

*** * IN THIS ISSUE: FOCUS ON THE FAMILY * ***



A Newspaper for patients and their families

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NUMBER 1

A LOVING AND DEDICATED FAMILY

by Kevin S. Goyette



Kevin (top center) gives credit to his family for their support and love, not to mention a new kidney. Also pictured: his mother, Jeannine; his fiancée, Tracey; and his father and donor, Donald.

SEE KEVIN'S STORY ON PAGES 8 & 9

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NKF National Kidney Foundation®

FROM THE EDITOR

It is entirely coincidental that the theme of this, my final issue as editor-in-chief of *Family Focus*, is "Focus on the Family." It is fitting, too, because all of you have become family to me. I am so thankful to have had the opportunity to get to know some of you personally.



Nancy S. Spinozzi

Eight years ago, when *Family Focus* was born, I was fortunate to be at the right place at the right time, and agreed to be the publication's first editor-in-chief. It took several months before we were up and running, but look at us now.

Over the years, I have received a lot of letters from you. These letters have left me

amazed at what many of you accomplish despite living with kidney disease. I have read how some of you have overcome serious medical problems, and I have read entertaining stories about traveling and climbing mountains. Whether you have made me laugh or cry, every letter, poem or story has gone straight to my heart. For me, *Family Focus* has always been a labor of love.

Now it's time to pass along this wonderful experience to a new editor-in-chief. One year ago I introduced you to Karren King, when she became our assistant editor. I am delighted to announce that Karren will take over the helm of *Family Focus* beginning with the next issue. Welcome, Karren!

Lest you think you've heard the last from me, I am already working on something for an upcoming issue. See you soon! 

Nancy S. Spinozzi
For the Editorial Board



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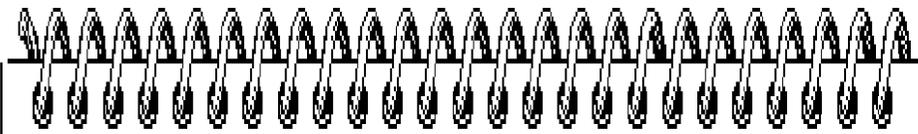
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MAILBOX



Dear *Family Focus*:

My husband, Al, is amazing! He has been dialyzing since June 1995 at Belmont Court Northeast in Philadelphia, Pennsylvania, three days a week, four and-a-half hours each day. He has been on Albert Einstein Medical Center's transplant list since November 1996.

We support him a great deal, but more often than not, Al is the one who supports us! As our sons Gary and Sam and I observe how he handles everything that comes his way, we realize how wonderful and truly amazing my mate of 26 years really is! Al's attitude is fabulous, his weight gain between treatments is minimal, his phosphorus and potassium levels are almost always where they should be and his smile is contagious! Gary, Sam and I always try to be there for Al whenever he needs us, but he gives us encouragement. Encouragement that one day the phone will ring and he will be told that a kidney awaits him. Encouragement to understand that even if his blood pressure should crash after a treatment, he will not only be all right, but he will still be able to go to work, and I won't have to come home from work in a panic. Encouragement to "thank God there is dialysis," so we can have a life together while waiting for his transplant.

Al never ceases to amaze me. He drives himself to and from his dialysis treatments, and still works a 40-hour week (thanks to the support of his wonderful boss, who allows him to work around his dialysis schedule). Al still does chores and fixes things around the house. He cooks meals; takes Sam out for driving lessons; leads when we go out dancing; attends all of our family's and friend's anniversary parties, holiday festivities, weddings, Bar and Bat Mitzvahs and helps Gary's band members transport their musical equipment in his van.

Oh sure, I prepare his morning, noon, evening and bedtime pills for him, and I set his alarm so that on dialysis days after his nap he gets up for work on time. I help him add up the ounces of fluid he ingests each day, and I even tested to be his donor (we only matched one of six antigens). And we all hug him a lot, but this support is nothing compared to what Al does every day of his life—and that smile is always there.

Sincerely,

Rhonda Frenkel

Rhonda and Al Frenkel live in Philadelphia, Pennsylvania.

Dear *Family Focus*:

My granddaughter, Jonyce Hollins, is eight years old. Jonyce attends the Langston Hughes Elementary School of the Arts in East Orange, New Jersey. She recently participated in the East Orange School District Science Fair, and won first place (second-grade level) for her project, "Keeping the Blood Clean: The Kidney and the Dialysis Machine."

Jonyce's mother, Venus Coleman, suffers from systemic lupus, and is on dialysis. Jonyce visited the dialysis center, where the manner in which the dialysis machine and the kidney work were explained to her. Jonyce was extremely interested, and her research paid off. Her presentation was wonderful.

Sincerely,

Linda Coleman Bridgeforth

Jonyce knows all about keeping the blood clean.



Dear *Family Focus*:

My introduction to dialysis was quite roundabout. First, I was examined for an enlarged prostate gland. In the course of the examination, the doctor offered his opinion that there were cysts on my bladder, and it appeared that only 15 to 20 percent of my kidneys were functioning. At his request, I saw a nephrologist and an oncologist. The oncologist discovered that I had multiple myeloma. I also had congestive heart failure, and was admitted to a hospital. Ten pounds of fluids were removed from my system, including the build-up in my lungs, which had caused severe wheezing.

I am now undergoing limited monthly chemotherapy treatments for cancer and dialyze three times a week, three hours at a time. I hope to convert to continuous ambulatory peritoneal dialysis, so that I can travel.

I am 77 years young. Although the restrictions on my movements and diet haven't depressed me, the discipline and the miserable boredom of the treatments have left me frustrated.

My greatest asset is my long-suffering spouse, who watches my diet and everything else of value to my health status.

Sincerely,

Paul Silverman

Paul Silverman and his wife live in Goleta, California.



PATIENT AND FAMILY CORNER

Rocky Mountain HIGHER and HIGHER

by John Cruzan

It is a beautiful afternoon in July and we're hiking a short trail (only a mile long) in Rocky Mountain National Park in Colorado. This trail leads to a geological feature called "The Crater." I find myself stopping to rest quite a bit. Perhaps it's the elevation (11,000 feet); perhaps it's the steep trail (an increase of 800 feet in elevation over the course of one mile); or perhaps it's the after-effects of my dialysis session just three hours earlier. It's probably all three.

This is not my first Colorado hiking experience. Back in the '60s, when Boulder was a mecca for hippies, I was a graduate student at the University of Colorado. That's when Tina and I started hiking and fell in love with the Rockies. After receiving my PhD in zoology, I began teaching at Geneva College in western Pennsylvania, a position I still hold. Having two active young boys made trips back to the Rockies impractical, so for awhile, we hiked in Pennsylvania and West Virginia. In time, we did return to vacation in the West, and as the boys grew, we did more and more hiking.

Then, in 1983, my kidneys failed as a result of an autoimmune disease, and I

“Once I adjusted to life on dialysis, we began thinking about travel.”

