

# Reflections of a Living Liver Donor

*Jen Mullman's liver was failing from autoimmune hepatitis and she needed a transplant. Her mother, Susanne, stepped in.*





In July 2009, I was a liver donor to my 21 year old daughter, Jen, whose liver failed due to autoimmune hepatitis. I first wrote about the experience in December 2009. Though I accurately captured the emotion and the gratitude I felt at the time, I glossed over many aspects of the journey. Our lives had not yet gotten back to normal, and although Jen would return to school in a few weeks, part of me was still holding my breath, overwhelmed by all we had been through and a little fearful of the future. Now, with the passage of time and watching Jen resume her life in continued good health, it is easier to write the story.

Our story begins in January 2008 with a phone call from her roommate letting us know that they were bringing her to an ER because she was vomiting blood. I remember telling myself, as I drove down to her college in Maryland, that she couldn't be that sick because she had just been home the week before. Finding her in the intensive care unit hooked up to IV's dispelled that illusion. Within the hour, one of the doctors informed me that they were readying her for transport to another hospital because they believed she would need a liver transplant. I thought I had misheard him. As he repeated it and the word 'transplant' reverberated through my head, all I could imagine was the nightmare of watching Jen getting progressively sicker as she waited for a donor organ. Given that Jen had two younger brothers back in NJ, and knowing that this would be a long journey, I suggested we need to find a hospital in NY. After some research and help from friends, we were flown to NewYork-Presbyterian Hospital/Columbia.

Dr. Brown began evaluating her to determine what had caused my daughter's liver to fail. Midway through the testing he mentioned to me that if she did need a transplant, she would be a good candidate for living donation. That was the first time I had ever heard those words, and as he described the procedure I felt as if someone had thrown me a lifeline. Here was a way to help Jen out of this nightmare. After two days of testing, he determined that a small portion of her liver was still working and, with medication, she could resume her life for a time. She went back to college that summer and continued until spring break - March 2009 - when, during a scheduled visit, Dr. Brown told us she now needed the transplant.

As hard as it was to hear those words again, we were prepared. Jen was listed for transplantation with UNOS and allowed to return to college to finish her semester. The next day we contacted the living donor office at NYPH/Columbia. Her father opted to be evaluated first, but the tests determined that he would not be a good candidate due to underlying health conditions. I am sure it was as hard for the doctors to say as it was for him to hear, but seeing that their paramount concern was for the safety of the donors was very reassuring. The next day I started the

evaluation, which involves several days of tests and meetings with various team members. I was relieved when they called to say I could donate! Jen could now have the transplant at an optimal time for her! (Because of the nature of her disease, Jen's MELD score would have remained low, resulting in a very long wait for a donor organ had she remained on the UNOS waitlist.)



*Dr. Robert S. Brown, Jr.*

In my opinion, living donation is easier on the family than waiting for a donor organ. I know that sounds counterintuitive, but it is true. You have time to make a plan, which gives you some control. You set a date that is optimal for the patient and all family members.

You have time to organize two care teams for the recipient and the donor. When I remember the chaos that ensued during Jen's first hospitalization, and the smooth organized weeks we had after the transplant surgery, the value of having time to prepare can not be overstated. Knowing that family and friends were caring for Jen and her siblings made it easier for me to focus on healing after the surgery.

All the preparation and planning got my mind focused and my spirit strong, at least until the week before surgery. Some personal issues and an awareness of my own weakness when it comes to needles and blood (I faint!) made me start to doubt myself. I was not afraid of the surgery because I trusted my surgeon, Dr. Samstein. But I was afraid that I would have a panic attack and I wouldn't be able to donate, and that I would let Jen down and myself. Jen and I went in together for our pre-operative appointments. Dr. Samstein explained the surgery - a partially laparoscopic procedure involving removal of my left lobe (about 40% of my liver). I remember sitting there numbly trying to control my rising anxiety. We discussed my issues with needles and agreed that we would decide the morning of surgery whether to have an epidural. Then Dr. Samstein looked at me in a very calm and kind manner and assured me that he takes special care of the living donors. I don't know what it was exactly, but this sense of calm enveloped me and I felt safe! On the way home I told Jen that I had been afraid, but now I believed everything was going to be fine. And it was!

