D AVID HOSLER AND REGISTERED DIETITIAN JANIE KANE teamed up last year to share some wonderful recipes with those on dialysis and their families, as well as the staff at their dialysis unit. The cooking show was recorded and later played for all to see.

There were cookbooks for everyone with recipes for the foods that had been prepared.

David created most of the recipes himself. All were good for people with kidney failure and all were delicious! It was the ultimate team effort. A dietetic intern took care of the nutritional analysis of the recipes and the taping of the event. Our social worker talked up the event and was part of our audience. Our audience also included our secretary, some of the family members of people on dialysis and the nursing staff. Even some of the transportation workers got in on the tasting!

Throughout the show, we shared kidney friendly tips to making many recipes taste great and fit into a renal diet. David shared how eating healthfully had helped him feel better. He even shared how it had affected his health when he did not do as well with his diet.

“David and Janie’s Cooking Show” was a success for everyone involved. We all had a great time and learned something new about fun and fabulous foods for our dialysis friends.

About the Author
Brian J. Mullinix, RN, is the Center Director at Gambro Healthcare in Decatur-Eastwood, Illinois.

This article has been published in memory of David Hosler. David was well known for his sense of humor, as he always had a joke to tell. That, along with his strong relationships with God and his family, helped David overcome many challenges in his life.
The title for this issue is “Toolbox for Life: Part II, Dialyze to Live, Don’t Live to Dialyze.” This was taken from the words of Wayne Nix. Wayne had chronic kidney disease (CKD) for many years and was on dialysis, as well as having had a kidney transplant. By telling you that, however, I am only telling you a very small part of who Wayne was. Wayne was a teacher and football coach professionally. He was a devoted husband and father. Wayne was also a dedicated and tireless volunteer for both the National Kidney Foundation (NKF) of Michigan and the national NKF. I had the privilege of working with Wayne on numerous projects and committees, one of them being Family Focus, where he served as Patient Editor. Wayne’s life exemplified his belief that a person should “dialyze to live, not live to dialyze.” It was indeed an honor to know him.

You have the opportunity to honor someone in your life who is on dialysis or has a kidney transplant by nominating the person for the NKF’s annual Wayne Nix Award. Be sure to call the NKF at 1-800-622-9010, or go to the NKF Web site for more information and to nominate someone: www.nkfwaynenixaward.org

Another feature I want to direct you to is the fabulous artwork produced by people with CKD. Amgen, the main sponsor of Family Focus, wanted to recognize the works of artists who are on dialysis by displaying patients’ paintings in their national headquarters. We have included a few of them so that you, too, can share in their beauty.

Many readers have responded online to our latest question, “Do you think it is helpful or harmful to have genetic testing to find out if you have an inherited disease?” This question is related to our next issue of Family Focus, “Kidney Disease: Does it Run in Your Family?” You can share your thoughts on this topic by going to www.familyfocusvoices.org We will use your responses to write a cover story for that issue. Also, please continue to look for a new question for each issue of our newspaper, and let us know your thoughts about the different subjects. We love hearing from you!

This issue of Family Focus is full of ideas on how you can dialyze to live a fulfilling and satisfying life, whatever your interests may be. You will find information on social activities, hobbies, traveling, school, employment, kidney camps, exercise, dining out and sexuality. Life is full of options. CKD cannot stop you from participating in life unless you allow it to do so. Your choices of how to enrich your life are many. It is just up to you to make the choice and to “GO FOR IT!”

Karren King
For the Editorial Board

corrections

▼ Jamie Shish, RD, LD, ATC/L, was not credited as being the author of “Eating on the Run,” an article full of nutrition tips in Family Focus Volume 13, Number 1. Jamie is a Registered Dietitian working at an outpatient dialysis center in Illinois. She is also a Licensed Athletic Trainer and has a bachelor’s degree in Kinesiology, and she enjoys volunteering her time for fundraising, giving lectures on nutrition and exercise, and writing articles.

▼ Many of you were pleased to point out, correctly, that some of the fruit (bananas and plums) pictured next to that article are not appropriate for people on dialysis! The grapes, apples and pears are OK to eat, though.

We sincerely apologize for these errors, and thank those who have corrected us!

In the next issue of Family Focus…

KIDNEY DISEASE: Does it Run in Your Family?
How do you look at dialysis? Do you dialyze to live or live to dialyze? Does it make a difference? Are there still possibilities for travel, fun and volunteering? Every now and then, it is worthwhile to take a moment to think about how you can rediscover your strengths and refocus your energy to accomplish goals that you had before you began dialysis or to set new goals.

WHAT ABOUT VOLUNTEERING? If you are looking for a way to be active and feel good about what you are doing, consider volunteering. The choices are endless. One great way to get involved is to contact your local National Kidney Foundation (NKF) affiliate. You can find the location nearest you by calling 800-622-9010 or searching www.kidney.org. Non-profit agencies like the NKF often need volunteers to help with phone calls, clerical tasks and special projects. You can also become more involved with your care by becoming a member of the NKF’s Patient and Family Council and/or a Legislative Advocate. Every community has many volunteer positions at places such as schools, libraries, 4-H clubs, scouting groups, churches and synagogues.

WHAT ABOUT TRAVEL? Travel is still possible while on dialysis but it may take extra planning. If you do peritoneal dialysis, you can order your supplies to be delivered at your vacation location. If you are looking for a place to have hemodialysis while traveling, you can find all the dialysis centers in the world by using the Internet. Take an active role in finding the place you would like to dialyze. Some favorite Internet addresses for locating a dialysis center are:

- www.dialysisfinder.com
- www.nephron.com
- www.wheredialysis.com
- www.globaldialysis.com

Dialysis Facility Compare (www.medicare.gov/Dialysis/Home.asp) provides information about dialysis facilities, including their outcomes (anemia management, adequacy and survival). ESRD Network 14 has a list of questions that you might want to ask a dialysis center where you are considering dialyzing. Some of these include:

- Does the clinic take transient (traveling) dialysis patients, and do they have spaces available when you plan to be in their area?
- Do transient dialysis patients have to pay the 20 percent of charges not paid by Medicare up front?
- Are transient dialysis patients charged any extra fees by the transient clinic to cover administrative costs?
- Do transient dialysis patients have to be seen by the doctor at the transient clinic before they can receive dialysis treatments at the transient clinic?

The complete list of questions can be found at www.esrdnetwork.org/facility_questions.htm

WHAT ABOUT YOUR LEISURE TIME? The hours that are left after dialysis and work or school are precious. How do you use those hours? Sometimes people like to think of kidney failure and dialysis as a part-time job and live the rest of their lives as fully as possible. Connecting with people who are going through the same things you are may provide you with ideas about how you may best use your free time.

