RECLAIMING HANUKAH

THE DONATION OF LIFE

By: Debbie Cohen

He has been defying the odds and stumpi doctors for years. But on Thursday, November 3, 2011, 37-year-old Ronen Bokovza entered a new era in his life. On that mild autumn day, in the company of his spiritual mentor, Rabbi David Ozeri, Ronen prepared to spend six hours attached to medical equipment at Columbia Presbyterian Hospital. For virtually anyone else, this would have been a grueling ordeal. But for Ronen, this experience was practically standard fare – and in fact a miracle for which he was excited and exceedingly thankful.

For the past 17 years, Ronen suffered from a chronic kidney disorder and spent 12 hours out of every day attached to a dialysis machine in his house. During last month’s six hour procedure at Columbia, he received a kidney transplant—and with it, a chance to live a normal and healthy life.

But the account of Ronen’s journey to that moment is itself a remarkable story. From the untiring support of Renewal, the organization which tested 250 potential donors for Ronen before finding a match, to the incredible generosity of Tomer Naftali, the kidney donor – whom Ronen had never met until the morning of the transplant. And, in the center of it all, was Rabbi Ozeri and Congregation Yad Yosef, extending extraordinary support throughout the process.

Diagnosis: Chronic Kidney Disease
Ronen, an Israeli native whose father is Tunisian and whose mother is from Iraq, has dark hair and eyes, a slight build, and a calm, humble demeanor. He grew up in Tiveria (Tiberias), and when he was about 13 years old, he woke up one day feeling pains in his head and stomach. Initially the doctor couldn’t find anything wrong, but when the symptoms persisted for a week, blood work and urine tests revealed a problem with his kidneys, confirmed by repeated tests several weeks later.

Ronen’s parents were sent to a nephrologist for consultation, and a year later, a biopsy of the kidney was performed and determined that Ronen suffered from glomerula nephritis, chronic kidney infection.

Ronen began taking steroids to decelerate the progression of the disease, but when he was 15 and in the ninth grade, he was told he would need dialysis. Within a relatively short time—a year and a half—he received a kidney from a cadaver donor.

“The hospital gives priority to younger people,” he explains, “and I was healthy except for the kidney disease, so there was no problem for me to have the transplant.”

The new kidney functioned very well in his body for three years and three months. Ronen remembers playing sports like any teenager, traveling, and playing music with friends; though, he was exempt from army service because of his medical condition.

But suddenly, one day in 1994, he felt unusual symptoms. He tried to ignore them for a few days, fearing the worst, but then woke up on a Shabbat morning with his face swollen, a result of water retention. He knew that meant his kidney was not removing fluids the way it was supposed to, and tests at Rambam Hospital confirmed that his body had “killed,” or rejected, the new kidney.

“It was the most traumatic experience of my life,” Ronen recalls, “much more so than being on dialysis. To have a kidney and then reject it—you know where you came from and now, where you’re headed. I was very depressed. I had to stay in the hospital for a long time. They did an open biopsy on the transplanted kidney. I had pain and fever and was very weak…”

From December 1994 until last month, Ronen was undergoing dialysis every day, hoping and waiting for a miracle.

The Search for the Perfect Match

Ronen says that he was raised in a traditional family, and he always believed in Gd. He even recalls speaking to Gd directly, already at the age of six. He was not, however, interested in formal religion — until he suffered the trauma of the kidney rejection. During this difficult period, he found that being with his friends helped him to forget his problems. One friend from high school had become religious, and this time, Ronen was ready to listen.

“I needed the hizuk (inspirational strengthening) that he was offering,” he recalls. He started to learn, to do missvot, and to put on tefillin.

During this process of spiritual growth, Ronen also began searching for a new kidney, but this time with growing faith that Hashem would show the way. He decided that he didn’t want to risk having another kidney rejected; if he would have another transplant, it would have to be a perfect match.

Around that time many transplants were being done in China, before it was revealed that Chinese prisoners were being killed and their organs sold, in violation of international law. World pressure soon closed the gates on foreigners seeking to have transplants done there. A similar situation occurred in the Philippines, after Ronen had already been in contact with a doctor and scheduled a transplant.

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Hope and Renewal

In 2008, he heard from a friend who had moved to Brooklyn about an organization called Renewal, that worked to match potential kidney donors with patients in need of transplants.

Renewal was founded in 2006 by Mendy Reiner, who knew someone on dialysis desperately waiting for a kidney transplant. In his efforts to help his friend, he discovered that this problem is widespread. He also found that there were many altruistic people willing to donate their kidney to save a life, but there was no one these people could turn to for direction and support.

