MAYO CLINIC

Winter 2008

# Renewal

*Sharing the journeys of Mayo Clinic transplant patients, donors and staff*

## One Week, One Team: Two Hearts for Kobe

Shane and Karmen Giesen were seasoned parents by the time son, Kobe, was born on Sept. 27, 2006. They had two daughters (Taylor, 7, and Brynn, 5), and were well acquainted with childhood illnesses that afflict infants. But when 3-month-old Kobe's appetite began to diminish, the Giesens had a nagging feeling that something was wrong.

The change in eating prompted a visit to their son's physician in Fargo, N.D. An initial EKG and chest X-ray suggested a heart murmur, and something more serious. A local pediatric cardiologist performed an echocardiogram and delivered the shocking news that their son was in heart failure. As the Giesens were still reeling from the news, Kobe was hospitalized.

On Jan. 5, 2007, the Giesens were given their son's diagnosis: dilated cardiomyopathy, a disease in which the heart muscle becomes weak and the heart chambers enlarge (dilate).

*Kobe Giesen received two heart transplants in one week at Mayo Clinic in June 2008.*

"On that first day in the hospital, we were told that Kobe might need a heart transplant…someday," recalls Shane.

### Someday comes soon

Kobe spent 22 days in the intensive care unit in a Fargo hospital — many on a ventilator. Complications arose, including pneumonia, and a blood clot. On Jan. 26, 2007, Kobe went home on medications, and with hopes for continuing improvement.

Over the next few months, life returned to a new normal. By age 1, Kobe started crawling again, then walking and playing. But always looming in the background was the fact that Kobe's heart was

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## *On the inside…*

# *Renewal*

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Mayo Clinic has offered transplantation as a treatment option for adult and pediatric patients since 1963. Mayo Clinic organ transplant programs have earned worldwide recognition for their expertise and success. In 1998 the separate organ and tissue transplant efforts united under the umbrella of the Mayo Clinic Transplant Center. This cooperation enhances the ability of Mayo physicians and scientists to share expertise and resources, offer comprehensive integrated transplant services, and to conduct innovative research in transplantation.

# One Week, One Team: Two Hearts for Kobe *- continued*

*Joseph Dearani, M.D.*

*Kobe and his family in Rochester on the day he was dismissed from the hospital.*

double the normal size, and he was weak. In April 2008, he was treated for pneumonia. Following this setback, Kobe seemed unable to regain his strength.

By early June, Kobe was in severe heart failure and was unable to walk. When his ejection fraction (a measurement of how much blood is pumped out of a filled ventricle) became dangerously low, physicians in Fargo arranged for him to be airlifted to Mayo Clinic. Kobe, accompanied by his mother, arrived at Saint Marys Hospital in Rochester on June 3. Shane made the five-hour trip by car.

By early the next day, Kobe's blood pressure had plummeted, and he was listed for transplant. By afternoon, as his condition rapidly worsened, he was taken to an operating room and put on a heart-lung machine. Throughout the day, surgeons, anesthesiologists, pediatricians, nurses, respiratory therapists, and other caregivers streamed in and out of Kobe's room on the cardiac intensive care unit. Among this large, multidisciplinary team was Joseph Dearani, M.D., who would become Kobe's transplant surgeon.

"At first, it was scary being here at Mayo Clinic," Shane says. "It was an entirely new place to us. We asked Dr. Dearani if we'd come to the right place. He said, 'yes,' without hesitation."

"When I first saw Kobe he was desperately ill," recalls Dr. Dearani. "He had signs of poor perfusion. His extremities were cool and clammy, which is a sign of a very low ejection fraction. Normal is 60 to 65 percent; Kobe's was 10 to 15 percent when he was first assessed at Mayo. He was dying."

The Giesens placed their trust in Kobe's caregivers, especially as his condition declined. On June 13, Kobe had an adverse reaction to a medication and also had a stroke, which affected his left side. The Giesens prepared themselves to say goodbye to their son.

Kobe needed a new heart — now. Because he was dependent on the heart-lung machine, his status was 1-A, which elevated him to the top of the list of pediatric patients awaiting transplant.