Try making exercise a part of your life. This will help you feel better emotionally and physically and keep you as active as possible. There are many free or low-cost exercise programs. You might encourage your dialysis center to begin a program that you can do while you are on the dialysis machine. Community programs might also be available. These may be provided through community recreation programs, schools, senior centers, the YMCA or the YWCA.

Learn all that you can to help you and your family manage kidney disease and treatment.

"I am still determined to be cheerful and happy, in whatever situation I may be; for I have also learned from experience that the greater part of our happiness or misery depends upon our dispositions, and not upon our circumstances.”

— Martha Washington (1732 - 1802)

Accomplishing Goals and Setting New Ones
By Mary Beth Callahan, ACSW/LMSW-ACP

“Although the world is full of suffering... it is also full of overcoming it.”
— Helen Keller (1880-1968)

JUMP START HOPE.
There are lots of reasons to donate a car to the National Kidney Foundation. A possible tax deduction* is only one.

Call 1-800-488-CARS
Make Your Car a Kidney Car. Cars That Save Lives.

*Consult your tax advisor for details.

Mary Beth Callahan, ACSW/LMSW-ACP
Do YOU Have Questions About Kidney Failure and Your Sex Life?

By Wendy W. Brown, MD, and Bobbie Knetek, RN, BSN

These are some of the most common questions about how kidney failure can affect your sex life.

- Ask your doctor if any of the medicines you are taking could be causing the problem. If so, your doctor may be able to change or adjust these medicines.
- Things that make your health worse will affect your sex life. You need to make sure that:
  - If you are on dialysis, you are getting enough dialysis (this means not skipping or shortening treatments). Your lab work will tell your doctor if you are getting enough dialysis.
  - Your blood count is good (Hemoglobin or Hematocrit) (Hint: If you are on peritoneal dialysis and take EPO shots, this is a good reason to take all of your ordered EPO shots.)
  - You follow your diet and do not gain too much fluid between treatments.
  - You exercise to improve your muscle strength and energy.
  - You try to stay away from other things that can affect your sex life, like too much alcohol, illegal drugs and smoking.

Why have I lost interest in sex since my kidneys started failing?

Many of the physical and emotional changes that happen with kidney failure may cause you to lose interest in sex. Changes that may affect your interest in sex are depression, hormone changes, not feeling well and being weak or tired. If you are like most people, it is hard to be interested in sex when you are not feeling well.

Can kidney failure cause sexual problems for both men and women?

Yes.

- Men may have problems with impotence. Your doctor may be able to prescribe medicines to help the impotence. If you cannot take the medicines or if they do not work, your doctor can prescribe a "pump" that works for many men. If none of these things help, your doctor can tell you about other ways to help impotence, like shots or surgery.
- Women often have vaginal dryness. This dryness can cause painful sex or a lack of desire for sex. If your vagina feels dry during sex, you can buy a special, clear lubricating (wetting) jelly that will help the dryness. You can find the jelly in the condom section in grocery stores and pharmacies. If you cannot find the jelly or are not sure what to buy, ask the pharmacist or a sales clerk. Make sure you buy a water-based jelly. Do not use an oil-based jelly (like petroleum jelly or Vaseline) because it can cause an infection.

Who can I talk to if I have problems with my sex life?

Do not be afraid to talk with your doctor, social worker or nurse. Ask if you can speak to him or her privately about a personal problem. If you are not comfortable speaking with anyone at your clinic, ask your social worker for the name of a professional sex therapist.

Also, even though it may be hard, it is important to talk to your partner about sexual problems. Remember—a big part of loving and caring for someone is sharing problems.

If I am on peritoneal dialysis (PD), will having a PD catheter and fluid in my belly affect my ability to have sex?

No—you can be on peritoneal dialysis and still have an active sex life.

- One of your biggest worries may be wondering what your partner will think about the catheter that is sticking out of your belly. Many men and women on PD have said that after awhile, they and their partner do not notice the catheter. It just becomes another part of their body, like an arm or leg.
- People on PD sometimes ask if it is uncomfortable to have sex when their belly is full of dialysis fluid. This is a very real concern for someone who does PD. Not only could it be uncomfortable to have sex with a fluid filled belly, the pressure of the fluid in the belly during sex could cause exit site leaks or hernias. Luckily, there is an easy
answer—you can drain the dialysis fluid out of your belly before you have sex and then fill back up afterwards. Talk to your doctor or PD nurse about timing your fills and drains in a way that you can have an empty belly during sex.

If I am a man with kidney failure, can I still father children?

A Men who are on dialysis or have a kidney transplant can father children. However, having kidney failure may affect your body’s ability to make sperm. If you have kidney failure and you want to have a child, talk to your doctor. Your doctor can talk to you about special tests that can be done to see if your sperm have been affected and if it is possible for you to father children.

If I am a woman on dialysis, can I get pregnant?

A Many women on dialysis have menstrual periods. However, their periods may not be regular or may even stop for short periods of time or even altogether. If you have kidney failure, are in your childbearing years and are sexually active, you could get pregnant. If there is a possibility that you could get pregnant, it is important to talk to your doctor about birth control.

If I am a woman with a kidney transplant, can I get pregnant?

A If you have a kidney transplant, are in your childbearing years and are sexually active, you could get pregnant. Many women with a kidney transplant have gotten pregnant and have had babies that grew up to be normal and healthy. You do need to know, however, that there are risks to getting pregnant after a kidney transplant.

The birth control method your doctor prescribes for you will depend on your medical history and the type of treatment you are getting for your kidney failure:

- If you have diabetes, lupus, high serum lipids or take anti-seizure medicines, your doctor may tell you not to use oral contraceptives (birth control pills).
- If you are on hemodialysis or have a transplant, you should be able to safely use most barrier methods (condoms, diaphragms, cervical caps and sponges with spermicide).
- If you are on PD (peritoneal dialysis), you should NOT use an IUD (intrauterine device). An IUD can cause infections that could harm the dialysis space (peritoneal cavity) inside your belly.

Most doctors advise women on dialysis not to get pregnant. There are many risks to both the mother and baby. Women on dialysis who do become pregnant need more dialysis treatments, changes in medicines and very close medical supervision to keep themselves and their babies as healthy as possible.

If I am the prettiest woman you ever saw, with a plastic tube coming out of my tummy, which I often attached to two plastic bags, one empty, which I filled, and one full, which I emptied. There was a needle in my thigh attached to a tube connected to a pager-size machine that every now and then went "click click". She couldn’t see me very well, which was greatly to my advantage.

Her breath smelled of sour fruit and, not knowing that I liked the smell, she was embarrassed.

Her fingertips were hard from countless needle-stabs, but I always felt so special, so chosen, honored, when she let me hold her hand. She graced my bed and held me in her arms. I was lost in blissful joy the entire time. Surrounded by the tubes and wires and plastic bags, I lay beside the prettiest woman of my life, wishing that the clock would stop forever.

