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CHOICES II: INNOVATIONS

Family Focus

The Renal Community's Newspaper

VOLUME 11 NUMBER 4

FALL 2002

UNDERSTANDING YOUR CHOICES



Ideal Dialysis Care in the Next 10 Years

By Dale Ester

Some years have passed since my kidney transplant, giving me a "vacation" from hemodialysis. I use the word vacation because we never know how long our transplants will work. As a result, regardless of our current treatment, dialysis or transplantation, for kidney failure it is important to be aware of dialysis-related technologies. Since this issue of *Family Focus* is exploring innovations in current treatment, as well as what we might expect in the future, the Editorial Board thought it would be interesting to ask people who have chronic kidney disease to share their views of ideal care in the future for those on dialysis. Here's what they had to say.

EDNA MARTIN



(Rainbow Flat, New South Wales, Australia)
"My ideal is for dialysis to almost disappear in the next 5 to 10 years,

replaced by transplants of genetically engineered, modified, non-rejecting animal organs."

CONNIE KRAMER *(Grand Blanc, Michigan)* "I see ideal care as a permanent implantable artificial kidney."

ROBIN TITTERINGTON



(Decatur, Georgia)

"My preference is that we would not need dialysis in 10 years! I guess more funding for nocturnal dialysis or even daily dialysis would be nice.

Then there are little things. I'd like to see all RN's and more staff so I could see a staff member near me at all times. And then those lovely dialysis chairs we've talked about... comfy, soft chairs, pillows, blankets, laptops, tables and snacks!"

EDWARD HANSETH

(Rosemead, California) "Dialysis

must become easier, so patients can administer treatment to themselves. Machines would be portable with their own filters, and the use of regular water



would be possible. Patients would manage their weight gain between treatments and adjust settings for fluid removal. Dialysis treatment would be revised according to blood lab results. Machines would be monitored by modem during treatment and adjustments could be changed during log-on. Equipment would run on normal household current, and necessities

like sodium bicarbonate, dialysate, etc., would be packaged as single-use and in disposable containers for ease of transport and clean-up. Call me a dreamer, but making dialysis easier and more portable can make patients capable of living a more normal life. Dialysis is all about the freedom to live."

K. JOY KEMPER

(Lancaster, California)

"In my ideal dialysis future, treatment decisions would be based more on a patient's well-being than on



economics. Ideally, treatment would be individualized. Information about dialysis options would be universally available. Patients could go to a specific center of their choice. Transportation to and from dialysis units would be provided. Patients who wanted to have more control over their treatments would not be met with many delays and setbacks when they select home hemodialysis. New home hemodialysis machines would be portable, self-contained and have a water processor with extended-use tubing. Machines would be convertible for short or lengthy sessions. People would have the choice of scheduling periodic, daily or nocturnal dialysis, whichever best improves personal quality of life. Patients could travel with their machine, hooking it up anywhere water and electrical power exist."

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FROM THE EDITOR



Karren King

The future... what does it hold? At this time last year I found myself writing the editorial a few days after the tragedy of September 11th. Ironically I am writing this editorial at its first anniversary. If the events of that day have taught us anything, it is that we cannot predict what the future holds in store. That is true for each and every one of us. You might feel that it is even more of a reality for those, such as yourself, who face a chronic disease. Yet we can learn from the tragedies that occurred that day and the behaviors that followed. We are indeed strong, and ever hopeful for the future. You have also faced another hurdle, kidney failure, and there is every reason to face it with the same strength and optimism.

The last issue of *Family Focus* stressed just how far we have come in the treatment of chronic kidney disease. A huge amount of progress has occurred in the past 30 years and we can expect even more in the near future. It is the hope of your Editorial Board that this issue will serve as a source of hope, inspiration and enlightenment.

This issue also represents closure for this year's *Family Focus* Editorial Board. Tiffany Shubert, our fitness editor, will be leaving us to return to school for her doctorate degree. Tiffany's knowledge and skill in the area of physical fitness will be greatly missed. I believe that all of the members of the Editorial Board have made major contributions to the education of those with chronic kidney disease. As the publication's editor, I want to acknowledge the devotion and tremendous voluntary effort of these individuals.

I also want to welcome our new Editorial Board members, Pedro Recalde, the Fitness Editor, and Roberta Bachelder, the End Stage Renal Disease Network representative. I also want to formally welcome Linda Harte, our transplant editor, who

joined us mid-year. We look forward to their contributions.

The 2002-2003 Editorial Board met in September to plan the upcoming four issues of *Family Focus*. The next issue will feature only items that have been submitted by you, our readers. Diabetes will be featured in the issue following, as it is the most common cause of kidney disease. The third issue will highlight the importance of understanding lipids (fat) and bone disease in chronic kidney disease. Improving relationships and communication in the dialysis unit will be the focus of the final issue of 2003.

As always, your thoughts and feelings are important to us. For that reason, we will soon be asking for help from many of you in completing a survey about relationships in the dialysis unit. The results of this survey will be published in the last *Family Focus* issue of 2003. Since you are the experts, we will rely on you to give us the feedback that can help foster positive relationships in the dialysis community. Thanks for your help! 

Karren King, MSW, ACSW, LCSW
For the Editorial Board



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Editorial Office:
National Kidney Foundation
30 E. 33rd Street,
New York, NY 10016
(800) 622-9010 • (212) 889-2210
<http://www.kidney.org>

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The Change of Things in Peritoneal Dialysis

By Sandy Hinton, RN, BSN

Because peritoneal dialysis (PD) is still fairly new as a treatment for chronic kidney disease, it is easy to overlook how much this treatment has developed in its short history, and where innovations are taking it.

When PD began to be used as a treatment in the 1960s, it was only done in the hospital, where it was extremely expensive and difficult to manage. It was not until 1975 that PD as we know it today came to be. The concept of creating a treatment that was simple enough for an individual to do outside of the hospital without any assistance was a major breakthrough. This treatment, known as Continuous Ambulatory Peritoneal Dialysis (CAPD), was accepted by the federal government as a viable treatment and approved for reimbursement. As a result, dialysis centers began to offer patients the option of home peritoneal dialysis training and this treatment took off.

At this time, however, PD still had numerous problems and limitations. The placement of the PD catheter was a major surgery that usually involved a weeklong hospital stay. This catheter was usually put to use immediately (someone discharged from the hospital Saturday might begin training on Monday), so the surgical wounds had not fully healed. This greatly increased the risk of infection and leaking.

The process of performing a CAPD exchange involved a 48-inch transfer set, which looked like IV tubing, that was connected to the PD catheter. This line was connected to a plastic bag of solution by penetrating the bag with a pointed plastic spike. The bag of solution was then hung on an IV pole so that gravity could fill the peritoneal cavity. This bag would remain connected to the transfer line and carried around under one's clothing (undergarments, belts and special bags were designed to carry this bulk) until it was time to drain the solution out of the peritoneum into the same bag, unfolded. After the drain was completed, the spike was removed from the old bag, which was now full of waste, and connected to a new one. Careful hand position was required along with good eyesight in order to transfer the spike, and it was on many a wish and a prayer that contamination did not occur.

