

Family Focus

HAPPY ANNIVERSARY



Family Focus



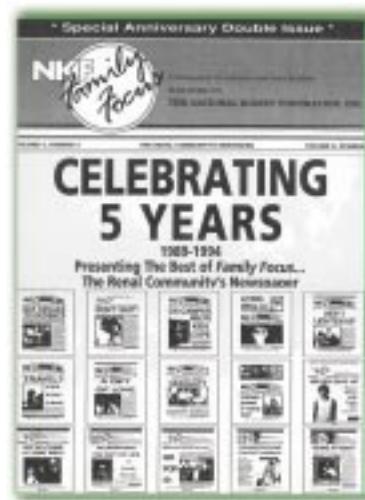
Happy 15th Anniversary

Family Focus Honors a Tradition of Helping People Affected by Chronic Kidney Disease

By John Davis, CEO, National Kidney Foundation



Issue 1, Volume 1 of Family Focus



5th Anniversary Issue of Family Focus



10th Anniversary Issue of Family Focus

NEXT ISSUE

Life Planning

OVER THE PAST FEW YEARS, THE NATIONAL KIDNEY FOUNDATION HAS HAD A PHILOSOPHY of creating and implementing specific and targeted programs which fill a specific need. While our

general widespread programs remain in place, we are working to establish high quality and effective programs designed to make a particular difference in one aspect of our cause.

Believe it or not, that is an excerpt from an article I wrote 15 years ago for the very first issue of *Family Focus*. It is hard to believe that 15 years have passed since a very dedicated group of volunteers planned that first issue. As we prepared for this anniversary issue, we looked through the archives and found file folders labeled "Patient and Family Newsletter Volume 1, Number 1" filled with handwritten notes with article ideas and newsletter concepts jotted on yellow legal pads!

A beloved National Kidney Foundation (NKF) volunteer, the late Wayne Nix, shared his personal philosophy with us: "Dialyze to live, don't live to dialyze." That really said it all. Kidney disease should not and cannot be allowed to take over the life of a person with kidney disease. With this in mind, *Family Focus* has strived to bring you what we believe to be the most relevant and important information you need to be an informed, effective advocate for your own health care.

Family Focus has always been about sharing. Sharing stories, poems, recipes, exercises, coping tips, news about medical advances and more, all in an effort to improve your overall quality of life. Whether you are someone on dialysis or have a kidney transplant, *Family Focus* has featured articles of interest to all.

We all know that a chronic illness does not only affect the person who is ill. Each family member is also affected in some way, so *Family Focus*

Continued on page 3



30 East 33rd Street
New York, NY 10016

NON-PROFIT ORG.
U.S. POSTAGE
PAID
Shakopee, MN
Permit No. 211

This publication is a part of the National Kidney Foundation's Kidney Learning System (KLS)™ and is made possible through an educational grant from AMGEN.



FROM THE EDITOR



Karren King

WHEN THE IDEA FOR *FAMILY FOCUS* WAS BORN, THE CONCEPT WAS THAT IT SHOULD BE THE KIDNEY COMMUNITY'S NEWSPAPER. For 15 years it has been exactly that. It has grown from the seed of an idea to a circulation of approximately 335,000, read by people throughout the United States and beyond its borders. From the beginning, *Family Focus* has sought to provide timely information about topics that the Editorial Board believed to be of great importance and relevance to people who are on dialysis and those who are important to them.

Many individuals have contributed to its success over the years. Nancy Spinozzi was its

first editor and she and her Editorial Board members were visionaries as they developed *Family Focus* in its early years. The National Kidney Foundation has always been the home for *Family Focus*, and the newspaper would not exist if not for the tireless dedication and devotion of many of its staff.

Amgen has been the sole sponsor of *Family Focus* since its inception and the company's support has been

immensely valuable. Lastly, I, too, have had the privilege of working with very talented, hardworking individuals who have served annually on the Editorial

Board. Thanks to each and every one of you for all you have contributed to the success of this newspaper through the years. It has provided an invaluable service and will continue to do so for many years to come.

Family Focus is all about you, the person who is on dialysis, and your family and friends. Thus, it is only fitting that this anniversary issue is devoted to the articles and poems that you have given us. We are privileged to receive your heartfelt contributions throughout the year and are proud to be able to showcase them. Thank you for sharing them with us. It is our hope that they will inspire and

touch our many readers as they have us.

The Editorial Board is very excited about the themes selected for the upcoming issues of *Family Focus*. The spring issue will focus on life planning, specifically how to balance your life and plan for the future. The horrendous impact of Hurricane Katrina on all in its path, including the special issues faced by those people on dialysis, emphasizes the importance of the topic, disaster preparedness, selected for the summer issue. Quality issues will be the theme for fall, and diabetes, the greatest contributor to chronic kidney disease, will be the focus for 2007's first issue. If you have experiences or ideas to share about any of these topics, please let us hear from you.

Happy 15th Anniversary, *Family Focus*!



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



Dear Editor,

Family Focus is a wonderful publication. It is also very helpful. I have been doing my home treatment for a month now, and I must tell you I feel 10 years younger. I am 77 years old, my balance is better and I feel so cleaned out. I can't thank the federal government enough. I am in such a good state of mind. I can't thank you all enough.

God Bless you all.

Howard Shaw
Bay Pines, FL



NKF Family Focus is published quarterly by the National Kidney Foundation.

