OPENING THE LOCKED DOOR TO DIALYSIS

Justin, 21, has had kidney problems his whole life. In 2005, he had his first kidney transplant. About five years later, when that kidney’s function started declining, he was offered the opportunity for a second transplant. After two failed attempts over two years, his transplant team told him he would be unable to receive another kidney transplant, and eventually he would have to receive dialysis treatments to survive.

“Dialysis was something we put off for 21 years,” said Sharon, Justin’s mom. “He’s had renal problems since birth, so 21 years is a pretty good amount of time to delay it.”

Sharon said that for his 21st birthday, she took Justin to Las Vegas. When they returned from this celebratory trip, however, his health worsened. Sharon said she knew it was time to begin his dialysis.

Finding a dialysis unit close to their home in the Pocono Mountains, Penn., proved to be a difficult feat. Sharon and Justin began a weekly commute to Cornell Hospital in Manhattan, commuting for more than 20 hours per week for his three dialysis treatments.

“We called so many units in Pennsylvania and New Jersey,” Sharon shared. “Nobody would take us. Pediatric units wouldn’t accept us because Justin is over 18. Adult units rejected us because he was underweight.”

Justin, who weighs just 40 pounds, seemed to be a special case in limbo between the adult and pediatric dialysis providers in the area. Sharon faced trial after trial, stunned that not a single dialysis unit in Pennsylvania could help her son. The social worker at the Cornell dialysis unit called every hospital within a 60-mile range of Sharon and Justin’s house. Her results were just as grim: nobody was willing to accept him.

Story continued on next page.
“I went and spoke with my local Senator about the lack of provision for people with kidney failure in our community. Because our case was so unique, he couldn’t really help us. I called the Quality Insights Renal Network 4… eventually, even they couldn’t help us. It felt like the Twilight Zone. Commuting to dialysis was a full-time job,” Sharon said.

Finally, Sharon spoke with Dr. Toros Kapoian, Medical Director of DCI North Brunswick in New Jersey. He assured Sharon it would not be a problem to dialyze Justin at DCI. Sharon completed the transfer paperwork and immediately their commute was halved. The commute to DCI is still 92 miles. The good news is that Dr. Kapoian was able to adjust Justin’s dialysis treatments to twice per week instead of three times.

“Typically we leave around 8:30 AM and he starts treatment around 10:30. We’re home again by 5,” said Sharon.

Sharon said now her biggest concern is facing the winter. She fears Justin could get snowed in on a dialysis day, which has prompted them to explore peritoneal dialysis, which is completed at home. This July, Justin had a peritoneal dialysis catheter placed.

“The doctors said they were able to put in a small catheter. It may not work since he’s had so many previous surgeries,” she said. “But to us, it’s worth a try.”

Dialyzing at home would be a benefit to Justin as he will begin his college education this fall. In August, he’ll start school at North Hampton Community College, where he plans to study animation.

At the summit, the Administration and private entities shared new visions and missions to improve outcomes for individuals waiting for organ transplants and to improve support for living donors. As part of the Nonprofit Kidney Care Alliance, DCI, along with Northwest Kidney Centers and The Rogosin Institute, pledged to launch new programs to increase access to transplantation for more than 4,000 chronic kidney disease (CKD) and end-stage renal disease (ESRD) patients.

DCI reported the expansion of its Reach Kidney Care Program to 27 communities in 17 states. Reach will provide patient education and assistance to 2,500 patients with less than 30-percent of kidney function over the next year with the goal of increasing access to pre-emptive transplant before a patient needs dialysis.

“DCI is committed to educating our patients about all treatment options well before kidney failure occurs. If patients desire a transplant, we will equip them with the resources they need to discuss organ donation with potential living donors,” said Doug Johnson, MD, vice chair of the board at DCI.

“Patients with kidney failure face a variety of challenges, however, a lengthy wait time for a transplant shouldn’t be one of them,” continued Johnson. “We will work closely to delay kidney failure as long as medically possible through education and counseling of individuals in the chronic kidney disease stages.”

