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CHAPTER 27

Long-Term Survivors...In Their Own Words

The transplant community knows and respects the surgeons, physicians and researchers who pioneered transplantation very well, but there is one group of pioneers that remains obscured in statistical summaries or is identified by initials in descriptions meant to preserve their anonymity. This year ***Clinical Transplants 2002*** would like to introduce some of the pioneers of transplantation who *received* the early transplants and who have survived for many years with their grafts. Their contributions to transplantation through the lessons they provided the surgeons who performed their transplants and the physicians and others who cared for then deserve recognition. These long-term survivors also represent the true goals of transplantation – to restore organ function and to extend and improve the lives of patients with organ failure. In developing this feature, we asked only that the recipients write about their experience of transplantation and that the surgeon submit an account of the transplant as well. The results far exceeded our expectations. The narratives are as varied and as real as the people who wrote in their own words. We were not able to reach all of the longest survivors, but these 19 represent many of the earliest transplants. The respondents are ordered according to their survival time, with the longest survivors first. We hope you will enjoy this special feature.

For the record:

Transplant:	**Living-Donor Kidney Transplant**
Date:	**January ,1963**
Hospital:	**Denver Veteran's Hospital**
Surgeon:	**Thomas Starzl, MD, PhD**
Age: At transplant:	**38** Current: **78**
Years Graft Function:	**40**

ROBERT PHILLIPS

Hello I am Bob:

Since my operation in January 1963, my health has been excellent, except for a few setbacks here and there. After leaving the Denver VA Hospital, I kept very busy working in Dr Starzl's lab, playing softball with the staff. In late 1963 I joined a bowling league and traveled around Colorado and in many other states. Then, I attended several schools in Denver, including classes in electronics, appliances and auto mechanics. I also delivered pizzas in the evenings for Chicken Delight.

Four years later, the wife and I returned to our home in Virginia. I did not get my old job back, but I secured a job at Goodwin House, a retirement home. Of course it was the night shift. I did not mind the night shift, and worked for 33 years, never missing a day due to sickness. The job provided me with health insurance and vacation time. I worked days at odd jobs, including masonry, carpentry and also repairing TVs.

Everything went along fine in my life until my wife fell and broke her hip. After her operation she needed complete care. Her speech was limited to a few words and she never regained her ability to walk. After this happened in October, 2000, I retired from Goodwin House to take care of her. We celebrated our 50th Wedding anniversary this past August and she is still with me.

When the doctors asked me to stop taking Imuran, more than 7 years ago, I was very happy, and anxious to do so. So far, there has been no trouble.

SURGEON'S REPORT: ROBERT PHILLIPS

In January 1963, Bob Phillips, who was then 38 years old, received a kidney from his 32-year old sister in violation of the subsequently delineated rules of ABO compatibility. He was A blood type and she was B. At the time, chronic hemodialysis was an available service in only a handful of hospitals, of which one was the University of Colorado-affiliated Denver Veterans Administration facility. The kidney worked immediately and well and for the next 3 weeks. Then a severe rejection developed that progressed to complete anuria.

The patient had been given full doses of azathioprine for 10 days prior to transplantation, based on studies in mongrel dogs showing that the mean survival of renal allografts was twice as long when the drug was given before and after transplantation than when azathioprine was started on the day of operation. After his transplantation, Bob was given 5mg/kg azathioprine until leukopenia developed. Small doses of prednisone were added. When the rejection progressed to anuria, a 5-day cycle of prednisone was started, in almost exactly the same way as is the common practice today. The steroid response to rejection also had been shown in preclinical canine studies to be effective.

During the one-week period of anuria, a cloud of despair settled over Bob's isolation room into which no one was admitted without a full shower and clothing in full surgical garb. With total anuria and a white count hovering near zero, the prognosis seemed hopeless. After the BUN rose to 160 mg%, a single dialysis was given. Then on the seventh day, a diuresis began that became torrential over the next week. It was our second case with a seemingly miraculous resolution.

The steroid doses were rapidly weaned and discontinued in the third postoperative month. Azathioprine was continued in daily doses of 1.5 mg/kg until September 1995, and then discontinued because of the ominous development of multiple pre-cancerous skin lesions which promptly regressed. These and other cases of that era defined the 2 features of the adaptive immune response to allografts that were destined to make organ transplantation a practical kind of treatment: ie., the reversibility of rejection, and the subsequent development of donor-specific nonreactivity. After Bob left the hospital, he returned to an uncontrolled environment and never looked back.

Our experience with this patient and with others of that era taught us how to treat patients by pattern recognition of reproducible posttransplant events that triggered an appropriate response. How the rejection response had been so dramatically turned off remained enigmic for another 30 years until Bob and others were studied in 1992. Then, it was demonstrated that these patients had low-level donor leukocyte chimerism. It was the beginning of the elucidation over the following decade of the chimerism-associated mechanisms of acquired organ-induced tolerance. In 6 weeks, Bob, now 78 years old, will pass the 40-year milestone with a creatinine of <1.0 mg%, 7 years off of all immunosuppression, and with every expectation of retaining good renal function for the balance of his remarkable life.

Submitted by:
Thomas E. Starzl, MD, PhD

For the record:

Transplant: **Living-Donor Kidney Transplant**
Date: **October 7,1963**
Hospital: **Colorado General Hospital, Denver**
Surgeon: **Thomas E. Starzl, MD, PhD**
Age: At transplant: **17** Current: **56**
Years Graft Function: **39**

NANCY WENNBLOM (LUDWIG)

When I was diagnosed with glomerulonephritis in early 1963 at age 17 it was quite a shock to our family. I was glad that finally there was a reason for my headaches, which had been bad for about 6 months. While I was in the hospital in Sioux City, Iowa, my Grandmother who lived in Denver, Colorado came to visit. She assured all of us that having kidney problems was not a big deal because they could put a new one in at the Colorado General Hospital in Denver. I was on bed rest for many months and finished my last 3 months of high school at home. I was able to graduate with the class.

When my disease became acute in the fall of 1963, I did end up in Denver at Colorado General Hospital. My mother was tested and was okayed for giving me one of her kidneys. I had the transplant on October 7, 1963 and have been fine ever since. There were about 3 or 4 of us recipients in the ward and some of the donors were on the other side. We were kept in reverse isolation. I was released from the hospital a month after the transplant. Because this was such a new procedure I had to stay in the Denver area. At first I went to the hospital 3 times a week to be checked. As the time between visits to the Transplant Clinic lengthened, the number of pills I was taking was decreased. Transplant Clinic was a social time for all of the transplants and families – it was a way of life that I will never forget. It was not always happy because some of the patients would develop problems and would need to be hospitalized. I don't know if we ever got used to friends dying, but it happened with regularity. We talked about being guinea pigs, but we didn't know if that was good or bad. It was good for me. Our lives revolved around our transplants so much that sometimes we needed to fight back to become independent. We were afraid to do much of anything without asking the doctors at clinic on Wednesday morning.

I was married in 1966 to Don Ludwig and we lived in Wisconsin on a dairy farm. We talked about having a child and after talking with the doctors finally decided to do that even though there were no guarantees about how the medicine would affect the baby. About a month before our daughter was born I went to Denver as requested by the Denver doctors and was in the hospital until she was born. She was in reverse isolation for about 10 days, but was fine and had no problems with the medications I had been on. When our next 2 children were born I decided I did not want to be so "watched" and decided to have them at our local hospital. All 3 children are fine. They are all grown and busy with their own lives. There would not have been these 3 people without the transplant so we are thankful.

Life has been good for me ever since the transplant and I still feel guilty that it has not always been good for others who had transplants. My mother, who donated one of her kidneys to me, is now on dialysis 3 times a week so I have become more aware again of the struggle some people go through. People are amazing – they just keep trying. My transplant is just part of who I am and it is difficult to separate out what would be different without having that experience.

SURGEON'S REPORT: NANCY WENNBLOM

When Nancy Wennblom came to Denver, I soon learned that she had been born and raised in a small town in northwest Iowa, located only 15 or 20 minutes from where I grew up. Consequently, I had a very personal interest in sending her home. I hoped very much that she might find the time to visit my father, who by this time had been gravely disabled by multiple strokes.

Nancy sailed through the operation, which at that time (the autumn of 1963) consisted of bilateral host ne-

phrectomy, splenectomy, and renal transplantation. She was treated with azathioprine before and after transplantation with the addition of high doses of steroids for clinically significant rejection, but with rapid steroid weaning thereafter. Although it was not recognized as such until many years later (*The saga of liver replacement, with particular reference to the reciprocal influence of liver and kidney transplantation {1955-1967}. J Am Coll Surg 195:587-610, 2002*), the strategy of immunosuppression was inherently tolerogenic.

As a consequence of the policy then in effect, Nancy already was on small maintenance doses of immunosuppression within a few months. In 1998, she stopped all immunosuppression and has had uninterrupted normal renal function ever since. Now approaching the 40-year milestone, she bears the third longest functioning renal allograft in the world. Her 4 decades of extended life have been full. It is noteworthy that her allograft has outlasted the kidney remaining in her maternal donor: ie., her mother is now on dialysis.

Submitted by:
Thomas E. Starzl, M.D., Ph.D.

For the record:

Transplant: **Living-Donor Kidney Transplant**
Date: **July 19, 1963**
Hospital: **University of Colorado**
Surgeon: **Thomas E. Starzl, MD, PhD**
Age: At transplant: **15** Current: **54**
Years Graft Function: **39**

DORTHEA STANTON

When I was first asked to write about my transplant experience, I thought it would be easy. The more I got into memory recall, the more difficult it became. I began to remember more than I wanted to. It was then that I realized what the problem was: Within the last 2 years, I have lost both of my parents. My parents gave me so much love and support, and to remember all the physical and emotional pain we all went through proved to be quite a task. To the best of my ability, these are my memories of my transplant and life experience.

I had polio when I was 15 months old. I was 10 years old and in the hospital for surgery on my leg when they discovered I had kidney disease. In 1963, I was 15 years old when my kidneys shut down and completely quit working. Back then, they couldn't do kidney transplants in Dallas. I stayed in the hospital here for one month before they sent me to Denver. This was a very painful and confusing time for me. There were no dialysis machines here then, either, so they did a peritoneal dialysis. There wasn't much they could do except keep me as comfortable as they could. My doctor knew a doctor in Denver – that's how I got into the transplant program. The doctor wanted me to fly to Denver, but I had never flown before. The thought terrified me. My uncle and cousin drove Mom and me in an ambulance with my Dad following in a car.

When I got to Denver, on June 26, 1963, everything changed. While I was in Dallas, my Mother, Dad and other family members were with me around the clock. Not only was I in a strange place with strangers all around me, I was told that no one in my family could stay with me in the room. Mother was quite adamant about not leaving me. With special permission, one family member was allowed to stay with me. My parents and grandmother took turns staying with me.

From the time I arrived in Denver, they started preparing me for a transplant. Several family members agreed to be tested for compatibility as my donor. My mother was the first one tested and they found her to be a good match. I went into heart failure again the night

before the transplant, but once again, my faith in God and the doctors' knowledge brought me through. Many of my family members were there for the transplant on July 19, 1963.

The first thing I remember after the operation was the next day when Dr Starzl was trying to keep me awake to eat. I had special duty nurses around the clock. My family could only visit me standing in the hall outside the room. Everyone and everything that came into the room had to go through a sterilizing process.

Forty-one days after the transplant, I started through a rejection period. My body was trying to reject my new kidney. For 3 weeks, we fought high fever as I lingered near death. Finally, on September 18, I got to go "home". My parents rented a house across the street from the hospital. I had to go back to the hospital every day for blood work and physical therapy. I had to be in bed for so long that I was unable to walk because of the polio. This was our daily life until February 1964, when I was allowed to return to Texas. I still had to return to Denver once a month for transplant clinic.

When I first returned to Texas, I was still weak. However, the quality of my life was so much improved that I recovered physically. The uremic poisoning that caused nausea, headaches, and near blindness disappeared. My sight cleared, and I could finally enjoy eating. I also really got the "prednisone bloat." In fact, when I first returned home, my grandmother didn't recognize me because I had put on so much weight.

I got married at 18, and after a very stormy 16 years, we divorced. Once again, I started life over. I got a job and began attending college. For a year, I continued to work and go to school. Then I was hit with the Post-Polio Syndrome. This put me back in a wheelchair. I had to quit school, but I was able to do office work and keep books for the small apartment complex where I lived. My mom and dad managed the complex for over 30 years.

I met my current husband on Christmas 1993. We married 2 years later on Christmas 1995. We enjoy traveling. While living in Denver, I loved the mountains and snow. I had always wanted to see Alaska, and last year, my wonderful husband took me there. It was fabulous and I hope to visit that beautiful state again.

This year was the first transplant anniversary without Mom or Dad. Every year on July 19, I took my parents out to dinner. I was feeling down because they weren't here to celebrate this important day with me. My husband reminded me that we celebrate every day. This is so true! I wasn't able to have children, but I love them dearly. I have one brother, a sister-in-law, 2 nieces, a grandnephew, and a grandniece that I love with all my heart. I enjoy my life and look forward to my husband retiring, so that we can spend more time together. I am so thankful for the extra life given to me by God, my mom and the doctors. I always thanked my mom for giving me life twice. I am grateful that I will always have a part of my mom with me.

A news reporter asked me why I thought my transplant worked so well. I think it is a combination of a great faith in God, the love and support of a wonderful family, and following the doctors orders completely. I still follow Dr Starzl's orders and always will. I have great respect for him. I watched him on Nightline with Ted Koppel. I thought Mr Koppel was very unfair to Dr Starzl, so I wrote him a 4-page letter. I tried to tell him what a great man Dr Starzl is and that he is loved and respected by people who know him. I never received a reply from Mr Koppel.

There are so many things I had to leave out, but I think I covered most. After all, this is a paper, not a book.

SURGEON'S REPORT: DORTHEA STANTON

When 15-year-old Dorthea Stanton underwent kidney transplantation in July 1963, renal hemodialysis was only available in a handful of centers, and was still a primitive art. Consequently, almost all recipients of that era were in metabolic imbalance at the time of operation. In my book, *Experience in Renal Transplantation (W.B. Saunders, Co., 1964)*, Figure 51 depicts the course of Dorthea, including her pretreatment with azathioprine for 18 days followed by azathioprine monotherapy for the first posttransplant month.

The point of the figure's caption, however, was the magnitude of the fluid and electrolyte correction that followed surgery. The caption read, "Postoperative management of a 15-year old girl who received a renal homograft from the mother. During the first 48 hours after operation, the child lost more than 30 pounds of weight. During the acute diuretic phase, intake was provided to replace approximately two-thirds of the fluid loss. The diuresis immediately after surgery was as much as 1,000 cc per hour. Bilateral nephrectomy and splenectomy were carried out at the same time as transplantation".

Dorthea surmounted not only this immediate obstacle but also the handicap imposed on her much earlier by poliomyelitis. Since her transplantation, she has walked

through life's rough patches with light footsteps. In a few months, she will reach the 40-year posttransplant milestone bearing the second longest functioning renal allograft in the world. Because of multiple immunosuppression-related complications, she had all immunosuppression stopped in 1996. Seven years later, her kidney function remains perfect.