Opinions expressed in this newspaper do not necessarily represent the position of the National Kidney Foundation.

EDITOR-IN-CHIEF: Karren King, MSW, ACSW, LCSW
Kansas City, MO

FITNESS EDITOR: Patricia L. Gordon, RN, PhD
San Francisco, CA

MEDICAL EDITOR: Wendy W. Brown, MD, Nashville, TN

NURSING EDITOR: Sally Burrows-Hudson, MS, RN, CNN
Sunnyvale, CA

NUTRITION EDITOR: Lori Fedje, RD, LD, Portland, OR

PATIENT EDITOR: David Jones, Glen Ellyn, IL

PEDIATRIC EDITOR: Barbara Fivush, MD, Baltimore, MD

SOCIAL WORK EDITOR: Mary Beth Callahan, ACSW/LMSW-ACP
Dallas, TX

TRANSPLANT EDITOR: Nancy Swick, RN, BSN, CCTC
Santa Rosa, CA

ESRD NETWORK LIAISON: Kimberly Thompson, RN, BSN, CNN
Kansas City, MO

EDITORIAL OFFICE: NATIONAL KIDNEY FOUNDATION
30 E. 33rd Street, New York, NY 10016
800-622-9010 • 212-889-2210
www.kidney.org
E-mail: info@kidney.org

EDITORIAL DIRECTOR: Gigi Politoski

EDITORIAL MANAGER: Sheila Weiner, MSW, LCSW

VICE PRESIDENT OF HEALTH POLICY

AND RESEARCH: Dolph Chianchiano, JD, MPA

EXECUTIVE EDITOR: Sara Kosowsky

MANAGING EDITOR: Helen Packard

PRODUCTION DIRECTOR: Sunil Vyas

DESIGN DIRECTOR: Oumaya Abi Saab





Family Focus Honors...

Continued from page 1

has always included stories and articles by and for them as well.

Patient Services is one of our highest priorities. At the NKF, Affiliate and Chapter levels, the NKF provides a wide array of effective services to the millions of people who are afflicted with kidney and urinary tract diseases.

Our commitment to the needs of the patient is just as strong as it was when I wrote those words 15 years ago. The NKF has always been dedicated to providing education and assistance to those with chronic kidney disease (CKD) and their families. It is one of our major goal areas. Over the years we have constantly challenged ourselves to create useful, valuable



Family Focus now

programs to aid people affected by CKD and their family members. We have hosted live programs, printed countless disease specific brochures and fact sheets and offered complimentary membership in the Patient and Family Council (a benefit of which is *Family Focus*.) Last year, in an effort to strengthen and unify the voices of the more than 20 million people with CKD, the NKF established “People

Like Us,” a movement to educate, empower and enable patients to become effective advocates on issues related to their health care. Since its May 2005 launch, “People Like Us” members have given input on public policy and other issues, met with and written letters to their members of Congress and presented a proclamation to U.S. Department of Health and Human Services Secretary Michael Leavitt formally thanking the government for providing dialysis and other life-saving treatments to thousands for more than 30 years through Medicare’s End Stage Renal Disease (ESRD) program.

Recognizing that kidney disease is much more common than people realize, especially among those who have often-ignored risk factors, NKF created the Kidney Early Evaluation Program (KEEP), a free health screening program for people at increased risk of developing kidney disease. The program raises awareness about CKD among high risk individuals and provides free testing and educational information to help prevent or delay kidney disease and its complications.

Another anniversary we recently celebrated was the 10th anniversary of the Kidney Disease Outcomes Quality Initiative (KDOQI). KDOQI creates evidence-based clinical practice guidelines to improve patient outcomes. By using the KDOQI Guidelines in their practice, health care providers are able to provide their CKD patients with evidence-based care for all five stages of CKD.

As a result of these two initiatives, NKF created the Kidney Learning System (KLS) to put the knowledge gained through KEEP and KDOQI into practice. KLS promotes CKD awareness and provides education to the public and to health care professionals to make the KDOQI evidence-based clinical practice guidelines available to improve patient outcomes.

As we begin the next 15 years of *Family Focus*, changes are taking place all around us—some positive, some not. But the more things change, the more they stay the same. The patient still is at the core of all we do. For this reason we felt that the most appropriate way to honor a milestone anniversary was to devote the issue to reader submissions. The next issue will contain the columns you have come to rely on and look forward to, but for this issue, we wanted to hear from you. We hope that you enjoy reading these personal stories and poems as much as we did.

I want to take this opportunity to thank Karren King, the current editor of *Family Focus*, Nancy Spinozzi, the first editor of *Family Focus*, and their entire editorial boards. These dedicated *volunteers* have devoted countless hours of their personal time to produce *the* kidney community's newspaper. Thank you as well to NKF staff members Gigi Politoski, Sara Kosowsky, Sheila Weiner, Helen Packard and Oumaya Abi Saab for giving so much of their time, energy and creativity to this newspaper. The combination of volunteer and staff talent and dedication to this publication is what makes it the incredible resource it is and will continue to be.

Happy Anniversary.