—Anonymous Author

Even though this article talks about sexual problems, sex is not the only way to show you love and care for someone. There are many ways to express love to your partner. Being on dialysis does not mean that you must give up having love in your life. This poem was written by an unknown author, about a man’s love for a woman with diabetes and kidney failure who is treated with PD.

Sara Love

The prettiest woman I ever saw had a plastic tube coming out of her tummy, which she often attached to two plastic bags, one empty, which she filled, and one full, which she emptied. There was a needle in her thigh attached to a tube connected to a pager-size machine that every now and then went "click click". She couldn’t see me very well, which was greatly to my advantage.

Her breath smelled of sour fruit and, not knowing that I liked the smell, she was embarrassed.

Her fingertips were hard from countless needle-stabs, but I always felt so special, so chosen, honored, when she let me hold her hand. She graced my bed and held me in her arms. I was lost in blissful joy the entire time. Surrounded by the tubes and wires and plastic bags, I lay beside the prettiest woman of my life, wishing that the clock would stop forever.

—Anonymous Author
Having chronic kidney disease (CKD) or being a family member of someone with CKD is about more than just figuring out how to deal with clinical treatments, doctors, insurance and Medicare. It can also be a personal challenge to figure out how to return your life to a “new” normal. Important parts of your life, like your relationships and career, have undoubtedly undergone change.

Fortunately, we live in a time when there are many sources of information to guide and support your adjustment to CKD. There are a number of good publications and Web resources that may aid your journey of personal growth while adjusting to CKD. We want to tell you about just a few, but further research can lead you to even more!

The National Kidney Foundation (NKF) was one of the first voices in the kidney community to talk about sexuality for people with CKD in its pioneering publication *Sexuality and Chronic Kidney Disease*. The NKF gives readers a no-nonsense guide to sexuality for people with CKD, including discussions of sexual intercourse, sexual development in young people, AIDS awareness, physical and psychological aspects, self-help and sex therapy. The American Association of Kidney Patients (AAKP) offers a similar publication on the topic of sexuality for people with CKD. The AAKP’s Patient Plan Phase Three booklet has a section entitled “Friends, Family and Your Social Life” which offers information on sexual and social adjustment. Call 1-800-749-2257. Both of these publications discuss sexual issues for people with CKD and family members with refreshing honesty.

Of equal importance in a plan for personal development is the pursuit or continuation of a rewarding work life. There is a new 108-page publication entitled *A Kidney Patient’s Guide to Working & Paying for Treatment* developed by Life Options Rehabilitation Program, which contains comprehensive information about working, job retention and career adjustment. This booklet offers great insights into how to live and work productively with CKD, including useful discussion about myths, responsibilities of employers, schedules, laws, rights, discrimination, self esteem and selling yourself in the job market. It is available at lifeoptions.org, or by calling 800-968-7777.

Within the last few years, Internet sites have also introduced informational resources to assist people with CKD in their adjustment to a new way of life. Kidney School (kidneyschool.org) features topics on coping, sexuality and fertility, while iKidney (www.ikidney.com) has a long list of personal growth topics called Lifestyle Tips, such as sexuality, communication, coping and psychological well-being.

A plan of personal development while adjusting to CKD presents a double challenge, but it is manageable with the help of resources such as those mentioned here. Adjusting is not always easy, and it is not always quick, but it can be done. Remember, your own research will lead you to many more resources like the ones you see here. There is a world of help and information “out there” for seekers of personal success. Keep asking questions, keep moving forward.

## Adjusting to CKD: Information and Resources

**By Roberta Bacheldor, MA**

### Many publications and Internet sites provide information about adapting to life with chronic kidney disease.

Three booklet has a section entitled “Friends, Family and Your Social Life” which offers information on sexual and social adjustment. Call 1-800-749-2257. Both of these publications discuss sexual issues for people with CKD and family members with refreshing honesty.

Of equal importance in a plan for personal development is the pursuit or continuation of a rewarding work life. There is a new 108-page publication entitled *A Kidney Patient’s Guide to Working & Paying for Treatment* developed by Life Options Rehabilitation Program, which contains comprehensive information about working, job retention and career adjustment. This booklet offers great insights into how to live and work productively with CKD, including useful discussion about myths, responsibilities of employers, schedules, laws, rights, discrimination, self esteem and selling yourself in the job market. It is available at lifeoptions.org, or by calling 800-968-7777.

Within the last few years, Internet sites have also introduced informational resources to assist people with CKD in their adjustment to a new way of life. Kidney School (kidneyschool.org) features topics on coping, sexuality and fertility, while iKidney (www.ikidney.com) has a long list of personal growth topics called Lifestyle Tips, such as sexuality, communication, coping and psychological well-being.

A plan of personal development while adjusting to CKD presents a double challenge, but it is manageable with the help of resources such as those mentioned here. Adjusting is not always easy, and it is not always quick, but it can be done. Remember, your own research will lead you to many more resources like the ones you see here. There is a world of help and information “out there” for seekers of personal success. Keep asking questions, keep moving forward.

### Do YOU Have Questions …

Continued from page 5

**Q** If I have kidney failure and am sexually active, can I get an STD? (sexually transmitted disease, which includes syphilis, gonorrhea, AIDS, Hepatitis B, genital herpes or genital warts (HPV))

**A** Having kidney failure does not make you more likely to get an STD. However, if your sex life puts you at risk for getting an STD, you should practice safe sex. If you have questions about safe sex, ask your social worker or your doctor. If you are worried that you might have been exposed to an STD, you can get a confidential blood test at most city/county health departments or health clinics.

Remember—everyone has questions about sex; it is a very important part of our lives. To get a copy of the NKF brochure *Sexuality and Chronic Kidney Disease* call 1-800-622-9010, or go to www.kidney.org and search for “sexuality.”

### Family Focus is available on the Web.

To find this issue or back issues of the newspaper go to www.readfamilyfocus.org
Your Exercise, Your Choice
By Pedro Recalde, MS, ACSM

How do you create an exercise routine that you can use for years, rather than weeks?

The secret is out. If you ask anyone around you if it is a good idea to start an exercise program, the most likely answer is going to be “YES!” The idea of exercising has become a priority in many lives, but for some the reality of exercising every day has yet to be discovered. Many people are experts at starting an exercise program—indeed, they have done it many times. The question is how to start a program that is right for you so you do not find yourself starting all over a month later. Although the term “exercise” might mean different things for different people, the basics of creating a successful routine are the same for everyone. We will help you get started.

Similar to a good diet, a good exercise routine is one that you enjoy and can continue for the rest of your life. Unfortunately, many people who start exercising are looking for a quick way to reduce the size of their stomach or buttocks. Just like dieting, the quick fix exercises almost never work. If they do work, it is achieved in a way that is impossible to continue on a regular basis, so the problem comes back.