Ronen spoke to people at Renewal, who advised him to come to America because they thought they could find a match for him.

"My friend set up a basement apartment in Bensonhurst where he lived with his wife," he recalls, and he ate his meals with them. "He and his wife did a great hesed for me, and it's something that I'll never forget my entire life... They were very kind to me."

Rabbi Menachem Friedman, program director at Renewal, said that Ronen was the first patient he worked with when joining the organization three years ago. "Typically, we are able to find a match for a dialysis patient within six to nine months, which is incredible considering that in the general population it takes six to eight years. For most patients, an average of 10 potential matches are tested before a donor is found. But Ronen has very high antibodies that caused him to reject many prospective candidates."

Rabbi Friedman explains that our immune system naturally works to fight off foreign objects, and different amounts of antibodies are produced in response to different stimuli, including viruses, an organ transplant, blood transfusion, and dialysis.

Rabbi Chaim Steinmetz, director of Renewal, adds that Ronen was at the top of their list for two years, and every possible donor was tested for him. However, none of them matched.

Clinging to Community

After several months of unsuccessful searching, Ronen’s friend thought that perhaps he should move back to Israel, since Renewal had all his information and could call him to fly back if a match was found.

"I thought, it’s better if I stay here so they don’t forget about me,” Ronen says. “At least here I would have a chance. In Israel for 14 years there was nothing, no chance, and then the gates closed in China, then in the Philippines… Here is where I have a chance and so I decided to stay.”

During the time he was living in Bensonhurst, Ronen wanted to pray in a Sephardic shul, and took two buses daily to Congregation Yam HaTorah. A friend there repeatedly told him that he should move to Flatbush, but he didn’t even know where to start. One day, during a doctor’s visit at Columbia Presbyterian, he was in the Bikur Holim room together with a Jewish family. They asked him what he was doing at the hospital, where he lived, and whether he would prefer to live in their basement in Flatbush.

"I said, ‘Take my phone number,’ and she said, ‘You take my number and call me.’” It was August and he had no air conditioning, so he called, and was told that they were in the mountains but he should take the combination number for the lock on their house and move into their basement.

A Walking Miracle

Ronen continued his daily 12-hour ritual at home of peritoneal dialysis, which requires a sterile room, gloves, and masks. Ronen says it’s a miracle that he never had a problem with...
sterile room, gloves, and masks. Ronen says it's a miracle that he never had a problem with infections, which are common. Most patients after three to five years maximum give up doing dialysis at home and instead go to a center three times a week for hemodialysis, which is more invasive and less effective at filtering impurities from the body. After 10 years, 80 out of 100 patients at a dialysis center will no longer be alive.

While patients doing dialysis at home fare slightly better, Rabbi Friedman says, they still cannot have any kind of a normal life, as everything revolves around their daily treatment. In general, they feel tired and weak. In addition, he explains that the kidneys do many things we don't even know about, and dialysis duplicates only one of those functions. For example, the kidneys regulate vitamin D, and Ronen's bones are very weak; he also has thyroid problems.

"His body was deteriorating," Rabbi Friedman adds. "How much longer could he continue?" Ronen says that it is extremely uncommon for someone to survive on dialysis as long as he did, and when he would tell doctors that he had been receiving the treatment for over 16 years, they would be shocked, and stand speechless for a few seconds.

Ronen describes how dialysis patients generally must follow a very restricted diet. For example, they must limit their intake of fruits and vegetables, especially bananas, as potassium is not being removed by the kidney and a buildup could cause a heart attack within a few minutes. They also cannot drink too much, because the fluid retention leads to high blood pressure, strain on the heart, and swelling of the face and legs. Most patients are thirsty, but instead of drinking, they eat ice.

"My whole life is a miracle, every day," Ronen adds, and quotes from the Modim prayer of the Amida: "For the hidden miracles that You do for us… in the evening, morning, and afternoon..." He says that "maybe many people have that, all the time, but don't feel it. It's not in our zechut (merit) [that we are kept alive]; it's only from the hesed of Hashem."

The Yad Yosef Connection

A friend of Ronen's at Yam HaTorah brought him to Rabbi Ozeri, who "tried to help in any way possible," including taking him to top nephrologists here. "I know the rabbi for two years, I see how many people are trying to reach him, and I'm very appreciative that he gave so much of his time to me. It was very kind of him to accept this burden on himself."

Ronen says that soon afterwards he began praying at Yad Yosef, which he describes as "my first home, not my second home." In addition to doing work there, the shul is "where I learn, where my friends are... It's like my family. I don't need to go anywhere else. I know everyone here. Without Yad Yosef it would be very hard."