Family Focus
is available on the Web.
To find this issue or back
issues of the newspaper go to
www.readfamilyfocus.org



Poetry Section

Washington RKC

By Robert Smith

Washington R K C
What it means to me.
When I first came for treatment
It was a scary sight to see

There were sick looking people
All around the room
Some were covered with blankets
Seemed a room filled with gloom

There were beepers and alarms
Going off all the time everywhere
If I would have had a choice
I would have been out of there

But I was so sick
I had no choice but to be there
So I walked to a machine
And sat down in the chair

After they got me hooked up
Things soon began to calm down
I was more able to relax
And take a better look around

I began to visit
With the people sitting near
I found they were all really nice
They just happened to be stuck here



One special friend God gave me
So he wouldn't die alone
If I ever make it to heaven
We will visit again, Jerome

The workers are all wonderful
Always hurrying here and there
But they make time to give us
The most excellent of care.



R K C #2

They make sure your dialysis
Is done safely and right
But they do so much, much more
They are in my prayers each night

They help you with your troubles
They listen when you are sad
They laugh and joke with us all
Makes you forget what's so bad

Dialysis is hard, hard work
For all the people involved
It seems a bittersweet task
That is possible to hate and love

But each treatment keeps me alive
And makes me feel much better
So with my brand new family
Three times a week we gather.

Robert Smith receives his dialysis in Washington, IN.

Sharing Love

By Anna Davis

The love we extend
Will bring contentment to ourselves
in the end.
Sometimes, some people
just won't bend.
Maybe, we can start
a new trend.
When part of ourselves
we extend.
We might even make a
new friend.

After a Heart is Broken

By Anna Davis

After a heart is broken,
these words are quietly
spoken:
"I can give myself only
so far,
My heart has no room to
be further broken."



Ms. Davis receives her dialysis in Portland, OR.



More Poetry

The Next Chapter

By Ted Pacheco

As I close one chapter in my book
 I start a new one with a different look.
 For you see, things are no longer fine—
 I live my life connected by a line,
 A tubing which has become my life support
 Without it, it could be my death report.
 I am connected to a kidney machine every
 night
 It keeps me going so I can see tomorrow's
 light.
 Not knowing what might happen next
 I pray just hoping for the best.
 Some say you've been given a second chance
 to fight
 So it's up to you to make your world just
 right.
 So instead of living life in the future
 I think I'll sit back and let this one nurture.
 So as I look forward and write the new pages
 to my book
 Maybe when the next chapter begins, I won't
 be connected by this hook.

A New Beginning

By Ted Pacheco

I thought the flame had gone out from
 my candle,
 And there were times I wished I were dead.
 Then I almost died, and how I begged
 for life instead.
 I thought about giving up and putting
 life to rest
 But that would have been a mistake
 For I found out that I am truly blessed.
 Though I have lost a few friends
 I have now gained a couple dozen others—
 In fact you can say I adopted a new family
 And their friendship is like no other.
 Some say they're just doing their jobs
 But I surely know better
 For they know and remember more about
 Me than just my name.
 Moving on would have been real easy but
 staying is a lot more pleasing.
 Life will always have its ups and downs
 and can be tough to handle,
 But with my new friends it looks much
 brighter
 For they've given me hope, if one candle
 burns out
 It's okay, go ahead and light up another.

Mr. Pacheco receives his dialysis in Casper, WY.

To My Buddies

By Stella Varian Ramos

A word of comfort
 To my buddies on dialysis;
 We have to have this for life
 So to deny it is useless.
 Let us therefore focus our minds
 On the benefits we get;
 Don't think of it as a trap
 One that we would like to forget.
 Remember that these procedures
 Prolong our dear lives;
 We continue living, wives with their husbands.
 Or husbands with their wives.

I specially mention the seniors
 Because they are usually the human faction
 Who has to undergo this treatment
 Due to failing human functions.
 Never mind the several trips
 To the clinic or hospital "caves";
 It is nothing compared to the pleasures it allows
 Of being with family, friends, or relatives.
 Just refrain from eating certain foods
 And be within the liquid intake ordered;
 Do not lift heavy objects
 With the arm where needles get inserted.
 We are put on earth by God
 For certain things to be accomplished;
 So, if we get sick and the mission is not finished
 He made man think of dialysis.

Ms. Ramos is 87 years old. She receives her dialysis in San Francisco, CA.



More Poetry

From Me to You

By Jessica Watson

Completely freaked out
Scared and alone
I came to this place
I've learned as a second home

Scared and lonely
I didn't want it to be
But as time went by
It got to be easy.

Jessica dialyzes in Fall River, MA.

But not for myself
From the kindness of you
My spirits were lifted
And then I wasn't so blue.

Each of you
In your own little way
Impact my life
Each and every day.



A Day at the DCA

By Emma Moody

I come here every other day
To this place called DCA,
To say that I like it would be a lie
But without it, I would surely die.

For it's at DCA
That they help me to live another day,
Maybe a little longer
And maybe help me to feel a little stronger.

The doctors, nurses and all the rest are all very fine
For they give me some of their precious time,
They all do all they know how to do
So I can feel like living all anew.

They all greet me with a smile.
And they never forget to say hi,
They all are so loving and so kind, too
Even if I have to come every other day
I thank Him for the doctors, nurses, patients and all the rest
For they all are the very best.

I thank God, for these people who have touched my life
And I thank Him for letting them put up with me for awhile,
I love and appreciate all that they do
And I want them to know that I love them, too.

Ms. Moody receives her dialysis in Valdosta, GA.

Family Focus VOICES

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

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

What have you done or are planning to do to prepare yourself for a disaster such as a hurricane, flood, or other emergency situation to ensure that your health needs are met?

You may visit the Web site above to share your thoughts, or send your response by April 1, 2006 in writing to:

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





CONFUSED ABOUT MEDICARE PART D?