## *An unforgettable Father's Day*

Shane will never forget Father's Day 2008. The news came that a heart — although not a great-functioning one — was available in Texas. "Kobe was in a very weakened state and we were concerned that he might have more strokes if he had surgery," says Karmen. "We asked Dr. Dearani what he would do, and he was honest with us. We decided to take a chance on a new heart, even one that that had been damaged as a result of resuscitation efforts. It was something we couldn't turn down." Hours later, the heart arrived in Rochester.

"Transplant surgery started about 9 p.m. and it wasn't until 2:30 a.m. that Dr. Dearani came out to talk to us," Karmen remembers. "He explained that the transplanted heart had an ejection fraction that was nearly the same as Kobe's own heart." Consequently, Kobe left surgery with a new heart, but still on the heart-lung machine.

Two days later, with no signs of improvement, Dr. Dearani re-listed Kobe for a second heart.

"It's hard to ask God for an organ for your child when you know that another family will have to lose a child to make that possible," says Karmen. "You feel hopeless and numb. You do lots of waiting. Even when you get the call that an organ is available, the team sent to harvest may decide it's not viable once they see it. Then you wait again." Fortunately, the Giesens did not wait long.

## *With time running out*

On June 18, a call came from a hospital — again in Texas — that a heart was available. "We knew the ejection fraction of this heart was considerably better, but we still had serious concerns," says Karmen. "Kobe looked tough. We asked Dr. Dearani if Kobe could survive another surgery. We decided to go ahead."

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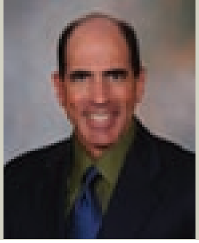
# One Week, One Team: Two Hearts for Kobe *- continued*



*Joseph Dearani, M.D.*

When the second transplant started, the Giesens began another long and eerily familiar vigil. Caregivers delivered updates when the incision was made, when the donor heart arrived, and at other key points in the procedure. After about four hours, Dr. Dearani emerged from the operating room.

“Dr. Dearani said the new heart started beating immediately on its own and fit in Kobe’s chest as though it were made for him,” recalls Shane. “When we saw our son at 4 a.m., there were fewer tubes in place and no heart-lung machine.”

Nearly 10 days later, after the sedation had worn off and a breathing tube was removed, Kobe held up his arms, gesturing for his parents to hold him.

## *The healing process*

In the days following the second transplant, Karmen stayed in Rochester with Kobe while Shane, an accountant, went back to work and to caring for their daughters in Fargo. In all, he made 16 road trips from Fargo (more than 300 miles away) to Rochester during Kobe’s hospitalization.

Karmen learned what would be required to care for Kobe at home, including managing his immunosuppressant drugs and other medications, diet and activity. And, she attended transplant support group meetings for parents while staying close by at the Ronald McDonald House.

“Through the support group meetings, I met a woman whose daughter had died and she described how their family had decided to donate her daughter’s organs,” notes Karmen. “She said this actually helped their family in the healing process. This was good to hear.”

Kobe was dismissed from the hospital on July 18. “We took pictures of members of the team and of Dr. Dearani,” says Karmen. “He was down-to-earth and didn’t sugarcoat things. Before we left, we thanked him for saving Kobe’s life. He said it was a big team.”

“Kobe and his family have been an inspiration to everyone at Mayo who has cared for him,” says Dr. Dearani. “Kobe is doing so well today as a direct result of everyone persevering and having a ‘never give up’ and ‘whatever it takes’ attitude. Kobe holds a special place in many hearts at Mayo.”

Following his hospitalization in Rochester, Karmen and Kobe stayed in an apartment for several weeks to continue follow-up care at Mayo. Once back at home, Karmen, also an accountant, returned to work and now manages appointments with Kobe’s physical, occupational and speech therapists in Fargo and at Mayo Clinic.

## *Defying the odds*

Today, Kobe is doing well. He faces challenges, including dealing with the side effects of anti-rejection drugs and of the strokes he suffered. In spite of the challenges, his spirits are undiminished. “He used to be a cautious child,” says his dad. “Now he’s fearless.”