Story continued on next page.
“If kidney failure is unavoidable, our team will coordinate with transplant centers to ensure that patients are fully prepared for a transplant,” Johnson concluded.

At the summit, three major actions were announced to reduce the organ waiting list:

1. Close the gap between the 95 percent of Americans who support organ donation and the roughly 50-percent who are registered.

2. Invest in clinical research and innovation that could potentially increase the number of transplants by almost 2,000 each year and improve outcomes for patients.

3. Facilitate breakthrough research and development with almost $200 million in investments.

It was an honor to attend the summit and meet with other organizations who share the same vision. DCI remains committed to working tirelessly to overcome the barriers to organ donation, and we strive to make dialysis the short-term solution for those desiring a transplant. Click here to learn more about all of the goals outlined in The White House Organ Summit.

Care coordinators had a wonderful time getting together in Nashville for the first annual Reach Kidney Care care coordinator meeting. The itinerary included leadership seminars, professional development, and group bonding through Nashville’s The Escape Game!
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When Joey Birch found out he had inherited Polycystic Kidney Disease (PKD) from his father, one of the most common, life threatening genetic diseases that affects thousands of Americans every year, he was determined to keep his kidney function stable for as long as possible.

After watching his father dialyze for five years before receiving a kidney transplant, Joey knew he did not want dialysis to be part of his future if he could help it. However, in 2012, Joey's glomerular filtration rate (GFR), or kidney function, began dropping, so his nephrologist referred him to Reach Kidney Care of Spartanburg, SC. “My care coordinator there told me what I needed to do to maintain my kidney health, and more importantly, that I was a good candidate for a transplant,” he said. “Reach Kidney Care was responsible for getting me on the transplant waiting list and educating me about the opportunity for a living donor transplant.”

After this Reach Kidney Care meeting, his wife, Paige, was tested to see if she could be a potential kidney match. It turned out that the woman he married was a perfect match in more ways than one! On December 5, 2013, Paige was able to become Joey’s living organ donor.

In Joey’s lifetime, he’s sent cancer into remission, walked again after a motorcycle accident required an amputation of his left foot, and in 2013, successfully prevented the need for dialysis by receiving a pre-emptive kidney transplant. Today, Joey works full-time making prosthetic limbs for amputees. “A pre-emptive transplant is a better life,” he shared. “This transplant was one of the best experiences I have ever had. Truly, one of the happiest days of my life.”

Learn more about Joey’s journey on our website: www.dciinc.org/ourpatients/

The Power of Pre-Emptive Transplants

This year, DCI has committed to quadrupling the pre-emptive kidney transplant rate from 2.3% to 11% through it’s Reach Kidney Care program. Take a look at some of these stories and facts about our patients who’ve received or prepared for a pre-emptive kidney transplant through Reach Kidney Care.

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TRUTH:
Less than 1/3 of kidneys transplanted were from living donors in 2013. (USRDS, 2015)

We offer early education to drive pre-emptive transplants & understand living donation.

TRUTH:
The kidney transplant waiting list currently has 99,886 candidates. The median wait time is 3.6 years, about 561 dialysis treatments. (UNOS, 2016; USRDS, 2015)

We recognize the wait is long. We strive to make dialysis the short-term solution for those desiring a transplant.

TRUTH:
16% of kidneys recovered from deceased donors were discarded in 2013. (USRDS, 2015)

We are persistent in the search of methods to overcome barriers to organ donation.
Grisel Burgos has been a Reach Kidney Care patient since 2014. With a family history of polycystic kidney disease and hypertension, she knew end stage renal disease could be a possibility. However, after meeting her local Reach team, she began working with them to delay dialysis for more than a year and a half.

“When we first met Ms. Burgos, she was really frightened and worried about end stage renal disease. As she continued to come to Reach Kidney Care, it was apparent that after several visits with our chronic kidney disease coordinator and dietitian, she was able to take hold of the tools necessary for her to make the changes in her life to slow her kidney disease progression. Through this process, we were able to witness Ms. Burgos’ change in demeanor and watch her enjoy life to the fullest,” said Ed Dennis, NP, Reach Kidney Care coordinator.