The enduring impression from the 1963 era was that in spite of her dreadful condition, this teenage girl was one of the most beautiful people we had ever seen. The passage of time - even 40 years - has not changed that perception.

Submitted by:
Thomas E. Starzl, MD, PhD

For the record:

Transplant:	**Living-Donor Kidney Retransplant**
Date:	**March 3, 1964**
Hospital:	**University of Colorado**
Surgeon:	**Thomas E. Starzl, MD, PhD**
Age: At transplant: **32**	Current: **70**
Years Graft Function: **39**	

JOE NEWMAN

My Transplant Experience

The circumstances leading to my transplant started the day I joined the Air Force on January 10, 1951. I left Springville, Utah, with only a windbreaker for a coat and arrived in San Antonio, Texas, after a long train ride, arriving in the evening. I was issued 2 army blankets, a folding cot and assigned to a tent along with about 20 other men. That night a rain and windstorm came up, blowing the tent off. The temperature was 40 degrees. The following morning we marched in wet clothes for several hours. As a result, 8 men contracted pneumonia. I ended up with a very severe case of strep throat and was given tablets, which were about the size of an aspirin. The strep throat infected my kidneys. I was hospitalized in Illinois for a couple of weeks. In 1953, I married Carma while stationed in South Dakota. I was discharged in 1955.

After the service I worked for Thiokol Chemical Corporation, making trips to the VA Hospital every now and then. Once they kept me there for 6 months and I came out just as sick as I went in. After working for 4 years for Thiokol, one day I collapsed on the job and was taken back to the VA Hospital in Salt Lake. They told me that my only chance to live was a kidney transplant and that if I had a donor I should get this done in Denver as it was the best place for this kind of transplantation.

Our family situation was not very good, as we had 7 children and not much money. My family arranged to care for the kids while Carma went with me to Denver. Eleven family members offered to donate kidneys. It is at times like this that a person really appreciates a loving and caring family. I was transferred to the University of Colorado Hospital (in Denver), and was put on dialysis for about 4 hours, 3 times a week. I felt sick and would lose weight every time. In addition, the doctors found I had a bleeding ulcer. When they operated on the ulcer, they also removed what was left of my kidneys along with my spleen. I was told that my kidneys had shrunk to about the size of a quarter.

Due to a reaction to the stitches the wound would not heal. Dr Marchioro reopened the wound with a pair of scissors. I cannot describe how bad that hurt. The wound was then left open and had to heal from the bottom up. I had to lie on my back for this healing process and the nurses put a salt solution on my abdomen several times a day. After about 6 weeks on dialysis, the date finally came for the transplant. Everything was set for my sister, Hazel, to be the donor. It looked like she would be a good match. Hazel came through the operation great. Postop the kidney started working, and everybody was very happy about the outcome. Then things started to take a downward turn. Bleeding began from the kidney, and after about a week, it was removed and I was back on dialysis. During these trials, Carma had been great, but she experienced an emotional breakdown

and was hospitalized for treatment.

The first transplant was in January. In February, I had another chance. At first, I was considered for receipt of a baboon kidney. But I developed a bad rash on my abdomen and the surgery was canceled. Looking back, this proved to be a blessing, since all attempts with baboon kidneys failed. Still, it was an uphill battle. Every time I was put on dialysis I lost weight. By the time of my second transplant in March, I weighed about 80 pounds, half or less of my normal. Then my sister Ethel volunteered to donate her kidney to me. Although tissue matching was not yet available, later studies showed that she was a good match.

A day or so before the second transplant, 2 doctors came into my room. Not knowing I could hear them, one said to the other "Have you ever seen anyone who looks more like a cadaver than him?" Although I did look awful bad, that made me feel real positive. The transplant went well. As I was coming out of the anesthetic, the first person I saw was Dr Dickenson. He had a bald head and little glasses and I said "Well if it isn't Porky Pig."

After surgery I would eat about 6 times a day and at midnight had cookies and milk or a cup of broth. Bobbie Read, another kidney transplant patient, and I would have a contest to see who could gain weight the fastest. I think I won. I can remember how thrilled I was when I could feel a little meat coming back instead of all bones. Recovery was slow, but by this time Carma was feeling all right and was back by my side. Just her being there really helped me get going. She rented a small apartment in Denver for the kids and us. By mid-April, I was able to go on rides and sometimes stay over night at the apartment. After discharge, I stayed at the apartment with visits back to the hospital. I used crutches for a while. One day I went out for a little walk. I fell and could not get up. I was very embarrassed when 2 little older ladies, about 80 years old, came by and lifted me up.

Finally I was told that I could go home, so we moved back to Logan, Utah, but had to return to Denver every 2 months for checkups. When I got home I got a job in a jewelry store. All of my checkups were fine, even though I kept forgetting to take my medicine. As time went on, I quit taking all of the medications; my checkups continued to be great. When I told the doctor I was not taking anything, he was not happy and very surprised I was doing so well without them. Dr Starzl called me a rebel and said I was acting just like him. He told me when he had been so sick with hepatitis, he also had quit his medicines. Two years after my last transplant was when I took the last medication. That was more than 37 years ago. I had only one setback, about 18 months after transplant. I fell against a rock and bruised the kidney, and I was flown to Denver for 6 weeks to heal. All went well from then on.

In 1971 we moved to Afton, Wyoming, and bought a jewelry store. In 2001, I retired to Mt Pleasant, Utah. We chose this location because it would be easier for me to care for Carma. While still in Afton, Carma had experienced 2 strokes, leaving her partially paralyzed, and in addition, she was also diagnosed with bi-polar disease. I am now 70 years old and I can do about anything I want. I try to keep up with the kids as best as possible, but that is not as easy as it used to be. My main job is to take care of Carma and to repay her for all she did for me.

I still have several problems, which are linked to my original illness. One is a partial blockage in my throat because of the windpipe and stomach tubes during those early hospitalizations. Another problem is that my potassium level is sometimes low. This causes me to almost pass out. I keep a box of raisins handy. This seems to do the trick. I also had a blockage in my urinary tract due to the urine tubes placed in my bladder getting infected before and during my transplant period. The blockage has now been corrected and has not given me any problems for years. I consider these minor problems, considering what might have been without the new kidney. I feel mighty fortunate.

The kidneys provided by my sisters meant that I had a second, and then a third chance at life. There is no way I can ever thank Hazel and then Ethel for the love they have shown me. Now after nearly 39 years, I realize that I was feeling sick all the time and living a nightmare before transplantation. This surgery has given me a whole new life filled with good times, bad times and everything a life should be. I have been able to watch our 7 kids grow and get married. We have 30 grandchildren and 7 great grandchildren with lots more on the way.

One day when I was in such bad shape in Denver, I told my dad that I was going to live until I was eighty-two. As of today my mind is still alert enough to realize that if I told him the truth, I still have 11 good years left in me before reaching the half-century mark. Without the help of my sisters, doctors, Carma, and many, many others, I would not have received such a gift.

Thanks,

Love, Joe Newman

SURGEON'S REPORT: JOE NEWMAN

There is very little one can add to Joe Newman's description of his remarkable saga. In common with many of the 46 kidney recipients treated at the University of Colorado from the autumn of 1962 until the beginning of 1964, he was at death's door by the time he presented for transplantation. The patients were treated with very simple immunosuppression that consisted of azathioprine (begun one or 2 weeks before transplantation), and secondary intervention with prednisone only for the specific indication of rejection. Nine of these 46 recipients still bear their allografts at or beyond the 40-year mark, and more importantly, 7 of the 9 have been off all immunosuppression for years (in Mr Newman's case, 37 years).

As it turned out, restudy of this pioneering cohort of recipients revealed that they had cryptic donor leukocyte chimerism (*Cell migration, chimerism, and graft acceptance. Lancet* 339:1579-1582, 1992, and *Cell migration and chimerism after whole-organ transplantation: The basis of graft acceptance. Hepatology* 17:1127-1152, 1993.). This discovery was the opening shot in delineating the mechanisms of alloengraftment and of better strategies of tolerogenic immunosuppression (*Transplantation tolerance from a historical perspective. NATURE Reviews: Immunology* 1:233-239, 2001, and *Tolerogenic immunosuppression for organ transplantation. The Lancet*, in press).

The bleeding that necessitated removal of the first kidney was caused by sagittal rupture of the kidney in essence by valving the allograft. This was not a rare event in the earliest days of transplantation, undoubtedly because of the relatively weak immunosuppression then available. When rejection occurred the swollen organs became susceptible to the complication. Mr Newman's second allograft is the longest surviving kidney retransplant in the world, and the seventh longest surviving allograft overall.

Submitted by:
Thomas E. Starzl, MD, PhD

For the record:

Transplant:	**Cadaver Kidney Transplant**
Date:	**January 30, 1966**
Hospital:	**University of Minnesota**
Surgeon:	**William D. Kelly, MD**
Age: At transplant:	**19** Current: **55**
Years Graft Function:	**37**

STEVE ERICKSON

World's longest surviving cadaver kidney transplant recipient - 2002

It was the fall of 1965, in Duluth, Minnesota. I had graduated from high school that spring and was starting carpentry class at the local trade school. My body didn't feel right: I was tired, I did not have a good appetite, and I was having some nosebleeds.

One Wednesday afternoon that winter, I was taking my mother downtown for a meeting. I smashed into the back of a car on a slippery street. They thought I had broken my nose, so I went to the emergency room. My mother told the emergency room staff that I was not feeling very good. She suggested I stay to take some blood tests and try to find out what was bothering me. They drew routine bloods and put me on a diet. In the next couple of days, the doctors did exploratory surgery and found out I had been born with only one kidney. And it was not functioning.

My family was told I would have to go to the University of Minnesota Hospital in Minneapolis as soon as possible. Duluth did not have the facilities to take care of my problem. The date was January 24, 1966. No one in Duluth had ever heard of a kidney transplant, except on television. I was put on the transplant list at the University and began the wait.

The day after I arrived at University Hospital, the doctors put a shunt in my arm so I could get hooked up to a dialysis machine. It was very big and looked like a washing machine. My doctor was William Kelly; he had

a very good group of people on the transplant team. All the doctors did all they could to make a 19-year-old boy feel at home. That home lasted 4 months: 2 before the transplant and 2 after. It was the first time in my life I had ever been away from my Duluth home and my close family: mother, father and 2 sisters, Joanne and Susie. Susie is my twin. She was told she would be the best match for a kidney and was tested. It was a perfect match. But the doctors told me that the effect of donation could be bad for her in her childbearing years, so I went on the cadaver kidney list. I waited for 2 months on the dialysis machine.

Then, on March 30, 1966, my mother was down to visit me from Duluth. We were walking outside the hospital when a nurse came running out to us and said, "Steve, your kidney is here!" It was the time we had all been waiting for, but it was also a shock. The doctors and nurses prepped me. I had been right next door to a 28-year-old man who was undergoing open-heart surgery. His family had already said that if anything happened, his organs could be donated. He did not make it. They immediately transplanted the kidney into me. What a blessing.

The kidney started working on the table, then shut down and began rejecting. After waiting all that time, now it was not functioning. But on Easter Sunday morning, a week and a half later, I woke up to a wet bed. The following day, the doctors had been planning to take it out and start all over again. Thank God it started working. And it has worked ever since. On May 24, 1966, I was released from the hospital and could go back home to Duluth. It was my mother's birthday.

At the time it seemed like it was the end of my young life. Little did I realize what a true blessing it was. It made me appreciate life more than most people do; gave me a positive attitude; and gave me some of the greatest friendships I could ever imagine.

Did I mention that when all this was going on I was going with a very pretty 16-year-old girl? Well, that girl's name is Patty and we are now celebrating our 33rd year of marriage this year. She is an R.N. – a super nurse. She takes great care of me and keeps me out of trouble. We also have 2 of the best kids in the world, Jodi (in law school in New York) and Juli (in her senior year at the University of Minnesota's Duluth campus).

In the 36 years since my transplant, I could write a book about the good life I have been blessed with. I spent 26 years with the same company as a reprographics salesman. But in 1997, I left that company and started Northstar Imaging Services, Inc. It is a great little company and growing every day. I am the President and am having a good time. Patty and I built a townhouse in Inver Grove Heights 3 years ago. We spend a lot of time on the golf course. Did I tell you I have had 3 holes-in-one? One of my pet things to do is volunteer work with the Kidney Foundation of Minnesota. I have been on the board of directors for more than 20 years. It has introduced me to some of the best people and friends I have ever met.

If I had never gone through a kidney transplant, I could have led a totally different life. But I probably would not have been on a national board of a great organization like the Kidney Foundation, or had so many opportunities to meet with such wonderful people. Did I forget to tell you that I threw out the opening pitch at a Minnesota Twins game? It was at a Kidney Foundation function.

I truly had a chance to turn a life-threatening situation into a super life that I would not trade anyone in the world for. When I start writing about just some of these things I have done, I think I could go on forever. I hope this lets people know that there is life after transplantation and that it can be very positive.

SURGEON'S REPORT: STEVE ERICKSON

The early history of the transplant program at the University of Minnesota was related to me by Dr J Bradley Aust. The first kidney transplant here was performed on June 7, 1963, between identical twins. This transplant was performed by Dr Richard L Varco and J Bradley Aust. The graft lasted 37 years, until the recipient died of cardiac failure in March 2000. After this inaugural transplant, Dr Varco personally did no further transplants but continued as a consultant to the transplant team. Upon my arrival in July 1967, one half of the kidney transplants had been performed by Dr Aust; one quarter by Dr William D Kelly; and one quarter by Dr Richard C Lillehei. Dr Kelly performed Steve Erickson's transplant on March 30, 1966: the 57th kidney transplant and the 31st cadaver kidney transplant at the University of Minnesota.

As Mr Erickson indicated in his essay, he had become friends with a patient in the next hospital bed, who was scheduled for open-heart surgery. That patient's case was considered a high-risk operation, so he and

his family agreed that, if things didn't go well, they would like to have one of his kidneys given to Mr Erickson who had been waiting 2½ months for a cadaver kidney. Unfortunately, the open-heart operation was not successful. Mr Erickson was given a call to receive a kidney from his recently deceased friend. The ischemia time was very short, since Mr Erickson had been taken to the operating room while his potential donor was maintained on cardiopulmonary bypass.

The transplanted kidney made urine initially, but a 20-day period of acute tubular necrosis (ATN) ensued. Just when the kidney was scheduled to be removed, it began making urine and recovered excellent function. About 2 weeks later, a single mild rejection episode was treated successfully with intravenous steroids. Immediately posttransplant, Mr Erickson had been on a regimen of 150 mg of Imuran and 225 mg of prednisone daily. In addition, in the first 3 days after the transplant, 3 doses of radiation (150R) had been given directly to the kidney, as was the practice in those days. The rejection episode that occurred on postoperative day 32 was easily reversed. Mr Erickson left the hospital on May 30, with a creatinine of 1.2 and a BUN of 26.

Since that time, he has done extremely well. He did have one episode of chickenpox in 1972. He also developed steroid-induced diabetes, which resolved after his steroid dose was reduced to 5 mg per day. In 1991, he noted dyspnea and chest pain and was found to have aortic stenosis. Cardiac catheterization revealed an injection fraction of 15% and an enlarged left ventricle. On August 21, 1991, he underwent a successful aortic valve replacement and has had no further trouble with cardiac dysfunction.