Here's Some New Information for You

Beth Witten, MSW, ACSW, LCSW
Medicare Modernization Program Manager
National Kidney Foundation, Inc.

The National Kidney Foundation (NKF) and more than 35 other groups joined together to form the Kidney Medicare Drugs Awareness and Education Initiative. Our goal is to produce timely, reliable and up-to-date materials to inform people with chronic kidney disease, families and professionals about Medicare Part D. Four new booklets are part of this effort:

- *What You Should Know About Medicare Prescription Drug Coverage (Part D) If You Have Chronic Kidney Disease*
- *What You Should Know About Medicare Prescription Drug Coverage (Part D) If You Are Undergoing In-Center Hemodialysis*
- *What You Should Know About Medicare Prescription Drug Coverage (Part D) If You Are Undergoing Home Hemodialysis or Peritoneal Dialysis*
- *What You Should Know About Medicare Prescription Drug Coverage (Part D) If You Have a Kidney Transplant.*

To find these booklets, go to the Kidney Medicare Drugs Awareness and Education Initiative Web site at www.kidneydrugcoverage.org. For a printed copy, call the National office at (800) 622-9010.

To help you compare Medicare Part D plans, check out the Compare Prescription Drug Plans packet on the Web site. Look under *Patients and Families for Compare Drug Plans*. You will find a packet of tools that includes: a tip sheet, frequently asked questions and two charts to help you learn if the drugs you need are covered by a specific Medicare Part D plan. Plus, you will find out how to do your own search using 800-MEDICARE and www.medicare.gov.

Sign up on our Web site to learn about new resources and activities related to Part D. When you do, you will receive an e-mail about our new 40 fact sheets on Medicare Part D. If you have chronic kidney disease, are on in-center hemodialysis, home hemodialysis or peritoneal dialysis, or have a kidney transplant, there is a fact sheet for you on how Part D works if you have:

- Medicare only
- Medicare and Medicaid
- Medicare Advantage plan
- Medigap drug coverage
- Employer, union or COBRA drug coverage
- Limited income and resources
- SSI or state help paying Medicare premiums
- TRICARE, VA, Federal Employees Health Benefit, or Indian Health drug coverage
- Other help for drugs (state kidney program, state pharmacy assistance program, drug card, etc.)
- You live in a nursing home or other long-term care residence

We want you to have the facts you need to make the best decision for you about Medicare Part D. If you decide you need Medicare Part D, we want to assist you in choosing the plan that will help you afford the drugs you need to live a long, healthy and enriched life.

More Poetry

I Feel Good

By Esther Burgess

I woke up this morning feeling good
 I really never ever thought I would
 Feel this way, especially on treatment day.
 So here I go to the center. Thought I'd have
 a snack and go to sleep, you see,
 But dialysis took the feel good out of me.
 Well they hooked me up, everything was fine
 didn't have a worry on my mind.
 Snuggled up in my blanket
 and was almost fast asleep.
 I sat up suddenly, and there was no doubt,
 something was wrong, so I let out a shout—
 Dialysis took the feel good out of me.
 The nurses fixed me up fast
 I didn't know they could do it.
 But that's my story,
 And I'm sticking to it.
 Dialysis put the feel good back in me.



Another Day in Dialysis

By Esther Burgess

Neither rain nor snow nor dark of night
 can keep me from my dialysis sight
 I go pretending it is spring
 Not knowing what my treatment will bring.
 I walk up to the big glass doors
 The girls inside are doing their chores
 I say hello to those I know
 I guess we all are in the same boat
 We're on our machines and some will sleep
 And pray to God our souls will keep
 Then when we're finished, we're on our way
 To dialyze another day.

Ms. Burgess dialyzes in Logan, WV.



Poetry

A Day on the Kidney Machine

By Carrie Butler

Being on the
kidney machine
is not much fun.
It is something
that must be done.

The sitting is very long.
While sitting there I might sing a song.
Sometimes I will even read a book
or at the TV I will look.

We can talk to each other while
we are there or out the window I might
stare.

Sometimes we might take a nap.
When it is cold I might bring a wrap.

Sometimes we bring a snack to
pass the time away.

But on the kidney machine I
must stay to see another day.

*Ms. Butler is on dialysis in
Roxboro, NC.*

Curse of the Killer Potatoes

By Derrick Moore

I am loaded with potassium, like an
enemy lurking at night.
Oh! How those french fries
are a lovely sight,
Sitting there next to that juicy
hamburger calling my name.
Oh! Look, there are the mashed
potatoes doin' the same.
I fail to resist a temptation
so great
And before you know it
I have cleaned my plate.
So limit your intake, beware
and be smart
Eat too much of the killer potatoes
and it will stop your heart.

Mr. Moore is 34. He dialyzes in Louisville, KY.

Dialysis

By Thomas Strickland

Floating through tubes back and
forth, back and forth,
it's amazing and cool
to watch my blood
flowing so smoothly.
Some say it's a death
sentence, others don't
understand; this is a life-
giving process to further
our big plan,

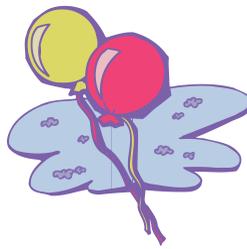
to be a part of the solution
for the renal failure revolution

It may appear being on this
machine would cause much fear,
but for a dialysis patient
it's urgently necessary
to be here.