Here are some of the things Grisel shared with us that she learned through her experience with Reach Kidney Care:

**Talking about kidney disease makes it less scary**

“Reach Kidney Care helped me out of a dark depression,” Grisel said. “It got that right out of my system. Talking with Ed Dennis made me realize I had to face the facts. Going through every detail of my kidney disease with a kidney specialist helped me understand it in a new light.”

**I can delay dialysis**

“I found out I had kidney disease when I was sixteen. I was scared of dialysis. Ed said if I stick to a certain diet and lifestyle choices, I can continue to delay dialysis. I followed the tips, like cutting out food with high salt, using phosphorous binders, and limiting how much I drink, and I was able to put dialysis off for nearly two years.”

**I can work toward qualifying for a kidney transplant**

Sometimes when people hear that they don’t qualify for a transplant, they don’t realize they can work toward it. “I am working now toward a kidney transplant,” Grisel said. “I am getting information and learning more about it. It is definitely an option I want to pursue.”

**Education is an important aspect of my care**

It is difficult to try and teach yourself about a complex chronic disease. Having someone guide you through the process and answer all of your questions can be a huge relief. Grisel shared, “At Reach Kidney Care, I was allowed to take it easy there. I was taught the steps I needed to prolong my kidney health. It started with the changes in my diet I needed to make. I was educated step by step.”
Many people dream of sipping lemonade while gently rocking in a hammock during the sultry summer days. Yet, for people with kidney failure, the lemonade, or more specifically the amount of lemonade they drink, could be a problem.

For people with normal kidney function, their kidneys help to regulate the amount of fluid in the body. When a person has kidney failure, the kidneys are not able to remove the excess fluid from the body. While many people with kidney failure rely on dialysis to remove fluid, they still must be careful to stay within strict fluid limits. Too much fluid may cause swelling, shortness of breath, or high blood pressure, which can have severe consequences. Also, the more fluid a person consumes between dialysis treatments means the more fluid that has to be removed during a dialysis treatment. This can lead to a longer or less comfortable treatment.

During the hot summer days, controlling thirst can become a complicated matter for people with kidney failure. We asked DCI dietitian, Amy See, RD, of DCI Warrensburg, Missouri, to suggest ways to control thirst while drinking less.

A LIGHT SPRAY MAY HELP COMBAT DRY MOUTH
Using a refreshing spray can re-wet the mouth and will use less fluid than drinking from a container. Amy suggests:

- Mint spray: 1 teaspoon peppermint extract in 1 cup of water. Mix together in spray bottle. Spritz as needed.
- Lemon spray: ½ cup lemon juice in ½ cup of water. Mix together in spray bottle. Use as needed.

FROZEN OR COLD FRUIT HELPS TO CONTROL THIRST
Ice can sometimes quench thirst better than water. Try freezing lemon juice with water to make lemon ice cubes. Also, try sucking on frozen grapes.

CHEW SUGAR FREE GUM OR SUCK ON SUGAR FREE MINTS
Eating salty and sugary foods can encourage thirst. Avoid high sodium & concentrated sweets. To combat cravings, chew sugar free gum or suck on sugar free mints.

TAKE MEDICATIONS WITH APPLESAUCE INSTEAD OF LIQUID
This is a great way to sneak medicine into your system without all that extra liquid.

AVOID THE HOTTEST PART OF THE DAY AND STAY OUT OF DIRECT SUN
Try avoiding the sun between 10 a.m. and 4 p.m., when the sun’s rays are strongest.

KEEP A FLUID AND FOOD DIARY
Many people with kidney failure may not realize how much fluid they eat or drink. Anything that pours or melts is a fluid. Keep a fluid and food diary to identify what is consumed over time. While a nephrologist, kidney doctor, will make an individual recommendation, most people with kidney failure should limit their fluid intake to around four cups per day.