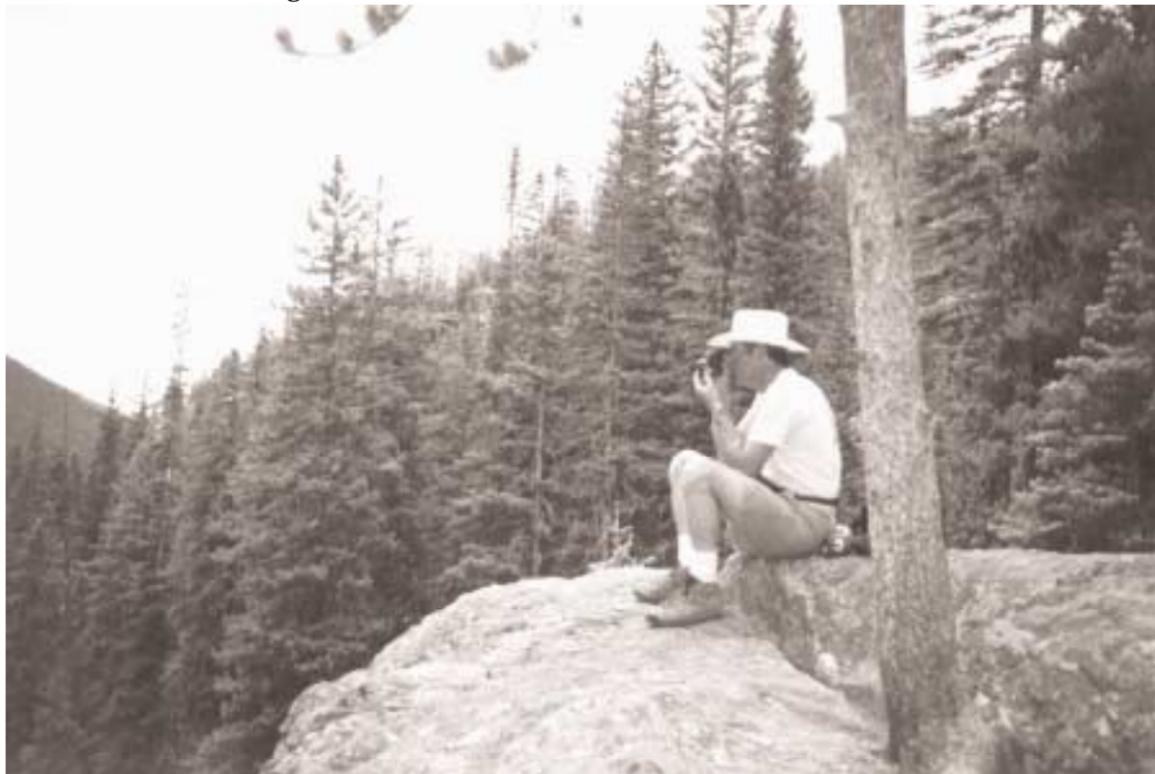
began hemodialysis. I remember lamenting to my social worker about my mental list of great hikes that now would never be. She encouraged me not to abandon that list, but to believe that I would, in time, feel well enough to make those hikes.

Tina is a registered nurse, and from the beginning, we agreed that we would do home hemodialysis. Within 10 weeks of my first treatment, we were dialyzing at home and have continued to for more than 13 years. Once I adjusted to life on dialysis, we began thinking about travel. Trying to arrange our first vacation was extremely frustrating. There were no

where we wanted to go. And we did go, from Maine to Oregon, from the Grand Canyon to the Canadian Rockies. Along the way, I checked off all those hikes on my list (including the 16-mile hike into the Grand Canyon, to the Colorado River and back out in one day) and made many others as well. My two favorites are Lake Isabelle in Colorado and Lake Solitude in the Grand Tetons.

The dialysis was a chore—supplies to haul in and out of motel rooms, dialysate to be mixed in five-gallon batches and late-night cleanup and disinfection routines. It was somewhat stressful, but we did

“She encouraged me to believe that I would, in time, feel well enough to make those hikes.”



John takes a breather on the North Inlet Trail.

clinics near where we wanted to go, and those that did exist, perhaps 100 miles away, didn't always have openings when we wanted to be there. We ended up vacationing where the dialysis machines were, not where we wanted to be. The next year we just stayed home.

In 1986, we were able to obtain a portable "suitcase" dialysis machine. It is very basic, noisy and only approved for three weeks of use at a time, but it gave us the freedom to go

have the freedom to be where we wanted to be. Usually, that was somewhere in the Rocky Mountains.

A few years ago, Tina read an article about a vacation destination in the Rockies, at which kidney patients can dialyze. She called for information, and we arranged for me to dialyze there on the following year's vacation. What a relief it was not to haul all the equipment and supplies across the country! For Tina, it meant

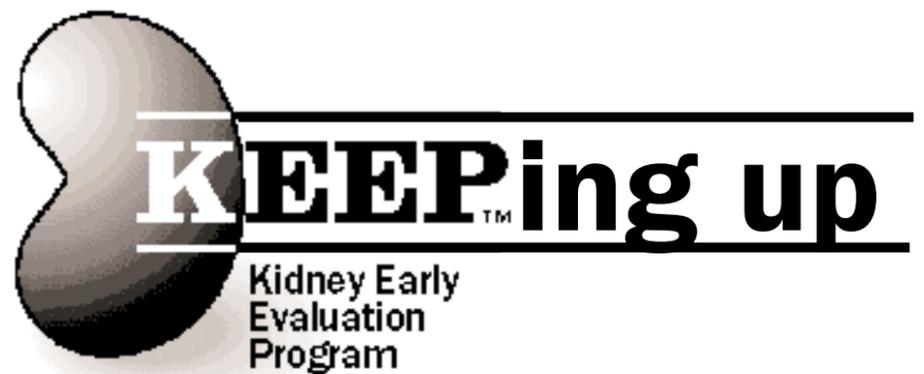
someone else was responsible for my dialysis for two weeks. And, it's where we wanted to be—in the mountains.

We didn't stay at the center; instead, we stayed about 30 minutes away, closer to Rocky Mountain National Park. We hiked about 60 miles during our 10-day visit. If you're not a hiker, the park is a great place to enjoy the scenery and wildlife. You can also fish and boat in several nearby lakes, and the ski slopes are relatively close.

After many rests, we eventually went to The Crater. The wind on the Continental Divide nearly blew us back the way we had come, but it was worth it. In addition to the great views, we saw about 30 bighorn sheep and several lambs. The trip back down to our car was much easier. Perhaps it was the thrill of hiking the Rockies again.

John Cruzan lives in Beaver Falls, Pennsylvania, where nothing is 11,000 feet high.





The National Kidney Foundation (NKF) piloted the Kidney Early Evaluation Program (KEEP) this year in 19 cities across the U.S. KEEP is a free health screening program that targets individuals who are at increased risk of developing kidney failure—those who have high blood pressure and/or diabetes, or family members with high blood pressure, diabetes or chronic kidney failure.

Approximately 900 “high-risk” individuals participated in this important early intervention and detection program, which consists of blood pressure and weight measurements, blood and urine testing, a health risk appraisal and an on-site consultation with a physician for everyone. Through KEEP, the NKF hopes to identify individuals at increased risk and inform them of their risk, so they can seek appro-

priate medical attention to delay or prevent the onset or progression of renal disease.

One enthusiastic supporter of KEEP is Doris Mitchell. A recently diagnosed diabetic who also has a family history of diabetes and high blood pressure, she recently attended a screening in Portland, Oregon. “I am deeply grateful to the National Kidney Foundation for offering this free health screening service,” Ms. Mitchell



At the Lab Station, a blood and urine sample is collected from each KEEP participant (NKF national office, New York, New York).



Volunteers review the health risk appraisal with KEEP participants at Station Three (Christ Pentecostal Temple in Jamaica, New York).

Dear Readers: Your Efforts Are Appreciated

We want to take this opportunity to thank all the individuals who have shared their personal stories with us. These stories have helped to make *Family Focus* the premier publication that it is. This is evidenced by the fact that the number of requested copies has continued to rise at a steady pace, and the feedback we have received from our readers has been extremely positive. Many readers note that while they find all the articles interesting, the stories from individuals describing experiences similar to their own are the ones they enjoy most.

We all continue to be inspired by the stories we read, and believe that no accomplishment is too small. Each one of us can make a difference in the lives of others who

are affected by kidney disease, even if it is in a small way. Therefore, we would like to encourage you to share your stories with us. Tell us about trips you've taken, hobbies you have or how you spend your day. If you don't like to write, just send us a picture with a sentence or two about who is in the picture and what they are doing. We also regularly feature poems and cartoons submitted by our readers.

Please send your submissions for consideration to *Family Focus*, National Kidney Foundation, 30 East 33rd Street, New York, NY 10016. All submissions will be reviewed by the *Family Focus* Editorial Board. 

the Good Work

says. I encouraged my brother to go with me to the screening, and he was told to follow up with a doctor because of his test results. Unfortunately, he did have a problem with one of his kidneys, but it was discovered early enough to be treated. He is now being monitored by his doctor. Had it not been for the

NKF screening, the problem may not have been detected until it was too late. Everyone at risk should have themselves screened.”

To find out more about KEEP, please call the NKF at (800) 622-9010. 



At Station One, participants register (Christ Pentecostal Temple in Jamaica, New York).



All KEEP participants have their blood pressure and weight measurements taken after registering (Norwood Dialysis Center in Birmingham, Alabama).



A physician reviews screening results with each KEEP participant when the screening process is complete (Revelation Lutheran Church in Detroit, Michigan).