The risk and incidence of peritonitis and the importance of patient comfort and satisfaction became the main focus of manufacturers of peritoneal dialysis supplies. In 1986 came the first big change: the Y-set was born. This eliminated the need to wear 48 inches of line and a folded up solution bag. This meant more freedom for everyone and contributed to improved self-images. The incidence of peritonitis became less and PD became more attractive to patients and physicians as a viable option for treatment.

"In the last several years, manufacturers have continued to strive to create patient-friendly systems."

In the last several years, manufacturers have continued to strive to create patient-friendly systems. Transfer sets are now a mere six to eight inches long and are smooth and sleek, making them undetected under clothing. Y-sets have evolved into pre-connected systems, so no one has to spike bags any more. Physicians now plan ahead and place PD catheters (now done in day surgery) four to six months before

they are needed, which promotes better healing and less risk of infection and leaking.

Cyclers, machines that were introduced to allow people to do PD while sleeping, can now be run by computer software. These computers will soon be able to download all kinds of treatment information that will be helpful to health care workers.

Another new development is research into new types of solutions. The high-glucose level of solutions has caused problems with some patients, so new solutions are being developed with fewer side effects, resulting in better blood sugar control and less weight gain.

PD has come a long way in the past 30 years. Yet new research will continue to find ways to make this treatment more convenient and more practical. **F**

About the Author:

Sandy Hinton, RN, BSN graduated from Texas Christian University. She has worked in dialysis since 1977 and worked with peritoneal dialysis patients from 1984 until this year. She is currently a Renal/Pancreas Coordinator in Dallas, Texas.

Ideal Dialysis Care in the Next 10 Years

continued from page 1

SANDI KNOWLES (Gilbert, Arizona)

- ▼ "Dialysis prescriptions must be individualized, with dialysate composition and ultrafiltration modeling to resolve the true medical needs of each specific patient.
- ▼ There would be higher hematocrit levels so that I would have more energy!
- ▼ A lot less turnover of nurses and technicians would take place.
- ▼ A blood access that lasts longer and can be used more often without problems would be available.
- ▼ There would be a single-stick, dual-lumen needle that is as efficient as the use of two needles.
- ▼ Improved education for those with chronic kidney disease would be routinely offered before dialysis is begun so that people would know what to expect before their first treatment. People deserve an opportunity to visit a dialysis unit and speak with staff before they begin dialysis.

- ▼ People would be given the opportunity to learn all about their modality choices and then make an informed decision for what will give them the best quality of life."

You might be wondering, "What can I do to help make change happen?" It is easy because you are a customer! You are an important part of how the goods and services of quality dialysis care are delivered. Your thoughts and opinions are very important because ideas imagined are a terrific way to make treatment better and improved. Positive change can happen if you speak out and allow yourself to be heard. Make suggestions to people who will listen and react! When I look back at how far dialysis has come in the past 10 years, I see tremendous growth. I hope we can look back together in the next 10 years and say, "Things sure did get better, and I helped make the changes happen!" **F**



Improving Nutritional Outcomes: Daily Dialysis

By Lesley L. McPhatter, MS, RD

You are what you eat. This common phrase might be more meaningful for people on dialysis than for others who are not on such a complicated diet. You limit sodium, potassium, phosphorus and fluid in your diet while trying to eat enough protein and calories. Add a diabetic restriction and the diet becomes even more complex. You need to study very carefully the nutrient content of all the foods you eat.



This can make it hard to just enjoy eating, something those without dietary limits take for granted.

Nightly home hemodialysis (NHHD) offers an opportunity for hemodialysis patients to mimic the diet of healthy individuals who do not have dietary limits beyond their own choices. Short daily hemodialysis (SDHD) also offers fewer dietary restrictions than standard hemodialysis. Both offer an alternative to standard hemodialysis that improves appetite and general well-being and overall nutritional status.

A common complication of standard hemodialysis is malnutrition. Malnutrition means that someone is not well nourished and can be caused by many things including an unhealthy diet or medical problems. It has been directly linked to more sickness and higher rates of death in people with kidney failure.

The United States has a higher death rate for people with kidney failure than France, Japan or Italy.¹ In some dialysis units in France and Japan people dialyze eight hours per treatment, three days per week. In some dialysis centers in Italy, people

dialyze two hours per treatment, six days per week.² People on NHHD usually dialyze six to nine hours five to six nights per week at home at night while they sleep. People on SDHD dialyze two to three hours, six days per week either at home or in the dialysis unit.

There are over 250 published articles that discuss the advantages of daily dialysis for the treatment of kidney failure. As early as 1969 and up to the present, studies have shown improvements in the nutritional status of people on daily dialysis, including increased blood protein levels, improved protein catabolic rate, increased dry weight and increased appetite.¹ People on SDHD have better protein and calorie intake and increased dry body weights with improved fluid control and blood pressure control.³ People on NHHD have

improved protein intake; improved potassium levels and lower serum phosphorus levels without using phosphate binders. Most people on NHHD have to increase dietary phosphorus intake and/or add phosphorus either in their dialysate bath or orally to maintain normal levels. Most people on NHHD do not have to limit fluid intake. Additionally, 75 percent of people on daily dialysis need fewer blood pressure medications due to their improved fluid control.^{4,5}

“Daily dialysis offers more nutritional freedom. For people with a long history of kidney failure, this takes time to sink in.”

Daily dialysis offers more nutritional freedom. For people with a long history of kidney failure, this takes time to sink in. They are cautious until they see lab result after lab result come back within the normal range. After a while, they are able to focus on enjoying a healthy diet that offers a variety of foods. This treatment is not current-



ly reimbursed by Medicare and therefore not widely available, but with the support of the kidney community, the government and you, it may soon be an option for all people who need long-term dialysis treatment. **F**

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About the Author:

Lesley L. McPhatter, MS, RD is a renal dietitian at Lynchburg Nephrology Dialysis, Inc. in Lynchburg, Va. She counsels patients with all types of kidney disease including chronic kidney disease, hemodialysis including nightly home hemodialysis, peritoneal dialysis and those with transplant.

Nutrition

A Cultural Exchange

Recipes contributed by Mariann Burkett
Analysis done by Nutritionist 4 Computer System

I dialyze in Florida. Where I sit for dialysis remains the same each week, and as a result I have developed a close relationship with fellow patients. It is very heart-warming, as we share many things, including family matters, what we do in our spare time, the methods we use to control intake of fluid and "your" weight, "my" weight. It is

so interesting because we are of different cultures, yet we share a unique, common bond—dialysis for us is life.

One of the activities we do is sharing recipes. I want to share three of them with you. One of them is from Jamaica, another is from Guyana and the last is from Israel. Enjoy!