Kidney Friendly Recipes for the Summer

There’s no denying it, summer is here to stay! Did you know the DCI website has over 100 kidney friendly recipes to enjoy in the warmer weather? Here are two of our favorite summer recipes:

1. Apple Salad

Ingredients:
- 2 c. diced apples (about 4 apples)
- 1/2 c. chopped walnuts
- 1/2 c. golden raisins
- 3 T. mayonnaise
- 3 T. low-fat, plain yogurt

Instructions:
- Dice apples.
- Combine all ingredients.
- Chill.

2. Avocado Dip

Ingredients:
- 2 oz cream cheese
- 1/2 ripe avocado
- 1 lime
- 1/2 tsp. sugar
- 1/8 tsp. salt
- 1/8 tsp. ground pepper

Instructions:
- Allow cream cheese to soften at room temperature.
- Cut avocado in half and remove pit.
- Using a spoon, scoop the fruit out of the avocado, leaving the skin.
- In a blender or food processor, blend together the cream cheese and avocado.
- Juice the limes and add juice to blender.
- Add sugar, salt, pepper, and blend until smooth.
TRAVELING ON DIALYSIS

Since starting peritoneal dialysis, Mike’s been to Florida, Oregon and Michigan. He’s been on a road trip to South Dakota. He takes many weekend trips with his wife, and he doesn’t seem to think traveling on dialysis is a problem. What’s his secret to traveling so often and so well on dialysis? We asked Mike, and this is what he shared.

PLAN PRECISELY FOR YOUR NEEDS
“It takes up to one week for your dialysis supplies to be delivered, so give yourself time when pre-ordering, otherwise if you run out of supplies or it doesn’t arrive in time, you’re at the mercy of staying in one place until it arrives,” Mike shared.

DEVELOP A PACKING SYSTEM, KEEP IT CONSISTENT
Mike said, “Always make sure you have your safety caps. Bring dialysate. Create a checklist so you don’t forget anything. Once you have it all together, pack it together. For instance, I use one specific suitcase for ancillary equipment every trip.”

ALWAYS PACK EXTRA SUPPLIES
“Traveling on dialysis has been no problem at all, your extra baggage just happens to be equipment. If you’re traveling in a trailer or on a road trip, the biggest thing to consider is space. The equipment takes up room. Also, remember you have to be able to move it yourself,” Mike noted.

If you’re flying, it is important to note that dialysis supplies qualify as lifesaving medical equipment, so the weight of the luggage won’t count against you. Remember, if you’re shipping dialysis equipment to a hotel or future destination, it cannot be delivered without your personal signature. Make sure you’re there when it’s scheduled for delivery!

KNOW THAT YOU CAN GET HELP ON THE ROAD
“On a trip to Sturgis, South Dakota, I got an infection that threw a wrench in the plan. But, my wife just took me to the hospital and they treated me right away. You can’t be afraid of hospitals. You have to understand anything can happen, just like at home,” he shared.

BE FLEXIBLE AND KNOW WHERE DIALYSIS CENTERS ARE NEAR YOU
“If your catheter fails, you'll have to find a hemodialysis center, and it may cut your trip short, or reroute you. That’s okay. Make sure you get there safely.” Flexibility is key to traveling on dialysis. Use the [Medicare Dialysis Facility Finder](https://www.cms.gov/Medicare/Prescription-Drug-Coverage/PrescriptionDrugs/DialysisFacilityFinder.htm) to locate dialysis centers in the U.S.

HAVE FUN!
“Traveling is really fun. I never saw dialysis as a setback. After my kidney transplant, my wife and I are going to Tucson, Ariz., and Portland, Ore., to visit the grandchildren. We’re also planning a trip to Ireland, to learn more about my ancestry. Don’t let dialysis or kidney disease slow you down.”

Mike wouldn’t miss his children’s graduations for anything! Top, his daughter obtaining her graduate degree; Bottom, his son achieving his undergraduate degree.

The medical professional says....
“We encourage our kidney patients to keep their trips planned. What they do on the road is the same as what they do at home. We tell them to monitor blood pressure, bring all of their doctor’s phone numbers and most of all, we assure them that traveling is a great opportunity. We don’t want them to feel held back in any way,” said Ed Dennis, NP, Reach Kidney Care of Middle Tennessee care coordinator.