The morning of the surgery was surreal. Walking into the OR is a strange experience. I opted not to have the epidural, but I did go under anesthesia before having any IV's inserted. I remember waking up, seeing my family and having them tell me that Jen was ok and then falling back to sleep. The following morning, much to my surprise, there was Jen, IV pole in tow, walking into my

room looking strong and full of energy. It is one of my favorite memories! The next four days in the hospital passed quickly. I was never really in pain because it was well managed. There was discomfort at the site of the scar, but most of my time was spent sleeping. I was glad to get home and shower and sleep in my own bed. I continued on painkillers for about a week and then would take Tylenol just at night for another few days. I started walking around the block. Friends would drop off food and we would venture a little further each day. I remained tired. There is deep fatigue as your body works to regrow the liver, but within five weeks it had dissipated and I resumed my normal activities. I do not work outside of the home but keep busy with my children's activities and volunteering.

Jen was in the hospital for two weeks with a small infection. She had some difficulty initially adjusting to the medications but has since done well. She returned to college and graduated in January 2011. She is working now and plans to return to school in September for her Masters. Often when we run into someone in town who has heard the story, they are surprised to see how well Jen looks.

What have I learned from this experience? I have learned that I have a strong daughter who faced this adversity with courage and grace. Though I know that this is still the beginning and there will be bumps in the road, she will be okay. The CLDT team will always be there to take care of her.

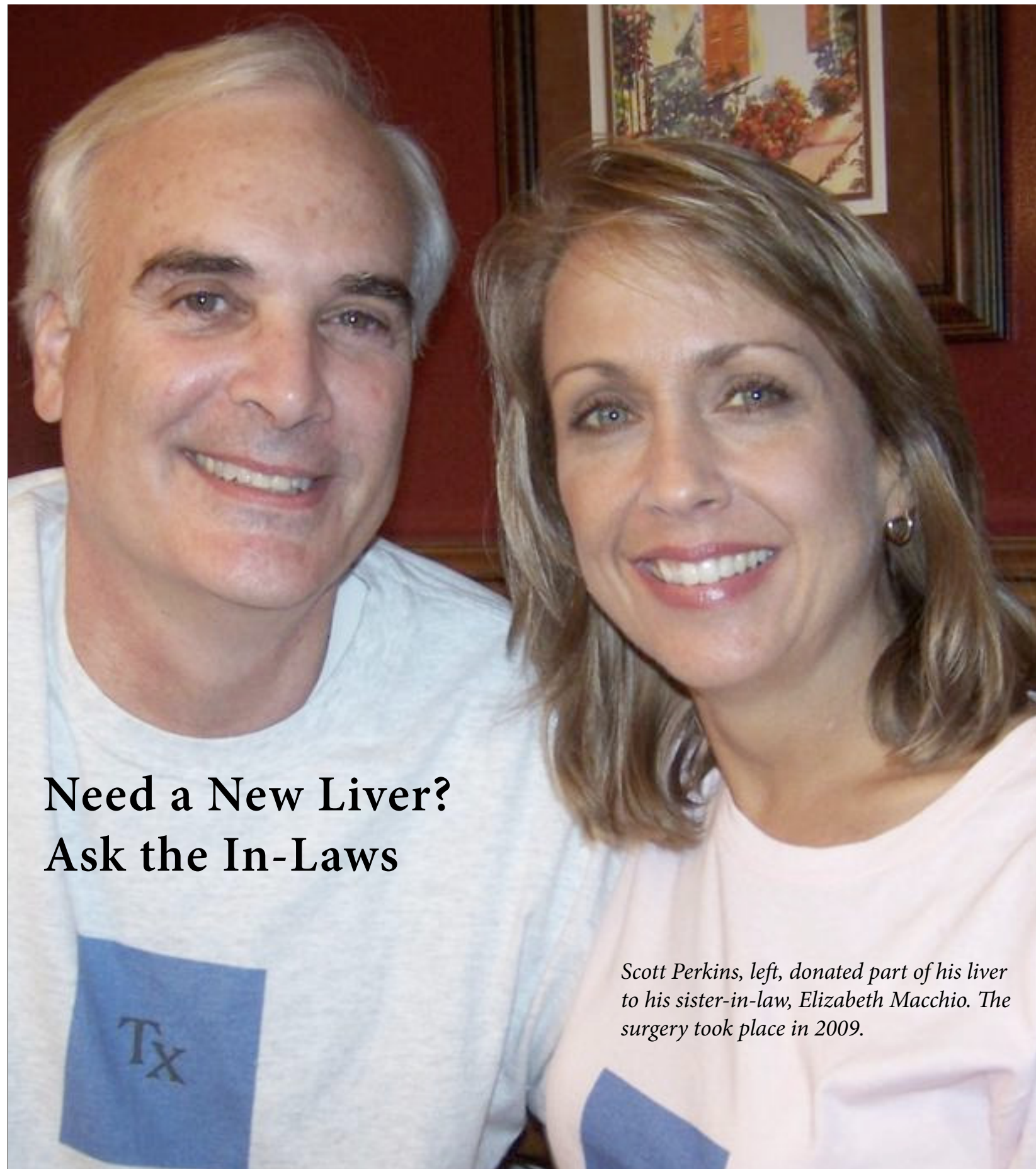
I discovered my own courage and strength and it has served me well as I travel through this life. I have a renewed appreciation for my own health, and I exercise and eat healthier than I did prior to surgery. I am thankful that I was given the chance to help my daughter. I think we all believe that if a loved one was sick, we would do anything to help them. Living donors get the chance to do just that. We are the lucky ones! That sentiment, and the fact that we would all do it again in a heartbeat, is echoed by all the living donors I have met.