Mr Erickson has been a "poster boy," if you will, for kidney transplantation at the University of Minnesota. He has been on the Board of Directors of the Kidney Foundation of Minnesota for more than 20 years and on the Board of Directors for the National Kidney Foundation as well. He is a frequently requested speaker on the subject of transplantation for churches and local civic groups. At least twice a year, I see him at various charity events for the Kidney Foundation, such as the Great Chef's Dinner every fall and the Kidney Foundation Workshop and award luncheons every spring. He has also been quite successful in business and is an avid golfer. As pointed out in his essay, he has even been fortunate enough to make three holes-in-one – a major accomplishment in the lifetime of anyone who plays golf.

It is unfortunate that we have no tissue typing data on Mr Erickson and his donor. As far as I know, a crossmatch was not done at the time of his transplant. Because of his excellent clinical result, I would have to assume that he was a good match with his donor. The fortuitous fact that the cadaver kidney was immediately available, without any significant cold or warm ischemia may have contributed to its long-term function. Mr Erickson represents one of over 6,000 kidney transplant recipients at the University of Minnesota. We are proud to have this longest-surviving cadaver kidney transplant recipient as part of our program and community.

Submitted by:
John S. Najarian, MD

For the record:

Transplant:	**Cadaver Liver Transplant**
Date:	**January 22,1970**
Hospital:	**University of Pittsburgh**
Surgeon:	**Thomas E. Starzl, MD, PhD**
Age: At transplant:	**3** Current: **36**
Years Graft Function:	**33**

KIM HUDSON

My name is Kimberly Kay Hudson Rasmussen. I was born on March 6, 1966 in Dixon, Illinois. I was born sick with a twisted bile duct, which destroyed my liver. I had a liver transplant on January 22, 1970 in Denver, Colorado by Dr Thomas Starzl to whom I am very grateful. He is a wonderful doctor. I have been through a lot

of medical procedures as a child and to this day I am still very afraid of doctors and hospitals. I still take medicine once a day. The medicine does have side effects, but I do enjoy life.

I was tutored at home for 8 years as a child because I have a low immune system. I did get to go to a public high school and graduated in 1985. I still had a very nice childhood. I have great parents, Bob and Ethel Hudson, who took great care of me. I also have one sister named Robin.

I met a great man, Curt Rasmussen, in 1984 and we have been married since 1986. In 1986, he joined the Air Force and we lived in Okinawa for 3 years. We have been living in Kansas for 13 years now. I have worked in the past, but now I am a homemaker and a mom of 3 great dogs and 6 sweet cats. They are our furry children. I have a fulfilled life with my husband and our wonderful pets. I am looking forward to growing old with Curt if God is willing.

Sincerely,

Kimberly Kay Hudson Rasmussen

For the record:

Transplant:	**Cadaver Liver Transplant**
Date:	**July 31, 1971**
Hospital:	**University of Pittsburgh**
Surgeon:	**Thomas E. Starzl, MD, PhD**
Age: At transplant: **3**	Current: **35**
Years Graft Function: **31**	

SURGEON'S REPORT: KIM HUDSON

On January 22, 1970, Kimberly Hudson underwent liver transplantation at the age of 4 years. Her diagnosis was biliary atresia, and in addition, she had a 1.5 cm hepatoma in the right lobe of her diseased liver. The native liver weighed 1,080 grams, and her spleen also was enormous, weighing 300 grams after its removal. Although she had previously undergone palliative surgical procedures for the biliary atresia, bleeding was not excessive and she received only 2 transfusions. The liver functioned promptly and normally from the outset.

Although Kim's serum alpha-fetoprotein was elevated prior to surgery, it became undetectable after the first 2 weeks. Liver function has remained normal for the ensuing third of a century, during which she has lived a productive and happy life. Because she is the longest surviving recipient of a liver (or of any extrarenal organ), she became a charming but reluctant celebrity. Although she is thought to be donor-specific tolerant, she remains on small doses of azathioprine and prednisone.

Submitted by:
Thomas E. Starzl, MD, PhD

STEVEN KENNEDY

Dear Dr Starzl:

How are you doing? Fine I hope, and staying healthy. I am doing okay, working once in a while for my cousin as a towing spotter. That means if a restaurant has a parking lot and people park there and they walk away and don't go into the restaurant, I call my cousin and he comes and gets the car. Three years ago I lost my mother. When she died it just killed me. I am getting over it little by little. Don't get me wrong, I miss her every single day, 24 hours a day and 7 days a week.

I just turned 35 years old on September 2. I almost got married, but it didn't work out too good. She was pretty. Her name was Kim. She had 2 boys. I was living in California and was staying by the bay area with my cousins out there. I am feeling great these days. I gave you a picture of me. It was taken at my aunt's house in Chicago. I'll also give you my cell phone number. I would like to hear your voice again because you saved my life, and I love you like a father.

Your friend always,

Stevie Kennedy

SURGEON'S REPORT: STEVEN KENNEDY

Steve Kennedy was 3 years and 11 months old when he underwent liver transplantation on July 31, 1971. His case had generated an ethical debate. Because Steve had never talked, he incorrectly had been pronounced dumb, and/or mentally retarded. Yet, we observed that he interacted freely with other children on the ward and appeared to be quite bright in many respects. His preoperative liver diagnosis was biliary atresia. His blood type was A negative and his liver was from a 4-year-old girl of O blood type who had been born on December 18, 1966 and was therefore about 8 months older than Steve. The donor liver was removed under conditions of brain death.

Steve's excised native organ was remarkably enlarged (902 grams). A small hepatoma was found in the left lobe. The transplantation was carried out in essentially the same way as would be done today except that the biliary tract was reconstructed by anastomosing the donor common duct to the recipient duodenum with a nipple and tunnel technique. Recipient treatment was with triple drug immunosuppression, ie., a short course of pre-and posttransplant ALG, with maintenance azathioprine and low doses of prednisone.

Steve recovered without incident and was returned to the care of his pediatrician and family in Chicago. In 1998, he stopped taking all immunosuppression and remains well today. Now, 31 ½ years posttransplantation, he is the second longest surviving liver transplant recipient in the world. As the years went by, he learned to talk and it was eventually recognized that he was intellectually capable. He was a loving child, and because of that, he enriched the life of all those who knew him well. Neither his early personality nor his character changed when he reached manhood, as is evident from the letter he wrote to me in October 2002 (see above). My response to his letter was as follows:

October 30, 2002

Steven Kennedy

Dear Steve:

I can't tell you how warmed I was to receive your letter and to realize how truly well you are. I know how much you miss your mother. My mother died in 1947, and I still remember everything as if it were yesterday. As you said, there is no crime at all in remembering, as long as you do not let it bring you to your knees.

As for your near-miss marriage, who knows? I have come to suspect that when these marriages are called off near the altar, it may have been the best thing for everyone concerned. It is better to be lonely for a while than to go ahead with a bad marriage and be miserable forever.

Finally, thank you for letting me have your cell number. Don't be surprised if you get a call.

Sincerely,

Thomas E. Starzl, MD, PhD

Professor of Surgery

For the record:

Transplant:	**Cadaver Kidney Transplant**
Date:	**March 9,1972**
Hospital:	**Denver Veteran's Hospital**
Surgeon:	**Thomas E. Starzl, MD, PhD**
Age: At transplant: **30**	Current: **60**
Years Graft Function: **30**	

MARCIA LORTSCHER

As I lay in bed awaiting the scheduled but dreaded dialysis treatment, I could not help but wonder what prospects for a future my life had in store for me. Having developed diabetes at the age of 10, complications from this disease resulted in the loss of my kidneys when I was 29. My husband, Randy, and I had just been married and were living on the Rosebud Sioux Indian Reservation when my kidneys failed. I was flown on a Medivac plane to the Public Health Service Hospital in San Francisco where I was refused treatment on arrival, because

I was diabetic.

At that time, before the End-Stage Renal Disease Bill was passed in 1973, there were hospital committees that determined whether you were going to live or die. Dialysis treatment was reserved for heads of household, under 40 years of age, without an auxiliary disease such as diabetes. As treatment became essential to sustain my life, permission was eventually obtained with great difficulty, and the ordeal of being dependent on a machine for life commenced for me.

During the 11 months I was on dialysis after I returned home, my blood pressures were running 280/160 and I developed dropfoot, requiring leg braces. As I had lost muscle control of my legs, I could no longer sit without jarring my back, resulting in excruciating pain. While I knew that pain medication was sitting on the bureau, I was told that I should not use it. Instead, I would sit up in bed, trying to rock myself to sleep, pretending that there was no pain. Sleep was a fitful process for me, and I was restless all night, waking at frequent intervals. There were times when I could no longer put words together or construct a sentence. I was sick to my stomach most of the time. Had God forsaken me? Truly, my life had become a burden to me and to others in my family.

Little did I realize then that on March 9, 2002, I would be celebrating the thirtieth anniversary of my kidney transplant. I was the first diabetic to be transplanted by the team of Drs. Thomas Starzl, Israel Penn, Charles Halgrimson, Charles Putnam and Mr Paul Taylor at the University of Colorado Health Science Center and the Veterans' Administration Hospital in Denver, Colorado. I am currently the longest-surviving diabetic kidney transplant patient in the world. I truly believe that God had a plan for me.

Although I am not always sure what God's plan is for me, I realize now that He gave me the ability to cope, the strength and fortitude to keep going, and experiences in my life so that I could empathize and comprehend those afflicted with similar probleMs Eventually, my transplantation led to my volunteer work with the National Kidney Foundation of Colorado, as well as my involvement with the ESRD Network Council including service on the Board as head of the consumer advisory committee. Overall, I was able to help suffering patients develop their own coping mechanisMs In common with me, they had not appreciated what they had until it had been taken away.

Although the gift of life had been given to me, the hardest concept to accept was that someone had to die in order for me to live. Without an identical twin or related donor, the chance of locating a compatible kidney match was highly unlikely. My kidney came from a young woman who had died at the age of 19 from a pulmonary embolism. My "kidney mate," the woman who received the other kidney, was a 38 year-old black woman. For a number of years, she and I still referred to each other as "sisters under the skin." Our donor was considered by some of the doctors to be a "universal" donor whose kidneys could have been accepted by anyone. Was this then a miracle?

Was God now challenging me to accept this "gift of life" and to move forward in order to achieve the goals I was to set for myself in the future? Was He now opening up the world to me by telling me to no longer fear the loss of my life but rather to take advantage of every opportunity that lay before me? At times I wondered. Posttransplant medical implications were to make my life even more difficult. Retinopathy caused loss of visual acuity and eventually total blindness in 1983 and more recently I had bouts of breast cancer, colon cancer and heart disease. In 1994, I discontinued Imuran and began to reduce my prednisone.

My vocation as a young woman had been in art and design. When I lost my vision, my interest turned to a love of people. After transplantation there is often great reticence on the part of the patient to move forward with his or her life. Because of my own experience, however, I was able to be a source of strength to others, and to impact their lives as they reciprocally have influenced mine. My motto in life is to always try to do the things that you think that you cannot do, and to pass on that attitude to others in the same boat. That simple approach has filled my days with beauty which I cannot see, but which I feel with all my other senses.

SURGEON'S REPORT: MARCIA LORTSCHER

In 1972, when I first met Marcia Lortscher, she typified a growing population of desperately ill but previously vital young patients who suffered from renal failure caused by diabetes mellitus. Kidney dialysis support was still an orphan in the medical armamentarium. Only a few centers provided this service, and those that did had fragile or non-existent financial support. Only the support of her biologic family and the loving care of her husband, Randy (a physician), had kept Marcia alive.

Transplantation was not being offered for such pa-

tients in most centers. Ultimately, her options narrowed to the pioneering renal transplant program of John Najarian and Dick Simmons at the University of Minnesota and our program in Colorado. After much discussion, the decision was made to go forward. Her transplant operation was carried out at the Denver Veteran's Administration Hospital where care was provided on a special ward that had been created to accommodate overflow patients from Colorado General Hospital.

Marcia was treated with ALG before as well as after transplantation, and with maintenance azathioprine and prednisone. ALG had been introduced clinically in Denver in 1966 in an effort to reduce the need for posttransplant prednisone. Consequently, she was treated with less prednisone than many of our earlier patients. There was very little difficulty with early rejection, and none later. Because of complications that were suspected to be associated with lifetime immunosuppression, azathioprine was stopped in 1991, and her daily doses of prednisone were weaned over the next 5 years from 10 mg to the physiologic range of 4 mg. She has had normal renal function since then. Now more than 30 years posttransplantation, she bears to my knowledge the longest surviving renal allograft in the world in a patient whose indication for transplantation was diabetes-associated renal failure. Her serum creatinine is 0.9 mg/dl.

Marcia has taught her attending physicians many medical lessons, not the least of which was the inherent possibility of achieving long-lasting donor-specific tolerance to a mismatched cadaveric kidney. The greatest lesson, however, has been how to live a heroic life. Rather than withdrawing from society, she plunged into useful activities working as a volunteer in numerous non-profit organizations. In addition to establishing a vacation center for victims of renal disease in the Rocky Mountains, she became a leader of diabetes control and liver disease foundations, and brought into her extended family more than 100 surrogate children, hiring many of them to help her service-oriented life.

At the time Marcia underwent transplantation, the 3-year mortality of patients with her medical condition was essentially 100%. Thirty years later, she can look back on her posttransplant life with profound gratification. She has received many distinctions, and is regarded as one of the great women of Colorado, and of the world. It is appropriate that her photograph, taken at her 30-year celebration, is with her loving husband, Randy.

Submitted by:
Thomas E. Starzl, MD, PhD

For the record:

Transplant:	**Cadaver Heart Transplant**
Date:	**December 21, 1979**
Hospital:	**Stanford University Hospital**
Surgeon:	**Bruce A Reitz, MD**
Age: At transplant: **28**	Current: **51**
Years Graft Function: **23**	

JOHN LABISSONIERE

My Story...Stanford Heart Transplant #182

This year marks the 23rd anniversary of my heart transplant. Just yesterday, it seems, I was having a conversation with the world's longest living heart transplant at the time, Willem Van Buuren. He had survived 23 years, and I remember how amazed I was at that seemingly unachievable record. Today I've matched his record and I'm doing so well that the doctors are tapering my anti-rejection medication. The heart is now mine.

Let me start this part of my story by saying that "well" is a relative word. It has been a bittersweet 23 years. I have had moments of supreme ecstasy, and moments where I didn't care if I lived or died. I have reveled in the warmth and love of friends and cried in the realization of being terribly alone. But these experiences have been granted to me by one thing: my heart transplant. By now, I would have been long, long gone without it.

The first thing I remember after the transplant sur-

gery was complete peace and quiet. My "old" heart had pounded in my chest incessantly. That, along with a popping and ticking ball-in-cage heart valve, was something I could never get away from. The pounding, ticking heart was gone now, replaced by a softly beating gift of life. The smiles on the faces around me told me that I was one of the lucky ones. I had cleared the first hurdle!