Curried Chicken (Jamaica)

- 
- 1 whole chicken (2 lbs) cut up in 8 or more pieces
 - 2 tbsp curry powder
 - 1 tsp black pepper
 - 1 large onion (cut up in rings)
 - 1 small green pepper
 - 2 stalks green onion (cut up small)
 - 1 stalk thyme
 - 1 tbsp Mrs. Dash (renal)
 - 1 large potato (soaked overnight)
 - 1 tbsp olive oil

1. Season chicken with all above ingredients
2. Rub seasonings in chicken
3. Marinate for 1 hour
4. Place oil in deep pan—heat
5. Sauté chicken in oil for 5-10 minutes
6. Add warm water to chicken just to cover
7. Cover pot with tight lid
8. Bring to boil—then reduce to medium heat

9. Cook on medium for 30 minutes
10. Cut potato into small wedges and add to chicken—Cook over medium low for another 15-20 minutes
11. Stir and serve over bed of rice with green salad or mixed vegetables.

Contributed by Mariann Burkett

Note: Curry powder is a greenish-yellow seasoning used in West Indian and Indian recipes. This can be found in most supermarkets and in local West Indian stores.

Recipe makes 12 servings. Each serving of curried chicken contains:

Calories	487	Sodium (Na)	67 mg
Carbohydrates	4 gms	Potassium (K ⁺)	217 mg
Protein	21 gms	Calcium (Ca)	24 mg
Fat	42 gms	Phosphorus (P)	140 mg

Does not include rice or whatever is served with it.

Stew Beef (Guyana)

- 
- 2 lbs beef stew (cut in small pieces) season and marinate for one hour
 - 1 large onion (chopped in small pieces)
 - 1 tsp cinnamon
 - black pepper to taste
 - 3 small peppers
 - 5 large cloves garlic
 - 2 tbsp tomato paste, low sodium

1. Place 1 tbsp oil to heat
2. Fry garlic, pepper and onions in oil until golden brown
3. Add beef to pot
4. Add 2 tbsp tomato paste
5. Let meat boil then simmer
6. Add 1 cup hot water to make gravy until it thickens
7. Add 1 tsp ground cinnamon
8. Add a touch of black pepper
9. Simmer until meat is tender

Eat over rice, roti (Guyanese pita bread) or just plain bread.

Contributed by Mymoon Abdulla

Recipe makes 12 servings. Each serving of stew beef contains:

Calories	253	Sodium (Na)	74 mg
Carbohydrates	7 gms	Potassium (K ⁺)	348 mg
Protein	15 gms	Calcium (Ca)	33 mg
Fat	17 gms	Phosphorus (P)	176 mg

Stuffed Cabbage (Israel)

- 
- 1 large cabbage
 - 1 cup rice, uncooked
 - 1 lb ground beef
 - 1 tsp black pepper
 - 1 tbsp cumin
 - salt to taste
 - 5 cloves of garlic (crushed)

1. Take out heart of cabbage
2. Separate leaves and parboil in hot water for 5 minutes
3. Remove from heat and separate leaves in a single pile
4. Wash rice well
5. Add ground beef and seasoning to rice
6. Mix well
7. On cutting board lay out cabbage leaves
8. Add to leaves 1 tbsp rice mixture
9. Roll into oblong rolls and place in flat dish
10. In medium size pot add broken leaves or leftover leaves to bottom of pot
11. Lay staffed cabbage rolls in pot in layers
12. Add water to cover and steam until tender.

Contributed by Nada Abusab-Farraj

Recipe makes 6 servings. Each serving of stuffed cabbage contains:

Calories	284	Sodium (Na)	49 mg
Carbohydrates	33 gms	Potassium (K ⁺)	346 mg
Protein	15 gms	Calcium (Ca)	42 mg
Fat	12 gms	Phosphorus (P)	196 mg

State Programs Promote Health of Kidney Patients

By Dolph Chianchiano, JD, MPA



Dolph Chianchiano, JD, MPA

Although state programs have played an important role in meeting the needs of kidney patients over the past 30 years, *Family Focus* readers should be aware that the design and funding of state programs may change in the future.

Medicaid, the health insurance program which is funded by the states and the federal government, provides a safety net for those Americans with the most financial need. It has helped those with kidney disease who have no other coverage, as well as those who are eligible for Medicare. However, 44 states have budget deficits and there is pressure around the country to lower Medicaid spending.

Furthermore, Medicaid payments for prescription drugs are rising faster than other components of the program. In an effort to cut Medicaid payments for prescription drugs, some states are discouraging Medicaid beneficiaries from using brand-name drugs, limiting the number of prescriptions that Medicaid will cover and requiring those on Medicaid to use specific medications to treat specific conditions. Additional states may use these methods in the future.

Some states are planning to open up their Medicaid drug programs to people whose income would ordinarily disqualify them for Medicaid assistance, while at the same time putting these cost-cutting strategies into place. Although this seems inconsistent, the states have chosen this course of action because Congress is deadlocked over adding a prescription drug benefit to Medicare. These programs to provide Medicaid drug benefits to those who would not ordinarily qualify for Medicaid are known as "Pharmacy Plus" plans. The typical state plan qualifies people for pharmacy benefits through Medicaid if they have an income at or below 250 percent of the federal poverty level.¹ Since the federal government shares in the cost of state Medicaid programs, these "Pharmacy Plus" plans must be approved by the U. S. Department of Health and Human Services. The agency has already approved proposals from Florida, Illinois, Maryland and South Carolina. However, it is

important to keep in mind that only senior citizens will benefit from these plans. People with kidney failure who are under 65, and who are not otherwise eligible for Medicaid, will not be able to use this kind of program.

Placing Medicaid recipients in managed care plans is another way that states have tried to control the cost of their Medicaid programs. Under managed care, state payments are limited to a specified dollar amount per month without regard to health services the patient needs or receives. The federal government recently issued regulations to control this practice. States, and the managed care plans with which they contract, must be in full compliance with those regulations by August 13, 2003. The regulations call for the identification

"Federal law requires that state Medicaid programs pay Medicare costs for certain elderly and disabled persons with low incomes and very limited assets."

and assessment of persons with special health care needs to insure their needs are met. People who enroll in the managed care plans who have an ongoing medical condition that requires special treatment or care must have qualified specialists available to them.

Twenty-one states and the Commonwealth of Puerto Rico operate other programs that offer financial assistance to transplant recipients and those who are on dialysis. For example, these programs help consumers with the cost of medications and transportation. In total, these 22 programs provide more than \$60 million in patient support annually. The budgets for these programs have grown in the last 10 years but generally they have not increased as quickly as the kidney failure population during the same period. In many programs, therefore, the funds available per patient are diminishing. Advancements in medicine have improved the health and well-being of people who are on dialysis and have transplants.

The cost of new and additional medications, however, has made even more demands on these state kidney programs. State kidney programs will be challenged by these trends in the years to come. Also, given the financial squeeze that state budgets have experienced, it will not be easy to convince legislatures to create and fund new state kidney programs in parts of the country which have not had them in the past.

Federal law requires that state Medicaid programs pay Medicare costs for certain elderly and disabled persons with low incomes and very limited assets. Patients who meet the definition of "Qualified Medicare Beneficiary," for example, do not have to pay Medicare Part B premiums and, depending on the doctor they see, may not have to pay the 20 percent of the physician's bill that Medicare does not cover. This program is designed for persons whose income is at or below the national poverty level and cannot afford the kind of private "Medigap" insurance that provides similar benefits. A related program, the Specified Low-Income Medicare Beneficiary Program, is for persons whose incomes are slightly higher than the national poverty level. If you qualify for assistance under this program the state is required to pay the monthly Part B premium for you, but you are responsible for Medicare's deductibles and coinsurance. We want to be sure that these two programs continue to be offered in the future. The National Kidney Foundation Government Relations Division will notify members of the NKF Legislative Advocacy Network if any changes in these programs are contemplated.