POETRY

CORNER

It Would Take Me a Lifetime

by Nancy Rhinehart

*It would take me a lifetime
to let you know how much I appreciate you.
It would take me a lifetime to list all the reasons why
you are so important to me.
It would take me forever to find words
for all the thanks I would love to express,
for all the deeply reassuring feelings that I
have for your willingness to sacrifice a
part of you for me.
And it would take an eternity to give you
back
even half of the love you've given me during
this troublesome time we've shared together.
But until eternity gives me a chance
to say everything my smiles try to show,*

*I will hold you in my heart more gently than
any feeling,
I will keep you on my mind more lovingly than
any thought and
I will feel blessed by your presence more than you'll
ever know.*



Nancy and David in May 1997, before the transplant

Nancy Rhinehart dedicates this poem to her brother, David Taylor, who donated a kidney to her in 1997. Nancy, who lives in Lakewood, California, says she hasn't felt so great in 20 years. 

Focus on the Family

Introduction

As kidney patients, you are constantly forced to make adjustments to your lifestyle, from time-consuming dialysis treatments to annoying restrictions on your diet. Coping can be difficult; you may even face depression.

Many of you, in your correspondences with Family Focus, have told us about the many roles your family and others have played in helping you cope with kidney disease. Just as there is great flexibility in the roles of those who provide support—from assisting with home dialysis to simply being there as someone to talk to—so is there flexibility in who provides the support. Sure, it can come from immediate family—parents, siblings, children, your spouse—but support can also come from friends, neighbors, colleagues, the medical staff and, as one reader adds, God. Maybe that's not family in the traditional sense, but as many of you know, support can come from places you would never to think to look. Support is where you find it.

Support can also be found in the form of "People Like Us, Live!™," an interactive patient education program that openly addresses the many fears and concerns which patients and family members face when diagnosed with chronic renal failure. The NKF program provides objective, factual information needed to make informed treatment and lifestyle choices. A seven-part "People Like Us" video series is targeted toward the newly diagnosed chronic kidney disease patient. Topics include: An Overview, Hemodialysis, Peritoneal Dialysis, Transplantation, Good Nutrition: Eating Right, Coping: Managing Your Kidney Disease and EPO: Treating Anemia.

For this issue of Family Focus, which begins the newspaper's eighth year of publication, we are taking the name of the newspaper quite literally, and focusing on the family. To those of you who shared your stories about the support you provide or the support you receive, thank you. To everyone else, we hope you learn as much as we did.

Never a Dull Moment

by Lori Strickland

I met Doug in January 1982 at a friend's house. After hearing about Doug's medical history—kidney disease at birth, surgeries, needles, hearing loss, hemodialysis, peritoneal dialysis, an unsuccessful transplant—I remember thinking, "Can you imagine being married to this guy?" Well, just seven months later, I married this guy. Any marriage is a challenge, but life with Doug has been nothing short of a roller coaster ride! After a while, I even made "Never a Dull Moment" the motto of our marriage. Doug has continued to provide me with quite a bit of excitement.

In Sickness and in Health

On our wedding day, I vowed to Doug that I would stay with him "in sickness and in health." We looked at each other and chuckled. You see, Doug should have been in a hospital bed, not in a church getting married. He had been admitted to a Kansas City hospital less than two days before our wedding with a severe case of peritonitis. He talked the doctor into releasing him the day before the ceremony. On the morning of the wedding, he was still doubled over in pain, and had to be taken to the local hospital for a painkiller just to get through the wedding. He was virtually

pain-free, but extremely sleepy. Luckily, we recorded the ceremony on videotape, so I could prove to him later that we did indeed get married. Needless to say, our honeymoon was one of a kind. Little did I know that this was only a taste of what was to come.

Within the first year of marriage, Doug required two hospital stays, one for six weeks after he received his second

it was difficult; only two days before, Doug's doctors removed the transplanted kidney Doug had waited seven years for.

During this trying time, I merely existed, working a full-time job each day and visiting Doug every night and weekend. I was often exhausted, both physically and emotionally, but Doug was battling frustration and loneliness, and I knew he counted on my visits and the



Doug, Lori and Danielle Strickland

transplant. Unfortunately, Doug suffered from so many rare complications from his transplant that he underwent six surgeries in that short span, and nearly died twice. We tried to celebrate our first wedding anniversary in the hospital, but

food I brought him to supplement the hospital food. I viewed this time as a bad dream that had to be happening to someone else. I simply kept going without thinking whether I should. I just did.

With hindsight, it isn't surprising that I found those early years of our marriage difficult. Naively, I thought I possessed all the information I needed, but our arguments centered on Doug's disease, particularly, my lack of understanding about how it affected me. I thought I could handle the situations alone, and I blindly felt my way through many emotional valleys for no reason. If I had known more about what to expect, coping with the tough times would have been easier.

The Setbacks Continue

Due to complications, Doug was forced to return to hemodialysis, after some time as a continuous ambulatory peritoneal dialysis (CAPD) patient. We decided that home dialysis was the best option for us. Doug and I trained together, and for three years I was his back-up. I was proud of myself; prior to our decision, I would get a weak stomach just walking into a hospital, and could never look at a needle, let alone help with the process.

As difficult as the loss of the kidney was, nothing prepared me for Doug's severe depression in the year to follow. For the first time, I saw my stubborn,



Focus on the Family

self-motivated husband giving up. I was in a daze, uncertain of what hit me. Around this time, I began to learn the importance of family members and friends and the power and strength I can receive from God.

Still, it wasn't easy to surmount all the obstacles we faced as a couple. I experienced health problems of my own, and Doug received and rejected transplant numbers three and four. The fourth transplant did last four years, providing both of us with a welcome reprieve from the dialysis routine.

We Are Family

My toughest personal battle through the years was stifling my incredible desire to have children. When I married Doug, I knew that it was unlikely that we would have our own children, but I still held on to that little shred of hope. With a lack of genetic information about Doug's disease, the doctors could only offer a 50-50 chance that our child wouldn't suffer from kidney disease. That was too great a risk, so we decided to consider adoption. In July 1996, after nearly 14 years of marriage, God blessed us with a beautiful newborn daughter,

who we named Danielle. She is a typical, energetic child, and has provided us with—you guessed it—even more challenges. Danielle is worth it, though.

We are blessed to have Danielle, but we continue to adjust and make the best of the challenges we face because of Doug's disease. I recently left my full-time job as a manager because the pressures of a demanding and stressful position, raising a child and caring for a husband with a chronic illness simply became too much for me. I realized that I was only partially there for the three roles, and not there for myself at all.

Doug currently completes treatments every other evening at home. This works best for us with our lifestyle and Doug's desire for independence. We have more time together, and that is important to us, especially with Danielle in our lives. It's hard to maintain a social life and keep regular commitments, but home dialysis allows us some flexibility.

Lori, Doug and Danielle Strickland live in Overland Park, Kansas, where it's never dull. 

Try Some Coping Mechanisms

by Lori Strickland

I wish I could say that I have always been the loving, supportive wife, but I am not perfect. I don't always say or do the right things, and I am not a selfless saint. I am committed to Doug, however, and he knows that I will always be there for him, no matter what happens. I believe I was granted a special role as Doug's wife, and I now have the opportunity to make a difference in other people's lives. If you are just beginning this journey, recognize that your life will be different, but it can be full and of great value. While I have learned many lessons the hard way, perhaps you can benefit by using some of the coping mechanisms that have worked for me:

- Make a commitment. If we count on happiness to determine our commitments, we will never be able to keep them.
- Educate yourself about your family member's condition and how the disease will affect each of your lives. Join the NKF's Patient and Family Council, a wonderful resource dedicated to the education of both the patient and family members.
- Maintain open communication. Depression, resentment and anger are some of the common issues that can become overwhelming problems if they are not dealt with. If you need help communicating, speak to a friend or seek counseling.
- Develop a support system. Your concerns are important, and often your loved one with ESRD has plenty to deal with already. It is critical that you have close friends or family members you can call at any time.
- Ask for help. Beyond providing emotional support, it is beneficial if your friends or family members can help out in any way. You may find that they welcome the chance to help.
- Use your sense of humor. If you don't have one, get one. Laughter eases the tension of a difficult situation.
- Live one day at a time. If you try to deal with everything at once, it will overwhelm you.
- Don't let worry control you. Strive to make the best of every situation. When we were first married, I was consumed with the thought that Doug could die at any time. I found that this preoccupation was keeping me from growing close to Doug and building a life-long relationship with him. I could have wasted several years if I had not realized this was happening.
- Keep it normal. A sense of normalcy will help you keep the balance when things get tough.
- Be a care giver not a caretaker. Caretakers do things for their loved ones that they should be doing for themselves, and therefore suppresses their natural desire to achieve goals. Care givers don't do everything for their loved ones; instead they encourage them to achieve results for themselves.
- Avoid unrealistic expectations. Be prepared to change plans and try to make the best of the revised situation. Expect the unexpected, because it is to be expected.
- Don't forget about you. You will lose your effectiveness as a supportive family member if you neglect yourself.
- Don't forget to have fun. Don't let the disease stop each of you from enjoying your favorite activities. About four years ago, my husband took up golfing and karate. (He's now a black belt!) I always try to set aside time for reading and my artistic projects. Possibly, you need to discover new ways to have fun and relax. 