It is a great idea to be goal specific when thinking about exercising. What does this mean? Being “goal specific” refers to creating a plan (what kind of exercise you want to do and how often you want to do it) in order to increase your chances of staying with the program. When you think about dialyzing and the medications you have to take, all are prescribed for a certain amount of time and at a specific time. You should think about exercise in the same way. What do you want your exercise prescription to be?

First let’s think about the effect dialysis has on your body, then we can think about how exercise can help. The average person on dialysis dialyzes for three to four hours, three times a week. During this time, several kilos of fluid are removed from the body. The body responds by tightening the vessels in your muscles, forcing more fluid to reach important organs like the heart and lungs. Muscles, especially in the arms and legs, lose important circulation during dialysis, so they do not get all the nutrients they need. This is accompanied by the fact that you must sit still for four hours, which can also lead to weakened and smaller muscles. Now let us think “goal specific” and see how you can fight this effect on your muscles.

The lack of circulation, or blood flow, to your muscles contributes to fatigue and cramping. If dialysis causes lower blood flow to muscles, then we have to increase circulation. Luckily, the body responds to stress by sending blood to the area being stressed. When you exercise your lower body, your leg muscles send a signal that work is being done and more blood flow is needed to get the job done. A great idea would be to schedule some time for exercise, even 15 minutes, right before dialysis to increase blood flow to your legs. If you are feeling up to it, you should try exercising for 15 minutes after dialysis to redirect blood to your muscles after sitting in the chair for so long. Then, it would be a good idea to try a short walk after dinner to help pass the food and increase blood flow to your legs before a long night of rest.

It is true that our muscles can quickly lose their strength and size if not used often. The greatest way to fight this is by doing some weight training. This does not necessarily mean that you need to find an expensive gym with fancy equipment. You can focus on your legs in the comfort of your own home by using your own body weight. Find a chair in your house that is sturdy. While using the back of the chair for balance, you can lower and raise yourself while bending at the knees. Switch that exercise with standing up on your toes, and you will have a quick exercise routine that focuses on your upper and lower legs.

The key to making this successful is finding activities that you love to do and trying them with people you enjoy. Some people stick with the same exercises every day, while others like to mix it up from day to day. The best thing you can do is think of fitness as part of your daily life, as something you have to do in order to live the life you want to live—an active healthy life.
THE CREATIVE SPARK IS NOT LOST FOR PEOPLE WITH KIDNEY FAILURE RECEIVING DIALYSIS TREATMENTS. The National Kidney Foundation (NKF) assisted in a project launched by Amgen, Inc., to show their support and commitment to patients. Amgen asked the NKF to help solicit artists whose work would be displayed in their corporate offices.

The NKF put out the call for artists in notices to its Patient and Family Council’s 1,648 list-serv members and the Council of Nephrology Social Workers. The first set of paintings was purchased and the work of four artists is now on display in Amgen’s corporate offices in Thousand Oaks, California.

Swee Choo Oh’s painting, “Heliconias,” was also used to create a holiday card for Amgen’s 5,000 employees worldwide. These artists are a good example of how you can keep doing the things you love in spite of the health issues you may be facing.

Artwork By Those in the Dialysis Community on Exhibition at Amgen

Swee Choo Oh was born and raised in Penang, Malaysia. Swee has produced many rendering and presentation drawings using mixed media—mainly colored pencils and watercolor.

In 2001, Swee moved to San Francisco to pursue her architectural career. Shortly after moving to the city, she was diagnosed with kidney failure and underwent dialysis for one and a half years. In November 2002, she received a kidney transplant. Her sister was her donor. Swee is now working full time as a Project Coordinator for an architectural firm in San Francisco.

Swee says, “When I was diagnosed with kidney failure in 2001, I was in shock and disbelief. I was unable to understand the medical crisis I was in and worst of all, I was unsure what the future had in store for me. However, I told myself that I was determined to live life to the fullest. What has helped me the most is the support of my family, friends, the medical support team and, most of all, my faith in God.

“In order to cope with my altered lifestyle, I decided to take things head on and keep myself mentally busy. To this end, I took up painting. ‘Heliconias’ was inspired by my short visit to Oahu, Hawaii, in February 2002. It was a trip I never thought possible since I was on dialysis at the time, but I did it.”

Maryann (Janikowski) Jones was born in 1923 in Winona, Minnesota. After graduating from Winona Senior High School, she began her first artistic assignment as an assistant display manager for H. Choate and Company department store, responsible for painting, drawing, draping and dressing the show windows for various departments.

After the war, Maryann married Dale Jones, a photographer, and became a photographic portrait painter and black and white negative retoucher. In 1990, Maryann expanded her artistic career in Vienna, Austria, producing painted hand-drawn illustrations for books. Working in various media, she rendered both life-like and impressionistic works of human and animal subjects. Maryann continued with her artistic illustration work upon returning to Rochester, Minnesota in 1996.

In addition to her aforementioned talents, Maryann enjoys cooking, sewing and working with her daughter as a laboratory assistant in kidney research work.
“My real interest in art began around the age of 12 with drawings in ink and pastels, developing into oil painting and eventually into the use of acrylics,” Tim Phalen explains.

“The main thrust of my craft has been toward display in summer art fairs which, I feel, has resulted in my subject matter being mostly recognizable objects and places. Nevertheless, I find all visual art exciting—whatever the medium—and I try to respond to this feeling with my interpretation of the subject matter.”

“Be it a landscape or a personal experience, painting is important to me and I am always aware of my surroundings as possible subject matter. What I display on canvas is something that has stirred me and what I hope will infiltrate the imagination of viewers.

“About eight years ago, I was diagnosed with Anti-GMB Nephritis, otherwise known as Goodpasture’s Disease. I have been on dialysis ever since. Although I am not as active with my painting as I once was, my love for art remains steadfast.”

Penny Young is 41 years old and lives on the Eastern shore of Virginia with her husband, Gary, and her eight-year-old son, Wesley. Before experiencing kidney failure in December 1999, Penny taught third grade in a local elementary school where she had worked for 16 years. When she is not having dialysis treatments, she volunteers at her son’s school and paints Eastern shore scenes in oils and watercolor. She also occasionally paints murals for friends and family members. Penny has been on the kidney transplant list for two years.
The function of your kidneys may change over time—and as it changes, your diet must change with it. Invest time to understand your unique dietary needs, and how meeting those needs can affect how you feel. These simple strategies will help you enjoy more success and have less stress with your kidney-friendly meals.

**THE CHALLENGE OF CHANGE**

Changing old habits can be overwhelming, but you can meet the challenge by approaching it the right way. For example, mastering your kidney diet at home is the first step to enjoying meals when dining out or traveling. Also, you should not feel that you have to stop eating the foods you love—talk to your dietitian about creating a diet that allows you to keep some of your favorite treats.