For additional information about state programs that benefit people with kidney disease or to learn how you can join the NKF Legislative Advocacy Network, please visit the National Kidney Foundation's Web site at: <http://www.kidney.org/general/pubpol/> or call (800) 889-9559.

¹ You can download the latest information on the 2002 poverty level guidelines and Medicaid eligibility at <http://cms.hhs.gov/medicaid/eligibility/pov0102.pdf> 

Dialysis Five or Six Times a Week Instead of Three

By Mary Dooley, MSW/ACSW

A growing number of people on dialysis are choosing to receive frequent dialysis (also known as daily dialysis) to achieve better health and a better quality of life. Dialysis centers and doctors around the country and the world are looking at dividing the three normally long treatment sessions into five or six shorter ones. This makes sense—the less waste and fluid that builds up in your body, the better you feel.

There has been a great deal of research around daily dialysis and it is clear that shorter, daily treatments have important proven health benefits.¹ Some of these health benefits include:

- ❖ Increased rehabilitation potential.
- ❖ Improved emotional health.
- ❖ Better control of high blood pressure. Some daily dialysis patients have been able to reduce or even eliminate blood pressure medications.
- ❖ Improved nutrition. Patients have a better appetite with daily treatments.
- ❖ Feeling better during and after treatment. When smaller amounts of fluid are removed, people feel less drained and tired after dialysis, and symptoms such as cramping during treatment are greatly reduced.
- ❖ Less stress on the heart because less fluid builds up.
- ❖ Fewer trips to the hospital as overall health improves.
- ❖ Improved sleep and “restless leg” syndrome.
- ❖ Fewer dietary restrictions. If you take waste out more often, you can have more food and fluid.

If daily dialysis is so great, why isn't everyone doing it? A big reason is that Medicare and insurance plans usually do not pay for dialysis treatments more than three times each week. Dialysis providers are not paid for the extra treatments, so few are able to offer daily dialysis. Some dialysis providers strongly believe in the improved quality of life that daily dialysis provides and have chosen to offer

this option to their patients regardless of payment.

Currently, there is a bill in the United States Congress, the Kidney Patient Daily Dialysis Act of 2001, which would extend Medicare payment for daily dialysis. Although additional treatments cost more, it is expected that overall costs to Medicare would be lower as people on daily dialysis typically need less medication and have fewer hospital stays.¹

There are other barriers to daily dialysis as well. Daily dialysis that is done at home means finding room for supplies and the machine, more time spent in setting up and taking down the machine, and finding someone, often a family member, willing to train as your assistant. This can be a stressful and demanding role for a family member.



New technology is being developed which will help make all this easier. A new kind of hemodialysis machine designed for daily home use has revolutionized daily dialysis. This machine makes its own saline, heat cleans the dialyzer and tubing so they can be used for a month and is designed so that the person on dialysis can operate the controls without an assistant. This means less work setting up and taking down the machine, less storage space and more independence for the patient.

One individual had been on hemodialysis at a center in Seattle for 12 years. He began dialyzing at home last year and dialyzes five days a week. He works full time and does his treatments at home after work. He solved the problem of getting a dialysis helper by offering free rent to a tenant who was renting a room at his house in exchange for the person's

“If you are interested in daily dialysis, but it is not offered in your area, there are steps you can take.”

assistance. He has noticed increased energy, better sleep and improved concentration at work with daily dialysis. Now, he also goes to a gym and walks for exercise. He does his own needle sticks for dialysis and has had no access problems. As for the increased time and effort, he says that two and a half hour treatments five days a week feels like less time and bother than three long treatments in the center. As for the increased responsibility, he says, “I'm not a transplant candidate, so dialysis is just what I have to do. I'm looking at what will give me the best health for the rest of my life and I just accept it.” He plans to switch to the newer machine and will soon be doing treatment without outside monitoring or an assistant.

If you are interested in daily dialysis, but it is not offered in your area, there are steps you can take. The most important factor in making this option more widely available is funding. Let your representatives in Congress know how you feel about the Kidney Patient Daily Dialysis Act of 2001 (H.R. 1759). Help them understand that daily dialysis helps to improve quality of life, physical functioning and emotional health. **F**

¹ Research supporting these points is summarized in “The Quality of Life and Economic Importance of Daily Dialysis,” Policy Analysis Brief, H. Series, Vol. 1, No. 2, October 1999. Full brief can be viewed online at www.projecthope.org/CHA/briefs.htm

About the Author:

Mary Dooley, MSW/ACSW, is a social worker at Northwest Kidney Centers, Home Dialysis Program in Seattle, Wash., one of the largest home programs in the country. Ms. Dooley has worked in dialysis nine years; the last four at Northwest Kidney Centers.

Hemodialysis Pioneers Receive Prestigious Lasker Award

By Lorette Murray, National Kidney Foundation

The fate of kidney patients has undergone a revolution in the last half century thanks to two scientists who initiated incredible breakthroughs in the field of hemodialysis. Dr. Willem Kolff and Dr. Belding Scribner's discoveries virtually transformed kidney failure from a death sentence to a survivable life challenge. This fall, Dr. Kolff's and Dr. Scribner's achievements were recognized with the 2002 Albert Lasker Medical Research Award, the nation's most distinguished honor for outstanding contributions to basic and clinical medical research.

Dr. Kolff's career in kidney dialysis began in 1938 while he was practicing at the University of Groningen Hospital in the Netherlands. There he encountered a young man who was suffering from kidney disease, and watched helplessly as toxic waste buildup slowly shut down the man's body and eventually claimed his life.

Moved by this event, Kolff set out on a quest to discover a way to artificially extract the poisons from a person's blood. He knew this would change kidney failure from a fatal to a treatable condition. He built upon experimental research done in 1913 by Dr. John Abel of Johns Hopkins University. Using an anti-coagulant called heparin and filtration material made of sausage casing, or cellophane, Kolff developed a process where toxins in the tainted blood traveled through the tiny pores in the filter to a rinsing fluid on the



Dr. Willem Kolff lectures to students at SUNY Downstate.

other side. During the next several years, Kolff built four different artificial kidneys, none of which were reliable enough for clinical use. During World War II, the Nazi occupation of the Netherlands made it extremely difficult for Kolff to obtain the materials he needed to continue his experiments. He persevered, and in 1945, Kolff achieved his first undeniable success.

Dr. Scribner's discoveries have also played a central role in prolonging life for kidney disease patients. While practicing at the University of Washington, Seattle, Scribner witnessed repeated dialysis destroy patients' veins and therefore render hemodialysis virtually useless. Dr. Scribner devised a way to allow doctors to administer dialysis time

after time by inventing the shunt, a U-shaped device that is permanently inserted into a patient's forearm to facilitate repeated rounds of hemodialysis. Suddenly, the prognosis for ESRD patients flipped from 90 percent fatal to 90 percent survivable. Scribner's shunt also gave rise to the field of kidney transplantation because it allowed potential recipients to be sustained while they awaited donor organs.