While doing two heart transplants on one child in one week was a first for Mayo, for the Giesens, the gift of life for Kobe defies description. To other parents who may be facing the same challenges, Karmen simply says, “Never give up hope.”

*Kobe Giesen.*

For more information about pediatric heart transplant at Mayo Clinic, visit *www.mayoclinic.org/heart-transplant/children.html*.

# Keeping his spirit alive: Kidney recipient meets donor's family

*Thomas Schwab, M.D. (left)*
*Mikel Prieto, M.D. (right)*

*Rakowski and her grandson.*

Ask Linda Rakowski about her kidney transplant, and she talks about her donor, Michael. "He was such an amazing young man," she says following a recent trip to Milpitas, Calif., to meet Michael's family and attend a dedication ceremony in his honor.

Rakowski, from Alexandria, Minn., received one of Michael De Jesus' kidneys in November 2005. The 18-year-old was an innocent bystander shot and killed at a block party in San Jose. Though Rakowski never met him, she feels Michael's spirit lives on in her as she's faced her fear of public speaking, embraced his Portuguese heritage and resurrected her love of baseball.

Rakowski's path to kidney transplant winds through health care complications that began in the early 1990s when she was diagnosed at age 33 with type I diabetes and had a pacemaker surgically implanted to deal with heart problems. By 2002, she suffered from hypoglycemic unawareness, a severe complication of diabetes where a patient functions normally through dangerous blood sugar highs and lows. A nurse in Alexandria suggested Rakowski be evaluated for a pancreas transplant at Mayo Clinic in Rochester, Minn. Hypoglycemic unawareness is one of very few conditions to be considered for a pancreas transplant, which Rakowski received in 2002 at Mayo.

In mid-2005, she was listed for a kidney transplant. "Linda experienced medication-induced kidney failure complications, leading to her transplant listing." says Thomas Schwab, M.D., a Mayo Clinic nephrologist. Just a few months later, on Nov. 29, Mikel Prieto, M.D., a Mayo Clinic transplant surgeon performed Rakowski's kidney transplant.

Following additional complications, Rakowski transferred in February to a hospital in Fargo, N.D., to recover closer to her family. While in Fargo, she broke her leg, which extended her hospital stay. Finally, late that spring, she returned home to Alexandria, though to a new apartment. A handicap-accessible unit had opened up, and the building owner had moved all of her belongings. "It was like magic," Rakowski recalls. "Everything was arranged in my new place when I got home. I didn't have to worry about a thing."

Something did weigh on her mind, though, as she began recovering at home. She began to wonder about her donor. Rakowski received a card and two photos of her donor, via the transplant coordinator, in December 2006. "I framed the pictures and put them out next to photos of my children and grandchildren," says Rakowski. "It just felt right." She didn't know his name, but the dark-haired young man in a baseball uniform had become a very big part of her life.

Rakowski received a letter from Michael's family in December 2007, inviting her to the dedication of a baseball field honoring their son. In January, the transplant coordinator phoned Rakowski, asking if she would be willing to speak with the donor's family. She was, and 15 minutes later Michael's mother, Maria De Jesus, called. De Jesus eventually asked if Rakowski wanted to know how Michael died. "When she told me how, at that point, I would have waited. I would have waited for a kidney if it meant Michael wouldn't have died like that," Rakowski says.

In February 2008, just two years after the transplant, Rakowski traveled to Milpitas to speak at the ball field dedication. "Everything I do now, I do for Michael and his family. I don't like talking in front of people, but at the event, I wasn't even nervous. It was like Michael was there with me," she recalls.

*Rakowski at the dedication.*

Michael is with Rakowski every day, she says. She considers herself part Portuguese now, Michael's heritage. She has resurrected her love of baseball by playing in the backyard with her grandson and by attending Alexandria Beetles and Rochester Honkers games. "I can relate to Michael's love of the game. I was one of only two or three girls who played baseball in the neighborhood when I was growing up," Rakowski says.

Rakowski isn't the only one who still feels close to Michael. According to his mother, friends still write on his MySpace page online, asking for advice or just sending a note. "As a mom, that's the most wonderful thing. To know your son helped, and keeps helping, so many kids," says De Jesus. "I've learned so much more about my son from his friends."