Lastly, I recognize how truly difficult it is to express the gratitude that we feel to all who helped us during this journey. To the family and friends who lovingly surrounded us with their support. To the doctors and nurses who cared for Jen. To the living donor team who safely guided me through this process, especially Dr. Samstein. I know how lucky I was to be on the receiving end of his extraordinary dedication, skill and compassion.

So in an effort to give back and, in some small way, help another family facing this situation, I became a living donor mentor and volunteer on the transplant floor of the hospital. By helping others I hope to honor those who helped us. This can be

a long and arduous journey, but with the exceptional care provided by the Center for Liver Disease and Transplantation, support of family and friends, and guidance from those who have gone before, the path is made easier. 🌸

- Susanne Mullman



## **Need a New Liver? Ask the In-Laws**

*Scott Perkins, left, donated part of his liver to his sister-in-law, Elizabeth Macchio. The surgery took place in 2009.*



Back in 2000, Elizabeth Macchio, an occupational therapist in her thirties, noticed herself feeling increasingly tired. Her local doctor found elevated levels of enzymatic activity in her liver, but even so, her condition eluded diagnosis for several more years. Finally, in 2004, a diagnosis was made: she had a rare autoimmune liver disease called primary sclerosing cholangitis (PSC). The functioning of her bile ducts was gradually worsening - without a new liver, she would eventually die.

Although she was placed on the waitlist for a deceased donor transplant, Elizabeth could not receive one because she was not sick enough to be at the top of the list. Yet although she wasn't quite sick enough to be a top-priority transplant patient, her doctors feared that when she did become that sick, there might not be enough time, at that point, to save her. They suggested that she try to find a living donor, someone willing to donate a substantial portion of his or her own liver to help Elizabeth survive. That man turned out to be Scott Perkins.

Scott Perkins is the Assistant Vice President of policy advertising at AT&T. He's also Elizabeth Macchio's brother-in-law, and has known her since she was 12 years old. Nobody ever specifically asked him to donate his liver, he says - it just seemed like the right thing to do. "She's such a good, basic, real person," he said. "It's not fair that she would get this disease."

Elizabeth's husband, Sal, had undergone testing to see if he could donate, but he had medical issues that would have delayed the process greatly. Elizabeth's sister's blood type was not compatible with her own, rendering a transplant between the two of them impossible. Scott, on the other hand, had the right blood type, and was more than sufficiently healthy. He decided firmly that he would donate the left lobe of his liver to help save his sister-in-law's life.

That he could do so is only possible because of a remarkable characteristic unique (in humans) to the liver: it is a regenerative organ; that is, a full-sized liver can grow back from a smaller piece. In living donor liver transplantation, or LDLT, the recipient's own diseased liver is removed. A portion of the donor's liver - in this case, the left lobe - is then transplanted from the donor to the recipient. Over time, that lobe will expand into a full-sized, fully functional liver. Similarly, the donor's remaining liver will gradually regenerate itself so that, before long, his or her original liver functionality is entirely restored.