Today, the artificial kidney remains the first—and still the only—method in which a machine replaces a failed internal organ. Kolff's and Scribner's triumphs in the field of hemodialysis continue to touch millions of people across the globe. 

Waiting for a Transplant

By Nancy Swick, RN, BSN, CCTC

Waiting for anything can be difficult. The hardships and stress associated with waiting for a life-saving organ transplant are difficult for the candidate and his or her entire family. With this in mind, recipients and transplant professionals worked together to produce *Waiting for a Transplant*, a book to provide support, insights and helpful tips on the waiting process. The book, published by the National Kidney Foundation, is dedicated to all transplant candidates who are hoping that they will find the courage and strength to survive the waiting process and then flourish



with a successful transplant.

Waiting for a Transplant starts from the very beginning of the transplant process and concludes with the difficult topic of end-of-life decisions. Quotes from those who have lived through the waiting process are a valuable perspective. We hope that the friends and family of those waiting will find this book useful.

For a free copy of *Waiting for a Transplant* contact the National Kidney Foundation at (800) 622-9010.

THE MORE YOU KNOW



Patient and Family Council: The Value of Membership

By Cate Lewis, RN, CNN

My name is Cate Lewis. As chair of the Patient and Family Council (PFC) Executive Committee, I would like to encourage you to become a member of the Council. It was founded in 1995 as a council of the National Kidney Foundation (NKF) that is dedicated to the needs of patients and families affected by kidney disease. Before I explain the purposes and goals of the PFC, I'd like to share some of my personal background with you.

In 1971 and 1974, respectively, my father and I were both diagnosed with a hereditary kidney disease called polycystic kidney disease (PKD). I was in my second year of nursing school when my dad's diagnosis was made and we received the news that his kidneys were failing. He began dialysis therapy soon thereafter. I remember



The Patient and Family Council Executive Committee: (from left) Cate Lewis, Glen Hayashida, Mike Zecca, Chauncy Williams and Susan Belkin. Not pictured: Angie Buse, Stephanie Page, Julie Ann Shambra, Gwendolyn Woodloe and Bina George.

being unable to find much helpful information in medical texts, and what I did find was extremely bleak and discouraging. Thus, I applied for a position at our hospital's dialysis unit, hoping that my new job would allow me to learn as much as possible about kidney disease and its treatment. That was the beginning of my journey. Today I remain committed to caring for people with chronic kidney disease. From my experience, I have learned that education and the support of family, friends and co-workers are essential to managing and coping with this disease. I have been inspired by the many people I have met; they have taught me how to deal with kidney disease and all its repercussions,

and most importantly, they have shown me that a sense of humor and a positive attitude help to gain control over one's health and life.

Many of you reading this article may just be learning of your diagnosis. You may feel overwhelmed and confused by your new health status. You may be wondering how your diagnosis will affect your future and your quality of life. You may feel like you are in a bad dream or are experiencing a roller-coaster of emotions. These feelings are all perfectly normal as you adjust to the discovery of having a chronic illness that requires lifelong treatment. It might be comforting to realize that your health care team is professionally prepared to help you with any lifestyle changes that you may need to make. There will be some bumps in the road from time to time, but with continuous improvements in dialysis and transplant therapies on our side, most are manageable.

Enter the Patient and Family Council, which is dedicated to "Making Lives Better." The PFC provides an opportunity for patients and families to express questions and concerns, get answers and have their educational needs met. With more than 22,000 members, it is the largest and fastest growing patient organization committed to issues that affect both individuals with kidney disease and their families. Through the use of the NKF publication, *Family Focus*, the NKF PFC Web site (<http://www.kidney.org/patients/pfcindex.cfm>), the many NKF educational materials and direct telephone

communication, the Council will address your individual needs.

Needless to say, I feel very strongly about the value of membership in the PFC. Membership, which is free, includes a lifelong, home mailing of *Family Focus*, which provides you with insight into the lives of others coping with kidney disease, broadening your understanding and awareness of your own situation.

Similarly, the Web site offers a host of valuable information on kidney disease, including a message board where questions can be posted and responses made by both health care professionals and members of the PFC. There is also information on how to begin your own local Patient and Family Council. The NKF has 51 affiliate offices around the country, and by contacting your local affiliate, you can find out about how to help either begin your own or join an existing local council. This will provide a means for valuable support in your own journey. For information about your local affiliate visit the affiliate page of our Web site at: <http://www.kidney.org/general/affiliates/> or call (800) 622-9010.

Please sign up today. I know you will be pleased with the abundance of support and services available to you. To become a member of the Patient and Family Council you can either go to the Web site at: <http://www.kidney.org/patients/memberinfo.cfm> or call (800) 622-9010 for a membership brochure. By remaining involved in your care, being knowledgeable about your treatment choices and continuing to learn as much as possible, you will succeed in maintaining control of your life and health.

My best wishes and blessings to all of you. 

 *Family Focus* is available on the Web. To find this issue or back issues of the newspaper, go to www.kidney.org/patients/backissues.cfm

One Size Does Not Fit All in Dialysis Treatments

By Jonathan Lorch, MD, FACP

During the last 30 years in which dialysis has become widely available, much progress has been made in the way dialysis machines and dialyzers are designed. The machines allow every part of a treatment to be planned for each person's needs. Some on dialysis need more fluid removed, while others need a dialyzer that can remove more of the waste products that build up in their blood when their kidneys are not working correctly. Many types of dialyzers are now available. They are made of different materials and sizes, and the membranes or fibers that fill them have different size holes or pores to control the amount of fluid (water) that is removed.



In addition to the improvement in the way dialyzers and machines are designed, drug companies have made medicines which can improve your blood count and help prevent the kind of bone disease common to people with kidney failure. To make sure that you get the benefit of all of these new improvements, the National Kidney Foundation has developed guidelines for treatment that help your kidney doctor and dialysis unit staff figure out whether you are getting enough dialysis and the right kind of dialysis treatment. With all these improvements you would expect that there would be fewer complications for people on hemodialysis and that they would be healthier and live longer than people did in the past. Unfortunately, that is not true for many on dialysis.

Many people on hemodialysis have hypotension (low blood pressure) or cramps during some or all of their dialysis treatments, and may feel tired and

weak after finishing a treatment. About one in every five people on dialysis die each year and the average person on hemodialysis spends 30 days a year in the hospital. These facts have not changed in years. If dialysis treatment has gotten better, why aren't there fewer deaths and complications?

Think about the kidneys you were born with. Together, the kidneys receive about one fourth of the blood your heart pumps. They work 24 hours a day, and at the end of each day they have cleaned 100 to 120 liters (quarts) of blood. Now, look at the usual dialysis plan. Treatments are typically three days a week and each treatment lasts about four hours. During these four hours about 75 to 85 liters (quarts) of blood go through the dialyzer. This means that at the end of a week, normal kidneys have worked on more than 700 liters of blood while a plastic dialyzer has worked on only 250 liters of blood. What does this actually mean?