Are we missing you?

We'd like to make sure that NKF Family Focus is making its way to every dialysis unit and transplant center in the country. If we're missing anyone, please let us know by dropping us a note or by giving us a call at (800) 622-9010.

COVER STORY

A Loving and

by Kevin S. Goyette

Life is a continuous cycle of peaks and valleys, and everyone in your life is affected, but nobody knows the ending. If you think about your own life, I'm sure you can relate this statement to several experiences, causing many pleasant and not-so-pleasant memories. Although some peaks are higher than others and some valleys cause you to hit rock bottom, there usually seems to be a happy middle ground, where we can be comfortable for awhile. A comfort zone. The key is to take charge of your life and make the best possible decisions to positively impact the way you live. Of course, it also helps if you have a family or some other support system to be there for you. What follows is my real-life story, which encompasses my highs and lows with chronic renal failure and the many decisions I have faced with the help of my family.

It all started at birth, as many things do. A young couple had a brand new baby boy, and they named him Kevin. Everything was wonderful. Relatives and friends gathered to visit the baby and express their congratulations. Life was great, and another generation had begun. During their first visit to the pediatrician, however, the doctor noticed that the size and firmness of the abdomen were abnormal, and told Kevin's parents to take him to Children's Hospital in Boston. After an examination in the renal unit, it was determined that he was born with only one kidney. The kidney, which was on the left side, was blocked by fatty tissue, which in turn obstructed the flow of urine to the bladder. Surgery was needed to correct the problem. It was a difficult time for the whole family, particularly Kevin's parents, who were extremely upset. Fortunately, the surgery to remove the obstruction was successful, but more difficulties were just ahead.

Kevin's parents made a strong commitment to continue with follow-up visits to Children's Hospital to ensure that kidney function remained at acceptable levels. Throughout Kevin's early childhood and into his adolescence they helped him in any way they could by making sure he took his prescribed drugs and followed doctor's orders. They even made the long trips to Boston as often as needed to positively affect Kevin's health. He grew normally and only suffered small decreases in kidney function. The hard work

and dedication of the entire family seemed to be paying off, and Kevin was living his life as close-to-normal as possible.

Everything Seems to Be OK

Visits to Children's Hospital became less and less frequent as high school graduation led to college enrollment. After all, Kevin felt like he was in excellent health. He constantly went out with friends and girlfriends and even participated in sports. Finally, a year or so had passed since he had a checkup in Boston. It had been too long, so he went in for routine blood work and a urinalysis, fully expecting another positive result.

The initial shock of increasing creatinine, protein and BUN levels was a major blow to Kevin and his family. The comfort zone had passed him by, forcing him to make decisions about his future. His family was fully aware of the serious nature of his condition and what it meant: medications and frequent visits to the renal clinic at Children's Hospital to monitor the effect of the new medications on his declining renal function. Dr. Sommers, who was in charge of Kevin's care, was a dedicated

and straightforward doctor. He told Kevin and his family what needed to be done to prolong the kidney function as long as possible, and what the choice would be when the kidney eventually failed. Initially, Kevin took medication for high blood pressure; later there were drugs for filtering what the kidneys could no longer filter. For several years, the drugs controlled the speed of the declining kidney function, and life was fairly normal. Dr.

Sommers explained, however, that the kidney would ultimately fail.

By September 1996, Kevin's creatinine reached an untreatable level of 14+, and his physical strength, mental

alertness and overall health were in decline. He and his family met with the renal transplant team, headed by Dr. Harmon, and all options were discussed, including dialysis, cadaveric donor transplantation and living donor transplantation. Kevin was told that none of these options constituted a cure; they were simply different forms of treatment. It was a tough time for the entire family, with many tough decisions to be made in a relatively short period of time. Kevin refused to ask any member of the family to

donate an organ because he felt it was his mistake for letting himself go so long without a checkup during his college years. He was determined to begin dialysis and wait for a cadaveric organ to become available, even though he knew it could take three or four years on the transplant list before an organ would become available to him.

After an AV fistula was surgically implanted into his arm, Kevin began dialysis treatments at Children's Hospital in October 1996. Before long, he was transferred from the dialysis center at Children's to Southern New Hampshire Regional Medical Center, a more convenient location in Nashua, New Hampshire. He underwent four-hour sessions three times a week. At first, he found the treatments difficult; his energy level constantly fluctuated, and it was tough to stay alert, especially at work. Fortunately, his boss allowed Kevin to rearrange his schedule to accommodate his dialysis treatments, but keeping up such a busy schedule was physically draining. Remembering what his parents had sacrificed for him throughout his life, he never succumbed to the urge to quit his job or give up in any way. Soon, his energy level improved—thanks to iron and erythropoietin treatments—and dialysis treatments became easier.



Kevin and his fiancée, Tracey, during Christmas 1997

Dedicated Family

Dad's Gift of Life

Despite Kevin's improvement, his family ignored his wish to wait for a cadaveric organ donor. All immediate members volunteered to get tested for the best possible match, knowing fully that the best match would donate a kidney. Kevin finally realized that if he were to live a normal life, he would need a kidney transplant from a living donor. Since he never asked anyone in his family to donate a kidney, he was especially touched by his entire family's desire to make such a huge sacrifice for him.

When the test results came back, there wasn't a 100 percent match in the family, and a few of Kevin's relatives were equal in terms of matching for donation. After much discussion, his father decided to donate a kidney to Kevin, which seemed fitting because it was his father

who made those long trips to Boston for Kevin's visits at Children's Hospital.

The surgery was performed on May 15, 1997, by Dr. Wilson and Dr. Lilliheigh at Children's Hospital. It was a huge success, despite the normal pain and discomfort, and the entire family was once again elated. Recovery for both Kevin and his father seemed to be ahead of schedule, but another setback was looming ahead. The doctors had always mentioned the possibility of rejection, and sure enough, two weeks after the surgery and one day after being released, Kevin needed to be readmitted because of an elevated creatinine level. A three-day prednisone pulse was necessary to reverse the anticipated rejection episode. The level dropped, and Kevin was released. All was peaceful. For two days.

During his next visit to the

transplant clinic, Kevin was told that his creatinine levels were once again inflated, and he was admitted to the hospital yet again. This time, a more serious measure had to be taken to prevent a chronic rejection episode. Kevin was prescribed a medication called OKT3, which he would need while remaining in the hospital for the next two weeks.

It was a depressing time for Kevin and his family because of everything they had gone through to get to this point. It was yet another valley in their lives.

Another Peak

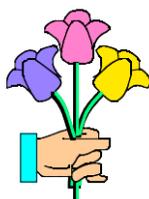
The medication proved effective in treating the rejection episode, and the creatinine levels have become stable. Physical and mental recovery have been slow, but everyday life seems to be getting back to normal. Kevin and his family

have reached another comfort zone, just waiting for the next peak or valley to come across their path and change their lives once more.

When a family comes together to solve a difficult problem such as kidney failure, a positive outcome is possible as long as everyone talks everything through and makes the best decision. Kevin is lucky to have such a loving and dedicated family supporting him. He has learned from his mistakes, and rest assured, he will take every precaution and medication necessary to help the kidney last for as long as possible. He will never again take living normally for granted.

Kevin has experienced no further rejections. He recently purchased a new house in Nashua, New Hampshire. He and Tracey plan to get married in June. 