And the hurdles seemed to get easier and easier. But that was for me; not so for my fellow transplants in the rooms around me. This was probably the toughest part of my stay in the glass cage. Why was I doing so well, I'd often ask myself, followed by when was it my turn to get sick? I wouldn't realize the significance of these questions for many, many years. But now it was full steam ahead, and in 37 days I was out of the hospital.

The agenda for my life was packed. I had spent more than 6 years feeling sick and worn out, and there was a lot of catching up to do. The first thing I wanted was a bicycle. I had ridden an exercise bike in the hospital, but I wanted to ride free and feel the wind in my face. Despite the warnings from my parents that I was a heart patient and might fall and hurt myself, I rode with a passion only those with a second chance at life could understand. The thrill of seeing my legs moving beneath me – the same legs that had been like thousand-pound weights months before – brought tears to my eyes. Within weeks I was riding 20 miles a day.

All this joy came to an end in February 1980, when I contracted pneumonia and later, septic shock. Nothing before or since has affected me like this second-to-second battle with death. Up to that point, hospitals had always been safe places for me, places to go when I needed help. Now the hospital was a prison. I was a heart transplant, an experiment, and no one really knew what could go wrong. Only my determination "not to die in this place" seemed to keep me going. And where was God, the force in which I had always relied on in the past? He was there! It would take years of self-destructive behavior for me to realize that God was always there, even in the very worst of times.

In the months that followed, I tried to get back on track with exercise and thinking positive, but the close brush with death took too much out of me. The world seemed different now; the myth that I was somehow protected from harm was gone. I wanted to escape, and found solitude in my model railroad. I'd spend hours in my spare bedroom, building and shaping my make-believe world. The real world – and my place in it – had become too terrifying. But the retreating didn't set well, especially with my new wife. Only months after our marriage, she decided she'd had enough. I was completely alone and haunted by the constant fear that no one would be there to take care of me if I got sick.

A little over a year after my transplant, things seemed quite bleak. Too proud and afraid to ask the doctors for help, I began to vent my frustrations by writing everything down. And I did a lot of writing! One day, my now ex-wife read some of my work and suggested I go back to school. I took her advice, and within weeks I was sitting in a college classroom. It was difficult for me to share my stories, but my classmates seemed truly interested, despite my trembling, shaking voice. A few weeks later, I got one of my stories published in a local magazine. Things were beginning to look up. Not only did I have a chance to go to college, but I also had the thrill of seeing my work in print – all because of the transplant.

I was now at the top of my form. Over the next year, I had 2 more articles published and was working a manuscript for my book. I began to do volunteer work for the American Heart Association, speaking to groups about my transplant experience and helping with publicity. A short time later, I became a staff member for the AHA and, separate from the heart association, co-founded a support group for transplant recipients and their families. I had also met and fell in love with the woman of my dreaMs Life had indeed come to me. But, there was still something wrong. Despite my busy life and all the people in it, I couldn't get away from the question, "how long was this going to last?"

So I retreated again, this time with alcohol. The stories are as old as time, but it started innocently with social drinking and ended years later with me facing the thing I had desperately tried to run away from: a second-to-second battle with death. The saving grace this time was 7 months in a recovery house. This, along with years of therapy, I attribute to the second saving of my life. The transplant saved my physical being; recovery saved me.

That was nearly 6 years ago. Today I am a healthy and sober individual. I still work for the American Heart Association, and still speak to groups occasionally about my experience. I'm also in the process of writing my book again. But there is one major difference between then and now: I have accepted what has happened to me. And, probably even more important, I've accepted what *will* happen to me. Since that day in 1973 when I found out I had heart disease, death had been my mortal en-

emy; I had fought it tooth and nail. Now, that doesn't seem to matter anymore. I am finally grateful for this day and this day alone. And despite all the difficulties this transplant life may bring, I can finally say I am living life with very little thought of the transplant. After all, isn't that what the transplant program is all about?

SURGEON'S REPORT: JOHN LABISSONIERE

I was privileged as a young cardiac surgeon in December of 1979 to perform the heart transplant for John Labissoniere. These many years later, it is so gratifying to see the promise of transplantation materialize for him. At the time of his surgery, we felt that it was somewhat of a challenge because very few patients with the diagnosis of corrected transposition of the great vessels had undergone a heart transplant.

John had been born with transposition of the great vessels, with his right ventricle serving as the main pumping chamber. He had previously undergone a valve replacement because of insufficiency of the tricuspid-type valve in that ventricle, and had gone on to develop a massively enlarged and poorly contracting ventricle, which caused him to have severe heart failure. With the transposition of the great vessels, there was some concern about exactly how to connect the normal donor heart in the patient whose great arteries were reversed.

The strategy we developed was to harvest as much as possible of the ascending aorta and pulmonary artery of the donor heart in order to "correct" the transposition. By removing the entire aortic arch of the donor, as well as the pulmonary artery bifurcation out into the hilum on both sides, there was adequate material to reroute the aorta to the left and the pulmonary artery towards the right. When we looked into the literature at that time, we found that there had been no previous report of this, so his operation was described in detail in the paper entitled "Method for Cardiac Transpantation in Corrected Transposition of the Great Arteries," which was published in the Journal of Cardiovascular Surgery, Volume 23, page 293, 1982. A year after his transplant procedure, an aortogram was done showing the new anatomy of the aorta, and that was also used as an illustration in the case report.

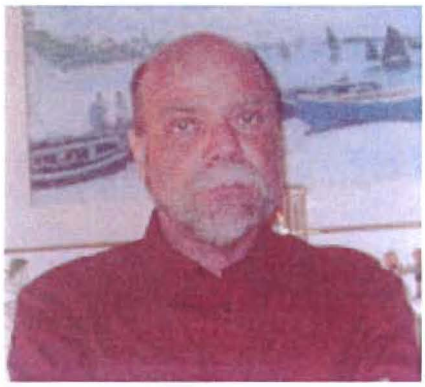
Despite the unusual technical considerations, which were easily taken care of, the mystery of his wonderful compatibility with the donor is still an unknown, which we desperately wish we could understand better. It might enable us to provide this type of wonderful outcome for all of our patients.

Submitted By:
Bruce A Reitz, MD

For the record:

Transplant:	**Living Donor Pancreas Transplant**
Date:	**November 4, 1982**
Hospital:	**University of Minnesota**
Surgeon:	**David ER Sutherland, MD, PhD**
Age: At transplant:	**30** Current: **50**
Years graft function:	**20**

WILLIE LAMB



My transplant odyssey began with my mother reading a small article about an experimental pancreas transplant done at the University of Minnesota Hospital. She mentioned the story at the dinner table one evening and it caught my father's interest. He had no information on how to contact the transplant office so he started with the local operator and worked his way through to the operator in Minneapolis who connected him to the hospital. The hospital connected him to the transplant office where they told him they would send an information packet. Within several days we had a severe case of information overload and a great deal to think about. My family was far more excited about the prospect of a transplant than I was but I felt it couldn't hurt to go along for a while. The next step was a tissue typing to find a donor. You would think it difficult to trash family members for

spare parts, but with my family you couldn't keep them away. In the end, my 3 sisters Chris, Mary and Rita were tested at Downstate Medical Center in Brooklyn, New York. Several weeks later we were told that Rita was a good match and would we like to come to the University Hospital for a week of testing. It was at this point I began to think that this might actually happen. My parents, Rita and myself flew to Minneapolis for a week of tests that left us believing we were the best-documented beings on the planet. We all went about our lives for a month or so wondering what if anything would happen next. Late one afternoon the call came, telling me that I was a good candidate for the transplant and we would have to return for more tests soon.

I now had to contend with a lot of difficult choices. It is one thing to risk your own life but to risk your sister's health and well-being is a difficult decision. Rita made the decision easier by insisting that the transplant be done with her as the donor. She had the family behind her so that was that. Now I wondered how I would react if the operation failed. I had neuropathy, retinopathy, uncontrollable blood sugar levels and the beginnings of kidney trouble. I decided at this point there was nothing to lose. We went for the first set of tests to begin the transplant protocol in the fall of 1982. This was when we came across the biggest problem most transplant patients face, payment. The hospital checked with my insurance carrier and they explained that it wasn't their decision to make but that of a corporate officer at United Technologies Corporation. The company I worked for was a business unit of UTC and I was surprised to see that they took such an interest in the employees. I was warned it was unlikely that anyone would be willing to foot the bill for what was considered experimental surgery. Less than an hour after the request was made, we were told that UTC would pay for the operation. Everyone involved was surprised and very happy. My parents, Rita and I flew home to wait for a date.

We have all wished that we could wake up from the nightmare that our lives have become at one time or another. Shortly thereafter most of us realize that this will not happen and deal with the problem as best we can. On November 4th 1982 I awoke from a nightmare that started when I was 8 years old - diabetes. I was 30 and had just come-to after many hours of surgery to realize I was still alive. So far so good! The next couple of days were a constant swirl of doctors, nurses, technicians and family. My graft began to work almost immediately, which surprised almost everyone except for the people who were praying for this miracle. Almost everyone who read my chart attached to the door agreed that there was more at work here than medicine. The days passed and I was moving up and down the hall dragging IV poles, pumps, and the hated NG tube as if doing my best impression of Frankenstein. They removed my NG tube and I discovered that although I was finally allowed to eat solid food, I couldn't. Unfortunately this was short-lived and by the time I was discharged I had gained over 60 pounds. Along with the medications and the surgery this newfound weight was making me miserable! The doctors, nurses and support staff on the transplant station at the University of Minnesota Hospital were very warm and understanding even though there were times I am sure they wished they could be rid of me. Their dedication and talent is beyond words.

I arrived home just before Thanksgiving feeling tired, bloated and generally uncomfortable but glad to be home and alive. Rita was doing well and we all enjoyed the holiday. Ten days later I woke up to a pain in my stomach, which grew worse by the minute. My parents took me to a local hospital where they didn't have a clue what to do for me and seemed skeptical about the transplant. My mother talked to the Transplant Office and they decided that it would be best if I would return there. I returned to the University of Minnesota Hospital for tests only to discover that there was nothing wrong. This is the only episode that I can attribute to the transplant in over 20 years! The next 10 months were an exhausting marathon of blood tests, doctors' offices and work. During all of this I began to notice the feeling coming back to my legs and gradual reduction in the pain from the neuropathy. We never expected the neuropathy to virtually disappear but this was very welcome. The first year post op was very difficult but after that I began to feel normal. Feeling normal doesn't sound like such a big deal but anyone who has lived with diabetes and its complications will tell you it is their greatest aspiration in life. I can do anything anyone else can without the fear that my diabetes will react badly. My blood tests are all normal with no indication of trouble. I am now 50 years old and work full-time at a job that is physically demanding and mentally challenging. I haven't used a sick day in 2 years. Working out 3 nights a week and watching what I eat keeps me feeling great and in the best shape of my life. None of this would be possible without the transplant and all those who came together to make it possible.

With the grace of God, the skill and dedication of Dr David Sutherland along with the doctors, nurses, technicians and other support personnel at the University of Minnesota Hospital, as well as the doctors who monitor my health in New York, the sacrifice and support of my sister Rita and my entire family, my dream of a normal life has come true.

SURGEON'S COMMENTS: WILLIE LAMB

Mr Lamb currently has the second longest functioning graft (>20 years) in the University of Minnesota series of more than 1,600 pancreas transplants dating back to 1966. The only longer functioning graft is a segmental pancreas transplant done in December 1980 with duct injection from a living donor (LD) who had previously given a kidney to the recipient. Mr Lamb had not had a kidney transplant and has the longest functioning pancreas transplant alone (PTA).

At the time of his transplant, we were doing a comparative study of outcomes in enteric-drained versus duct-injected pancreas grafts from both LD and cadaver (CAD) donors.

LD segmental pancreas transplants were initiated at the University of Minnesota in 1979, not because of a shortage of CAD donors, the driving force behind most LD transplants of all kinds today, but because of the high rejection rate of pancreas transplants and the observation in kidney recipients that the rejection rate was much less with LDs. Indeed, that turned out to be the case with pancreas transplants, especially with the LD segmental transplants we did in diabetic recipients of a previous graft from the same donor, a situation where an anergic state to the donor had already been established (Transplantation 1984; 38: 625).

With PTA we still had a high rejection rate with LDs until cyclosporine began to be used. Thereafter, the rejection rate was low with LD segmental grafts, regardless of match. Mr Lamb was done in the pre-cyclosporine era but had the advantage of an HLA-identical sibling donor. On the other hand, we had a recipient of an HLA-identical sibling PTA done the year before who had the graft fail within a year because of biopsy-confirmed recurrence of disease, as shown by selective loss of pancreatic islet beta cells, mimicking the original autoimmune etiology of Type I diabetes (Transplantation 1982; 34:330 & Lab Invest 1985; 53:132). Thus, it was possible to have an immunosuppression regimen sufficient to prevent rejection of an HLA-identical sibling graft but not recurrence of disease. Fortunately for Mr Lamb, he escaped both rejection and recurrence of disease, as evidenced by his course and that of many other LD PTA recipients (Ann Surg 2001; 233:463).

We have now done over 120 LD segmental pancreas transplants, ~7.5% of our entire series. The proportion of LDs was much higher 20 years ago when the rejection rate of cadaver donor solitary pancreas transplants was high. Now that it has become low, emphasis on LD pancreas transplants has shifted to the simultaneous pancreas-kidney (SPK) category (Ann Surg 1997; 226:471). An LD SPK transplant allows elective correction of uremia and diabetes by one operation without a wait. However, as more non-uremic diabetics seek pancreas transplants, waiting time for solitary cadaver pancreas transplants will increase to the point where the incentive to have the graft from a LD will also be increased. Willie Lamb shows how well a LD solitary pancreas transplant can do long term.

Mr Lamb also illustrates some other points. First, the financial aspects: no coverage, no transplant, unless paid out of pocket. Pancreas transplant did not develop with grant support or by writing off expenses by the University of Minnesota Hospital, but by imposing both medical and financial requirements for proceeding. Second, pancreas transplant recipients provided the first evidence that constant euglycemia had a beneficial effect on diabetic complications, in Mr Lamb's case on neuropathy, proving that they truly were secondary (Transplantation 1988; 45:368 & N Eng J Med 1990; 322:1031) well before the Diabetes Control and Complication Trial (DCCT) was completed (N Eng J Med 1993; 329:977).

Submitted by:
David ER Sutherland, MD, PhD

For the record:

Transplant:	**Living-Donor Pancreas Transplant**
Date:	**December 8, 1983**
Hospital:	**University of Minnesota**
Surgeon:	**David ER Sutherland, MD, PhD**
Age: At transplant:	**38** Current: **57**
Years Graft Function:	**19**

SALLY BECKER

The nurse at my bedside explained to me that I was finally conscious after a 3-day coma. My blood sugar had set a record up to that date in the New York metropolitan area for one to survive. After a deliberate fast to lose weight, I was a 15-year-old Type I diabetic.

After 23 years of diabetes, at the age of 38, I had a pre-proliferative retinopathy and early peripheral neuropathy, in addition to advancing nephropathy (heavy proteinuria [3-4 gm/day]) and decreasing creatinine clearances. As an RN, I was fully aware of how far these complications could go and had little hope for the future. I had rejected the idea of kidney transplantation as I had cared for a diabetic patient who lived 8 years after a kidney transplant but was blind with bilateral below-knee amputations. The prospect of a pancreas transplant represented the possibility to remain an independent and productive person, and the chance to live longer and enjoy a higher quality of life.