First, it means that the three to five pounds of water that a person on dialysis gains over the day or two before a treatment must be removed in only four hours. No matter how good a dialysis machine or a dialyzer may be, the fact is that the body has a hard time adjusting to the removal of so much fluid. Normal kidneys remove water not long after you drink it.

Second, the dialysis machine and dialyzer can not remove enough of the toxic waste products your body makes to keep you feeling well and healthy. The four-hour treatment causes great swings between blood values before and after dialysis, with some levels, such as the blood urea nitrogen (BUN), in your blood falling more than 70 percent and then quickly increasing to the level before dialysis. The way dialysis is usually performed is just not good enough to remove the amounts of waste products that are carried in the blood, as well as in your cells and the fluid between the cells. What could be done differently that could make dialysis better?

One way would be to spend more time on dialysis. Unfortunately, additional time is not as simple as it might seem. The government only pays for three, four-hour treatments a week for each person on dialysis—no one can receive more than 13 treatments a month and have it paid for by Medicare.

However, even if your dialysis unit could dialyze you for six or eight hours, five or six times a week, you probably would not want to spend that much time in the dialysis unit—there would not be much time to do anything else! However, there is another way to solve this problem, and that is to provide more dialysis when it does not interfere with your life—at night, while sleeping.

“Though all the daily dialysis schedules that might work are not clear, what does seem clear is that the three sessions a week, four hours a session, one-size-fits-all dialysis schedule may be right for some, but is certainly not best for everyone.”

About five years ago, Dr. Andreas Pierratos of Toronto began dialyzing people eight hours a treatment, six nights a week, while they slept. This type of dialysis is called nocturnal hemodialysis (dialysis at night). The key to this treatment is how the dialysis is done and that a person's treatment is automatically watched during the night. People on nocturnal dialysis are trained as if they were to perform usual hemodialysis at home. They learn to stick their fistula themselves or connect themselves with a catheter. When they have been completely trained in self-dialysis, they set the dialysis machine up in their bedroom, connect themselves, start the dialysis and then go to sleep. Special computer software is used to send information from a person's machine in a safe and private way over the Internet to monitoring equipment. If the machine alarms, the person on dialysis and the dialysis staff hear the alarm at the same time.

Several things other than time and number of treatments make dialysis at night different. First, the blood flow and dialysate flow are much lower than standard dialysis. Why? With six to eight hours of treatment, six nights a week, there is no need to rush and make the flows higher. Second, since the treatments are almost every day, the amount of fluid that needs to be removed each day is quite low. In addition, the fluid that needs to be removed every day can be taken off over the six conventional treatments. As a result,

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MAILBOX

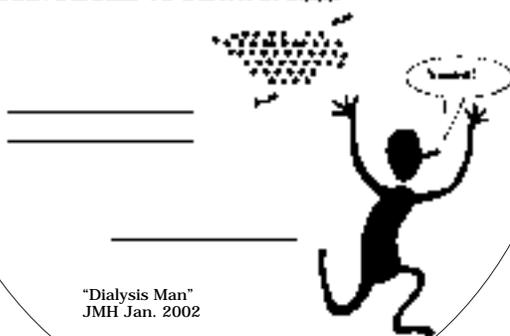


To the Editor:

I wanted to send out a quick note to let you know how much I enjoy reading *Family Focus*. As a hemodialysis patient awaiting a transplant, I appreciate the learning opportunities as well as reading about how other patients deal with this condition.

Thank you,
Joan Mitchell Humrich

Ever since he overheard a nurse telling a new patient that a shot of lidocaine would feel like a bee sting, he has been SCARED TO DEATH of bees!



"Dialysis Man"
JMH Jan. 2002

To the Editor:

While visiting with my nephrologists, I had the good luck of reading a copy of your newspaper.

I found it very informative and interesting, and I read it cover to cover.

Thank you,
Roasario M. Aguinaldo

To the Editor:

Hi. My name is Robert Waller. I am 17 years old and have had serious kidney and bladder problems since I was nine months old. I was born with an obstruction in my urethra which caused damage to my kidneys. I have had at least 12 surgeries to try to correct the problems. My creatinine is 6.5. I was told by a number of doctors that I would not have a lot of energy or be very active with my blood levels the way they were. Yet, I have plenty of energy from taking my medication and catheterizing myself. As a result, I am able to do many, if not all, of the things that I love to do. I race BMX Bikes, and just last weekend, at my second race, I placed 6th at the Western Regional Championship Series Race.

I would like to pass on this story to other children to give them hope and to encourage them not to give up on their dreams...

Sincerely,
Robert William Waller

To the Editor:

I have a three year old son who was born with a partial blockage of his post urethral bladder valves. He celebrated his two year kidney transplant anniversary on August 29, 2002, and is doing well. We had heard that this condition was not considered hereditary. I gave birth to a premature baby boy on August 5, 2001, we found out he had the same blockage. We and the doctors did all we could to try to help him but we lost the battle. But in another way, we won, for we now know that this has to be inherited. I say we won because our loss will push research for the connecting gene that causes this condition and maybe save other children before the damage is done. If you can connect me with other families that have been through this, I would appreciate it.

Alicia Ary

If you would like to contact Ms. Ary, write to:
Family Focus, 30 East 33rd Street
New York, NY 10016

Thank you from Russia

Dear Editor,

Thank you for the spring 2002 *Family Focus* that I received. It's very interesting and useful for me. Thanks again.

All the best,
Fedor Medvedev
Moscow, Russia

One Size Does Not Fit All...

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low blood pressure or cramps during a treatment are rarely problems for those on nocturnal hemodialysis. Lab values are also very different. It is not unusual for some people who had a creatinine of 12 or 14 and a BUN of 80 before treatment to have a creatinine of four to five and a BUN of 35 after doing nocturnal hemodialysis. The real question is: does all of this dialysis make a difference?

We do not have enough experience to know whether you would be healthier or live longer on this type of dialysis. But we do know that those on this form of treatment feel better. It should be said that self-dialysis six to eight hours a night,

six nights a week may not be the only possible way to do this. For example, those who are on conventional home hemodialysis may have their home assistant help them dialyze more often. Though all the daily dialysis schedules that might work are not clear, what does seem clear is that the three sessions a week, four hours a session, one-size-fits-all dialysis schedule may be right for some, but is certainly not best for everyone. 

About the Author:

Jonathan Lorch, MD, FACP, is Associate Professor of Clinical Medicine at New York Presbyterian Hospital-Weill Medical College of Cornell University. He is Director, Medical Informatics and Director, Nocturnal Dialysis at The Rogosin Institute.

Your Life, Your Body, Your Treatment — YOUR Choice!

By Bobbie Knotek, RN, BSN, CNN

During my 27 years as a dialysis nurse, I have heard these words many times:

- “I don’t want to learn anything. I just want to show up and get my treatment.”
- “Why should I learn how to do anything for myself? That is what the nurses and technicians are paid to do.”

If you have ever spoken these words, here are three reasons to change your “tune”!

Reason # 1 — It is Your Life

You and only you choose how to live with kidney failure.