**ANTICIPATE CHANGE**

- Develop a “dietary tool kit” to handle meals effectively.
- Ask for a meal plan that can be customized for you by your registered dietitian.
- Learn to compare food labels so you can buy the foods that will meet your needs. A useful booklet, “Your Renal Guide to the New Food Label,” is available from the National Kidney Foundation (NKF) at 1-800-622-9010.

**MONITOR CHANGE**

Invest time in developing your collection of recipes. Organize them in a notebook or plastic page protector and watch the collection grow into a customized plan. Your confidence will grow as your skills improve!

- Learn about nutrients. Your dietitian can provide lists of foods with important nutrients that can help you add variety to your foods. Your dietitian may use software such as “DINE Healthy” to analyze menus and recipes easily. Books like Bowes & Church's Food Values of Portions Commonly Used by Jean Pennington, or Nutrients in Food by Elizabeth Hands can be helpful because they list the nutrients that are in different types of foods.
- Learn how to dine out on a kidney diet. Request a copy of Dining out with Confidence from the NKF (1-800-622-9010). The best foods are those that are broiled or grilled a la carte items rather than combination dishes, such as those served with French fries or other side orders.

**ADAPT TO CHANGE**

If you fly, inform security screeners if you wear an insulin pump or carry supplies. Store supplies in original pharmacy packaging and carry a copy of important medical information.

Airlines offer special meals on some flights. When you request your meal, ask for a low salt or diabetic meal. Call to confirm the meal. Meals are not transferred with last minute flight changes. Anticipate this by packing a few protein bars.

**THE CHALLENGE OF CHANGE (try this out)**

Unscramble each of the clue words. Take the letters that appear in boxes and unscramble them for the final message.

**ANSWERS:**

- Have adventurous vitamins
- Monitor changes
- Anticipate changes
- Enjoy changes!
When you have kidney disease, it may seem as if you need to put your goals and dreams on hold. You may ask: Can I finish school? Can I get or keep a job? Have I achieved all I can? Will I need to retire early or take disability? Kidney disease is a bump in the road—but do not give up your dreams!

Your social worker can help you get the help you need—to go to school, work or volunteer. He or she knows community agencies, can explain these services and can refer you to them.

**DO YOU WANT TO GO TO SCHOOL?**

The more educated you are, the more choices you have, the more you will earn and the more stable your job will be when times get tight. Your social worker can refer you to your state vocational rehabilitation (VR) agency. After meeting with you, doing work skills and interest testing and helping you write a plan that includes your work goals and how you expect to get there, your VR counselor may be able to help you find money for college or a trade school. Want to earn money for school? If you are a student under age 22 and earn less than $1,370 a month or $5,520 a year, you can keep your full Supplemental Security Income (SSI).

Whether you go to school, work, or volunteer, you are a kidney disease ambassador. Your attitude and actions show others that people with kidney disease can live full and rewarding lives.

**DO YOU WANT TO WORK?**

There are many benefits to working—better income, more affordable health insurance and often a greater feeling of self-esteem or confidence. The biggest work barriers for people with kidney disease are low energy, “helpful” others (family, friends and even doctors who think you should take it easy), schedule conflicts, the need for workplace accommodations and fear of health setbacks and loss of benefits. Each of these is addressed below:

1. **Low Energy:** Tell your doctor if feeling tired or having low energy keeps you from doing normal activities. Your doctor may change your medicines—including the medicine you take for anemia—your diet, your dialysis prescription or may suggest exercise. When you are tired, it is amazing how exercise can give you more energy!

2. **Helpful Others:** If your doctor suggests you quit working, say you want to be active and productive and you know people with kidney disease work in many types of jobs. Ask why you cannot work, too. Tell your doctor, friends and family that people with kidney disease who work live longer and better than those who do not work. Ask for their support!

3. **Schedule Conflicts:** Ask your doctor or clinic to schedule your treatment time during non-work hours. Consider changing to home hemodialysis or peritoneal dialysis. Home dialysis allows you to schedule your treatments to fit your life.

4. **Workplace Accommodations:** Ask your boss for an extra break, a place to do a peritoneal dialysis exchange or a chance to sit while you work. These are “reasonable accommodations” under the Americans with Disabilities Act.

5. **Health Setbacks:** Instead of quitting for a health setback, consider taking a leave of absence. Take up to 12 weeks of unpaid leave yearly under the Family and Medical Leave Act (FMLA). You must have worked 1,250 hours over the last 12 months and be employed by a company with at least 50 employees who are within 75 miles of your work site to be covered under the FMLA.

6. **Fear of Loss of Disability:** Ask Social Security about work incentives that let you ease into work if you get SSI or Social Security Disability Income (SSDI). Earn up to $1,128 before losing all SSI cash. Keep Medicaid at higher incomes than other people with disabilities who do not have a fee depending on your income. If you are age 18 through 64 and get either SSDI or SSI, you should have received a “ticket to work.” Your ticket pays for job placement services. If you lost this ticket, contact Social Security. Remember to ask about work incentives that let you work without losing disability right away.

**DO YOU WANT TO VOLUNTEER?**

There are many places—schools, hospitals, kidney and other organizations, churches and more—where you can volunteer and use your skills to help others. Volunteer work lets you test full or part-time work while gaining experience and a job reference. Finally, volunteering gives you a chance to make a difference.

There are countless options for living an active life.

**The Benefits of School, Work and Volunteering**

By Beth Witten, MSW, ACSW, LSCSW

The more educated you are, the more choices you have, the more you will earn and the more stable your job will be when times get tight. Your social worker can help you get the money for college or a trade school. Want to earn money for school? If you are a student under age 22 and earn less than $1,370 a month or $5,520 a year, you can keep your full Supplemental Security Income (SSI).

Whether you go to school, work, or volunteer, you are a kidney disease ambassador. Your attitude and actions show others that people with kidney disease can live full and rewarding lives.

**3. Schedule Conflicts:** Ask your doctor or clinic to schedule your treatment time during non-work hours. Consider changing to home hemodialysis or peritoneal dialysis. Home dialysis allows you to schedule your treatments to fit your life.

**4. Workplace Accommodations:** Ask your boss for an extra break, a place to do a peritoneal dialysis exchange or a chance to sit while you work. These are “reasonable accommodations” under the Americans with Disabilities Act.

**5. Health Setbacks:** Instead of quitting for a health setback, consider taking a leave of absence. Take up to 12 weeks of unpaid leave yearly under the Family and Medical Leave Act (FMLA). You must have worked 1,250 hours over the last 12 months and be employed by a company with at least 50 employees who are within 75 miles of your work site to be covered under the FMLA.