Now, 19 years later, each day reminds me of the gift given to me by my sister, Barbara. That segment of her pancreas has given me a life, which is very full and wonderful. I've gotten to see my children grow up and develop into fine, caring, responsible adults, and I've had the pleasure of knowing grandchildren. I've gone to many interesting and exciting places and have experienced so much: rafting the Grand Canyon, canoeing the Salmon River, canoeing and snorkeling in Honduras, touring Ireland, camping and canoeing in the far woods lake country of northern Saskatchewan – to name a few in recent years.

Since the transplant, I've continued to work full time in critical care and medical-surgical nursing at our county hospital and to teach fellow RNs and patients about diabetes, as well as other aspects of medical and critical care nursing. My experiences as a patient have given me empathy and a better understanding of my patients' needs. Despite being immunocompromised secondary to antirejection medication (Cyclosporine, Prednisone, Cellcept), I've been very fortunate in not contracting any conditions or illnesses from my patients.

Although I continue to be active, I do experience some limitations imposed by osteoporosis (bone fractures), deteriorated vision (macular edema, retinal tears with hemorrhages, cataracts), and frequent skin cancers (23 squamous cell carcinomas in the past 5 years). Through vigilant heath care and a positive attitude, I look forward to years of continued enjoyment of life.

SURGEON'S REPORT: SALLY BECKER

Ms Becker is a vibrant recipient in a series of living donor (LD) pancreas transplants alone (PTA) that began at the University of Minnesota in the late 1970s, an era when the rejection rate of cadaver (CAD) PTAs was extraordinarily high. We had just begun to use cyclosporine for PTAs when Ms Becker received her graft, and we were still uncertain of the relative risks for rejection with LD versus CAD donors, but even though the results with CAD PTAs improved, our guess for the long-term was correct: late rejection of LD PTA grafts would be rare (Ann Surg 2001; 233:463).

Although we are very liberal in accepting candidates for PTA today, even without diabetic complications or just with metabolic control problems, at the time of Ms Becker's transplant most had 2 or more complications, in her case classic triopathy. Again, the reversal of the lesions by graft-responsible constant euglycemia preceded the DCCT in showing that the complications are truly secondary, and almost certainly Ms Becker escaped end-stage renal disease by lieu of the pancreas transplant.

Ms Becker also reveals the improvement in well-being that occurs. I will never forget the periodic calls I received from her as she renewed her athletic life in a

non-diabetic state, including while on a ski vacation. She was transplanted in an era when prednisone was a mainstay of immunosuppression. Now steroids are disappearing from the scene as modern protocols evolve. Nevertheless, it is evident from her testimony that the tradeoff to be insulin-independent was worth the price.

Submitted by:
David ER Sutherland, MD, PhD

For the record:

Transplant:	**Cadaver Pancreas**
Date:	**May 21, 1983**
Hospital:	**University of Minnesota**
Surgeon:	**David ER Sutherland, MD, PhD**
Age: At transplant:	**33** Current: **52**
Years Graft Function:	**20**

NOREEN HARMER

"Every day for the rest of your life you will need to take a shot of insulin to stay alive," my doctor said as I lay in the hospital bed. It was 1960 and I was 10 years old. "Diabetes," he said. I had never heard of it. That word changed my life in a thousand ways. It was the first of many moments in time where a doctor's statement turned my world upside down. Later that week I heard the same doctor talking to my Mom down the hall. "She probably won't live to be 18," he said. Over the next few years many doctors said to me, "chances are you won't be alive to see 40." In the 1960's and 1970's that was commonly true with Type I Diabetes.

There were several difficult events over the next 20 years. In 1980, several doctors later, in another city, with another infection that wouldn't heal, this physician said, "If you are alive in 10 years, you won't want to be," with defeat and sadness in his eyes. Next, in my silence, he asked, "Have you heard they are doing pancreas transplants? I probably shouldn't tell you, it's dangerous, but I can't stand watching your life waste away." My response was simple. "Where do I sign up?" I had developed most of the complications of diabetes; the future looked bleak. And so began a 3-year period I called "the pursuit of cyclosporine." I became one of the first to take this new transplant medication, which was revolutionary to the success of transplantation.

After a year of numerous phone calls and letters I finally went to the University of Minnesota where I got the results of my pancreas transplant workup from Dr David Sutherland. "Yes, your diabetes is more life-threatening than the risk of immunosuppressive drugs. We know from your kidney biopsy that you will have kidney failure in 2-3 years. Come back then and we will give you both a kidney and pancreas at the same time." My immediate response was, "Since it's the diabetes that's destroying my kidney, why not give me a pancreas first and save my own kidneys?" Dr Sutherland said "We'd love to believe that could happen but we don't know if it will." "So let's find out," I replied. Dr Sutherland had to convince the board before I was placed on the transplant list.

Ten years later Dr Michael Maurer, the nephrologist, sent me a copy of his article from the New England Journal of Medicine and a thank-you card. We had proved the reversal of renal disease in pancreas transplant patients. The research changed many lives. My risk was well rewarded. I have now had my pancreas transplant almost 20 years, just a little less than the time I struggled with my Type I diabetes. I refer to my life in the 1960's

and 1970's as my "last life." Improvement in quality of life – yes- about 300%!

In the life I started in 1983 with my new pancreas I have stayed very busy, feeling that I'm making up for the time when the complications of chronic disease affected both my body and spirit. During the first year after my transplant I went back to college and completed a degree in Health Education. In 1985, I started and developed a Diabetes Education Department at our local hospital. I asked for an appointment with the CEO of the hospital. I explained to her that there was a great need for Diabetes Education in our area. "What makes you think you can run this program?" My answer was "I may not know what to do but I know what NOT to do because I've been on the other side of that desk for many years." I started my new career that next Monday. The program developed and grew rapidly. A few years later during a job evaluation, the only negative comment was the I "may be too involved with my patients." I tried to give the hope, knowledge, and empathy that I had not received from my health care professionals.

It helped most of the patients too, that I truly did understand their fears and frustrations. I told them about the days of no blood glucose meters, glass syringes that had to be boiled, my painful nerve damage and the laser treatment that saved my sight. The focus of my work is always on prevention and hope.

In addition to my work in Diabetes Education, I had the energy to design and build my own home. Not only was I able to see my son graduate, but I was also present when my granddaughter was born. My mother had a terminal illness and I was there to help her through it and she died peacefully at home surrounded by her family.

There are, of course, some difficult issues of living with a compromised immune system. Several rejection episodes required immediate plane trips from Michigan to Minnesota. There have been viruses that wouldn't go away and the constant vigilance with the medications and maintaining good health insurance. Those things are so minor compared to the fact that I had reversal of my diabetes complications.

My long-term success included the effort of many people – continued care form my transplant team, help from my local physicians and their staff, support and encouragement from my family and friends. Most of all, in reflection of what might have been, I simply thank God I was given a choice.

SURGEON'S REPORT: NOREEN HARMER

Ms Harmer was one of the first pancreas transplant alone (PTA) recipients of a cadaver (CAD) graft treated with cyclosporine at the University of Minnesota.

In the first series of 14 pancreas transplants at the University of Minnesota from1966-1973, under the direction of Dr Richard Lillehei, the last 3 were non-uremic recipients of cadaver PTAs. Unlike his experience with simultaneous pancreas-kidney (SPK) transplants, where graft loss from rejection was rare even with the immunosuppression of the time, all 3 PTA recipients rejected the graft within a few weeks (Acta Endocrin 1976; 83 (Suppl 205):303). Thus, when the current pancreas transplant program at the University of Minnesota began in 1978, for PTAs as well as pancreas after kidney (PAK) transplants, we began using living donors (LDs) in order to reduce the rejection rate.

In the pre-cyclosporine era, LD pancreas grafts did indeed have a reduced rejection rate compared to CAD donor grafts, and especially in the PTA category where until Ms Harmer's transplant, all 8 recipients of pancreases from CAD donors had rejected in <1 year. In contrast, most of the LD PTA and PAK grafts were functioning, as well as some of the CAD PAK grafts. Our reliance on LDs at this point is reflected by our numbers. Of the 72 pancreas transplants done from July 1978 until Ms Harmer's, in the PAK category, 11 were from LD and 34 were from CAD donors, while in the PTA category, 19 were from LD and 8 were from CAD donors; all 8 in the latter subgroup had rejected in one year. Thus, it was apparent that our immunosuppression protocol for CAD PTA recipients was inadequate. We were able to get cycloporine on a compassionate need basis for Ms Harmer, and the cases to follow, prior to its licensing by the FDA in 1984. Ms Harmer was the first PTA recipient in our series to have a CAD donor graft function (defined as maintaining insulin-independence) for >1 year, and indeed the graft is still functioning now some 20 years later.

Her success encouraged us to continue to emphasize PTA as much as SPK or PAK transplants in our program, and of the nearly 1,600 pancreas transplants done at the University of Minnesota through 2002, >400 have been in the PTA category.

Ms Harmer got off to a rocky start. At the time we were comparing enteric drainage and duct injection (DI),

and for CAD pancreas transplants we were using the whole pancreas without the duodenum. Although DI had been associated with relatively few technical complications, Ms Harmer's graft developed hemorrhagic pancreatitis that, on re-operation, was found restricted to the tail, probably because the polymer had obliterated only the ductal system in the head and triggered pancreatitis by obstruction of a tail that had retained full exocrine secretory activity. The tail was simply resected and the proximal pancreas (head) had sufficient endocrine (beta-cell) reserve to maintain Ms Harmer in an insulin-independent state.

Ms Harmer experienced one rejection episode, diagnosed by slight elevation in basal glucose levels and confirmed by open biopsy. Unlike ED pancreas grafts, monitoring for rejection in duct-injected grafts was difficult because exocrine markers were obliterated. The next year we began to do bladder drainage for PTAs, after the lead of Sollinger in resurrecting urinary drainage for SPK pancreas transplants. In the PTA cases, the technique was most valuable because it allowed urine as well as serum pancreas exocrine enzyme activity to be used as markers of possible rejection in a situation where serum creatinine levels were not relevant to the process. However, Ms Harmer did not have that advantage, and almost certainly was prevented from rejection because of cyclosporine.

Ms Harmer had relatively advanced diabetic nephropathy on a pretransplant native kidney biopsy and, along with other CAD and LD PTA recipients, participated in a study of its course by Dr Michael Mauer by undergoing serial posttransplant kidney biopsies. She was one of several in whom the lesions of diabetic nephropathy resolved between 5-10 years after transplantation, a remarkable contribution to clinical research (N Eng J Med 1998; 339:69).

Almost for certain Ms Harmer would have progressed to end-stage renal disease had her diabetes not been corrected. Certainly she was aided greatly in achieving her personal and professional goals by having life-time function of a pancreas graft.

Submitted by:
David ER Sutherland, MD, PhD

For the record:

Transplant:	**Cadaver Pancreas Transplant**
Date:	**December 15, 1985**
Hospital:	**University of Minnesota**
Surgeon:	**David ER Sutherland, MD, PhD**
Age: At transplant:	**32** Current **49**
Years Graft Function:	**17**

BONNIE SMITH

If Only My Heart Could Talk

On December 15, 1985, I received a Pancreas Transplant at the University of Minnesota. I was 32 years old and had Juvenile Diabetes for over 18 years. That day would be the beginning of a new life for me...a journey, which I had pursued as the complications of long-term diabetes now controlled every moment of my life and of my family's too. I was having severe low blood sugar attacks, retinopathy, kidney changes, neuropathy and my future looked very dim. My quality of life was poor and I had almost given up when I was given the hope of a pancreas transplant at the University of Minnesota. Dr

Sutherland had been experiencing success with his Pancreas Transplant program reaching out to patients who were in early stages of their diabetic complications. His hope was to succeed in alleviating complications from progressing and have patients experiencing a reversal of their complications. Even upon learning of the risks involved with surgery and the unknown risks of long-term immune suppression medications, I decided having this transplant was much better then staying diabetic. I decided that if diabetes was going to take me, it was going to have a fight on its hands. I had a desire to help not only myself, but other diabetics through research even if

it meant that I might give up my life. At this point it was worth it. My last words to my husband as I left for surgery early that December morning were "I hope you understand that if something happens, this is something I had to do!

So now how do I describe the last 17 years? Words like miraculous, wonderful, and healthy come to mind first. I now had a future. My hopes to extend my life have been exceeded, my hope for adding quality to my life surpassed. I finally remembered how to feel good. I traded medical conditions that require education, dedication and determination in order to maintain the best health possible. I started new medications and going to labs on a regular basis. They were intense the first year, but a balance was reached and I now live what most consider a normal life. No more highs and lows of blood sugars that left me dependent on others - so dependent that I could not be left alone for fear of reactions. No more clock watching, shots, frequent blood sugar monitoring and I did not have to eat if I did not want to. It was as if a heavy cloud that hung over my head had passed and I felt the sunshine for the first time in a long time!

My diabetes was and is no more. I have continued to follow Dr Sutherland's follow-up studies to help with their successful transplant program and tracking of transplant patients. Each patient brings a unique quality to learning more as our transplanted organ survives. I participate in Dr Mauer's kidney studies at the University of Minnesota. Kidney biopsies taken prior to transplant and during the first 15 years afterwards have provided proof that having regular blood sugars reversed my kidney damage. I also participate in the study program of Dr Robertson at the Pacific Institute in Seattle, Washington named "Glucose Potention of Arginine-Induced Insulin Secretion". Another benefit I experienced as a result of my new pancreas was a significant improvement in the loss of feeling that was caused by the neuropathy. My eyesight has remained stable. So the promises and possibilities have become realities.

Over the last 17 years, I have experienced some side effects of the immunosuppressive drugs. There have been some challenges but nothing to compare with what the diabetes had done to me. The main effects of the use of my medications include: Cyclosporine (Neoral) has caused some skin conditions that require regular treatment. I have lost some skin quality and have experienced some basil skin cancers, all of which have been treatable. Predisione has depleted my bone density, which has resulted in bone fractures, but taking Fosamax has helped create a balance. I have been very fortunate that the side effects have been minimal. Most people who know me now would never guess that I have had health problems or that I have had a transplant. Not that I try to hide it, but I have certainly surprised a few people! I have been honored and willing to speak to groups about my pancreas transplant experience and enjoy helping others who are pursuing their own transplants. The joy this has provided me cannot be measured. Being able to give back to others for what has been given to me is extremely gratifying.

What is my life like? I was unable to work outside my home before my transplant but in January 1986, I started working part time and now work full time for the State of Nebraska as an Administrative Assistant. I love the freedom of being independent and having a career. It has added to my quality of life. Most important, I got to celebrate 31 years of marriage to my husband Tim. We love to dance and travel. I was able to see our daughter Jennifer, graduate with her Masters Degree in Education and get married to her husband Alan. They have blessed us with our first grandson, Davis, and now we are looking forward to the arrival of our new little granddaughter. They all have joined me during this journey through the good times and bad. They are my reason for living and my transplant has given me life.