After extensive testing to ensure that Scott met the rigorous requirements for organ donation, the operation was arranged. On July 21, 2009, Benjamin Samstein, MD, Surgical Director of the Living Donor Liver Transplant program at NewYork-Presbyterian/Columbia University Medical Center, and his team operated on Scott in order to remove a portion of his liver. Down the hall, James Guarrera, MD, FACS, Surgical Director of Adult Liver Transplantation, and his team removed Elizabeth Macchio's diseased liver, and then implanted Scott's left lobe where Elizabeth's own liver had been. Everything went smoothly; the operation was a tremendous success.



*Dr. James V. Guarrera*

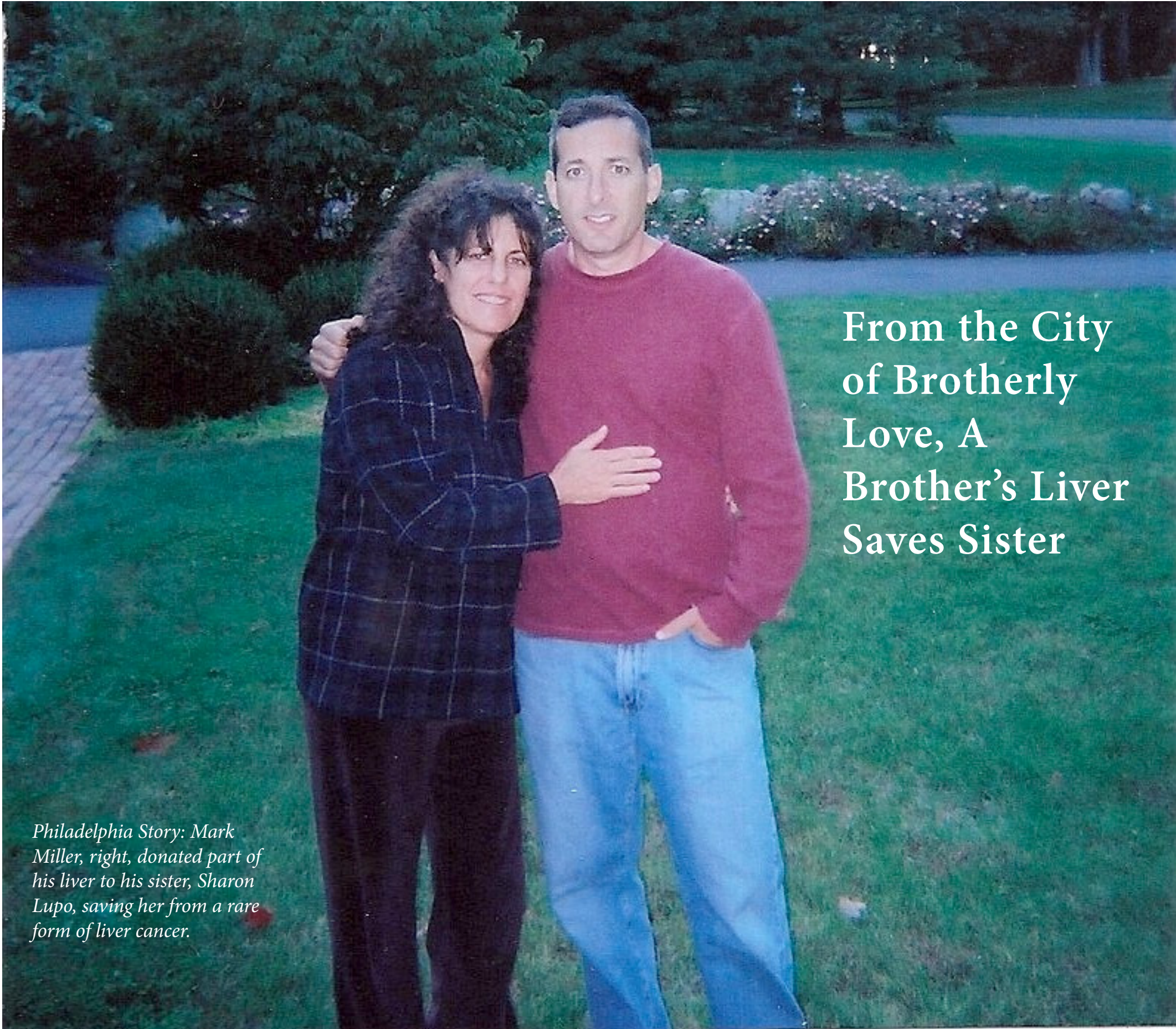
Scott's recovery, he says, was relatively swift. In a matter of days, he was home and walking again; within a month, he was back to work. Elizabeth's recovery was not quite as smooth due to some complications. Eventually, though, she made a full recovery. "She's got way too much energy now," Scott jokes; indeed, she feels better now than she has in the last six years.