Some people will never see how
important their health
can be; just look
at me.

I'm still here after several years,
over time I stop my tears,
so let the treatment begin.

We welcome you to a
life-long friend.



Sensitivity

By Thomas Strickland

Cherish this walk down this hall,
thank them all, today
we come and go, standing
tall, don't be sad nor feel
sorrow. This treatment is
to ensure our tomorrow
Be we weak or strong, the
staff here keeps our lives
moving on. Praise the staff,
thank the nurses. The care they
give is for us to live, we're
all in this together.

Smile a while. Things will get
better.

Consider other people's feelings. Don't
forget about our friends.

A pleasant day here you'll
spend.

Thank you, thank you, those
kind words could make
someone's day; it's so
easy to say.

This is so simple. Do what
your doctor says, you'll live
a longer, joyful life.
Refuse, you'll pay the
price.

Mr. Strickland receives his dialysis in Charlotte, NC.



“Dialysis Is a Small World”

By Gina M. Sikon, MSW, CSW

Do you know the saying “Be careful how you treat people, because you never know when you will see them again”? This story is a testimony to that statement.



Tracey Quinton

I am a Social Work Field Instructor for Wayne State University. That means that I supervise social work students when they are doing the clinical portion of their studies, or their “real world experience.”

In September 2003, I received a call from my student placement candidate, Tracey Quinton. I

thought that her name was familiar, but I did not know why. She was thinking the same thing. When she came for her interview, it was then that I realized why she was familiar. Tracey was my client when she dialyzed at a former dialysis unit where I worked until 1998. When I left there, we lost touch. Since then, she has had a successful transplant and returned to school. She graduated with a Bachelor of Social Work Degree from Wayne State. I have enjoyed being Tracey’s mentor, teaching her what it is like to be in the professional side of dialysis. If Tracey goes on to seek her Master's Degree in Social Work, hopefully she will consider a career in dialysis.

Ms. Sikon is a renal social worker in Southfield, MI.



Gina M. Sikon

If you would like to receive *Family Focus* at home, please call 888-JOIN-NKF.



Letters to the editor



Dear Editor,

When I meet old or new friends I always tell them that I'm still here, alive and continue to be active after passing 30 years, all on hemodialysis. I always enjoy *Family Focus*.

I began home hemodialysis on September 19, 1974. I ended home hemodialysis on September 19, 2002, completing 28 years at home. I must say with much enthusiasm that my 28 years on home hemodialysis were the best years of my life. I lived an active and positive life.

Today, I drive myself 18 miles away to a dialysis center in Humboldt, TN. They are excellent. They take very good care of me and meet all my needs. They treat me with dignity and respect three days a week. Actually, they make me and all patients feel very special.

For many years, my “motto” was “Don't live to dialyze, dialyze to live.” I do not quite measure up to my motto today, but I still try to be active and maintain an interest in something special.

Sincerely,

Willard “Moody” Richardson



Donna and Willard “Moody” Richardson
Atwood, TN, 1985

Dear Editor,

My clinic always has the most recent copy of *Family Focus* available for patients. All the articles are helpful. Your paper provides sound recommendations and has been very helpful to me during my three years on dialysis. I do CAPD and am still working full time. Your current issue on Mental Health was very inspiring. Issues such as this help me to keep going, even when I feel down and tired.

Thanks, and continue the good work.

Randolph Slay
Savannah, GA



More Letters to the editor

Dear Editor,

As an RN and caregiver to my husband, I was thrilled to read the spring issue of *Family Focus* dealing with home dialysis. Although, sadly, my husband died in October of 2004, we had dialyzed him at home for nearly 25 years (traditional 3x per week hemodialysis).

During the entire time, he continued to work full time, became involved in our community and played golf several times per week. Additionally, we raised our now 23 year old son, traveled and enjoyed our life. Admittedly, the last six months were difficult ones, but we never considered any other alternative to home treatments. It allowed us flexibility to live our life in an unbelievably normal manner.

In an era when phrases like “personal responsibility” and “calling the shots” seem to be overused clichés, why aren’t more patients embracing the opportunity to take charge of their care? My observations (supported by research, I think) are

that educated, involved patients are healthier patients. I will grant that center patients can be in control to an extent, but what is better than being “boss”—empowered, totally in charge of treatment outcomes? While not an option for everyone, with proper training, self care can be an attainable goal for many more people.

So why aren’t people battering down the doors of the home training programs, eager to take on the challenge of home care? Besides the usual list delineated in your “burdens of dialysis checklist,” with which I agree by the way, I feel there is another issue— FEAR! In our years of talking with others, Jerry and I heard statements like: “Machines scare me,” “What if I do something wrong?” “I’m afraid I can’t put a needle in my wife,” “I’m afraid of not being where there is a nurse or doctor.” The list could go on ad infinitum.

Home hemodialysis offered my husband and me the opportunity to lead productive, full (and, yes, wonderful and fun filled) lives. Thank you for focusing on an issue vital for ESRD patients.

