support of the commissioners as well as Dana Warren and Stacey Geilert who work with Randy. Crowders, the Schafers' neighbors, helped out with chores at home, and numerous other people contributed in every way imaginable.

As if they didn't have enough to deal with the past two months, Randy's mother passed away on Christmas. With his new lungs and new strength, Randy was able to sing at her funeral. "It was a lovely use of those lungs," said Joy.

With new lungs Randy has been given new life. It has opened up a lot of things he didn't have the energy for before. Among other activities, Randy is simply excited to be back at work. The couple laughed, thinking about how they have been more social in the last 1 1/2 months than they have been in the last two years. Randy said he will probably still wear a mask in big crowds, around children and in hospitals, but he has been blessed with a new freedom.

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Randy hopes to keep in touch with his “heart sister,” and he plans to stay connected with other lung transplant recipients.

“How far are you out?” Randy and Joy explained that’s what to say to someone with a transplant. Nov. 2, 2009 is almost like a new birthday for Randy. He looks forward to when he can say, “I’m six months out...one year out...seven years out.”

To Randy and Joy, the theme running through all of this is simply God’s grace. Through God’s grace Randy has been given a gift. A gift of renewed hope and renewed life.