Thank You!



...to Nancy Spinozzi, for her many years of outstanding service as editor of Family Focus. Over the years, Nancy has demonstrated great commitment to the renal community by ensuring that Family Focus has offered patients, their families and professionals the opportunity to share their experiences in a balanced and informative way. Through her tireless efforts, Family Focus has become the premier publication in the renal community.

Again, we say, "Thank You, Nancy."

Best wishes From All of Us at the NKF



Thanks to Nancy's many years of contributions, Family Focus has become the outstanding publication it is today.

Focus on the Family

Back on My Feet Again

by Evy Eugene Mavrellis, BA, MPA, EdS

I was first diagnosed with chronic glomerulonephritis when I was a college student in 1965, during an emergency appendectomy. I was lucky that it took 30 years for the disease to progress to renal failure. In January 1995, at age 49, I was shocked when my doctor told me that in nine months to a year, I would lose all kidney function, and must either receive a transplant or undergo dialysis.

No one in my immediate family was either able to or willing to donate a kidney. It took my husband Tim's sister, Maro, living on the Mediterranean island of Cyprus, off the coast of Greece, to offer a kidney. Maro didn't understand the English language, and she had never traveled outside of her homeland, but she was coming to the U.S. to help her sister-in-law. After a series of medical tests, she was approved as an unrelated living donor by the University of Michigan Medical Center.

The big day for the transplant surgery arrived a few days after Thanksgiving, on November 28, 1995. There was initial joy, but after a week, it became increasingly apparent that my body wasn't accepting my sister-in-law's kidney. To make matters worse, I had severe, life-threatening

pulmonary and cardiac complications. On December 24, 1995, I underwent emergency surgery to remove the transplanted kidney. Christmas and New Year's were spent in the hospital. I was told that I was near death during that critical time and didn't know it. Slowly, I came back.

After six surgeries and three

roller coaster; I suffered through many crying spells filled with misery, self-pity and anger. I also experienced feelings of grief, blame and guilt. My hopes for the future seemed forever lost and forgotten as I felt a death sentence hang over me.

Thankfully, I was under the



Evy Eugene Mavrellis is fit and working again.

months of intensive care, I was discharged on February 18, 1996. The ensuing spring and summer became a long, arduous period of four more hospitalizations, physical therapy and rehabilitation. I had to learn to walk and not rely on my wheelchair. I had to adjust to a restricted diet, weakness, depression and long, boring hours of hemodialysis.

I was now on an emotional

care of an extremely supportive medical, nursing and social work staff. Gradually, I grew stronger, both physically and emotionally. Within a year, I had become empowered through self-control and plain old will power. A major turning point occurred when I became friends with someone who convinced me to transfer to peritoneal dialysis (PD).

The transition to PD marked

a vast improvement! I ate better and felt better; mood swings, debilitating high blood pressure and depression were all in my past. PD restored my zest for life. I have returned to work as the chief administrator of a local youth service agency. After all I've been through, I feel productive, and I am satisfied that I am almost as active as I used to be. As a mother of two teenage sons, I am blessed with enough energy to enjoy them as they grow and mature.

More than two years since I received my transplant and subsequently suffered rejection, my well-being continues to improve gradually. For that, I thank my husband, friends, parishioners, co-workers, neighbors and medical staff. I am now willing to take a second chance with transplantation, and have signed on to the transplant waiting lists for both Michigan and Wisconsin.

To commemorate the occasion of our 20th wedding anniversary, and to celebrate the joy of living, Tim and I went on a Caribbean cruise on November 28, 1997. What a difference two years can make. Life is good.

Evy Eugene Mavrellis and her husband, Tim, live in Ann Arbor, Michigan.

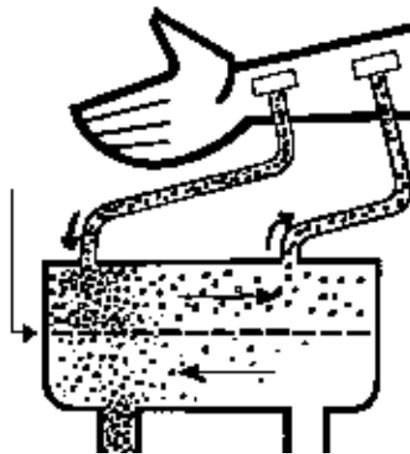


My Dad Is on Dialysis

by Sarah K. Schaffer

My dad is just like any other dad, except he's been on dialysis since he found out he had kidney failure three years ago. Since my dad's kidney failure, some things have changed and some things are the same. When he feels good, he plays tennis and plays with us just like normal. But sometimes he gets tired easily. We still go out to eat, but he has a different diet so we can't go to all the restaurants we used to go to.

Sometimes my dad has to go to the hospital. It makes me feel funny when he's in the hospital, like something's missing. I



This illustration is from the NKF brochure, Dialysis, © 1991 National Kidney Foundation, Inc.

visit him often and get lollipops at the gift shop or snacks from the vending machines. I like visiting his room. I can lie down on his bed and snuggle with him and watch TV. My brother and I like to push the buttons on his bed and get rides. My dad saves us the desserts on his tray.

Maybe there have been some changes and things are different, but that's OK. My dad is on dialysis. I love dialysis because I love my dad.

Sarah K. Schaffer lives in Alexandria, Virginia. She is ten years old.



Focus on the Family

Finding Support When You Need It

by Carlton Coker

Very few people with kidney disease will function well or live long without some kind of support. It's not uncommon for patients to feel so ill or depressed that someone else has to step in and do what's required for their well-being. Finances have to be worked out. Transportation to and from medical facilities and diet restrictions have to be dealt with. Numerous forms and papers must be filled out and signed, and the list goes on.

I have lived with kidney disease for 31 years, and I have encountered many people who have been willing to lend a hand. Their support has been essential to my well-being:

- Initially, my main support came from my parents. They

first helped me face kidney disease and the mental, emotional and financial strains it placed on me. My parents pushed me at a time when I was so sick that I didn't care about anything.

- After I got married, my wife, Edwina, took over my parents' role and became my strongest supporter. One reason I believe we have such a close rapport and empathy for one another is the fact that Edwina also has kidney disease. Our 24 years of marriage have provided me with some of the happiest years of my life.
- Support can also come from other family members, friends and church groups. My experiences with these people have varied from hot

to cold to lukewarm. Sometimes they're there for you and sometimes they're not. Fortunately, there are people from each of these groups who have always been supportive of me.

- Your medical staff can offer support, but the quality of medical care varies from doctor to doctor, nurse to nurse and hospital to hospital. It may be in your best interest to check around for the best possible care.
- Social workers can be a great asset. They have helped me obtain costly medications, financial aid, lodging, meal tickets, transportation, parking and even airline tickets, all for free. Of course, many social

workers are limited in their support by what programs are available.

- Last, but certainly not least, is your God, if you believe. A good relationship with your God can bring much strength and hope. I can't imagine living my life without Him.

Carlton Coker dialyzes at Hillcrest Okmulgee Dialysis Facility in Okmulgee, Oklahoma. He met his wife, Edwina, while both were on dialysis in Oklahoma City. 



Creating a Positive Attitude

by Henry L. Morris

Recently, I was told that my creatinine (a substance derived from creatine, which is a product of protein metabolism found in muscle) had to be watched. I was a candidate for dialysis. My future was uncertain, and I wasn't prepared.

I went to the library, and I used my home computer to find reading material. I phoned the National Kidney Foundation. I even visited some of the dialysis centers in my area, but found that although the nurses and

technicians were gracious, my research had not prepared me for this crisis. My wife and I joined a support group, but we were left with the memory of patients and spouses who were unhappy with what dialysis was doing to their lives.

While preparing for dialysis, I figured that I had to devote 20 percent of my time three days a week to dialysis. I knew that my medical team would monitor my time at the dialysis center, but it was up to me to reschedule the remaining 80 percent of my life

on those days. Fortunately, my wife and two daughters kept me upbeat. I brought my favorite newspapers and reading material to dialysis at 6:30 a.m., so I had time to go home to eat lunch, surf the Internet and play bridge. As for exercise at the fitness center, I knew I had to throw my shoulders back, stick out my chest and get up and do it. I knew there was a renal dietitian who could advise me about serving sizes, protein, potassium, sodium, fluid control, foods that may cause trouble and foods to enjoy.