I also would like to take a moment to share a few words of love for my donor, a young man who died at the age of 23 and to his family, who, during their grief reached out, thought of others and me that day and gave us the gift of life. Their son lives on within me and not a day goes by that he is not in my thoughts and prayers.

I have been given a new life, a wonderful life and if only my heart could talk I would then feel like I had finally been able to express how I truly feel. I would be able to express my thanks to Dr Sutherland, the transplant team, my donor, and my family and to my God adequately. I have been blessed and I am happy, healthy and anxious to continue this journey that started with a whisper of hope, a desire to help, and a will to live.

SURGEON'S REPORT: BONNIE SMITH

A variety of surgical techniques were compared in the new series of pancreas transplants begun at the University of Minnesota in 1978 (Ann Surg 1984; 200:414), but Bonnie Smith's transplant was the first to revert to

the technique of whole pancreatic-duodenal transplantation with duodeno-enterostomy for enteric drainage that had been used by Lillehei in the 5th through 12th of his 13 cases, including 3 in the PTA category (Ann Surg 1970; 172:405). The technique Lillehei employed in his last case (4th PTA), whole pancreas transplantation with retention of only the graft papilla of Vater for anastamosis to recipient bowel (Acta Endocrin 1976; 83 [Suppl. 205]: 303), was used in several cases of the new series prior to Bonnie Smith's transplant, but it was labor-intensive. Avoiding the step of complete duodenectomy shortened the time spent during procurement or benchwork, and made the enteric anastamosis technically much easier. Other groups had also begun to use variants of the original Lillehei technique, but until Ms Smith's case, an exact replication had not occurred. Starzl, at the University of Pittsburg, reported a series of enteric-drained whole pancreatico-duodenal-jejunal transplants (Surg Gynecol Obstet 1984; 159:265), but the length of bowel was much longer than what Lillehei used (Ann Surg 1970; 172:405). Ngheim and Corry at the University of Iowa prepared the pancreatico-duodenal graft in a fashion similar to that of Lillehei, with a segment of bowel that encompassed only the donor duodenum, but in the recipient they did bladder-drainage via a duodeno-cystostomy (Am J Surg 1987; 153:405).

Bonnie Smith was the initial recipient in a series of whole pancreatico-duodenal transplants comparing enteric vs bladder drainage for solitary pancreas transplants (Surgery 1987; 102:680), much as we had earlier compared duct injection and enteric drainage. The analysis of data in the late '80s showed that for solitary pancreas transplants the rejection loss rate was lower with bladder than with enteric drainage, primarily because more rejection episodes were diagnosed and treated early enough to reverse the process in the BD group (Transplantation 1987; 43:71), especially in the PTA category (Surgery 1988; 104:453). Bonnie Smith, fortunately, was one of those in the ED group who escaped having a rejection episode at all and who is now in the subset of recipients who seems destined for life-long PTA function.

She was the 126th pancreas transplant overall and the 66th PTA recipient in the new Minnesota series begun in 1978, showing the emphasis we gave early on to beta cell replacement in non-uremic diabetics. Because of the availability in the mid-1980s of cyclosporine and the resultant decline in rejection rates, by the time of Ms Smith's transplant the proportion of PTAs from CAD donors had increased (with her transplant, 43 PTAs were CAD, 23 LD). There was no shortage of CAD donors given the availability of a national pool for the solitary transplant candidates listed at Minnesota.

Ms Smith's course was typical of the non-uremic recipients with persistent pancreas graft function: secondary complications were ameliorated, including resolution of biopsy-proven lesions of diabetic nephropathy (N Engl J Med 1998; 339:69). However, her testimony is also typical of the diabetic patients who found the management of glycemia by exogenous insulin so difficult—free, free at last!

Submitted by:
David ER Sutherland, MD, PhD

For the record:

Transplant:	**Cadaver Kidney Pancreas Transplant**
Date:	**October 10, 1986**
Hospital:	**University of Minnesota**
Surgeon:	**David ER Sutherland, MD, PhD**
Age: At transplant:	**37** Current: **53**
Years Graft Function:	**16**

MARY JANE HOUSTON

"Does diabetes run in your family?" At those words, my mother paled and almost fainted. That was the day that I, 13 years old, was diagnosed a diabetic. The only diabetic in our family was my father's cousin who was blind, had both legs amputated, and was on his deathbed. My parents were devastated, but I wasn't because

my youth prevented me from believing that I would ever face any of those probleMs

A routine began which included boiling syringes, checking my urine for sugar, counting calories, and making regular visits to my doctor. As time progressed, I moved on to disposable syringes, becoming the first insulin-dependent diabetic to live on campus at Clemson University, marriage, and a beautiful 6-pound daughter born in a military hospital after 2 months of hospitalization with specialized care.

Although I had been an insulin-dependent diabetic for more than 22 years and had been constantly warned about the complications of diabetes, I was truly shocked when my eyes began to hemorrhage in 1985. My ophthalmologist used the laser as much as he could and then sent me to a retina specialist for a vitrectomy on my left eye.

A few weeks after the vitrectomy, my endocrinologist informed me that my kidneys were deteriorating very fast. When I looked around for help, someone told me about pancreas transplant research being done at the University of Minnesota. I called immediately and requested information and an application.

"You will trade in one hell for another!" These were the first words that Dr Sutherland said to me when I met him at the research clinic. He explained that the immuno suppressive drugs that the transplant would require could have serious side effects. He talked about the possible side effects, the monitoring for rejection, the drugs, and the expense over time, other risks, and the lack of guarantee. He did not paint a pretty picture. During the week of evaluation, I was tested for degree of neuropathy, nephropathy, and retinopathy. I thought that I had received every test possible including psychological tests. When I returned home, I carried a lot of mixed emotions and some serious reservations concerning a pancreas transplant. No on had said the magic words: "You will do fine".

Dr Sutherland called me on October 9, 1986, and told me that he had a cadaver pancreas and that it seemed to be an excellent match for me. I knew immediately what I should do but I asked him to give me 10 minutes to talk to my husband. My husband said "Go for it". When I called Dr Sutherland back, he told me to get on the next plane for Minneapolis and he would do my transplant as soon as possible after my arrival.

Dr Sutherland talked with me at the transplant center and presented me with another decision. One of the cadaver donor's functioning kidneys was also available. We knew that my kidneys were deteriorating and that the drugs were toxic to the kidneys, so Dr Sutherland asked if I would let him transplant the cadaver kidney with the pancreas in hopes that the transplanted kidney would take some of the pressure off of my native kidneys. He explained that the pancreas and the kidney would empty into the bladder and that monitoring for rejection would be much easier. He also told me that I would be the first for this particular plumbing.

The transplant went fine. I went from a Type I diabetic to a Class I guinea pig. When Dr Sutherland did a cystoscope (not my favorite thing) in order to view the bladder with the pancreas and kidney connected, several other doctors came to view his handiwork. Just when I thought that the ordeal was over, he sent for a camera to take pictures. I decided then that guinea pigs did not lead peaceful lives. After 2 weeks in the research center, I flew home. If I considered myself a guinea pig in Minnesota, I was a curiosity in South Carolina. I was the first person in South Carolina to receive a pancreas transplant.

The first 2 years after the transplant were difficult. I had to return to Minneapolis with each problem that I encountered. Five trips were due to rejection. I went through treatments using steroids, ALG, and OKT3. My body puffed up so large that even close friends had trouble recognizing me. Although I had returned to teaching 4 weeks after the transplant surgery, the rejection treatments caused me to lose a great deal of time from work. The rejection treatments would keep me in Minneapolis for one to 3 weeks at a time.

Complications due to the transplant, the drugs, and the immunosuppression have caused me many problems over the last 16 years. A few of the problems that I have faced since my transplant include: steroid cataracts, osteoporosis, arthritis, pneumonia which caused me to become septic and kept me unconscious in the ICU for seven days, a herpes zoster ophthaliais infection - which left scar tissue on my left cornea, Charcot's arthritis in my feet, blood pressure problems, and various infections.

I have listed problems relating to my transplant. Now I will mention some of the benefits of the transplant. I have not been insulin dependent since my transplant and my blood sugar levels have remained normal. The retinopathy, both proliferative and background, have stabilized and shown no progression after the transplant. I can read and drive. The Charcot's joint has put me in

braces but I can still walk and retain my independence.

I continued to work full-time for 13 years after my transplant. I took an early retirement with a disability in 1999 because I needed time to take better care of myself. I continue to stay active and enjoy my life. There are no regrets concerning my transplant and I will do it again if necessary. Transplants do not come with guarantees but they do come with hope. I am very fortunate to have the hope that people did not have in the past and that many people do not get the opportunity to experience today.

SURGEON'S REPORT: MARY JANE HOUSTON

Although 10 of the first 14 pancreas transplants at the University of Minnesota, in the pioneering experience of Lillehei between 1966-1973, were done simultaneously with a kidney (SPK), the new series begun in 1978 initially focused on solitary pancreas transplants in non-uremic or post-uremic (previous kidney graft) diabetic recipients. After 149 consecutive solitary pancreas transplant cases (84 pancreas transplants alone [PTA] and 65 after a kidney [PAK] transplant), the first SPK transplant was added to the series in 1986 in a diabetic patient on dialysis. Both grafts (pancreas and kidney) are still functioning at >16 years, as are the organs placed in Ms Houston a few weeks later.

Ms Houston received the kidney graft to preempt the eventual need for dialysis, a need that most likely would have arisen sooner rather than later, if she had had a PTA, from the superimposition of cyclosporine nephrotoxicity on the advanced diabetic nephropathy shown by a pretransplant native kidney biopsy. Of the >600 SPK transplants done since 1986 at the University of Minnesota, nearly a quarter have been preemptive in regard to need for dialysis. Indeed, only ~5% of our PTA recipients (out of ~400 done) have needed a subsequent kidney, either because they have had the pancreas transplant early enough so progression of diabetic nephropathy could be prevented ((N Eng J Med 1998; 339:69), or because candidates thought to be beyond the stage where a reversal of the process could occur were directed towards a cadaver or living donor SPK, or a PAK (~500 done), the latter done most often after a living donor kidney that nearly always allowed the need for dialysis to be preempted (J Am Soc Neph 2001; 12:2490).

Ms Houston got lucky when a free cadaver kidney became available from her pancreas donor, allowing her to receive therapeutic doses of cyclosporine without the need to adjust for native renal function. Otherwise, the rejection episodes she experienced likely would have been even more severe, or to avoid that scenario, the cyclosporine levels would have been kept high, either precipitating the need for a living donor kidney or the need for dialysis while awaiting a cadaver kidney.

Although Ms Houston's recall is that we *unexpectedly* found a functioning kidney in the donor, what was unexpected is that the surgeon on call for the kidney transplant service refused the offers out of fear that the kidneys might be unsuitable because of past infections related to the bilateral cutaneous ureterostomies that had been created in the donor years ago to manage the problem of bladder dysfunction. There was no current infection and the serum creatinine in the donor was <1 mg/dl, so the pancreas service accepted the kidneys, one to use as an SPK in Ms Houston and the other for transplantation to a previous pancreas recipient in need of a kidney. The grafts in both recipients are still functioning.

Ms Houston has experienced side-effects secondary to the immunosuppressive drugs and protocols employed at the time. However, it took time to evolve the steroid-free maintenance immunosuppressive regimens that have now become standard in our program for pancreas and kidney recipients (Transpl Proc 2001; 33:1663).

It is interesting to see how Ms Houston describes the pretransplant counseling, particularly the hanging of the black-crepe, something I think I always try to avoid but obviously not always successfully since it is the patients and not the doctor's perception that is important. I try to express both realism and the optimism she craved, but in her case it did not come through. Nevertheless, her goal of reversing or stabilizing the secondary complications of diabetes was achieved, and the need to manage diabetes was abolished.

Although Ms Houston's impression is that she was the first in our series of bladder-drained pancreas-duodenal transplants, following the technique that was already being employed at the Universities of Wisconsin and Iowa, she was actually the 20th and we went on to compare bladder and enteric drainage in all categories of recipients, ultimately setting on enteric drainage as the routine for SPK transplants. However, except for the need for one cystoscopy to remove a foreign body, Ms Houston tolerated the bladder-drainage technique and escaped the need for conversion, as have 90% of our bladder-

drained cases.

Finally, Ms Houston comments on the shortage of organs for transplantation that persists to this day. Although the annual number of pancreas and other transplants done world-wide has greatly increased since hers, the need could not be met in spite of the increase in cadaver and living donors. Insulin-independence can now be achieved with islet transplantation, but the need for multiple donors (unless a single large donor is available for a low-insulin requiring recipient) dictates the continuing application of pancreas transplantation to avoid reducing even further the number of diabetics who can benefit from beta-cell replacement therapy, a concern so passionately expressed by Ms Houston.

If the efficiency of islet isolation from cadaver pancreases were improved, of course, the application could be increased since one pancreas has sufficient islets to induce insulin-independence in at least 2 recipients, as shown by the successful application of split cadaver donor pancreas transplantation (Transpl Proc 1990; 22:585). Meanwhile, every pancreas should be used for either islet or pancreas transplantation in integrated programs that can eliminate the need for major surgery in some patients while achieving insulin-independence in the maximum number possible, giving hope to the diabetics who continue to have the problems that prompted Ms Houston to seek a transplant.

Submitted by:
David ER Sutherland, MD, PhD

For the record:

Transplant:	**Cadaver Liver-Pancreas Transplant**		
Date:	**July 1,1988**		
Hospital:	**University of Pittsburgh**		
Surgeon:	**Thomas E. Starzl, MD, PhD**		
Age:	At transplant: **38**	Current: **53**	
Years Graft Function:	**15**		

ALEX BUCHSBAYEW

It is difficult for me to recall my medical history, in part because it was so complicated. I have experienced far more than the average person. My problems began when I was born prematurely, with pneumonia and a congenital heart defect (artrial septal defect). At the age of fifteen, while living in Poland, I had open-heart surgery. During the operation, the blood transfusion that was administered infected me with active chronic hepatitis "B," which slowly resulted in cirrhosis of the liver. Further, I was diagnosed with "brittle" diabetes in 1977 and was required to take insulin with every meal.

I was not aware that I had hepatitis until September 1986, when I had massive bleeding from a ruptured varix in the esophagus or stomach. Three such episodes occurred between September 1986 and June 1988, and in May 1988, I had a bad infection of the fluid that had made me look like a 500 pound fat man. It was obvious my life was in serious danger. Dr Albert Haray, my primary care physician suggested and arranged a trip to the Falk Clinic in Pittsburgh, PA. I arrived in Pittsburgh on June 28, 1988, for an evaluation. One of the examining physicians told me I was at the "end of my rope" and in desperate need of a liver transplant. Miraculously, a donor was located at precisely the same time as my visit. Dr Starzl decided that I was a perfect candidate for the transplant. My operation, performed on July 1, 1988, was the first combined liver-pancreas transplant in the United States.

Since the operation was rather unexpected, the feeling I recall most vividly was one of tremendous fear. On one hand, I did not want an operation with the unavoidable suffering, while on the other hand, I realized I had

little choice in the matter. The surgery went smoothly. My wife and I lived in Pittsburgh for 3 months. The total rehabilitation took about 6 months. Since then, I have been able to return to work and lead a reasonably normal life. The new liver has functioned normally and the diabetes has been cured.