**6. Fear of Loss of Disability:** Ask Social Security about work incentives that let you ease into work if you get SSI or Social Security Disability Income (SSDI). Earn up to $1,128 before losing all SSI cash. Keep Medicaid at higher incomes than other people with disabilities who do not have a fee depending on your income. If you are age 18 through 64 and get either SSDI or SSI, you should have received a “ticket to work.” Your ticket pays for job placement services. If you lost this ticket, contact Social Security. Remember to ask about work incentives that let you work without losing disability right away.

**DO YOU WANT TO VOLUNTEER?**

There are many places—schools, hospitals, kidney and other organizations, churches and more—where you can volunteer and use your skills to help others. Volunteer work lets you test full or part-time work while gaining experience and a job reference. Finally, volunteering gives you a chance to make a difference.

Continued on page 13
Most children who receive hemodialysis spend about eight percent of their time getting treatment. However, many children and families feel that hemodialysis takes up much more than eight percent of their time and energy. The purpose of this article is to help children and families think about ways of making the most of non-dialysis time.

Planning is the key. Eight percent of a typical child’s week equals about 12 hours, or three half-days. In order to make the most of non-treatment time, children and families need to carefully plan how they are going to use their time. Remember, your child is receiving dialysis to live and NOT living for dialysis.

Making and keeping friends is especially important for children with a chronic illness. Unfortunately, many children on hemodialysis admit that making and keeping friends is hard work because treatment interferes with regular school attendance and with after school activities—places where friendships are often born. Many children have an easier time beginning friendship when they are in a semi-structured social environment that is activity focused (e.g., scouting, youth groups, music groups, sports, dance). Trendy hobbies such as scrap booking, collecting and trading cards, and doll collections are also great ways for children to kick off new friendships. Parents may need to insist that their child try new social activities, and parents may need to actively encourage the development of friendships available. If these activities do not exist, it is possible that the dialysis center social worker could help you put together a support group or a family program. Some very exciting Web-based programs for children with kidney problems have recently become available. Entertainment and health education are combined at www.starbright.org, a site that seeks to empower children with chronic illnesses. Summer camping programs are also a great way to meet children with similar experiences. The NKF has put together a list of camp programs that routinely work with children receiving dialysis at www.kidney.org/patients/kidney_camp

Spending time with family is a fun way to use non-dialysis time. On weekends, families can take advantage of fun (and often free) seasonal activities from your experiences. A child’s emotional and social experiences are important to his or her overall development and quality of life.

About the Authors
Arlene Gerson, PhD, is a pediatric behavioral psychologist at the Johns Hopkins Hospital in Baltimore, Maryland, and an Assistant Professor of Pediatrics in the Division of Pediatric Nephrology at the Johns Hopkins University School of Medicine.

Beth Bounds, LCSW-C, is a clinical social worker at Johns Hopkins Hospital. She has been a licensed social worker for 15 years and with the Pediatric Nephrology Division for the past four years.

<table>
<thead>
<tr>
<th>Sunday</th>
<th>Monday</th>
<th>Tuesday</th>
<th>Wednesday</th>
<th>Thursday</th>
<th>Friday</th>
<th>Saturday</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Morning</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Afternoon</td>
<td>Dialysis</td>
<td>Dialysis</td>
<td>Dialysis</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Evening</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Make time for non-health related activities with your child.
Kidney Transplantation: Not for Me
By Linda Harte, RN, BSN, MA, CNN, CCTC

With many improvements over the years, dialysis is the best treatment for many people with kidney failure.

There have been tremendous improvements in the treatments for kidney failure. Dialysis has drastically changed since it was started in the 1960s. People used to dialyze for 8-10 hours at a time and have a plastic tube coming out of their arm as their dialysis access. Home dialysis was not available in all dialysis units, which meant always going in for treatments. Also, there were not as many dialysis units so it was not unusual to have to drive long distances to reach your unit. Peritoneal dialysis was not available for those with chronic kidney disease. It was difficult to keep working because of the time spent on dialysis. Most people were just too tired to do anything on their off days.

Blood transfusions used to be very common because there was no other way to treat the anemia that kidney patients have. Anemia is now managed with the use of medications like intra- venous iron and erythropoietin (a medicine to help the bone marrow make red blood cells). Treating the anemia that goes along with kidney disease gives people more energy.

Home dialysis is now available for both people who use hemodialysis and those who use peritoneal dialysis. It can be performed on your own schedule. This allows more time to work and enjoy normal activities with family and friends.

People with kidney disease can develop a bone disease called renal osteodystrophy because of the calcium and phosphorus imbalance. There are now drugs that can lessen the bone problems, such as vitamin D preparations and better phosphorus-lowering medications.

Blood pressure is now easier to control because there are so many different medications for your doctor to choose from. Medications can be prescribed for your particular disease that can protect your heart, blood vessels and other organs.

Dialysis accesses (fistulas, grafts, catheters) have come a long way. Instead of a plastic tube (shunt) coming out of the arm, most accesses are now under the skin. This allows more freedom for activities such as swimming. Most hospitals have specialists, both surgeons and radiologists, who are experts in dialysis accesses.

Dialysis has come a long way and transplantation—even with the improvements in anti-rejection medications—is not without its problems. Rejection of the kidney is always a possibility. Even though anti-rejection medications are very effective, they are not without side effects. Some of the side effects are high blood pressure, high blood sugars, weight gain, viral and other infections and certain kinds of cancer. People often take more medications after a transplant than before, and these medicines can be quite costly.

While kidney transplantation allows life without dialysis, it is important to know that some people choose dialysis and do better on dialysis than with a transplant. Discuss all the options with your health care team and make the most of your choice. There are patient and family educational publications and programs and kidney patient organizations that can help. Ask your social worker for information, Web sites and contacts. Be your own advocate and insist on having a voice in your health care.
One day I began to suffer from a serious problem and entered the hospital for a diagnosis. I was suffering from kidney failure. Death and the end of my summers appeared to be my lot. Then a miracle: A doctor jammed “prongs” down my neck, and I was able to get emergency dialysis. I fell into a coma, and about two months of my life were spent in a time of crisis.

I survived that, but when I was told I would have to be on dialysis the rest of my life, I prayed that all treatments would end, as I no longer felt that life could be worthwhile.

“...sticking out. What kind of a life is that?” I yelled.

The treatment was administered, as I looked about the room. All eyes that met mine were smiling. Some people were being helped around the room and appeared to react as though they had climbed Mt. Everest. Others smiled as they were being helped.

Then I realized: This world is where people who dedicate their lives to helping others usher the unfortunate about the room, helping them realize that they are loved and their lives are important, too. I, like so many others, was not aware of this world, but now when I receive my treatments, I find I want to smile rather than brood in a melancholy way, to make just a little contribution where people devote their lives, to show my appreciation for a world that only love can make possible.