Despite my support system, it was a morbid sight to see the patients when I entered the dialysis center. I wanted to create a positive attitude for myself, so I began to say, "Good morning" to all the patients and hoped my smile would help. My feeling has become, "Sure the needles hurt, but that only lasts seconds." There are some not-so-good days, but there are also good days.

Henry L. Morris lives in Boca Raton, Florida. 

Changing of the Guard



Frank Germinaro (left), past chairman of the NKF's Patient and Family Council is pictured at left with Marion McBryde, the new chairman of the council as of this past November. We want to thank Frank for his years of service and for his efforts in making the Patient and Family Council a major success, with more than 7,000 members. We would also like to welcome Marion and wish him success in his new role.

Both Frank and Marion are long-time kidney patients. Frank resides in Racine, Wisconsin, and Marion in Dallas, Texas.

Family Size Exercise

by David Miller, MS

With your busy schedule, it can be difficult to find the time to spend with your family. Doctor's visits, dialysis appointments, school and work schedules compete for your limited time.

Including your family in your regular exercise program is a great way to spend time together. The activity doesn't have to be very strenuous or elaborate; just go out, do something and have fun as a family. Exercising with your family is something to look forward to each time, and you may find it provides a great way to break from your busy day. Some of my fondest memories of growing up are of family camping trips and the hikes we took together.

Beyond togetherness, exercising with your family provides a healthy outlet for everyone involved and sets a

healthy example for the children. It's much more productive than spending hours in front of the television.

When planning an exercise activity for you and your family, try to choose something that everyone can do easily and will enjoy. Most activities can be adapted for a wide range of ages and abilities. Also, pick an activity that is appropriate for the time of year and where you live. In an area with a warm climate, like

Florida or California, outdoor activities are a possibility year-round. In other parts of the country, you may be limited to indoor activities during the winter months.

Here are a few exercise ideas you and your family may want to consider:

- **Biking**

Your local bicycle store will have information on where you can find the bike paths in your area, if there isn't one right in your town. For younger kids, you can use child seats or pull carts. (Don't forget their helmets!) Pack a lunch and ride to a nearby park or lake and have a picnic. Or wake up

on a weekend morning and ride your bikes to a nearby restaurant for brunch.

- **Hiking and Walking**

These activities can be done just about anywhere. Many clubs sponsor hikes on the weekends, allowing hikers to explore local parks and nature preserves. If you and your family want to plan your own adventures, you can find information about hikes in your area from your local bookstore. (Look in the outdoors section.) Most hiking

and walking books describe the length and difficulty of the hikes they list, making it easier to pick a hike that is appropriate for every family member.

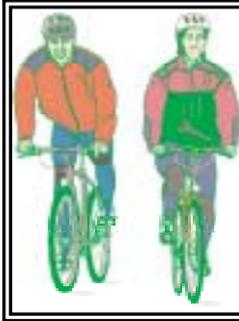
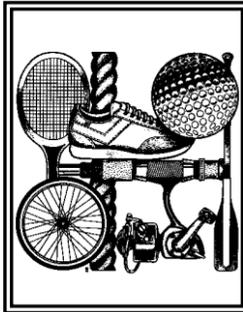
- **Competitive Sports**

Basketball, softball or tennis are fun ways to exercise together, and they don't have to be competitive. Simply shooting hoops or playing catch are also forms of exercise, and the children love these kinds of activities! Most communities have easily accessible sports facilities. Check out schools and parks.

- **Health Clubs**

Many health clubs offer family memberships. Some even offer classes for kids and child care. One of the greatest benefits of health clubs is that they can be used year-round—no bad weather excuses!

Consult your physician before starting an exercise program. 



Immunosuppressive Drugs Coverage Act of 1997 Introduced

The miracle of transplantation gives people the Gift of Life. It does not make sense to put this gift at risk because the recipient is unable to pay for anti-rejection drugs."—U.S. Senator Mike DeWine

Senator Mike DeWine (R-Ohio) introduced legislation on November 8, 1997, to help organ transplant recipients maintain access to anti-rejection medications. If passed, the legislation, known as the Immunosuppressive Drugs Coverage Act of 1997 (Senate Bill 1481), would eliminate the current Medicare limit for coverage of anti-rejection medications and extend coverage for anti-rejection medications for Medicare transplant recipients.

Medicare coverage for anti-rejection medications began in 1986 and covered anti-rejection medications for the first year post-transplant. The Omnibus Budget

Reconciliation of 1993 extended this benefit to its current coverage limit of three years. After the third year, transplant recipients must find another way to pay for anti-rejection medications. In many instances transplant recipients are unable to get other insurance coverage and are unable to afford to pay out-of-pocket for these essential medications.

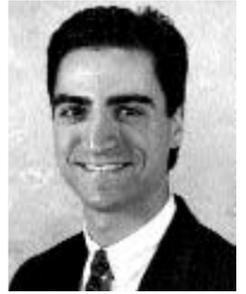
Senator DeWine's bill attempts to ensure continued access to anti-rejection medications, thus decreasing the risk for rejection of a transplanted organ, by eliminating the financial burden that often drives transplant recipients to either ration or stop taking these essential medications altogether. While anti-rejection medications are expensive—at least \$6,000 annually—the cost is far less than the cost that would be expended by Medicare if a transplanted kidney is rejected and an

individual is forced to go on dialysis or receive a second transplant. By providing continued access to anti-rejection medications, Medicare can avoid such additional costs.

Patients and family members who would like to support this legislative issue should write to their U.S. senators and ask them to cosponsor Senator DeWine's bill. Also, it would be appropriate to contact Senator DeWine's office and thank him for his efforts: The Honorable Mike DeWine, United States Senate, Washington, DC 20510. He can be reached by phone at (202) 224-2315.

If you would like additional information on this issue, or if you need information about your representative or senator, call the NKF's Office of Scientific & Public Policy at (800) 889-9559. 

Dialysis-Related Amyloidosis: A Common Complication of Renal Failure



David M. Burstein, MD

by David M. Burstein, MD

Dialysis-related amyloidosis is a disorder that results from the accumulation of a protein called *beta 2-microglobulin*, which is present in most cells of the body. A certain amount of this protein is released every day when cells break down, but blood levels remain low because it is easily filtered, metabolized and eliminated via the kidneys. When the kidneys fail, however, this protein accumulates in the bloodstream and body as a whole.

Beta 2-microglobulin appears to have a strong capacity to bind to *collagen*, a connective tissue that is found in many organs and tissues. Because of this affinity for collagen, beta 2-microglobulin tends to deposit in many areas throughout the body, leading to inflammation. The most common sites of involvement include the bones, joints and joint spaces, and this can lead to arthritis or bone pain. Other less common sites include the skin, liver, spleen, heart, blood vessels and gastrointestinal tract.

Widely occurring complications of dialysis-related amyloidosis include:

1 *Carpal tunnel syndrome*—This is the most frequent complication seen. It results from the accumulation of beta 2-microglobulin in the tendons of the wrist, leading to pain and loss of mobility of the hands. It is seen in up to 30 percent of patients who have been on dialysis more than eight to 10 years.

2 *Chronic shoulder pain*—The shoulder joint is the most common joint affected. Arthritis of the shoulder results from the accumulation of beta 2-microglobulin in the joint space and tissues surrounding the shoulder.

3 *Joint effusions*—This is otherwise known as accumulation of fluid in the joints, and may lead to swelling. Joint effusions are most common in the knees and shoulders. Often, this fluid needs to be drained to provide pain relief and improve mobility. If this fluid were analyzed, beta 2-microglobulin would be seen.

microglobulin, thus reducing blood levels and tissue deposition of this protein.

The type of dialyzer may also affect beta 2-microglobulin levels and tissue deposition. Certain dialysis membranes may cause white blood cells to release “factors,” which can enhance the production of beta 2-

2 An X-ray demonstrating multiple cysts within the bones.

3 The amyloid deposits found in the rectal muscle or in the fat present under the skin of the abdomen. (This happens occasionally.)