To this day, Scott considers his decision to donate one of the best decisions he's ever made. To potential future donors, he has the following to say: "You have to commit. It can't be a rational decision; it's got to come from someplace inside you that you don't even know you have. Once you do, you'll never regret that decision. It's not for everybody. But the reward of knowing what you've done... well, it's not an external reward; it's very much an internal peace with yourself." ❁



*Dr. Benjamin Samstein*





## From the City of Brotherly Love, A Brother's Liver Saves Sister

*Philadelphia Story: Mark  
Miller, right, donated part of  
his liver to his sister, Sharon  
Lupo, saving her from a rare  
form of liver cancer.*



When 46-year-old Sharon Lupo started having stomach pains before Christmas, she brushed it off as a case of too much pre-holiday indulgence. But the pain persisted even after the holidays ended, landing her in the local emergency room. Many tests, scans, and biopsies later, she was shocked to learn the source of her pain: malignant epithelioid hemangioendothelioma, an extremely rare type of liver cancer. This type of cancer affects the lining of the blood vessels within the liver and strikes only 200 to 300 Americans each year.

Referred by her local doctor to Robert Brown, MD at the Center for Liver Disease and Transplantation, Sharon was sick and in great pain. Yet because of the nature of her rare cancer, her entire liver was not affected, and therefore her MELD score – the criteria by which priority for liver transplantation is determined – was low. That meant she was unlikely to receive an organ from the national organ waitlist any time soon. Yet ironically, waiting meant that the cancer could spread beyond the liver, which would disqualify her from eligibility for transplantation.

Sharon accepted Dr. Brown's suggestion of allowing a transplant from the 'extended criteria' list of donor organs. This includes organs that might not meet the usual criteria for transplantation, but are healthy enough for a successful transplant. She knew that living donor transplantation was a potential option, but she did not ask anyone in her family to consider it. She remained on the extended criteria waitlist, all the while undergoing frequent scans and injections of chemotherapy into her liver to try to keep the cancer at bay. She also underwent lung surgery to remove a small lung cancer during this time, a completely unrelated tumor detected during one of her many PET scans.

After the third of the chemotherapy injections (chemoembolisms), her liver suddenly began to fail. "I was in excruciating pain, I couldn't eat, I was losing weight," says Sharon. "Dr. Brown said we need to do the transplant now." Sharon's mother-in-law offered to be a donor, but her age exceeded the accepted limit.

Sharon's brother, Mark Miller, called after learning of her situation. Having been out of touch with him for some time, Sharon was "utterly floored" that he wanted to donate part of his liver. Mark drove from the Philadelphia area to NYPH/ Columbia, where he was evaluated as a potential donor. Thorough testing was done to see if their blood types were compatible (they were) and to ensure he was healthy enough to tolerate the operation (he was). Mark mobilized his family so that his children would be cared for while he and his wife were in New York.

According to Mark, "Dr. Samstein explained the risks of the surgery, and they gave me every opportunity to reconsider my decision to donate." But his resolve stayed

firm, and the surgeries proceeded in October. There were no complications; the operations went beautifully. The smaller left lobe of Mark's liver was removed and transplanted into Sharon's abdomen, where it would regenerate to the correct size and functionality, as would his remaining liver.

"The first few days after the operation were the most difficult of the recovery," Mark says, because tasks that we take for granted like walking, eating, and breathing were very daunting. In only six days, however, he was well enough to leave the hospital; only a month later, he was back to work.