I hold close to my heart.
Then I go to bed a peaceful soul
Looking forward to sunshine, the birds,
The beautiful butterfly, the green bush around me.
In my silence, my world holds a lot of good blessings.

They are there for you, too.
Look up beyond the chair
See the beauty of God’s world
The beauty of life
The hope of a smile
The thrill of laughter
It is there
Reach out and grab it.

Mariann Burkett, age 72, has been on dialysis four years. Dialysis in its early stages was not one of her treasured moments, but when she compared the silence of her home to just being at dialysis, from waiting for the driver and the great moments she shares at the unit, she was inspired to write this poem. It is dedicated to the nurses and technicians at her dialysis unit in Broward, Florida, and to her beloved grand nephews, Isaiah and Josh Hyndman of Maryland, whose weekly phone call shatters the silence.

A Silent World

I live in a silent world,
No one at home to talk to,
But the break in monotony
Of a telephone call or my friendly neighbor.
Then comes my dialysis day!
Which I grasp onto like the bee to the honey.
Ironically, though it has its pain, there are joys.
I step out in the sunshine
Of the day—even if it rains,
My thoughts are on the smiles,
The sharing, the encouragement from patients and staff.

Even in the chair, where the hours seem endless
There are so many stories to tell,
So much laughter.
I come home, refreshed,
Sometimes too tired to think
But a healthier person.

Later in my quiet moments on my porch
in the evening twilight
I can reminisce, I can smile.

Dialysis, though a gruesome ordeal
I look back, then forward
With joy in my heart.
The silence is shattered by the memories

Mariann Burkett, age 72, has been on dialysis four years. Dialysis in its early stages was not one of her treasured moments, but when she compared the silence of her home to just being at dialysis, from waiting for the driver and the great moments she shares at the unit, she was inspired to write this poem. It is dedicated to the nurses and technicians at her dialysis unit in Broward, Florida, and to her beloved grand nephews, Isaiah and Josh Hyndman of Maryland, whose weekly phone call shatters the silence.

A Silent World

By Mariann Burkett

I live in a silent world,
No one at home to talk to,
But the break in monotony
Of a telephone call or my friendly neighbor.
Then comes my dialysis day!
Which I grasp onto like the bee to the honey.
Ironically, though it has its pain, there are joys.
I step out in the sunshine
Of the day—even if it rains,
My thoughts are on the smiles,
The sharing, the encouragement from patients and staff.

Even in the chair, where the hours seem endless
There are so many stories to tell,
So much laughter.
I come home, refreshed,
Sometimes too tired to think
But a healthier person.

Later in my quiet moments on my porch
in the evening twilight
I can reminisce, I can smile.

Dialysis, though a gruesome ordeal
I look back, then forward
With joy in my heart.
The silence is shattered by the memories

Mariann Burkett, age 72, has been on dialysis four years. Dialysis in its early stages was not one of her treasured moments, but when she compared the silence of her home to just being at dialysis, from waiting for the driver and the great moments she shares at the unit, she was inspired to write this poem. It is dedicated to the nurses and technicians at her dialysis unit in Broward, Florida, and to her beloved grand nephews, Isaiah and Josh Hyndman of Maryland, whose weekly phone call shatters the silence.
Dear Editor,

I have been on the waiting list for a kidney for over four and a half years, and the prospects for a kidney becoming available in the foreseeable future was not good.

Purely by accident, I became aware of alternate opportunities that were available. One is the “ABO Incompatible Kidney Transplant Program” and the other the “Paired Kidney Exchange Program.” We are now pursuing the Incompatible Kidney Transplant Program, and by all accounts my waiting time will soon be over.

Most people are not aware of these options, which I think is unfortunate as I suspect there may be many who could benefit from these procedures. I think you could provide an excellent service to patients awaiting a kidney transplant by publishing the existence of these programs in Family Focus.

Yours truly,

Kai Gertsen

Dear Mr. Gertsen,

Thank you for your letter. I would encourage those who may be interested in these programs to discuss them with their physician, or contact transplant centers in your area. The UNOS Web site (www.unos.org) has a listing of transplant centers. Click on “member directory.”

Karren King

Dear Editors,

I would first like to say thank you for Family Focus. This newsletter, along with a caring, informative dialysis staff, has helped me in better understanding chronic kidney disease and my dialysis treatments.

Sincerely yours,

Keith Ferguson

Keith Ferguson receives his hemodialysis treatments and lives in Waupan, Wisconsin. He wishes to thank both the permanent and traveling dialysis staff at his unit.

Family Focus VOICES

WE LOVE TO HEAR FROM OUR READERS, and so every issue of Family Focus now includes a special question.

Read the question below, also posted online at www.familyfocusvoices.org, and let us know what you think.

How did you make the treatment decision about whether or not to pursue a kidney transplant?

You may visit the Web site above to share your thoughts, or send your response in writing to:

Family Focus Voices
30 East 33rd Street
New York, NY 10016.

“Your nurses said I could have one cup of water before treatment, but you didn’t say anything about the size.”

Drency Dudley was on dialysis for six years. In 2002 he received a kidney transplant. He lives in Flint, Michigan.

Dear Editors,

I would like to say thank you for Family Focus. This newsletter, along with a caring, informative dialysis staff, has helped me in better understanding chronic kidney disease and my dialysis treatments.

Sincerely yours,

Keith Ferguson

Keith Ferguson receives his hemodialysis treatments and lives in Waupan, Wisconsin. He wishes to thank both the permanent and traveling dialysis staff at his unit.

Dear Editors,

I would first like to say thank you for Family Focus. This newsletter, along with a caring, informative dialysis staff, has helped me in better understanding chronic kidney disease and my dialysis treatments.

Sincerely yours,

Keith Ferguson

Keith Ferguson receives his hemodialysis treatments and lives in Waupan, Wisconsin. He wishes to thank both the permanent and traveling dialysis staff at his unit.

Dear Editor,

I have been on the waiting list for a kidney for over four and a half years, and the prospects for a kidney becoming available in the foreseeable future was not good.

Purely by accident, I became aware of alternate opportunities that were available. One is the “ABO Incompatible Kidney Transplant Program” and the other the “Paired Kidney Exchange Program.” We are now pursuing the Incompatible Kidney Transplant Program, and by all accounts my waiting time will soon be over.

Most people are not aware of these options, which I think is unfortunate as I suspect there may be many who could benefit from these procedures. I think you could provide an excellent service to patients awaiting a kidney transplant by publishing the existence of these programs in Family Focus.

Yours truly,

Kai Gertsen

Dear Mr. Gertsen,

Thank you for your letter. I would encourage those who may be interested in these programs to discuss them with their physician, or contact transplant centers in your area. The UNOS Web site (www.unos.org) has a listing of transplant centers. Click on “member directory.”