4 Characteristic findings on an echocardiogram or ultrasound of the heart.

Dialysis-related amyloidosis is a progressive condition. Treatment is directed at easing the pain and limited mobility of the affected area. Pain medications are sometimes required for the treatment of discomfort that results from enlarging cysts in the large bones. For individuals with carpal tunnel syndrome, surgical intervention is often helpful. Other treatments include joint replacement surgery, arthroscopy or open surgery to clean out the joint space and bone grafting. Although not proven, longer dialysis treatments with a high-flux biocompatible dialysis membrane may be useful, if it is available. Renal transplantation has also proven to halt the progression of this disorder, and, in many cases, may actually lead to an improvement in the condition.

Dialysis-related amyloidosis remains a common, difficult and frustrating problem for individuals with renal failure; however, with continued improvements in dialysis efficiency and medical science’s improved understanding of the causes, the problems associated with dialysis-related amyloidosis should diminish. **FF**

“Certain dialysis membranes may cause white blood cells to release ‘factors,’ which can enhance the production of beta 2-microglobulin.”

4 *Bone disease*—Beta 2-microglobulin deposits in bones, leading to cysts within the bones. These cysts can enlarge with time and become painful. They can also weaken bones, making them more prone to fracture, with minimal trauma or none at all. Bones in the hands, legs, hips and arms are most commonly affected.

5 *Gastrointestinal disease*—Although less common, dialysis-related amyloidosis can affect the gastrointestinal tract, leading to diarrhea, abdominal pain, dilation and weakening of the bowels.

Dialysis-related amyloidosis becomes more common as patients spend more and more time on dialysis. It becomes apparent in many individuals after five to eight years of dialysis. By 12 years, approximately half of all patients have some evidence of amyloidosis and, by 20 years, virtually all patients have it to some degree. Individuals with some residual kidney function seem to be protected, because the kidneys still break down and filter at least some beta 2-

microglobulin. Over time, this can lead to higher blood and tissue levels, which leads to more symptoms of this disorder. Therefore, dialyzers that are more biocompatible may be less apt to cause significant beta 2-microglobulin production. In addition, it has been shown that dialysis membranes, which are more permeable (porous), tend to clear beta 2-microglobulin better and lower blood and tissue levels. Thus, high-flux dialyzers may remove these proteins more efficiently than standard dialyzers. Peritoneal dialysis probably poses a similar risk for this disorder, because the peritoneal membrane doesn’t efficiently clear beta 2-microglobulin. In individuals on CAPD or CCPD, elevated blood levels are found.

Typical bone-related symptoms and findings influence the diagnosis of dialysis-related amyloidosis. The diagnosis can be further supported by:

1 The evaluation of tissue or fluid from an affected joint, demonstrating the presence of beta 2-microglobulin or amyloid deposits.



Good Nutrition

Herbal Supplements for the Kidney Patient: Buyer Beware

by Bev A. Cohen, MHS, RD

There is something almost magical about herbal drugs that prevents them, in their natural state, from inflicting harm. True or False? False it is! Remember your history? The famous philosopher Socrates was poisoned with hemlock, an herbal remedy, more than 2,000 years ago.

As kidney patients, you already are aware of the need to consult your physician before taking any over-the-counter drugs. What may be safe for most people may not be safe for you. Herbs should be thought of as nothing more than diluted drugs, and, like drugs, they should not be taken before consulting your physician.

What Are Herbs?



Herbs, in a medicinal sense, can be defined as crude drugs of vegetable origin, used to diagnose, cure, treat or prevent disease. Ginkgo biloba, ginseng, golden seal root, echinacea, sassafras and chamomile are among the herbs used for medicinal purposes. Herbs, in a culinary sense, are defined as vegetable products used to add flavor or aroma to food. Small amounts of herbs, such as thyme, nutmeg, basil and rosemary are fine to use in cooking. In fact, they are a good way to enhance flavor in salt-free recipes.

The overwhelming difference between an herbal supplement and all over-the-counter and prescription drugs is government regulation. Herbal supplements are not regulated by the FDA because they are marketed as food supplements, which, in turn, are not subject to the strict standards required by prescription drugs. No

regulation means no testing for safety and efficacy. In other words, the questions "Is it safe?" and "Does it work?" are not required to be answered.

Also, there are no legal standards of identity established for herbs, which means quality control is non-existent, and the risk of contamination or substitution in herbal supplements is ever-present. When it comes to issues of purity, the buyer is dependent solely on the reputation of the manufacturer.

To thoroughly understand herbal drugs, you need to know the herb's botany, chemistry and pharmacology. This is information that very few herbalists have, and is why they must rely on anecdotal information or the opinions of "experts." In fact, these "experts" tend to freely offer advice about the treatment of serious illness with herbal supplements without mention of the potential side effects.

Labels Can Be Deceiving

No two herbs are exactly alike, even if labeled on the package as the same plant. The popular names of plants are numerous and not exact. For example, the name "Mistletoe Tea" on an herbal tea label could refer to as many as 200 different species of this plant. And, there is no way of knowing if the herb is safe, uncontaminated and in a chemical form that your body can use.

Tales of Toxicity

Herbal supplement use in kidney patients is potentially dangerous for many reasons. Herbs contain potent active ingredients that, if used regularly (even in small doses) can accumulate in your body and cause problems. For example, herbal supplements may have ingredients that could

affect blood pressure control (e.g., ginkgo biloba and ephedrine). They also may have ingredients that affect fluid and sodium retention and potassium excretion (e.g., licorice). Many herbal supplements also have laxative properties (e.g., senna, aloe, and rhubarb) or act as a diuretic (e.g., juniper berries and buchu leaves). These properties could alter the delicate electrolyte balance that kidney patients are working hard to maintain, and may also cause dehydration. In addition, many herbal supplements may cause nausea, vomiting, diarrhea or constipation. Of course, this would be an unpleasant side effect for anyone, and would be especially harmful to a kidney patient already battling malnutrition. Finally, there are even herbs that are directly toxic to the kidneys (e.g., sassafras, periwinkle and chaparral).

Herbal supplements can also interfere with the action of prescription medications (or another herb) if taken simultaneously. Multi-medicated kidney patients have a great potential for this type of problem. The message is clear: Review any potential problems for herbal supplements with your physician and dietitian.

Suggestions and Ideas for Herbal Supplement Use

- Do not take herbs with a known toxicity.
- Address the potential for contamination or substitution in an herbal product.
- Buy herbal supplements from reliable sources. Look for a label containing a list of ingredients, precautions, the name and address of the manufacturer, the batch or lot number, the date of manufacture and the expiration date.

- Use caution with herbs purchased in foreign countries or through mail order.
- Be especially careful with Oriental herbs.
- Start with low doses. Do not take more than the amount recommended.
- Take only one herb at a time. Do not combine herbs.
- Monitor interactions between prescription drugs and herbal supplements. Stop taking herbs if there is any type of problem or side effect.
- Consider the difference between conditions under which it may be safe to self-medicate and those that require timely, professional medical care. Self-medication involves potential risk.
- "Natural" does not mean harmless.
- Do not take herbal supplements without consulting your physician.

Do not take an herbal supplement if there is already a drug available that is quality-controlled and tested. Be wary of anyone who steers you away from standard medical treatment. If a promise sounds too good to be true, it probably is. Be careful. Be smart. Ask first.

*Bev A. Cohen, MHS, RD,
works at the Western Dialysis
Center in Boulder, Colorado.*



Good Nutrition

Winter Recipes the Whole Family Can Enjoy

by Patty Stewart

YUMBERRY CASSEROLE

Canned yams, because they have been cooked in water, are lower in potassium than fresh yams or sweet potatoes, but they are still a high-potassium food and must be eaten sparingly. In this recipe, the cranberry sauce adds color and a nice tartness but very little potassium. The oatmeal mix provides a healthy crunch to the topping.

- 1/2 of a cup of flour
- 1/2 of a cup of oatmeal
- 1/2 of a cup of light brown sugar
- 1/2 of a cup of soft butter or stick margarine
- 1 16-ounce can of whole cranberry sauce
- 2 2-pound cans of yam pieces, drained



Mix the first four ingredients in a small bowl and set aside. In a large bowl, gently mix the yams and cranberry sauce. Don't stir so the yams get mashed, but keep breaking up the cranberry sauce so it evenly surrounds the yam pieces. Gently stir in one cup of oatmeal mixture until it's evenly distributed.

Butter a deep round casserole dish and place yamberry mix inside. Top with the remaining oatmeal mix. Bake 35 minutes at 350 degrees, or until it is hot throughout. Makes six to eight servings.