Mark attributes the speed of his recovery, and his overall success in getting through such a challenging ordeal, to the fact that he went into the operating room fully at peace with his decision to donate.

To future donors, he advises preparing oneself both physically and psychologically for the surgery. Being mentally comfortable with the decision, he says, will make the surgery easier to undergo, and the recovery much smoother.

Mark's health is completely back to normal; in fact, he's in better shape than he was before the surgery. He would be doing triathlons if only he were a better swimmer, he jokes, and he's still waiting for Dr. Samstein to take him up on his racquetball challenge.

Sharon's recovery took longer, but today she is cancer-free, back at work, enjoying her family, and very grateful to be alive. "This taught me to live in the moment and enjoy every day," Sharon says. There were bumps in the road, including an incisional hernia, which is very common, as well as two brief episodes of organ rejection that occurred when her doctors tried to wean her off the medications she takes to prevent organ rejection, but overall she feels well. She says she does not understand God's plan in all of this, but she firmly believes that it "happened for a purpose" and that she is still here for a reason.

"I am completely grateful to Mark for saving my life," she continues. "It takes a really special, selfless person to do what he did. I just celebrated my 20-year wedding anniversary, my 50th birthday (last year), and I was able to see my daughter graduate from high school. None of that would have been possible without this transplant." Although the experience was difficult and frightening at many points, Sharon says the doctors, nurses and staff at the center were "incredible... They made something bad into something good," she says. ❀



One Family's Happy  
Ending is a Happy  
Beginning





When parents Lindsay and Alexander learned their second child, Cooper, might need an organ donor, they decided immediately who it would be. Lindsay explains, “We knew that I could be more of a multitasker after the transplant, when the family would need me to do a lot of caretaking. Plus, Alexander was gung ho. He is a fixer, and he wanted to fix Cooper.”

Cooper suffered from biliary atresia, a condition in which bile flow from the liver to the gallbladder is blocked. This can lead to liver damage and cirrhosis of the liver, which is deadly if not treated. Diagnosed at six weeks, he was relatively stable and healthy for seven months. Then last November, his condition deteriorated, and it was time for a transplant. So Alexander, age 32, donated a portion of his liver to his eight-and-a-half-month old son in December 2011.

Cooper was in NewYork-Presbyterian/Columbia’s Morgan Stanley Children’s Hospital for eight days and arrived home just in time for Christmas. Alexander, whose surgery was laparoscopic, went home three days later. Within three weeks, he was back at work as an insurance agent, and at six weeks he was playing basketball again.

Cooper weighed 15 pounds at the time of the transplant, and now weighs a robust 20 pounds. His mother, a social studies teacher, said, “He’s ravenous and eats all the time. He’s a textbook case. You would never know he had been sick.”

Cooper celebrated his first birthday in March 2012 and is talking, pointing, and almost walking. He can look forward to a healthy, normal childhood thanks to the work and passion of the living donor transplant team at NYP.

“We can’t say enough about Cooper’s doctors Jean Emond, Benjamin Samstein, Steven Lobritto, Nadia Ovchinsky, Mercedes Martinez, and Sylvia Halfiger,” Lindsay said. “We are in their debt for saving our son’s life.”



During the months leading up to the surgery, Lindsay said she and her husband were very frightened about their son.

“If I had known how hopeful I would feel the day he received his transplant,” she continued,

“I wouldn’t have had to spend all those months feeling so scared. It was like a fresh start, he was a brand new baby. It was truly like it was his real birth day.” ❀



*Father and son: Alexander and Cooper share a moment in the hospital.*



# Journey to Health: Aidan Ward Thriving After Father Donates Liver

People are often surprised when they first learn that a living person may donate his or her liver - “don’t you need your liver?” is a common question.

In fact, living donor liver transplantation, or LDLT, is not only possible, but is the optimal choice for patients who need a liver transplant.

