I would like to thank the American Federation for Medical Research for allowing me the opportunity to share my story with you. I am honored to be a part of this conference, as medical research has impacted my life in the past 4 years. I hope that I can illustrate today how research personally affected me.

I would like to think back to July 8, 2005, a hot and humid day in Chicago. I had been on sick leave for approximately 7 months. I was weak, I had no energy, and when I looked in the mirror, I saw my face and my eyes were so yellow that the reflection in the mirror made me cry. I had severe jaundice from an elevated bilirubin level: in the high 20s at the time. My liver was in bad shape. I had lost approximately 25 pounds over 6 months, and I did not know how much longer my body as well as my mind would be able to endure.

My transplant nurse called me early that afternoon, and I remember her words: “We have the perfect organ for you.” The organ was a small bowel from a deceased donor. Even today, I struggle with the emotions that I went through and the thoughts that raced through my mind, as that day would be the single worst day for a family but would be the day that my life was saved.

Seven months before this day, my life changed in one day. I was a healthy 30-year-old woman who was 3 months pregnant and excited to start our family. In early December 2004, all but the intestine. As we researched this procedure, we found few addressees of survival was a small-bowel transplant. I hoped to receive approach failed: I traded constant output into an ostomy bag for not an ostomy bag for chronic diarrhea as frequently as 10 times a day. During that need a transplant, but I was afraid and willing to try anything to prevent that. For 6 months, I carried a backpack that contained a huge bag filled with a milkshake-like solution, the TPN, which served as my nutrition. I was infusing this TPN for up to 18 hours a day in addition to the IV hydration; therefore, I spent almost no time outside of our home. I felt like a prisoner in my own home. As much as I needed this nutrition, it destroyed my liver at an unusually rapid pace. Weekly laboratory draws showed that my liver enzymes were getting worse every week.

Second, my physician reconnected my small bowel to my remaining colon, in hope of reducing the TPN. However, this approach failed: I traded constant output into an ostomy bag for chronic diarrhea as frequently as 10 times a day. During that time, I lost more weight and more energy. At the very least, for those few months without an ostomy, I felt more like a human being, more like a woman again. However, my life was becoming increasingly unbearable both physically and emotionally.

At one point, I self-injected a growth hormone every day for approximately a month (Fig. 2). The goal was to grow the surface of my small bowel and help with absorption. Unfortunately, that did not work. Finally, I realized that my only option of survival was a small-bowel transplant. I hoped to receive this transplant in a timely manner so I would not need a liver in addition to the small bowel, a need that would require a more dangerous multi-organ transplant.

Sharing My Story

Sabine Miller

Key Words: transplant, medical research
I was on the waiting list for only 4 months, and when I said goodbye to my husband and was wheeled into the operating room, I felt calm and happy and ready for whatever was going to come, as I knew my circumstances could only improve from that point. The surgeons told me afterward that when I awoke from anesthesia, I had a smile on my face. I knew that the organ donation had benefited me, that my doctors had succeeded, and that my life would go on (Fig. 3).

I still experienced a long and difficult recovery. I was in the hospital for only 3 days. I was then released to a nearby hotel to recover outside the hospital and still easily get to the hospital for my daily follow-up visits. Three weeks after my transplant, I took my first walk to the Chicago Lake Front (Fig. 4). I walked with my friend, Scott, and I remember digging my feet in the sand and feeling so alive for the first time in several months. I was amazed as my body recovered: I gained weight and energy every week, my liver was recovering, my bilirubin levels decreased, and I could hardly wait to eat solid food after 3 weeks of not eating.