Of course, there have been unpleasant side effects of the numerous medications, including headaches. Curiously, during 2001 I had severe complications after another operation on my artrial septal defect. The liver was the only organ that functioned normally throughout the difficult recovery. The combined liver-pancreas transplantation certainly prolonged my life, allowed me to take numerous trips abroad, and attend my nephew's wedding.

SURGEON'S REPORT: ALEX BUCHSBAYEW

Although we did not realize it at the time, the liver-pancreas transplantation performed on July 1, 1988, was the first one to be done successfully in the United States. The grafts were provided by a 12-year-old male donor. After the liver was revascularized and functioning, the pancreas was transplanted to the right paravertebral gutter with venous drainage into the superior mesenteric vein. Drainage of the exocrine pancreatic secretions was provided by anastomosing the first part of the donor duodenum into the second part of the recipient duodenum (end to side) and by a second anastomosis between the donor jejunum which was retained with the graft and anastomosed to the first part of the host jejunum.

The patient was treated with cyclosporine and prednisone despite an early rejection and a bout of recurrent acute B virus hepatitis, the patient returned to a relatively normal insulin-free life (pretransplant insulin requirements had been 70-80 units/day).

Mr Buchsbayew's subsequent medical problems have been primarily cardiovascular. He had 2 small embolic strokes in 1997, and in the spring and summer of 2001, he underwent 2 very difficult open heart operations that included re-repair of his atrial septal defect, tricuspid valve annuloplasty, coronary artery bypass, removal of an aberrant left ventricular pacemaker wire, and ultimately porcine mitral valve replacement.

Now 53 years old, and a hepatitis B virus carrier for half of his life, Mr Buchsbayew is the ultimate survivor in spite of the suffering and inconvenience caused by his diseases and treatment. He has unfailingly returned to work after each crisis. He continues to have a penetrating wit and remains an avid student of history – all the while modestly overlooking the fact that he has, in fact, been a maker of history in his own right.

Submitted by:
Thomas E. Starzl, MD, PhD

For the record:

Transplant:	**Cadaver Liver-Intestine Transplant**
Date:	**August 12,1990**
Hospital:	**University of Pittsburgh**
Surgeon:	**Satoru Todo, MD, PhD**
Age: At transplant:	**26** Current: **38**
Years Graft Function:	**12**

MAUREEN COMO

Growing up like many other children, I believed that my parents and my brothers had taught me everything I needed to know to live a good life. I was married in 1987 and gave birth to a beautiful baby boy in January of 1988. There was no way to predict that the following 2 years would be 2 of the most important years of my life. The incredible reality of my medical condition left me confused, angry and without faith.

The months following my original diagnoses of mesenteric artery infarction (resulting in the loss of my small intestine) were filled with endless tests, evaluations and a constant feeling of sickness and desire to be well again. It would be 2 long years until the day would come when I would be give a second chance at life.

Nothing could have ever prepared me for what my life had in store. August 2, 1990 began as any other day. As I had done every morning for 4 months I wondered if today would be the day. Would I get that phone call that I so wanted to receive? Then it would hit me, the overwhelming guilt. As I prayed for my organs to become available, I knew that someone, somewhere would have to lose their life to save mine. How selfish of me.

On that day the beeper did go off, and the phone rang. Organs had become available. The wait was over, and I thought that I was more than prepared for the journey ahead. The transplant began at approximately 4:30 a.m. on August 3, 1990. Sixteen hours later, Satoru Todo and the other surgeons came to tell my family that all had gone well. What is our next move? "We wait". Will I reject? The doctors assured me that rejection was common but with proper treatment I would be able to overcome that particular obstacle.

Within the next few months, I suffered many let downs. Fortunately, I was able after only 2 months to have both my jejunostomy and iliostomy removed with restoration of intestinal function. I felt certain that the worst was over until I developed my first pseudo-aneurysm. It developed in my left leg where the main artery had been punctured with a needle. That was treated, only to have it return again. Ultimately, an artery graft was placed in my left leg, and my battle with pain medication began. Cold turkey was the cure for that, or so they thought. I would have preferred a different treatment. Nevertheless, I was discharged on Decemember 23, 1990. Merry Christmas to me! I spent the holidays surrounded by my loving husband, my beautiful 2-year-old son and my wonderful parents. I could not have asked for more.

The new year was filled with more complications. January through April found me in and out of the hospital suffering from rejection and pancreatitis, among other things. I went from one treatment to the next, and by summer I was beginning to feel good again. October 4, 1991 found us headed to our hometown, New York City, where I was to be a bridesmaid in my younger brother's wedding. It felt like old times.

In September of 1993 we bought our first house, in Pittsburgh, staying close to my doctors whom I would continue to visit all too regularly. In October of 1993 I was again given the honor of being a bridesmaid. This time it was for my older brother, who interestingly enough married my husband's sister. Once again the pleasure was mine.

In the ensuing years, I suffered other complications. It was never easy, but I had a lot to live for and I fought as best as I could. Support from my family, friends and the entire transplant team kept me going. Tough love was the game, and they played it well. In September of 1995 I was diagnosed with posttransplant lymphoproliferative disease, a disease that had taken a few of my transplant friends. I truly feared for my future. Dr Kareem Abu-Elmagd had been a member of the team from day one, and I knew that I could count on him once again. Eight months later I was given a clean bill of health.

I never regretted the choice that I made. After 12-1/2 years as a survivor I have had a life that could never have been if I hadn't taken the chance. Now, life is great. There is still so very much out there that I would like to be part of. My immune system is suppressed. This has prevented me from doing the one thing that I would truly love to do, and that is to work with children. With the further passage of time and less medication, even that could change. In the meantime, I try not to be a victim but a survivor. I try not to dwell in the past but look forward to a wonderful future.

I have learned to be grateful for what I have, remembering that someone, somewhere, has it worse than I do. Another lesson is to respect and be kind to your physicians and surgeons. They are there for you. Appreciate all they have done for you. I know I do. Follow their direction, take your medication regardless of how it makes you feel or look. Live each day as if it were your last. Be close with your family. Make good friends and keep them. Find your faith. That is what gives me the strength to go on.

SURGEON'S REPORT: MAUREEN COMO

On February 24, 1988, Maureen Como lost most of her small bowel except for a few centimeters of the terminal ileum due to thrombosis of the superior mesenteric artery. Then on the third of August 1990 at the age of 26, she received a combined liver and intestinal transplantation. The lead surgeon was Satoru Todo who is Chairman of the Department of Surgery, Hokkaido University (Japan), with the collaboration of Andreas Tzakis (now Professor of Surgery at the University of Miami), and me. Loss of the native intestine was secondary to idiopathic thrombocytopenic purpura that had been diagnosed at the age of 17.

After 24 months of TPN therapy, Maureen had developed secondary liver failure. Her new liver and intestine came from a 16 year-old male. The transplantation was with a positive lymphocytotoxic crossmatch (after DTT treatment). The organs were not altered with irradiation or any anti-lymphocyte depleting agent. Recipient immunosuppression was with tacrolimus and prednisone begun at the time of transplantation. Mrs Como stayed in the intensive care unit for 3 days. Her lengthy hospital stay (140 days) reflected the early phase of our experience. The early postoperative course was complicated with a few episodes of intestinal and liver allograft rejections, pseudo-aneurysm of the left femoral artery as described by the patient (see above), deep femoral vein thrombosis, and gastric dysmotility. Later, Maureen experienced pancreatitis, intestinal obstruction due to internal hernia, Clostridium difficile colitis, posttransplant lymphoproliferative disease (PTLD), and skin cancer. All of these complications were promptly diagnosed and treated successfully.

Mrs Como was the first adult patient to receive a combined liver and intestinal transplant at our institution. At that time, the liver and intestine were being transplanted en-bloc after removal of the duodenum. Thus, a Roux-en Y biliary reconstruction was required. A "temporary" portacaval shunt between the native portal vein and vena cava was performed to circumvent intraoperative upper abdominal portal hypertension. The decompressing shunt was left in place, similar to our current practice. Because of the fear of contaminating the abdominal cavity with the bowel contents at the time of transplant, establishment of gastrointestinal continuity was deferred for 2 months with exteriorization of the proximal and distal ends of the transplanted intestine as end stoma. When continuity was restored, a chimney ileostomy was created to allow frequent endoscopies and biopsies. This was closed 3 months after transplantation. Insertion of a gastrostomy and a jejunostomy tube for early decompression and enteral feeding was not our policy at that time.

Maureen experienced dysmotility of the native stomach, necessitating nasoduodenal tube feeding for 3 months. Full nutritional autonomy was then restored with enjoyment of unrestricted oral diet. She currently is on a diet regimen to avoid body overweight. Several years later, she developed intestinal obstruction due to an internal hernia that was successfully treated with reoperation. The most significant morbid event, however, was the development of PTLD 6 years after transplant. This involved both the native stomach and allograft jejunum. Reduction of the maintenance immunosuppression combined with intravenous antiviral therapy resulted in complete resolution of the tumor. There has been no evidence of recurrence in the last 6½ years.

After 12-1/2 years, Mrs Como and Tracey Gonzales whose operation at the age of 4 years was done 10 days earlier by the same team (see description elsewhere in this case collection) are the longest surviving adult and pediatric recipients of liver-intestine allografts in the world. Similar to Tracey Gonzales, Maureen now enjoys a good quality of life. Having achieved a substantial level of donor-specific tolerance with the passage of time, Maureen was able to reduce her immunosuppression and restore immunologic surveillance enough to eliminate her PTLD without rejecting her life-sustaining allograft. Currently, she is on 1 mg per day tacrolimus and 5 mg every other day of prednisone.

Submitted by:
Kareem Abu-Elmagd, MD

For the record:

Transplant: **Cadaver Multi-Visceral Transplant**
Date: **July 23,1990**
Hospital: **University of Pittsburgh**
Surgeon: **Satoru Todo, MD, PhD**
Age: At transplant: **3** Current: **15**
Years Graft Function: **12**

TRACEY KAY GONZALES

My Unexpected Journey

Come, come follow me, I will take you on a journey down the road I have traveled on since birth. Hi! My name is Tracey Kay Gonzales, I am 15 and a half years old, 5 feet 3 inches tall, and weigh 114 pounds.

I was born on May 26, 1987, in a hospital in Texas. On September 22nd, I developed necrotizing enterocolitis, which led to the removal of my small bowel. I spent my first 4 years of life in a hospital room. I came to Children's Hospital of Pittsburgh on April 18th, 1990 with the additional problem of liver failure. I waited for over 3 months before organs became available. On July 23rd, 1990, I had a life saving transplant at Children's.

My mom raised me to be a fighter, with a never give up attitude. I do remember that when things looked bleak, my mom would tell me, "Tracey, what do you need to do?" I remember making a little fist and telling her that "I am going to fight, fight, fight." Somehow it worked. The many transplant surgeons that treated me did their part. It was now up to me to do mine. I'm not saying it was easy, but I always gave everything 110%. I fought hard. With the help of my doctor's and my mom, here I am today.

People ask me, "What does your transplant mean to you." The simplest answer is that I am alive, and have a second chance at life. Most people just don't get this kind of chance. The cards we are dealt in life are usually what we have to live with. I am so thankful that I was given some extra ones.

I never got to choose how my life was going to be. I came into life already at a fork in the road. It was like I was dropped there. I took the road less traveled, that is to say transplantation. I stumbled many times at first, but I kept walking. Some of the rocks I stumbled on were just pebbles, but in October 1991, a boulder hit me head-on when I developed Pneumococcal sepsis. My spleen had been removed when I was 6 months old. I had now broken through the medicine that I was taking to make up for not having a spleen. It took me a while to overcome this, and I had to fight harder than I ever had before or since to make it through this crisis. I did though, and I kept on going. I didn't give up, and no one can ever take that kind of fight out of me.

I refuse to let rejection of my liver and intestine be in control of me. I am in control of my body, and I let it know that I will overcome what it has to throw at me. Sometimes when things don't go just right, adults and children alike ask, "Why me?" A few years back, I remember asking my mom this same question over and over again. The answer I got was, "Why not you?" That was not the answer I wanted, but it made me stop and think. My mom told me that we do not get to pick and choose what happens in life. I was told that maybe God was testing us. They always say that God only gives you what you can handle. I now know that this is true, so I adapt in life and overcome what is thrown at me out of the ordinary.

My life has changed in such a dramatic way since my transplant a little over 12 years ago. Yes, I said 12 years ago. Now, I live in Lancaster, New York, a suburb of Buffalo. I am in tenth grade at Lancaster High School. I live a normal teenage life. I get no special treatment. The grades I get in school are from all my hard work and determination to succeed at what I am doing. I love learning and going to school. Teachers tell my mom that I am so quiet in class. To my mom and dad, this almost knocked their socks off because I ask them millions of questions. I am like a blank page, and everyday, I fill up page after page with information. I love to read. The library down the street is like a second home to me. I go there to get books, use the computer to type my school papers, and just to think.

I have dreams and goals in life that I want to accomplish. I want to run track and become a cheerleader. My list goes on and on. With this second chance in life due

to my transplant, I treasure each and every moment. I don't take my life for granted. I take my meds faithfully and always will. Just to go outside and wait for the school bus is a breath of fresh air, and another day to accomplish something. I go to school dances, I roller blade, ride my bike, run, jump, and do what I want to do. I've always said, "Don't tell me I can't do something because I will prove you wrong."

I want to tell you some of the goals in my life that mean the world to me. I can't wait until the day comes when I can walk across that stage, and receive my high school diploma. I can't even imagine what that will feel like to me. I don't think anyone can. After high school, I want to go to college to become a doctor. Does this seem like a tall order? Yes, it might be, but nothing says I can't try. I can only give it my best shot. With the continued help of my doctors, I will make my dreams come true. I love life, and no one can ever take that away from me: not my goals, and not my dreaMs These are mine and only mine. I can do all these things in life because of a group of skilled surgeons, and a donor family who gave permission to remove the organs from their own child. I really want to meet them, just to say "Thank you" for this gift of life they gave me.

To end, I have taken you down the road I travel. It may not mean much to some people, but to me it is the biggest gift one could ever ask for. In turn, I would like to thank doctors Satoru Todo, Andy Tzakis, and Jorge Reyes for doing my operation, and to Dr Jorge Reyes for all the care and smiles he has since brought to my face. To Amy Smith, my transplant coordinator, you have always been there for me. I thank you all. To Dr Thomas Starzl, I owe you my life. The work you do, and the work you have done to perfect this transplant allowed me to live and will live on in my heart forever.

I have described my "unexpected journey." I hope you can understand why I love my life.

SURGEON'S REPORT: TRACEY KAY GONZALES

Tracey was the victim of a disease called necrotizing entercolitis at the age of 4 months. After the disease devitalized her small bowel and was surgically removed in September of 1987, she developed short gut syndrome with irreversible intestinal failure and her life was rescued with TPN therapy. Similar to about half of the children who require permanent intravenous nutrition, Tracey suffered cholestatic liver failure 38 months after initiation of therapy and was transferred to Pittsburgh for liver and possible intestinal transplantation in early July 1990. Although multivisceral transplantation had previously been done 3 times in the 1980s at the Children's Hospital of Pittsburgh under cyclosporine-based immunosupression, maximum survival had been 6 months. Tracey was the first pediatric patient to receive a composite visceral transplantation under tacrolimus.