The advantages of LDLT are dramatic, as the family of Aidan Ward recently learned. The teenage boy from New Jersey, his liver failing due to primary sclerosing cholangitis, was placed on the organ waitlist in January 2010. But for someone in need of a new liver, he was relatively healthy, which meant that he was far down on the list and was unlikely to receive a liver from a deceased donor for several years. Alternatively, a living donor transplant would allow their son to receive a liver much sooner. With a living donor operation, Aidan would be in much better health during the transplant, enabling him to better withstand the surgery and recover more quickly. Second, his long-term outcomes, including his liver function and overall survival, would be significantly better with a living donor than with a deceased donor organ.

For the Ward family, the choice was clear: according to Aidan’s father, Michael, “If Aidan had to wait several years to receive a deceased donor liver, his health would continue to deteriorate. Getting a new liver sooner would likely enable Aidan to catch up with his peers and return to a normal life much faster.” The thought of Aidan going through high school with persistent health issues ‘sealed the deal,’ his father recalls, and Michael began the thorough process of medical and psychological evaluation to determine whether he was a suitable living donor. He was deemed eligible to donate in early April, and the operation was promptly scheduled for April 13 - less than four months after Aidan was initially placed on the transplant list.

LDLT is made possible by the unique capability of the human liver to regenerate. It is the only internal organ in the human body with this capability. This allows a living person to donate part of his or her liver according to the following procedure: first, the recipient’s diseased liver is partially or entirely removed; at roughly the same time, a portion of the donor’s liver is removed (up to 60% for an adult transplant, and up to 20-25% for transplant to a child); and that portion is implanted in the recipient where the original liver had been. Over time, that small portion will grow into a full-sized, fully functional liver. Similarly, the donor’s

remaining liver will regenerate over the following weeks, eventually regaining full functionality. In short, two livers are generated from one.

On the day of surgery, Benjamin Samstein, MD, Jean Emond, MD, and their team removed about 25-30% of Michael’s liver - a little less than usual, partly because Michael’s liver was especially large and partly because of Aidan’s youth and size. The surgeons were able to do the procedure laparoscopically, which reduced the likelihood of complications, greatly reduced scarring, and prompted a smoother recovery. Meanwhile, Tomoaki Kato, MD and his team placed the liver segment in Aidan’s abdomen in a nearby room. In a matter of about eight hours, it was all over, both operations completed successfully.

Only four days after the operation, Michael was feeling well enough to go home. An avid cyclist, he was soon back to riding his usual distances. The after-effects of the surgery were relatively minimal, he says, including a few weeks for normal GI function and sleep patterns to return, and a month to recover from a torn nerve in his shoulder (it was unclear whether this occurred from arm placement during surgery or stress on the shoulder during recovery). Mike’s liver maintained acceptable function throughout the post-transplant period and by three months had grown to its original size.

Aidan’s recovery took longer, not only because of the more demanding nature of his operation, but also because his subsequent medication regimen was complicated by his Crohn’s disease. He had missed many months of school, but thanks to in-home tutoring provided by the school district over the summer, he was able to make up for lost time, and he enrolled in eighth grade, with his friends, in the fall. He was feeling well enough by then to attend school full-time.

According to Aidan’s father, “My wife and I were both so impressed with the entire staff at NYPH/Columbia, I felt confident that the medical team was the best in the world and they would do everything in their power to make sure I came out okay. I put complete trust in them.” He found it reassuring that the surgeons had expressed a willingness to halt the procedure for any reason: “They said they can stop at any point, and that if they ever felt I was at risk, they would stop. That was one thing that came across very clearly. They’re extremely focused on ensuring the health and safety of the donor. The donor is a healthy person and they don’t want to change that.”

Aidan’s mother, Frances Ward, said that her son’s and husband’s successful results were due not only to the surgeons who performed the transplant, but to the “extraordinary” nursing care at every step from pre-operative testing through



post-surgical care, from physical care to psychological care. She also appreciated that the staff was meticulous about ensuring that family members were fully informed about each aspect of treatment before it was done.

By way of advice to other prospective organ donors, Mike shares that the emotional aspects were perhaps more challenging than the physical for him. He advises others against underestimating the mental aspect of the process: “I certainly underestimated the effect the entire experience has on one’s mental state. I found I was more keenly aware of and responsive to emotional situations... It was as if my emotions were always ‘on edge.’ However, not once do I regret what I went through, especially as I watch Aidan – now in high school – continue to thrive. I’m still amazed that I was able to give a piece of my liver to my son to save his life.” ❀