Please note: this is not medical advice. If you are planning a trip, please talk with your dialysis nurse, social worker, and nephrologist.
Although Randy only had one kidney, life was pretty normal for him until 2005. That’s when his nephrologist, Dwayne Bergeaux, MD, medical director of DCI Jennings, said something needed to change in his lifestyle if he wanted to avoid dialysis. Dr. Bergeaux recommended gastric bypass surgery to help Randy expedite his weight loss, which would enable Randy to regain some kidney function.

“He told me I needed to lose weight or I would need to begin dialysis within the year,” Randy said.

Randy knew he didn’t want dialysis, but he told Dr. Bergeaux the only way he would move forward with the surgery was if his wife, Laurie, did too.

“At the mention of dialysis, a brick wall went up,” Laurie said. “It didn’t make sense to change our diet and lives so drastically if we both weren’t in it together.”

Later that year, both Randy and Laurie underwent gastric bypass surgery, which enabled Randy to maintain his kidney health for nearly 11 more years.

In 2015, Randy’s kidney function started dropping again. His nephrologist said it was now time to prepare for dialysis or a transplant. Laurie knew a transplant would offer a better life for her husband, so she began seeking out educational opportunities to learn more about the risks and benefits of this treatment option. She referred herself to a transplant center and soon learned that in Louisiana, a kidney transplant must be done within the state to be covered by her insurance. She went to Tulane Medical Center and began meeting with a transplant coordinator to learn more about Randy’s options.

In October of 2015, Randy began home peritoneal dialysis after training at DCI Jennings. Life on dialysis was hard for Randy and Laurie. Randy had to learn how to keep detailed treatment records, and since peritoneal dialysis requires a sterile environment with no pets, Randy had to dialyze in a separate, “no-dog” room at night. With dialysis, Randy and Laurie also learned that there are a lot of restrictions on diet, causing Randy’s weight to drop significantly.

“Life on dialysis was completely different. He was so tired, he was always trying to catch up on his sleep,” she said.

During this time, Randy continued to work. As a cook at the Southwest Louisiana War Veterans Home, his employer provided a sterile room for him to dialyze in at work if the need arose. About three months after he began dialysis, Randy became a transplant candidate and 19 friends and family members stepped up to see if they were a match for him. Of those, five were viable, and on January 27, 2016, Randy’s younger sister was scheduled to donate her kidney to him.

“Any one of the matches was ready to step up, but the hospital thought his sister would be the best fit,” Laurie shared. “The surgery was actually scheduled on our twentieth wedding anniversary, which would have been the best gift ever.”

Unfortunately, Randy caught a cold and the transplant had to be delayed about two more weeks. But finally, on February 17, 2016, Randy’s sister became his living organ donor.

“It’s been amazing,” Laurie said. “I have seen God’s hand in this without a doubt. It’s a shame more people don’t understand the power and purpose of organ procurement. Life is completely different now.”

Laurie said that even though they had to make sacrifices along the way, Randy’s kidney transplant made it all worth it in the long run.

“At one point, Randy didn’t know if he would live to be past 50. He’ll be 60 in October and he feels amazing. He might outlive my dad who’s 90!” Laurie teased.
REACH KIDNEY CARE PARTNERS WITH UNIVERSITY OF NEW MEXICO’S KIDNEY PAIRED DONATION PROGRAM

Last August, UAB Hospital completed the 51st kidney transplant in the longest living-donor kidney transplant chain. This chain included nine altruistic living donors and involved people from 11 states. The youngest person transplanted was just 15 years old.

Through Kidney Paired Donation Programs like this, the chances of someone in need receiving a kidney transplant significantly increase. Now, our Reach Kidney Care of New Mexico team has the opportunity to participate in a similar program in its own backyard. This July, Reach Kidney Care of New Mexico will officially become a partner with the University of New Mexico (UNM) Hospitals’ Kidney Paired Donation Program.