When people feel they have lost control over their lives, they may make dangerous choices trying to regain control. They may choose not to follow their diet or take their medicines, to gain more “water weight” than is safe or to shorten or miss dialysis treatments or clinic appointments. If you have made poor or dangerous choices in the past, it is never too late to start taking better care of yourself.

Some people let kidney failure take over their world. They choose to build their lives around dialysis, ignoring friends, interests and hobbies. Dialysis does use up about 12 to 15 hours a week, but why should it be the center of your attention for the remaining 153 hours as well? Spend those 153 hours doing the things you have always enjoyed such as visiting friends, working on hobbies, volunteering, or going to church or synagogue.

Many people see dialysis or transplant as a way to stay healthy and live as normally as possible. They choose to take charge of their kidney failure by:

- Learning all they can about kidney failure and the treatment they are receiving.
- Asking questions when they need more information.
- Participating in scheduled team care planning meetings.
- Trying to make choices about diet, fluids, medicines and treatment that will keep them as healthy as possible.

Which of the above situations describes how you have chosen to live your life? Do you need to think about making better choices?

Reason # 2 — It is Your Body

You only get ONE body in this life. If you do not take care of it, who will? Choose to take better care of your body today!

Go to every dialysis treatment and stay the prescribed time. Every minute counts! When your kidneys worked, waste products were cleaned from your blood 24 hours a day, seven days a week (a total of 168 hours or 10,080 minutes). Now that your kidneys are not working, the only time waste products are cleaned from your blood is during the 12 to 15 hours (or 720 to 900 minutes) you are on dialysis.

Memorize your medicines—learn the name, reason, dose and time for every medicine you take.

Know the results of your lab work and how they compare to normal lab work. Learn how your choices (good and bad) affect your lab work.

Protect your heart and blood vessels by choosing to gain less weight between treatments. If you usually gain more than 2 ½ to 3 pounds (1 to 1 ½ kilograms) between treatments, you are hurting your heart. Your heart, like a water balloon, is only supposed to hold so much fluid. When it has to stretch to hold more fluid, your heart gets weaker and weaker until the heart muscle is permanently damaged. Learn how to keep track of what you drink, then control the amount of fluid you drink.

Reason # 3 — It is Your Treatment

Your treatment (hemodialysis, peritoneal dialysis or a transplant) is keeping you alive—it is your personal gift of life. Life on dialysis or life with a transplant may not always seem like a gift, but before these treatments were available, kidney failure was a death sentence. As recently as the 1960’s and 1970’s many people died of kidney failure because there were not enough dialysis machines. I urge you to take the gift of life you have been given and make the most of it.

One way to do this is to learn self-care. Do not be confused—self-care is not self-dialysis. Much of self-care is learning about your dialysis machine and your treatment. You can choose to

learn a little or learn a lot—it is up to you! To get started, ask your nurse to teach you one or more of these self-care learning steps:

- Tear tape strips to be used on your needles.
- Know your dry weight and how much fluid should be removed.
- Learn how and why dialysis needles are “rotated” (moved to different spots on your fistula or graft) each treatment. Let your nurse or technician know which areas on your graft or fistula are “due to be stuck.”
- Know the areas on your fistula or graft where dialysis needles should never be “stuck.”
- Learn which needle attaches to the “pull” or arterial tubing (the tubing taking your blood to the dialyzer) and which needle attaches to the “return” or venous tubing (the tubing returning the blood to your body).
- Clean your graft or fistula with the antibacterial solution before the needles are put in.
- Learn about the dialysis machine and what the machine alarms are “saying.”
- Learn your normal venous and arterial pressures.
- Learn your desired and usual blood flow rates.
- Take and write down your temperature, blood pressure and weight before and after dialysis.
- Take and write down your blood pressures during treatment.
- If your facility reuses dialyzers:
 - check the dialyzer to make sure it is yours.
 - check to make sure all of the disinfectant has been rinsed from your dialyzer.
- Ask the technician or nurse to show you the correct set-up of the machine.
- Insert your own needles with help (believe it or not, many patients say it hurts less if you do it yourself).

I encourage you to take the time to stop and think about the choices you have made in your life and the choices you will make in the future. I respect the fact that it is your life and how you live it is your choice, but I sincerely hope you will make choices that will help you live longer and feel better in mind, body and spirit. 

T R A N S P L A N T

R A N S P L A N T

Innovations in Transplantation: Some Thoughts on the Present and Future

By Daniel R. Salomon, MD

There has never been a time in the history of transplantation that better shows the connection between medicine and new research in science. In fact, the following improvements are significantly changing the way all of us understand and practice transplantation medicine.

New Drugs and Biologicals. In the last several years, a whole new series of drugs and engineered biologicals (such as laboratory-created proteins) have been approved by the Food and Drug Administration for use in transplants. The significance of this is that we now have the opportunity to select from a variety of immunosuppressive treatments. Due to current research, there is a possibility that in the future there would be no need to use steroids for the treatment of organ rejection, which would eliminate the steroids' long-term toxic effects on bones, skin, fat cells, glucose control and blood lipids. In addition, there may be treatments for chronic kidney rejection, ways to reduce the long-term cancer risks that can be caused by some of the medications and even elimination of the need for drugs to deal with rejection of the transplant. These exciting advances are already being translated into fewer rejection episodes, infections and hospital admissions, while giving better long-term transplant organ function and survival.

Understanding Immunosuppression. Probably the single most frustrating thing in transplantation for over 40 years has been the lack of a reliable test to measure how much immunosuppression each person needs. Of course, we measure levels of the drugs regularly and have improved guidelines to determine the right amounts of these drugs to give. But, the truth has always been that these measures are different for everyone. In the end, making decisions to change a drug dose on any given day is always a matter of physician experience and judgment. As a result, we have to accept the reality that some recipients are on too much immunosuppression and some are on too little. The results of the Human Genome Project, which maps the entire human body according to its genes, make possible a whole new

understanding of how genes determine the way cells work. This knowledge will soon help us learn better ways to measure the right amount of anti-rejection drugs for each person. If this research is successful, there will be a dramatic improvement in safety and transplant organ survival.

Cell Transplantation. For many years the word "transplantation" has usually meant whole organs like kidneys, livers and hearts. However, the working definition of transplantation is quickly growing to include transplantation of cells. Rather than replacing whole organs, researchers are studying the replacement of damaged tissue with healthy tissue. This sort of transplant can help the body repair itself. For example, recent advances in the transplant of pancreatic islets have promised an entirely new therapy for insulin-dependent diabetics. Research also includes the use of cells from the brain to treat people with Parkinson's disease, cells from joints to treat arthritis, muscle cells to treat diseases like muscular dystrophy and cells from blood vessels to treat people after heart attacks or strokes.

Stem Cells. A special type of cell, called an embryonic stem cell, is present during early development of the fetus. Embryonic stem cells eventually form all of the body's tissues and organs. More recently another type of stem cell was discovered in adults. Scientists think that these adult stem cells are probably important in keeping tissue healthy. Thus, fetal stem cells create the tissues during development and the adult stem cells are part of the process to keep them healthy during adult life. A new concept is that these stem cells could be transplanted to help get tissues back to health and cure kidney failure, heart disease and various nervous system disorders including spinal cord injuries, diabetes and muscular dystrophies. While the incredible possibilities of stem cell transplantation are obvious, it is important to remember that this is more than a decade away from any kind of real medical treatment. Many questions will need to be answered through research before the use of stem cells becomes a reality.