Denise Eilers, RN, BSN
Davenport, Iowa



Dear *Family Focus*,

My mother and father have both been on dialysis. My mother passed away in February and had only experienced hemodialysis. My father had experienced both hemodialysis and peritoneal dialysis (PD). His kidney function decreased dramatically in a short amount of time so he had to have dialysis as soon as possible and was directed to hemodialysis. After awhile, Dad decided that he would like to give PD a try. Dad has many other health problems so his body is very frail, so he was unable to do any of the lifting of the solution bags for set-up or disposal. As time passed, Dad also required more and more PD exchanges. During this time, he was always complaining of “not feeling very good.” The PD nurse explained that he was still not getting enough dialysis. So we opted for a 30-day trial period back on hemodialysis. He has since regained his appetite, can taste his food again, has more energy and feels revitalized. Peritoneal dialysis was no longer an option for Dad if he wanted to feel better and live longer.

Anyone who has dialysis as part of his or her life knows the pros and cons to each type of treatment. Because of Dad’s situation, all of the responsibility became mine. I felt like I had lost my freedom because I had to schedule my life around his dialysis exchanges. I started to experience burn-out and found myself becoming depressed and feeling as if I was being drained of energy. Even though we had to drive to the dialysis unit three

times a week now, I feel as if I have been relieved of a great responsibility. I am still doing many things for my father and I enjoy being his caregiver, but when it becomes so involving that you are too tired to spend time with your own family, cancel your own doctor appointments, or quit work to care for someone, it is time to take a look at different options. My advice to family caregivers is to stay supportive in as many ways as you can but make sure you reserve time for your own family and for yourself! If you become drained as a caregiver, you will no longer have the energy needed to give quality care to your loved one.

Sincerely,

Faith A. Kresser
Presque Isle, WI



Dear Editor,

I am a new chronic kidney disease patient. I read *Family Focus* all the time. I have found it a great help. It touches on so many issues.

Sincerely,

O.E. Bradley
Cincinnati, OH



I STARTED RECEIVING *FAMILY FOCUS* IN AN ATTEMPT TO LEARN AS MUCH AS POSSIBLE about kidney failure. My mother was told she needed to be on dialysis immediately and this was quite devastating because she went to doctors yearly for her annual checkups. One year she had an abnormal urine test and so starts my story.

My mother, Teresa, was 68 years old. She had gotten so ill in a short period of time. We could not wait for the fistula to mature in her arm, so she had surgery and had her first catheter placed in her chest. She was so frightened. All of a sudden I knew what a parent must feel like with a child because now I was in that role, trying to provide comfort to my mother.

I live 35 miles from my mother. So three days a week, I would wake up at 4 a.m., drive to pick her up and arrive at

“I know my mom appreciates what I have done for her, and I would do it again in a second.”

the dialysis center at 6 a.m. for her three-hour treatments. I would take her to breakfast and also take a book to read to her. I sat with her through each treatment for the entire year she was on dialysis. Sometimes I would actually get the chance to read to her, sometimes she would fall asleep and sometimes she would have anxiety attacks. It

A Daughter's Love

By Ginny Hernandez

was at those times that I felt truly helpless.

With every visit, I learned something new. I would look at her chart that listed everything from her albumin to



“I want Family Focus to know how important it is to let those we love know it now, while they are here. We never know when they will leave us, and then it is too late.”

hemoglobin levels. I asked questions and got to where I knew what her levels were supposed to be. I asked more questions if they weren't.

There were times my mother seemed to go into a deep depression. She felt so sick and weak and at times told me she just wanted to die. I started talking to her about a kidney transplant and she was somewhat interested until I told her that I wanted to be her donor. She was not receptive at all and was adamant: “Absolutely

not!” she said. “What if something goes wrong? I have lived my life. I cannot risk something happening to you.”

I was at a loss. I started calling the hospitals that were covered under her insurance and got

information on

transplants. With that information and feeling that I had to do something to help my mom WANT to live, I started to pray. I prayed to God and asked that if I was meant to help my mother in this way, to please give me a sign and guidance on what to do.

After two weeks of praying and asking for an answer, my job of 22 years was eliminated. This was bittersweet news, but just what I needed to again approach my mom about being her donor.

After some time, my mother finally agreed to the transplant. I was thrilled and thankful that after all of my conversations with her, something had made a difference. The joke was on me. Apparently she had seen something on TV where a basketball player had his brother donate a kidney. He was the first to return

to the NBA as a kidney recipient, and his brother was doing fine too. So much for all my speeches!

We were side by side up until the pre-op room. When I finally saw my mother after our surgeries, she said she had not felt this good in several years. She also found it great to urinate. Funny how many things we take for granted!

My mom is doing great and is able to truly enjoy life. She has had very few side effects to the anti-rejection medications. We feel truly blessed to have her in our lives.

I know my mom appreciates what I have done for her, and I would do it again in a second. One day she told me, “This is really special. I gave you life as a child, and now, you have given me life.”

I want *Family Focus* to know how important it is to let those we love know it now, while they are here. We never know when they will leave us, and then it is too late.

Life is truly a gift. May we all treasure it. May those who are having second thoughts about being a donor find the strength through our God almighty to give the greatest gift one can give—the Gift of Life!

Ms. Hernandez lives in Rosharon, TX. 

Letters

to the editor

Dear Editor,

I started dialysis in November 1985. I began on PD because my kids were small and I wanted to be home with them. I am now on hemodialysis in Jessup, Georgia. The staff and center are so caring and loveable. They are like family, and all of the patients are too.

I started reading *Family Focus* and fell in love with it. There are so many great things to read.

Sharline Hollingworth
Jessup, GA



Dear Editor,

As a dialysis patient and a recipient of your magazine, it is very informative. Thank you.