Rakowski values deeply her relationship with Michael's family, and believes strongly that reciprocating contact from a donor's family is the right thing to do. "People need to make their own decision, but for me, it's about respect. Respecting the decision they made to help me live," she says. "Michael brings out the best in me. I need to keep his spirit alive."

For more information about kidney transplant at Mayo Clinic, visit ***http://www.mayoclinic.org/kidney-transplant/***.

*In your own words*

# Finding Miracles at Mayo Clinic *by John Walker*

It can be said, if we think about it, we are all recovering from something. Be it of physical, emotional or other sort of pain, we all have our crosses to bear.

My medical journey started in early 2003 in Fort Myers, Fla., where we were spending the winter. To say that my symptoms were elusive to diagnose is a major understatement. In early 2003, I started to experience extreme rib and sternum pain, across the center of my chest. Upon our return to Minnesota, I sought treatment at our local clinic. This experience was frustrating because they were not able to find the cause of my pain, and none of their suggestions were bearing any fruit.

The pain continued and when my doctors recommended a stress test for further investigation, my wife, Betty, stepped in. A registered nurse, Betty thought that this latest recommendation was not going to be of value since my heart was not the issue. With the frustration at an all-time high, we turned to Mayo Clinic, and I was able to get an appointment a few days later.

Within 45 minutes, the doctors at Mayo diagnosed me with multiple myeloma, a rare cancer of the plasma cells. Bone pain is a common symptom of the cancer, which explained my rib and sternum pain. I was hospitalized immediately to restore my strength and begin preparing my body for a bone marrow transplant.

Not surprisingly, Mayo does specific research and outreach education in this area. I have often thought how could I be so blessed with the right medical resources for my illness — it seems nothing short of a miracle!

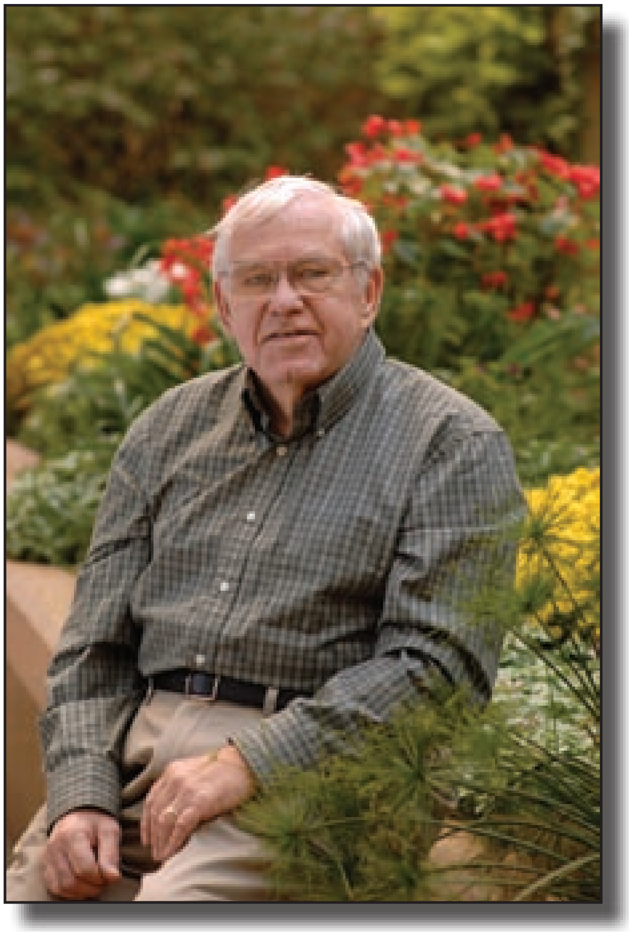
From that point on, I was introduced to a lot of terminology I would have liked to avoid all together. Chemotherapy, oncology, autologous transplants, the list goes on and on. However, the staff at Mayo demonstrated their dedication to research, education and treatment that must certainly be unparalleled in the medical community.

In September 2003, I received a successful bone marrow transplant that saved my life. Post-transplant, I stayed near Mayo to undergo nutrition treatments to help my body stay strong, and the care I received while there was top-notch.