SPICY CHINESE NOODLES WITH TURKEY

This is the perfect solution if you ever have leftover turkey, and it's a wonderful dish in its own right. It's also great with chicken, or without any meat at all. Doubled or tripled, these noodles are a wonderful party buffet dish, served in a huge bowl.

- 1 pound of linguine noodles (wider linguine is nice)
- 2 cups of turkey meat, cut into half-inch cubes
- 3 tablespoons of sesame seeds
- 1 small red bell pepper, sliced in thin strips
- 1 small yellow bell pepper, sliced in thin strips
- 2 cups of chopped green onions

Dressing:

- 3 garlic cloves
- 1 1-inch piece of fresh ginger, peeled
- 2 Tablespoons of ground coriander
- 1/8-1/4 of a cup of low-sodium soy sauce
- 1 Tablespoon of honey
- 3 Tablespoons of rice vinegar
- 1/4 of a cup plus one tablespoon of peanut oil
- 2 Tablespoons plus 1 teaspoon of toasted sesame oil
- 1 heaping Tablespoon of Chinese hot chili sauce (Use 1 teaspoon of hot pepper sauce if you don't have chili sauce.)
- 2 Tablespoons of cilantro, chopped fine
- 2 Tablespoons of fresh basil, chopped fine (Do not use dried basil. Omit if you can't find fresh basil.)

Boil the linguine, but do not overcook. Rinse with cold water to stop the cooking process and cool. Set aside in a large bowl.

Place the garlic and ginger in the bowl of a food processor, and press the "pulse" button until minced freshly. Add soy sauce, rice vinegar, honey and chili sauce, pulsing to mix well. With the motor running, add the peanut and sesame oils in a fine stream. Finally, add the ground coriander, chopped basil and cilantro, pulsing to mix. Set the dressing aside. If you want more dressing, add a tablespoon or two of low-sodium chicken broth.

Place the sesame seeds in a wide skillet over medium heat and toast lightly, only for about one minute. Watch closely; they burn easily. Take the seeds off the heat immediately.

Add the sesame seeds, turkey, bell peppers, onions and dressing to the cooked noodles and toss thoroughly so everything is well-coated. Serve cold or at room temperature. As a main dish, it serves six people. As a side dish, it serves eight people.

CAPONATA

Don't tell anyone this is eggplant, and they will be captivated by the color, the crunch and the sweet and sour taste of this great side dish that's also fantastic on a pizza crust. Caponata keeps well for a week in the refrigerator, so it's a perfect make-ahead dish.

- 1 large eggplant (firm and uniformly shiny)
- 1/2 of a cup of olive oil, plus 2 tablespoons
- 1 1/2 cups of yellow onion, chopped
- 1 cup of celery, chopped
- 1 16-ounce can of Italian pear tomatoes, chopped
- 1 red bell pepper, chopped
- 1 yellow bell pepper, chopped
- 1/4 of a cup of sliced black olives, drained
- 1/4 of a cup of red wine vinegar (not cider or white vinegar)
- 2 Tablespoons of sugar
- fresh ground pepper
- a pinch of salt

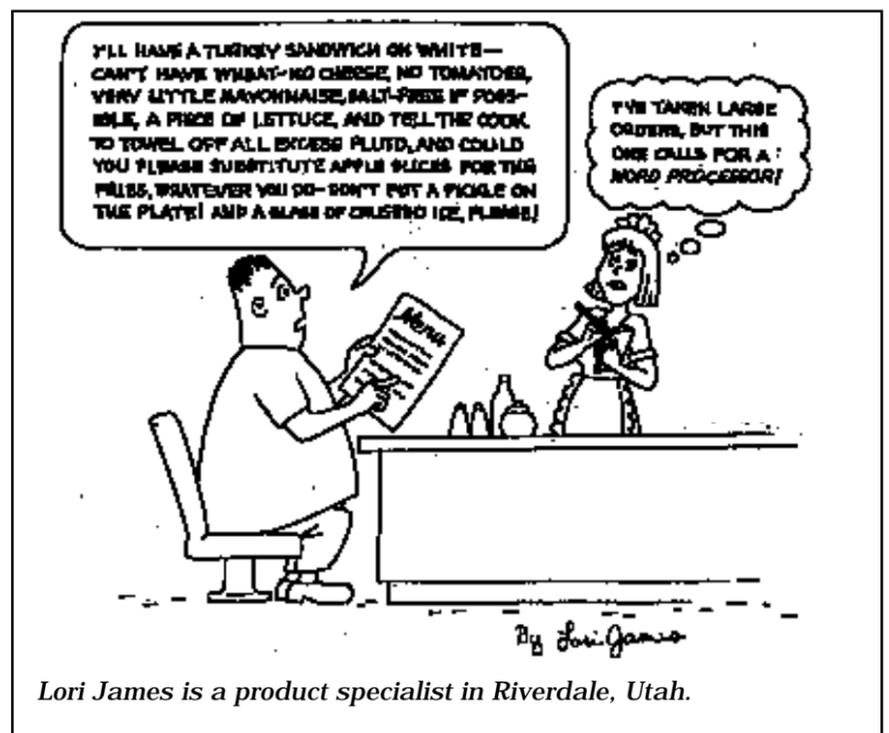


Peel the eggplant with a vegetable peeler and cut it into half-inch slices width-wise, then into half-inch cubes. In two batches, using 1/4 of a cup of oil at a time, fry the eggplant. Turn it occasionally so it is slightly browned on as many sides as possible. Set aside in a big bowl.

Heat the remaining two tablespoons of oil and saute the celery for two minutes, then add the onions and the red and yellow peppers. Saute another two to three minutes, or until the peppers soften a bit. Add to the eggplant, and stir in the olives so everything is evenly mixed.

Pour the vinegar and sugar into a small saucepan. Stir well to melt the sugar, and heat the mixture to a boil. Boil for two minutes to reduce slightly. Turn off the heat and cool. When cool, pour over vegetables and add lots of fresh pepper and just a pinch of salt. Stir well. Chill for at least four hours or overnight. Serve cold or at room temperature. Yields about four cups.

Patty Stewart has been on dialysis for 15 years, both in-center and (the past five years) at home. She is a past member of the NKF of Northern California's Patient Services Committee, and a current member of the ESRD Network 17 Consumer Action Committee. Patty is avidly interested in adapting exciting cuisines for the kidney diet, and writes regularly about food and travel for several patient publications. 



NKF Officially Launches Grassroots Recruitment Campaign

The NKF Office of Scientific and Public Policy has established a grassroots program called Renal Representatives with a goal of enlisting at least one renal representative from each congressional district by February 28, 1998.

The program is designed to identify and mobilize individuals—such as patients, family members, health care professionals and concerned volunteers—to advocate for the renal community. Volunteering as a renal representative doesn't require a large time commitment or special knowledge. All it requires is a desire to improve the lives of all people affected by kidney disease by helping to sensitize state and federal policymakers to kidney disease issues.

To become an NKF renal representative, mail or fax this form to Tracey Pribble, NKF public policy director, 1911 North Fort Myer Drive, Suite 801, Arlington, VA 22209. She can be reached by fax at (703) 522-8586, or phone at (800) 889-9559.

NAME: _____

ADDRESS: (home) _____

PHONE: (work) _____ (fax) _____

(home) _____ (E-mail) _____

Please check the appropriate box(es):

(1) I am a:

- Dialysis Patient
 Family Member/Friend
of a Dialysis Patient
 Dialysis Health Professional

(Please Identify Profession)

- Concerned Member of the Community

- Transplant Recipient
 Family Member/Friend
of a Transplant Recipient
 Transplant Health Professional

(Please Identify Profession)

(2) I am a member of the NKF Patient & Family Council:

- Yes No

(3) I am a member of the NKF transAction Council:

- Yes No

(4) I am active with the NKF at the local Affiliate level:

- Yes _____ No
(Affiliate)

(5) I want to be a Renal Representative and I am willing to:

- Write Letters Meet with Lawmakers
 Make Phone Calls Testify at Legislative Hearings

(6) I am interested in being a Renal Representative for the NKF and agree to be contacted by NKF staff and volunteers on legislative issues affecting individuals and families with kidney disease.

- Yes No

Signature: _____

Date: _____



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New York, NY 10016