Marcello Trotta
Maspeth, NY

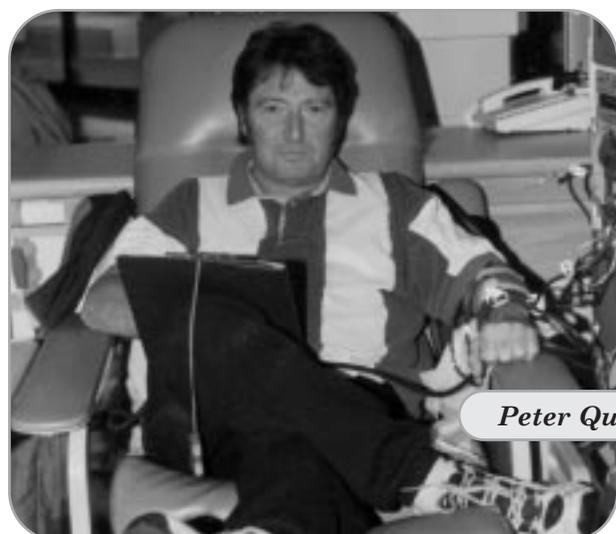


Cartoon Corner

The Lighter Side of Dialysis

By Peter Quaife

As you well know, sitting in the dialysis chair three times a week can get a little boring, so a few years ago I decided that I had to find something to do besides watching TV and doing crosswords. So I began to draw cartoons depicting the trials and tribulations familiar to all of us people on dialysis. Much to my delight (and chagrin!) the end result has become *The Lighter Side of Dialysis* cartoon book.



Peter Quaife during dialysis.

I grew up in England and was a member of The Kinks, a fairly popular rock & roll group in the 1960's. If you can remember "You Really Got Me," "Sunny Afternoon," "Lola" and the other hits we were fortunate enough to have, that's me on bass. I moved to Canada in 1981 and entered the wonderful world of kidney failure in 1998.



Don't worry, she's new. She'll get the hang of it soon.

Reprinted with permission from "The Lighter Side of Dialysis," a book of cartoons by Peter Quaife, a kidney patient since 1998.



(Left to right): Peter Quaife, Dave Davies, Ray Davies and Mick Avory.



Drency Edward Dudley was on dialysis from 1996-2002; now he has a kidney transplant. Mr. Dudley lives in Michigan.

Sorry, Mr. Dracula; the renal unit somewhat cleans the blood, the blood bank you want is on the 5th floor.



A Dream Come True

By Geri Morgan

I RECENTLY PICKED UP MY FIRST COPY OF *FAMILY FOCUS*. I READ YOUR NEWSPAPER FROM COVER TO COVER. I was so moved by many of the articles written by my fellow kidney patients as each one shared their own experiences and hearts' feelings. I thoroughly enjoyed each article. As we ESRD (end stage renal disease) patients know, no one really understands until they've "been there." So, as the funny little saying of today goes, "Been there, done that, and got the T-shirt." I think most of your readers fall into the last category, like me. We're all wearing T-shirts! We understand each other as no others can.

After reading your newspaper, I decided that I would share my own experience in hopes that it might help inspire others as I received inspiration from reading other patients' experiences.

spent with them. Sadly, my work in China had to cease due to kidney failure.

My family had a genetic kidney problem. I lost my father to it in 1945, when I was just five years old. In 1997, I lost my only daughter to the same genetic disease. So, kidney disease has not been kind to my family. I was diagnosed with Alport's Syndrome as a young woman. The nephrologists cared for me for many years and I led a completely



Gerri Morgan at The Forbidden City, China.

“DIALYSIS AND TRANSPLANT have truly been one of my life's greatest blessings. Not only have they extended my life, but they have changed my heart in so many ways.”

I am 66 years old and worked in China for the past 22 years. I helped build an eye hospital for the blind where the poor receive free eye surgery. In my heart, I believe God called me to help those dear people who have had such tremendous needs. I loved every minute

normal life with no ill effects from it until I was 61 years old. The tell-tale signs began to show up: high creatinine, lack of energy, etc. I was faced with ESRD very quickly. I tried my best not to become alarmed, but as most of you know, it's a scary situation to

find oneself in. It truly was for me, especially having seen both my father and my daughter succumb to it.

One night, about six months before my doctor told me that I needed to begin dialysis, I had a dream that I was sitting in a dialysis chair, along with a group of about six other ladies on dialysis. I saw the plastic tubing that is used with the dialysis machine beside my chair. I reached to pick it up but to my amazement, I discovered that I was not attached to the machine. Seeing that, I laid it back down and I got out of the dialysis chair and left the center. Now, that was my dream in early Spring 2001.

In reality, six months later, I found myself in a dialysis chair, only this time I was hooked up to it as it cleansed the impurities from my blood. However, I never forgot the dream I had earlier. I truly believed that the dream was from God. With all my heart I believed the day would come that I would get out of the chair and walk away from it, just as I had done in the dream. In the meantime, I just went in to my regular Monday, Wednesday, Friday treatments with a grateful heart that I was still alive. After I had

been at my regular dialysis center for a few months and got to know my nurses, techs and doctors, I shared my dream with them. As time went on they, too, began to believe my dream along with me. Many times they would come by my chair and say encouraging words such as "It won't be much longer"; "You won't be here with us and we're gonna miss you"; "Soon you are going to walk away from that dialysis chair." I would reply, "Yes. I don't know when, but I will come out of this chair."