Xenotransplantation. One way to address the organ shortage is to figure out a way to use animal organs and tissues for human transplantation. This type of transplant is called xenotransplantation. The most practical nonhuman animal source at the present time is the pig because it is the right size and shares a similar physiological make-up with humans. Another advantage of the pig is that it can be genetically changed to make its organs better fit humans. Unfortunately, the first efforts at kidney and heart transplantation with pig organs have not been as successful as had been hoped. However, progress has still been remarkable. Only a few years ago, the idea of a pig organ working after transplantation would be measured in just minutes to hours. Now the pig organ has routinely worked for one month or longer in nonhuman primates. Another major issue has been the possibility of getting a new infection from the pig through xenotransplantation. There remains much more to learn about this type of infection as a potential threat. Despite negative press in the last several years, xenotransplantation is continuing to make progress. My prediction is that a successful pig cell transplantation therapy, with islets for diabetes for example, will happen long before a similar success is reported using any human stem cells.

Gene Therapy. It is fitting to follow a discussion of xenotransplantation with one of gene therapy. There were high hopes for success in both fields because they were based on sound science principles. Unfortunately, serious problems developed along the way. However, like xenotransplantation, a lot of exciting progress has been made. With the completion of the first stage of the Human Genome Project, scientists are trying to better understand how genetic programs make cells function. Learning to change these genetic patterns could improve the treatment of many medical problems. Though many of the first efforts in research are being made in cancer treatment, the possible effects of gene therapy on organ and cell transplantation are huge.

In conclusion, the reality of transplantation today has been greatly

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Innovations in the Treatment of Pediatric Dialysis Patients

By Barbara Fivush, MD

Over the last five years there have been many advances in medicine that have changed the care that children on dialysis receive. These changes include not only new medications but also improvement in dialysis equipment.

Recently a new peritoneal dialysis cyclor machine was introduced. This new dialysis cyclor machine is small enough for children and has a small data card (the pro card) within it. If changes need to be made in the dialysis treatment plan, the doctor at the clinic can program this data card. If the child is dialyzing at home, the reprogrammed card is simply placed

“Over the last several years, studies have shown that whenever possible, fistulas or surgically created grafts are preferred to catheters...”

into the dialysis machine and the prescription change is made. Also, the data card is able to record information about dialysis treatments over several days, including ultrafiltration, time on dialysis, fill volume, drain volume, daytime exchanges and more. This means that families do not need to record this information by hand. Having the right information will also allow physicians to improve the dialysis treatment plan.

There have also been advances in hemodialysis equipment that have helped children. Children may be above their ideal or dry weight when they come to the hemodialysis unit for treatment. When extra fluid is quickly removed, they may develop cramping, decreased blood pressure and nausea. The use of a newly developed device can help with these problems by closely checking and helping control the rate of fluid removal from children

during their treatment. This can help make sure the needed fluid is removed without causing the child discomfort.

Children on hemodialysis require an access. Over the last several years, studies have shown that whenever possible, fistulas or surgically created grafts are preferred to catheters as hemodialysis accesses for both adults and children. These accesses need to be monitored carefully to be sure there is no area of narrowing and that the access is operating efficiently. New devices using ultrasound technology are becoming very helpful for this monitoring.

Medications are an important part of treatment for most children on dialysis. One medication commonly given to children on dialysis is erythropoietin. Erythropoietin is a hormone that is naturally produced in the kidneys. This hormone stimulates the bone marrow to produce red blood cells and keeps people from becoming anemic. In those on dialysis, the damaged kidneys cannot make this hormone naturally, and it must be given to them. Those on hemodialysis receive this drug with their treatments, and people on peritoneal dialysis receive the drug by injection under the skin.

Recently, a new form of this hormone has been developed that acts for a longer period of time. This form of the hormone stays in the bloodstream longer and makes more red blood cells over time. Studies with this new form of the hormone in adults have shown that it is well tolerated and effective. Early studies in children who are on dialysis have also been very promising, and it is felt that this long-acting hormone will be very effective for them as well. Its use will decrease the number of injections needed by children on dialysis and could result in better control of their anemia.

In addition to erythropoietin, chil-

dren on dialysis usually need iron therapy. Iron taken by mouth is not always effective, and many children on dialysis (particularly those on hemodialysis) need to have iron given to them through a vein (intravenous). A new form of intravenous iron will soon be tested for use in children.

In summary, there are many advances in medication and equipment that will continue to improve dialysis for children on both hemodialysis and peritoneal dialysis. These advances include:

- 1) A new peritoneal dialysis cyclor with the pro card
- 2) A device to regulate fluid removal in hemodialysis patients
- 3) Ultrasound monitoring of hemodialysis access
- 4) Long-acting erythropoietin
- 5) A new intravenous iron preparation

Over time, these advances should improve the quality of care the children on dialysis receive and result in better long-term outcomes. **F**

Innovations in Transplantation

continued from page 13

shaped and advanced by the growth made in science over the last decade. The innovations are giving us wonderful opportunities to make immunosuppression safer and more effective. At the same time, continued scientific advancements give us important information about health and disease, setting the stage for future therapies based on cell transplantation, stem cells, xenotransplantation and gene therapy. **F**

About the Author:

Daniel R. Salomon, MD, is Director of the Center for Organ and Cell Transplantation at the Scripps Research Institute and Scripps Health in La Jolla, Calif.



POETRY

C O R N E R

Life

By Joshua Rosado

All of a sudden I woke up older,
 And asking myself
 Where is my life, where has it all gone?
 Death seems so near to me,
 And I feel time is running out
 To do what is important;
 To love, to give, to forgive
 And to receive the love we need to survive.

This is the secret of life itself,
 To know what is truly important,
 And that we are here on borrowed time.
 Life is not yours, nor mine,
 It is God's own to determine our purpose
 And then collect to
 Return to his loving arms. 



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Hemodialysis and Nutrition Word Search

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S	W	G	I	P	N	O	O	I	K	E	A	K	D	L
G	J	W	S	U	L	P	O	R	A	S	C	U	O	S
A	Y	O	W	K	M	Y	Z	O	H	L	A	Q	M	K
T	H	S	I	S	Y	L	A	N	D	T	Y	Y	E	Z
P	P	O	T	A	S	S	I	U	M	I	Y	Z	H	L
Q	O	Q	L	X	D	L	Z	C	A	E	W	R	E	I
S	X	D	I	O	D	R	N	D	M	V	S	P	E	R
K	I	D	N	E	Y	Y	D	G	J	V	K	D	B	S

- Calcium
- Calories
- Dialysis
- Dialyzer
- Erythropoietin
- Fluid
- Hemodialysis
- Iron
- Kidney
- Nightly
- Phosphorus
- Potassium
- Protein
- Reuse
- Sodium
- Vitamins



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