Karren King

Dear Editors,

I would first like to say thank you for Family Focus. This newsletter, along with a caring, informative dialysis staff, has helped me in better understanding chronic kidney disease and my dialysis treatments.

Sincerely yours,

Keith Ferguson

Keith Ferguson receives his hemodialysis treatments and lives in Waupan, Wisconsin. He wishes to thank both the permanent and traveling dialysis staff at his unit.

Family Focus VOICES

WE LOVE TO HEAR FROM OUR READERS, and so every issue of Family Focus now includes a special question.

Read the question below, also posted online at www.familyfocusvoices.org, and let us know what you think.

How did you make the treatment decision about whether or not to pursue a kidney transplant?

You may visit the Web site above to share your thoughts, or send your response in writing to:

Family Focus Voices
30 East 33rd Street
New York, NY 10016.

“Your nurses said I could have one cup of water before treatment, but you didn’t say anything about the size.”

Drency Dudley was on dialysis for six years. In 2002 he received a kidney transplant. He lives in Flint, Michigan.

Dear Editors,

I would like to say thank you for Family Focus. This newsletter, along with a caring, informative dialysis staff, has helped me in better understanding chronic kidney disease and my dialysis treatments.

Sincerely yours,

Keith Ferguson

Keith Ferguson receives his hemodialysis treatments and lives in Waupan, Wisconsin. He wishes to thank both the permanent and traveling dialysis staff at his unit.

Dear Editor,

I have been on the waiting list for a kidney for over four and a half years, and the prospects for a kidney becoming available in the foreseeable future was not good.

Purely by accident, I became aware of alternate opportunities that were available. One is the “ABO Incompatible Kidney Transplant Program” and the other the “Paired Kidney Exchange Program.” We are now pursuing the Incompatible Kidney Transplant Program, and by all accounts my waiting time will soon be over.

Most people are not aware of these options, which I think is unfortunate as I suspect there may be many who could benefit from these procedures. I think you could provide an excellent service to patients awaiting a kidney transplant by publishing the existence of these programs in Family Focus.

Yours truly,

Kai Gertsen

Dear Mr. Gertsen,

Thank you for your letter. I would encourage those who may be interested in these programs to discuss them with their physician, or contact transplant centers in your area. The UNOS Web site (www.unos.org) has a listing of transplant centers. Click on “member directory.”

Karren King

Dear Editors,

I would first like to say thank you for Family Focus. This newsletter, along with a caring, informative dialysis staff, has helped me in better understanding chronic kidney disease and my dialysis treatments.

Sincerely yours,

Keith Ferguson

Keith Ferguson receives his hemodialysis treatments and lives in Waupan, Wisconsin. He wishes to thank both the permanent and traveling dialysis staff at his unit.

Family Focus VOICES

WE LOVE TO HEAR FROM OUR READERS, and so every issue of Family Focus now includes a special question.

Read the question below, also posted online at www.familyfocusvoices.org, and let us know what you think.

How did you make the treatment decision about whether or not to pursue a kidney transplant?

You may visit the Web site above to share your thoughts, or send your response in writing to:

Family Focus Voices
30 East 33rd Street
New York, NY 10016.

“Your nurses said I could have one cup of water before treatment, but you didn’t say anything about the size.”

Drency Dudley was on dialysis for six years. In 2002 he received a kidney transplant. He lives in Flint, Michigan.

Dear Editors,

I would like to say thank you for Family Focus. This newsletter, along with a caring, informative dialysis staff, has helped me in better understanding chronic kidney disease and my dialysis treatments.

Sincerely yours,

Keith Ferguson

Keith Ferguson receives his hemodialysis treatments and lives in Waupan, Wisconsin. He wishes to thank both the permanent and traveling dialysis staff at his unit.

Family Focus VOICES

WE LOVE TO HEAR FROM OUR READERS, and so every issue of Family Focus now includes a special question.

Read the question below, also posted online at www.familyfocusvoices.org, and let us know what you think.

How did you make the treatment decision about whether or not to pursue a kidney transplant?

You may visit the Web site above to share your thoughts, or send your response in writing to:

Family Focus Voices
30 East 33rd Street
New York, NY 10016.

“Your nurses said I could have one cup of water before treatment, but you didn’t say anything about the size.”

Drency Dudley was on dialysis for six years. In 2002 he received a kidney transplant. He lives in Flint, Michigan.

Dear Editors,

I would like to say thank you for Family Focus. This newsletter, along with a caring, informative dialysis staff, has helped me in better understanding chronic kidney disease and my dialysis treatments.

Sincerely yours,

Keith Ferguson

Keith Ferguson receives his hemodialysis treatments and lives in Waupan, Wisconsin. He wishes to thank both the permanent and traveling dialysis staff at his unit.
Quality of life is an important factor when studying outcomes of people with chronic kidney disease (CKD). While tools are available to measure the health-related quality of life of adults with kidney failure, no similar tools have been designed specifically for children. Stuart L. Goldstein, M.D., the first recipient of NKF’s Franklin McDonald/Fresenius Medical Care Clinic Research Young Investigator Grant, aims to create a clinically valid tool to help assess health-related quality of life in children. Dr. Goldstein, an assistant professor at Baylor College of Medicine/Texas Children’s Hospital in Houston, says that standard outcome measures used for adults with kidney failure, such as death and hospitalization rates, are important, but they are clearly insufficient as outcome measures for children.

Other factors including growth, exercise capacity, school attendance and performance, self-reliance and functional development are crucial components for assessing the health-related quality of life (HRQOL) for children with chronic kidney failure (also called end stage renal disease or ESRD). Dr. Goldstein’s grant will fund development of the first pediatric ESRD-specific HRQOL tool. A group of children receiving treatment for kidney failure (dialysis or kidney transplant) and their parents were interviewed to give their insight into the factors affecting quality of life in children with kidney failure. The results have been distilled into an initial tool, the PedsQLTM ESRD Module. This tool is being pre-tested in five patients of four age groups (2-4, 5-7, 8-12, 12-18).

The module will be revised based on the pre-test information and then field tested in children with kidney failure at Texas Children’s Hospital and Children’s Mercy Hospital and Clinics in Kansas City, Mo. In the final part of the study, the effects of anemia status, hemodialysis adequacy, nutrition status and ultrafiltration modeling on HRQOL will be assessed using the module and exercise capacity testing at three-month intervals for one year in a minimum of 12 patients. As a result of these investigations, Dr. Goldstein hopes to create a clinically valid tool to help with assessment of HRQOL in children with kidney failure throughout their pediatric years.

Each year, the NKF provides close to $5 million to fund research projects, such as Dr. Goldstein’s. For more information about the NKF’s research program, visit www.kidney.org/professionals/research.