The United Network for Organ Sharing (UNOS) defines a kidney paired donation (KPD) as a transplant option for candidates who have a living donor who is medically able, but cannot donate a kidney to their intended candidate because of an incompatibility. If both the donor and recipient are willing, UNOS will work with transplant centers to search for cases where the donor in each pair is compatible with the recipient in another pair (or multiple pairs). By exchanging donors, a compatible match for both recipients can be found, and eventually a chain can begin.

“Having this partnership with UNM is huge because now I can explain to patients that their chances of receiving a kidney transplant are actually higher if they choose to enroll in this program,” said Charlie Campbell, Reach Kidney Care of New Mexico care coordinator.

Reach Kidney Care will act as a referrer to the program, ensuring each patient fully knows his or her transplant options. Reach Kidney Care of New Mexico’s goal with this partnership is to reduce the number of patients on dialysis and increase the number of transplanted patients in the state.

UNM Hospitals is one of two transplant centers in New Mexico. Nearly 3,000 New Mexicans are on dialysis, and today there are 476 candidates on the kidney transplant wait list for New Mexico.

“The biggest benefit of partnering in a Kidney Paired Donation Program is increased access to pre-emptive transplants,” Charlie said. “The more patients who receive transplants, the less who have to undergo dialysis treatment, and that's our goal.”

SUCCESS STORY FROM THE FIELD

Translating Medicine to Burmese

Recently, one of the Reach MTM Clinical Pharmacists, Maggie McNamara, had a Burmese-speaking patient who was not taking any of his medications because he could not understand the drugs or labels. Because he was unable to read the English labels, he was disposing of the medications.

Maggie worked with MissionPoint and the patient’s care coordinator to find the root cause. After looking into the situation, it was found that his filling pharmacy was not offering translation services to Burmese. Maggie was then able to attain his medication list with specific drug codes and directions from his filling pharmacy and provide it to a translator.

“We were able to create a document in our software with the drug name (in English) and had the directions translated to Burmese for him,” she said. “The handout we provided to the patient also included a picture of the exact tablet (with markings) enabling him to identify medication accurately so he may become compliant with his prescriptions.”
1. The patient has the right to choose the best treatment for his or her lifestyle. Before treatment begins, all patients are provided education concerning the advantages and disadvantages of each treatment offered for kidney failure. The options include in-center hemodialysis (90% of the adult US population uses this option), home hemodialysis, peritoneal dialysis, transplant and medical management without dialysis.

2. Home visits help determine needs when considering home dialysis. Home nurses provide an at-home visit prior to training. This is to assist the patient in learning how to successfully plan for his or her dialysis sessions at home. The home team will ensure each of their patients’ homes is a safe place to complete dialysis treatments.

3. Self-care is the first step to going home. For patients interested in home hemodialysis, they will be taught self-care prior to their formal training. This includes learning to weigh, check blood pressure, how to insert their needles and properly document each treatment.

4. Surgery may be required for a new access. For patients interested in peritoneal dialysis (PD), the home nurse will set up an appointment with a vascular access surgeon for a PD catheter placement. After the catheter is placed, the home nurse will keep close communication with the patient to answer any questions or concerns. Appointments are made weekly, usually before or after hemodialysis treatments, to flush the PD catheter and perform dressing changes.

5. Complete training and full support are available. For several weeks, each patient and his or her care-taker are taught the ins and outs of home dialysis. After training is complete, the home nurses remain available 24/7 for questions, concerns, or assistance.

6. Follow up with the care team ensures good health. When receiving care in the home setting, patients are still seen by medical professionals. Each patient will continue to be monitored closely by the home nurse to ensure treatment is going well. Also, all patients will continue to be seen monthly in the clinic to monitor their lab work and to ensure they are receiving quality care.

<table>
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<tr>
<th>STAGE</th>
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<td>5</td>
<td>Less than 15</td>
<td>VERY SEVERE SYMPTOMS, OR END STAGE RENAL DISEASE (ESRD).</td>
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83.5% of patients used reach resources before stage 5 of CKD.

23 MILLION AMERICANS HAVE CKD. ONLY 7% OF PEOPLE WITH STAGE 3 CKD KNOW THEY HAVE KIDNEY DISEASE.