On the 24th of July 1990, a suitable 2.7 year-old female donor was found and the composite visceral allograft that contained the liver and intestine was transplanted across a positive lymphocytotoxic crossmatch. The surgical team was headed by Satoru Todo and included Andreas Tzakis and Jorge Reyes. Both organs were harvested and transplanted en-bloc maintaining continuity of the portomesenteric venous system. The arterial reconstruction was established by an arterial conduit that was anastomosed to the recipient aorta and connected to a single Carrel aortic patch containing both orifices of the donor celiac axis and superior mesenteric artery. Permanent venous drainage of the residual native upper abdominal organs was via a portocaval shunt.

Multiple episodes of liver and intestinal rejection were documented and successfully treated early after transplantation. Tracey was one of the very few combined liver and intestinal recipients who experienced isolated liver allograft rejection. Apart from rejection, the postoperative course was uneventful and TPN was discontinued 60 days after transplantation. By the end of the 11th postoperative week, Tracey was able to eat normal diet and support her nutritional needs. The long-term follow-up documenting the normal growth of Tracey is a testimony of the excellent allograft function with achievement of full nutritional autonomy.

Now 15½ years old, Tracey Gonzales bears the world's longest-surviving combined liver and intestinal allograft with a follow-up of 12½ years. Her current immunosuppressive medications are tacrolimus (3 mg/day) and prednisone (2.5 mg every other day). Tracey's own report (see above) documents how a baby who almost died 4 months after birth is currently close to receipt of her high school diploma with the dream of becoming a physician in the very near future.

Submitted by:
Jorge Reyes, MD

For the record:

Transplant: **Cadaver Intestine Transplant**
Date: **March 3, 1993**
Hospital: **University of Pittsburgh**
Surgeon: **Satoru Todo, MD, PhD**
Age: At transplant: **58** Current: **67**
Years Graft Function: **9**

ADINE GREEN

In 1991 during an operation at the Harrisburg Hospital to remove adhesions from prior surgery, my small bowel was lost and I began intravenous feeding. I was then 56 years old. After the doctors sent me home, I ended up lying flat on my back for 2 years. During a visit to my doctors office, I read an article in the *"Doctor's Magazine"* about small bowel transplants. I immediately became overwhelmed with excitement and asked my doctor to sign me up right away.

My doctor called Dr Kareem and set up my initial consultation. At that meeting, Dr Kareem and other members of the team told me that I was too old. After numerous examinations, it was established that I had a bad heart and I wouldn't be able to survive a transplant operation. I was finally able to convince the doctors that at that point in my life I didn't have any quality of life and to me it was worth the risk.

I was approved for a transplant in December 1992 and in March of 1993, I received a call stating that a donor had been found. Drs. Satoru Todo, Hiro Furukawa, Andreas Tzakis, and Kareem Abu-Elmagd performed the surgery on March 3, 1993, which lasted for approximately 15 hours. I was then 58 years old.

After the operation, I expected to feel horrible, but surprisingly, I was alert and showing off my new belly to my family. Before the operation, my food immediately came out of the stoma into a bucket. After the surgery, the first thing I saw was that this no longer happened. As long as I didn't see or feel the end of the intestine hanging out of my body, I was overjoyed. After 3 months of being in the hospital in Pittsburgh, I was able to go home to Harrisburg with an entirely new outlook on life. Now I could sit up, eat, walk, and do all the things I couldn't do before.

Seven years after the bowel transplant, it was determined that because of the long-term use of tacrolimus, I now needed a kidney transplant. I was put on the kidney candidate list and waited for over a year. During that time, I had to get dialysis 3 times a week, 4 hours a day. It made my life miserable, even with my new intestine. Finally, one of my nieces, Deborah Shaw, volunteered to donate one of her kidneys to me. After both of us endured extensive testing, I was approved for a kidney transplant. The surgery took place in May 2000 and I have once again regained a great deal of my quality of life.

I shed a lot of tears before and after my 2 transplants. I know that through all of the pain and suffering, I would not have been able to survive without Christ in my life and without the strength and care of my husband, Rev Sterling Green. I give God all the praise for providing my doctors with the wisdom and the knowledge needed in order to successfully perform on my 2 transplants and give me back my life. I am living proof that God still works miracles.

SURGEON'S REPORT: ADINE GREEN

Adine Green, a now 67-year-old African American lady received an intestinal transplant with inclusion of the donor colon at the age of 58. As Mrs Green described, she lost most of the small intestine and all of the large bowel following an operation for recurrent adhesive intestinal obstruction. The adhesions were secondary to an abdomino-perineal resection for colorectal cancer 20 years earlier. Seventeen months after total enterectomy, she could no longer be maintained on efficient TPN because of recurrent line infections, declining central venous access and histopathologic evidence of mild hepatic fibrosis.

In spite of her older age, she was accepted for intestinal transplantation. After a relatively short period of waiting (49 days), a suitable donor was found and the

patient received an intestinal allograft which included the colon. The donor was a 21-year-old white male with a poor HLA match but with a negative lymphocytotoxic crossmatch. No donor pretreatment or recipient conditioning were given. The primary immunosuppression was with tacrolimus and prednisone. The graft was perfused with and preserved in the University of Wisconsin (UW) cold solution. Cold ischemia time was 6.7 hours. Because of potential physiologic and immunologic advantages, the venous drainage of the allograft was directed into the recipient portal circulation rather than to the systemic circulation (inferior vena cava).

Most of the donor colon was included with the small bowel allograft to reduce the risk of postoperative diarrhea and bacterial overgrowth, with particular reference to preservation of the ileocecal valve. She is one of our 2 recipients who achieved truly long-term survival and are currently alive despite the high early risk of serious infection and allograft rejection that appeared to be associated with inclusion of the colon (ie., 2 of 13 isolated intestine or composite visceral recipients). Six weeks after transplantation, she returned home on an unrestricted oral diet.

Mrs Green continued to volunteer at her church in Harrisburg, Pennsylvania despite the progression of diabetic retinopathy. In May of 2000, she received a live-related kidney transplant with perfect renal functions. Of interest, she never experienced either intestinal or kidney rejection. In October of 2002, a surveillance endoscopic biopsy of the intestine showed heavy plasma cell infiltrates with negative EBV stain suggestive of plasma cell rich PTLD. Immunosuppression was stopped with discontinuation of her daily doses of 2 mg tacrolimus and 5 mg prednisone. Fortunately, Mrs Green continued to be free of rejection as well as immunosuppression with significant reduction in the plasma cell infiltrate and fully functioning intestinal and kidney allografts. Her follow-up is 9.9 years after small bowel transplantation and 2.8 years after kidney transplantation. She has been immunosuppression-free for 4 months.

Submitted by:
Kareem Abu-Elmagd, MD

For the record:

Transplant:	**Cadaver Multivisceral Transplant**
Date:	**October 31,1996**
Hospital:	**University of Pittsburgh**
Surgeon:	**Satoru Todo, MD, PhD**
Age: At transplant:	**22** Current: **28**
Years Graft Function:	**6**

CHASE BREWER

Life After A Multivisceral Transplant

On November 28th, 1994 I was experiencing abdominal pain and called my Mom to see if we had some Pepto-Bismol. By that evening she said we should go to the emergency room, but being tough (hardheaded), I said no, even though I was having to crawl to the bathroom. I spent the night on the couch in a lot of pain. By the morning of November 29th, my mother got up at about 5:00 am to go to work and came into the living room. I looked over and said, "Mom, come feel my head." She said I was cold, sweaty and clammy to the touch. I was looking towards her but unable to see or focus. She took my temperature, but it did not register. She then said we needed to get to the emergency room.

By this time, I was ready to go. She said, "Why didn't you wake me up?" I said, "Because you were sleeping." She said, "Chase, that wasn't important. We have to go now!" My stepfather helped me out to the truck, got a pillow and helped me to lie down on the back seat. He wanted to go with us, but Mom said no, that we would be fine. She got in the truck, going the way that would be the fastest, but I said, "Mom, why did you come this bumpy road?" She said, "We can get there faster this way. Son, I'm sorry."

When we got to the ER, they placed me on the bed and I waited. After giving all the needed information,

Mom came to my room and then they started monitors and, again, no temperature registers. So, comes the rectal temperature check, subnormal. The ER doctor calls the Medical Clinic. One doctor came and called another. Dr Stanley Miller checked me and said I've got to call a surgeon. I told my mother it felt as if I were dying several times.

Dr Michael Koury came, checking my chart and me. He turned to my mother and said, "We need to go straight to surgery; he has a distended abdomen and we can't wait for any tests or CT." Mom said, "what do you think, Sugar?" I said, "I have to do something." My mom called her mom, dad and my father to let them know I was in surgery. Dr Koury came to the waiting room and they called for my mom. She and dad went to talk to Dr Koury. He told them that my small intestine and most of my large bowel were gangrenous and had to be removed. I was the closest to death he had ever seen and still be alive. Then, he calmly patted my mom's shoulder and somberly said, "He can still die." Mom then broke down crying and told daddy that she couldn't go back in there. "You go and tell the others." They then went to the ICU waiting room.

Living on hyperalimentation after the operation, I carried on with life, hunting mostly till hunting season ended. I always carried my life-supporting pack with me. My attending physician, Dr Stanley Miller had investigated the small bowel transplant, and arranged a visit with the Thomas E Starzl Transplant Institute. I was told at that time that I was too healthy for a transplant as I still had most of my body mass. We headed back home (my mother, grandmother, and me) all disappointed. After being on hyperalimentation, 24 hours a day, however, it started taking a toll on my body. I started having sudden uncontrollable nosebleeds. My skin was extremely yellow. I returned to my doctor who told me that I was losing blood platelets. He told me that if I did not get a transplant soon, I would not live much longer. Dr Miller then contacted the Transplant Institute again in November and we were on our way back. Upon re-evaluation and finding out I was on hyperalimentation 24 hours a day, I was sent to a nutritionist and was told that I needed to be off hyper-al 8 hours a day.

After this, I lost most of my body mass and became extremely yellow. Blood work showed that my organs were being destroyed. A multivisceral transplant now would be needed. We then made all the rounds talking to different team members. They explained transplants and said that I would receive a beeper. They emphasized that I needed to return any call immediately. We headed home again. Even before actually receiving the beeper, I received a phone call at about 5:00 – 5:30 PM saying they had the organs and asking if I could be there by 11:00 – 11:30? We said, "Yes!" and started calling the airport.

The airport manager said he would hold our flight 15 minutes. We really had to move fast, leaving our house 25 miles away. There was a sheriff's escort to the airport. I had been hunting that day and upon going through the checkpoints, I had to clean out my pockets, giving my bullets and knife to my grandfather. They then told me that my bag would need to go through the screening machine. I said, "It is attached to me." We then ran to the plane. We took our seat and were on our way. Upon arriving at the hospital I went straight to my room, and then down to surgery.

I'm not very good at writing, but here is the rest of the story. I have had my transplant for more than 6 years and I feel great. Most folks never even know that I have had a transplant. Everyone who doesn't know about my transplant says that I am a picture of health. The people who know about the transplantation are amazed at how well I have done throughout this process. Most people call me a MIRACLE, which, all in all, is true. Without having lots of faith and plenty of prayers and a strong will, I probably would not be here today. My family and friends kept me strong.

I would like to say "thank you" to everyone who has touched my life. I appreciate all of the support that I had and I hope that this article will help people understand about transplants and realize how much they can help people. The transplant changed my life dramatically. In fact, it literally gave me back my life. I was 20 years old when I started having probleMs My 21st birthday was spent in the hospital, but thanks to my transplant I spent 7 more birthdays out of the hospital doing what I wanted to do. I have been working for about 6 years. I am an ASE Certified Mechanic. I work on whatever needs to be worked on.

Without the transplant, I would not be here today, I am very grateful about what has been accomplished. It's unbelievable. I continue to live a very normal life years later. But no matter how many years go by I will never forget what I and my family and friends have been through. Having this transplant changed my life dramatically for the better, made me slow down and realize how very short

life really is and how much you should cherish and enjoy life because one day something might get in your way and you might have to slow down. Take it from someone who has been down, you have to hold your head up and keep going. It will get better.

Being a multivisceral transplant patient says a lot. It's hard for me to explain how I have changed since this happened. This has taught me to be patient and not to rush things, but also to pay attention to things and not take anything for granted, which we all tend to do. The transplant has not changed me or affected me physically in that I let nothing stand in my way. I don't know what the word quit means. I try to conquer any obstacle that stands in my way. That's what having this transplant has done for me. With patience, hope, faith and lots of prayer, you can overcome anything. I have. I would like to say thank you to the UPMC and their transplant team for doing a great job. I hope there are many more great jobs performed there, but hopefully, none on me.

SURGEON'S REPORT: CHASE BREWER

Mr Chase Brewer received a multivisceral transplantation on 10/31/1996 with inclusion of the stomach, duodenum, pancreas, intestine and liver. In November 1994, Chase lost his small bowel and suffered intestinal failure at the age of 20 due to a hereditary defect (mutation) in one of the coagulation factors (Leiden factor 5) with development of anti-cardiolipin antibodies that resulted in thrombotic occlusion of the arterial blood supply to all of the abdominal organs except the kidneys. After 24 months of TPN therapy, the liver failed and a multivisceral transplant was the only therapeutic option. Inclusion of the stomach, duodenum, and pancreas was essential.

At the time, cyclophosphamide was part of the immunosuppression protocol that was primarily based upon tacrolimus and prednisone. None of the patient's 5 organs experienced rejection, and he returned back to Crystal Springs, Mississippi 6 weeks after transplant. By then, he was free of TPN. He had no postoperative morbidity, and did not develop a cytomegaloviral (CMV) infection despite receiving a CMV positive graft (he was CMV negative). Because of full time employment, his first follow-up visit to Pittsburgh was 3 years after transplantation.

To the best of our knowledge, Chase is the first case to receive a multivisceral transplant due to a hypercoagulable disorder primarily induced by mutation of factor 5. The potential therapeutic impact on Chase's hypercoagulable state of the liver and of the concomitantly transplanted donor leukocytes was of interest. Utilizing serologic and immunohistochemical tests as well as PCR techniques, a significant reduction in the anti-cardiolipin antibody titer was documented nearly 4 years after transplantation with detection of donor leukocytes containing normal (non-mutant) factor 5 in both the recipient peripheral blood and allograft liver tissue. The anticoagulant therapy was then discontinued. Six months later, however, the patient developed severe headache with visual field defect because of acute thrombosis of the central cerebral venous system. Anticoagulation therapy was then promptly re-instituted with full recovery.

Mr Brewer is one of the longest (6¼ years) multivisceral allograft survivors with excellent graft functions enjoying a normal and fully productive life. In addition to minimal daily doses of tacrolimus (4mg) and prednisone (5 mg), Chase will continue to receive a life-long anticoagulant therapy.

Submitted by:
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