When a routine blood test showed the cancer had returned, I received a second bone marrow transplant in 2006. After two transplants, I am happy to report that I am currently in remission.

In my view, Mayo Clinic provides what I call "door-to-door" service. From the minute I arrived there and throughout the process, I was impressed with the level of service, professionalism and extreme sincerity from my doctors and everyone else I came in contact with during my journey.

My expiration date has yet to arrive, and I am proud to say that I am an active volunteer in my community and continue to live life to the fullest. I am so thankful to have found Mayo Clinic as I continue on with my life journey.



*John Walker, bone marrow transplant recipient.*

For more information about bone marrow transplant at Mayo Clinic, visit ***http://www.mayoclinic.org/bone-marrow-transplant/***.

# Research Update:
## *Rule Changes for Kidney Donor Allocation*

*Mark Stegall, M.D.*

Possible changes in rules for allocating deceased donor kidneys are being considered by the transplant community and public feedback is being sought.  The United Network for Organ Sharing (UNOS) which has the charge of developing organ allocation policy under a contract with the Federal Government called the Organ Transplant and Procurement Network (OPTN) has been working on this issue since 2004. At that time, the UNOS/OPTN Board of Directors asked its Kidney Transplantation Committee to review the issue.

As part of the review, the committee held a series of public hearings to help understand the scope of the issues associated with the current system. Speaking at the hearings were a broad range of transplant professionals, patients and the general public. Following that review, the committee began investigating a proposal called Life Years from Transplant (LYFT) as a possibility for a new kidney allocation system. LYFT is the estimated number of additional life years that a transplanted kidney (or kidney-pancreas) would give a candidate, versus that candidate remaining on dialysis.

In February 2007, the committee held a public forum in Dallas to inform the transplant community and general public about the LYFT concept.

According to Ciara Gould, policy analyst at UNOS and liaison to the committee, feedback from the forum was considered by the committee to modify the plan in a way that would better match donors and recipients under the proposed new system. One modification the committee included is a Donor Profile Index (DPI).

“The new DPI provides a larger amount of clinical information about the donor, which will help foster better decision making about matching kidneys from donor to recipient,” says Gould.

Additionally, the DPI helps determine which kidneys go to which candidates by adding a new way of categorizing donors to better match donors and recipients. Feedback from the 2007 meeting focused on the idea that candidates for kidney transplant should have a way to gain additional priority over time. The committee determined that time on dialysis (DT) should be another concept considered for the new allocation system.

A formal Request for Information (RFI) was issued by UNOS in September 2008, asking the transplant community and the public for feedback on the proposed LYFT, DPI and DT concepts.

The feedback received will be shared at a public forum in January 2009. According to Mark Stegall, M.D., surgical director of the Mayo Clinic kidney transplant program, who is the immediate past chair of the committee, a formal proposal has not yet been created, because the committee plans to continue to educate the transplant community and public on the three proposals and ask for feedback. Any proposal that is developed will be submitted through the established OPTN/UNOS policy development process for review, says Dr. Stegall. Anyone can comment on this initiative via www.optn.org/kars.asp. This Web site has information about the proposals and the avenue for feedback, including the process for submitting a comment. Once a final date and location for the public forum have been selected, this information will be posted to the site.

## Briefs

### Join a Transplant Facebook Group

A Mayo Clinic heart transplant recipient, Bob Aronson, has started a Facebook group for transplant patients, caregivers, donor families and anyone else interested in organ transplantation.

If you have a Facebook profile already, search for “Organ Transplant Patients, Friends and You”and join this group. If you don’t have a Facebook page, visit www.facebook.com and sign up. Facebook is a free social networking site that helps you connect with other people.

### Transplant Picnic Update

The annual Mayo Clinic Celebration of Life Transplant Patient Picnic took place on Saturday, July 12, at Essex Park in Rochester. Picnic highlights include lunch, music and a gift basket raffle.

The 2009 picnic is set for Saturday, July 11.

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## For More
## Information…

For more information on the Mayo Clinic Transplant Center, visit us online at

**www.mayoclinic.org/transplantcenter-rst**

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