In late August of this year, after becoming a familiar face at Yad Yosef, Ronen described his predicament to Morris, a longtime congregant. While listening sympathetically to the decades long search for a match, Morris suggested advertising the need for a kidney with Community magazine. Realizing that funds were tight, and being an advertiser with Community himself (GlobalCellularRental.com), Morris volunteered to take care of placing the ad at no cost to Ronen. Some ten days later, an appeal for a kidney donor appeared on page 30 of the September issue of Community. Meanwhile, in Monsey New York, the ad caught the eye of one Tomer Naftali. And though Tomer would go on to be Ronen's donor, Hashem's plan had already been put into motion long before.

A Stranger Gives the Gift of Life

By the time he saw the ad, Tomer had already decided to become a kidney donor for Ronen. And just two months ago, after Tomer's screening was complete, Ronen received the phone call he had been waiting for, the one that would change his life.

"A few days after Rosh Hashanah I heard from Renewal that they found someone who’s a match," he says. He was given only the first name of his benefactor, and the fact that he was also Sephardic. Ronen points out that the word torem in Hebrew, which means donor, has the same letters as the name Tomer.
Nearly a month after learning of the impending transplant, one week before the surgery, Ronen had still not shared the news with many people. The only one who knew at that point were his mother, Rabbi David Ozeri and his son Rabbi Ezra, and his best friend in Boro Park—or what Ronen collectively describes as, “my family here.”

Rabbi Steinmetz adds that Ronen has a very strong will to live and believes that’s what got him through 17 years of dialysis. “He fought to stay alive and he got himself into a community where he found the support he needed. Then Hashem, using the shelhim (messengers) Tomer Naftali, Rabbi Ozeri and Renewal got him to the finish line.”

The Final Stretch

Approximately a week before the transplant, Ronen went to the hospital to have a port put into his neck, in preparation for the procedure he would undergo the following week called plasmapheresis. Three days before and again a day before surgery, his blood was filtered to temporarily reduce his antibodies. “They could do the transplant without this treatment, but the doctor didn’t want to take a chance,” he explains.

Ronen found the procedure quite painful and was praying the whole time for everything to go smoothly, adding what he had learned about bitahon (trust in Gd): he made his request based not on his own merits but simply as a favor from Gd, a gift from Hashem’s rahamim (mercy). At one point during the procedure, the nurse became concerned upon seeing Ronen muttering to himself, but the doctor, a Muslim, explained to her that he was praying. And Hashem seemed to send a sign that He would answer Ronen’s request for mercy. When Ronen asked the doctor his name, he replied, “My name is Dr. Rahman.” (“rahman” in Hebrew means “merciful.”)

Rabbi Ozeri, who wanted to accompany Ronen the day of the surgery, thought it would be too difficult for Ronen to have to travel into the city from Brooklyn at 5:30 in the morning. He offered to stay with him in a hotel near the hospital the night before the transplant, and helped set up the dialysis machine, for the last time. After checking in on Ronen, the Rabbi went down the hall to his own room for a few precious hours of rest before the early morning surgery.

Meanwhile, miles away, Ronen’s extended family at Yad Yosef remained engaged. Renewal founder Mendy Reiner was amazed by the absolute devotion and concern for Ronen displayed by the congregants. “It’s mind boggling to me to see how this shul adopted someone from another country... the love shown to someone from across the world who they never met before, to do whatever was necessary to help him,” he says. “There was a buzz in the air throughout the shul: ‘Ronen got a kidney!’ They were up at 5:30 in the morning reading Tehilim for him, they organized shifts and came to visit, and everyone was involved to make him as comfortable as possible... If this is not going to bring Mashiach, I don’t know what will.”

Mr. Reiner goes on to describe the scene at the hospital on the morning of the surgery. Renewal’s policy is that the donor and recipient don’t meet until that day, so that if the donor decides to back out, there is no pressure or guilt involved. The donors appreciate this freedom and the clarity it ultimately lends to the decision-making process.

At Columbia Presbyterian there is a long, semi-circular hallway where everyone registers; those on either end of the hall can’t see each other. Ronen and Tomer each moved into their own room at opposite ends and prepared for surgery. “They only meet after we clear it with both of them,” Mr. Reiner says. “First we ask the donor, because sometimes they prefer to remain anonymous. But Tomer was okay with it, so then we asked Ronen.

“He said, ‘I’m scared to meet him, because I have no words to tell him what I’m feeling. What can I say to someone who’s saving my life?’”

Next month: Tomer’s story, and their meeting for the first time.
*Please pray for a speedy recovery for Ronen ben Aviva and Tomer ben Dahlia.