After those 3 weeks, I followed a strict no-fat diet to ensure that fat would not leak into my abdominal cavity. Three months after the transplant, after I had healed, I was able to return to a regular diet with a few restrictions. I had to maintain an ostomy bag for 1 year so Dr Buchman could frequently biopsy the grafts to ensure that there were no signs of rejection or, in case of rejection, to identify the issue early. Looking back, I think the ostomy was one of the worst parts of the experience. One year after my transplant, in July 2006, the ostomy was taken down.
and all permanent IV lines were removed from my body. I left the hospital that day and felt an incredible freedom: I did not have to hook up to an IV every day for TPN or IV hydration. I felt like a woman again. I had no external hardware or “Tupperware,” as I called the all-plastic parts. That day was a very emotional day for me.

Every year, my parents and my husband and I celebrate my transplant anniversary with a big party in our backyard. Last year, we celebrated my third transplant anniversary. Today, almost 4 years after my transplant, I continue to take approximately 10 pills a day, half of which prevent rejection and infection. I go to the hospital for laboratory tests every month and biopsies approximately every 3 months. I am doing well, and I can again do the things I love to do, like traveling, doing sports, and working full time (Fig. 4). I must know my limits, and I have been frightened by adverse effects from the medication—adverse effects such as nausea, diarrhea, and fever, which could all be symptoms of rejection. I have gotten to know my body well in the past 4 years, and if I sense a signal that something could be wrong, I know to immediately inform my doctors.

Two particular factors contributed to where I am today. First, a selfless person in North Carolina decided to be an organ donor. Second, an amazing team of physicians successfully performed a rare and complicated transplant and provided compassionate care. Third, my recovery was possible because of medical research in transplant surgery, in medication and the immunosuppressant drugs, and in follow-up care; and one is not possible without the other. Finally, but not least, I benefited from the support that I received and continue to receive.

FIGURE 3. Two days (left) and 2 weeks (right) after transplant.

FIGURE 4. At Chicago Lake Beach 3 weeks after transplant (left); with family on the third anniversary of the patient’s transplant (right).
from my husband, Dan, and from our family and friends and from my own determination because a patient does need to do her part in the recovery. A patient must find a team of physicians that she trusts, and she must follow the physicians’ orders, or the best medical care will be ineffective.

Medical research has given my physicians the means to dramatically improve the outcome of small-bowel transplantation. This transplantation is a new procedure, and I am amazed at the advances that researchers have made since the first small-bowel transplant in the 1990s and even since my own transplant in 2005. I think about how many lives have been saved by this procedure and about the quality of life that has been improved for so many patients with bowel diseases. For me, improvements for these patients prove the necessity of medical research in this area.

I hope that medical research will lead to more spectacular improvements in transplant surgery, in immunosuppressant drugs, and in the treatment of rejection. I want my physicians to have the knowledge and resources that they need to continue to conduct this medical research and to meet any challenges that we may face in the future. The results of medical research saved my life, and my well-being depends on continued research.

As you can imagine, a traumatic event like this changed my perspective on life. Today, my goals are to lead a happy and healthy life, to maximize my quality of life, and to give back to the transplant community. I am an active member of Organ Transplant Support (OTS), which is a support group based in Chicago. I also work to raise awareness for organ donation and the power that we all have to save the lives of as many as 8 people and to improve the quality of life for many more people.

American physicians are seeing an increasing shortage of organs, and too many people die waiting for a life-saving transplant. Unfortunately, we do not think about organ donation or transplantation until we or someone we know is affected. I want to get people to talk about organ donation and transplantation with their family and friends.

I would like to thank my donor and the donor’s family for making the ultimate sacrifice and allowing me to celebrate 2 birthdays each year. I also want to thank my physicians at Northwestern Memorial—Dr Koffron, Dr Iyer, Dr Fryer, and Dr Buchman—for their amazing skills and compassionate care.

I am European, and I lived in Vienna, Austria, for 24 years until I met a young US Marine guard who was guarding the US Embassy. This year, we will celebrate our 10th anniversary and the fourth anniversary of my transplant. My transplant experience was a tremendous burden on us as individuals as well as on our marriage. But this experience has also made us stronger. Dan, I want to thank you for your love and support.