Due to a genetic kidney problem, I went into ESRD in the summer of 2001. I had a wonderful medical team who put in my access and started me on hemodialysis.

Personally, I never dreaded my days on dialysis, not one time. Now, that is not to say that I would not have chosen another way to spend those hours of my life. But dialysis was not a bad experience for me as it sometimes can be for some. Aside from the needles, my 10 months on dialysis were easy for me. I used those 635 hours to write a book, which will soon be published. I would never have had the time, nor taken the time to write the book, if it were not for all of those hours on the dialysis machine. So I used the hours productively.

Continued on page 15



I ACCEPTED THE FACT THAT I HAVE KIDNEY DISEASE AND WILL NEED TREATMENT FOR THE REST OF MY LIFE, yet I still have trouble adjusting to the changes in my life that the disease often brings. During this course of treatment, deep personal feelings of guilt, denial, anger, depression and frustration are not uncommon. In fact, they are quite understandable for my family and me.



I stay involved in the pleasures, activities and responsibilities of my life. I also find time to exercise.

I realize that the stresses and frustrations of kidney failure are real and at times very difficult for both my family and me. You may feel as though your world is caving in, especially if you have not faced a major crisis before and the diagnosis was unexpected.

“Most importantly, I am very blessed to have my own donor, my brother, to give me the best present of all, the gift of life. Thanks, Big Brother!”

I have felt helpless at times because I cannot do anything about my illness. I have been angry that kidney disease has happened to me and affects my family and friends. My biggest fear is that I may die. Periods of confusion and tension occurred as I tried to cope with the demands of the illness, anxiety about treatment and the disruption of everyday life.

A Sister's Love

(To her big brother)

By Kinita Williams

I had many questions about kidney disease and its treatment. These included questions like: “What kind of treatment is for me?”; “Do I need to quit my job?”; “How will I get to my treatment center?”; “How will I pay for my treatment?”; “How will I handle my diet?”; “How long will I need to wait for a transplant?”; “Can I exercise?”; “Will I be able to travel?”

Having this disease is overwhelming at times, but it is important to know that help is available and that your questions will be answered. I am very interested in my own care. It is very important to me to find out more about my kidney disease and its treatment. The treatment center and the National Kidney Foundation can help provide the answers.

Also, the social worker is a patient's best friend. He or she can help you get answers to many of your questions, and also help with nonmedical issues. The social worker is dedicated to helping you make your treatment a manageable part of your life.

I stay involved in the pleasures, activities and responsibilities of my life. I also find time to exercise. I share my feelings with my family and a few close friends. I also allow them the opportunity to share their feelings with me. We can learn together. I try not to focus on

my problems but instead on the good things that are happening in my life.

Most importantly, I am very blessed to have my own donor, my brother, to give me the best present of all, the gift of life. Thanks, Big Brother!

Ms. Williams lives in Dallas, TX. 

“ATTENTION ALL YOU UNDER USED CARS!”

“IF YOU'RE HANGING OUT BY THE GARAGE, JUST RUSTING, CALL KIDNEY CARS AND DONATE YOURSELF TO HELP FIGHT KIDNEY DISEASE AND SAVE LIVES.”



“THE BOSS WILL GET A RECEIPT FOR HIS TAXES, AND SINCE HE'S NOT DRIVING YOU AROUND MUCH LATELY, HE'LL PROBABLY ASK FOR THE FREE PICKUP.”



“SO DON'T JUST PARK THERE LEAKING OIL, PUT IT IN GEAR AND CALL THE NATIONAL KIDNEY FOUNDATION... BECAUSE IT'S DONATE OR OXIDATE!”



1-800-488-CARS
www.kidneycars.org



CAREGIVERS *Have Needs Too!*

By Alexandria

HELLO! I HAVE BEEN A CAREGIVER OF MY HUSBAND, WHO HAS SERIOUS DIABETES WITH ITS VARIOUS MEDICAL CONSEQUENCES, FOR THE PAST 22 YEARS. For the last four years he has also been on dialysis. It has been a roller coaster lifestyle for us and our children. Emotions, finances and relationship role changes took their toll. I have found that a caregiver support group was essential. It has been helpful in giving preventative information and encouraging me as I hear other experiences far worse than mine. We found we



have all had the same issues of grief, denial, anger, sleeplessness, loss of concentration, depression and the feeling of never getting anything done. The one consistent upside is—opportunities abound for character refinement! We decided we would encourage each other to exercise, eat right, watch for discouragement and depression and call and pray for one another, for we all saw we could not be a caregiver on only our own strength for very long. I highly recommend starting an informal caregiver support group in your dialysis clinic. In those caregivers you will find the unsung heroes of today.

Talk to the clinic doctor, nurses and social workers about starting one.

The doctors, nurses, social workers, staff, volunteers of many special programs, neighbors, church friends and pastors and chaplains were all part of the community needed to inform, help and steer us through all the extremes we live with to find our new balance, purpose and role in it. It may not be what we expected or desired. But, there is a new, yet different, fulfilling life for the person on dialysis and the caregiver after dialysis.

Alexandria works and lives in La Grange, GA.

Alexandria

A Dream Come True...

Continued from page 13

I saw the reality of my dream come into being. I got out of the dialysis chair on June 4, 2002, and walked away from it, just as I had done in my dream. The next day, I entered the hospital for transplant surgery. I believe God gave me an outstanding miracle as I received a perfectly matched kidney from the 28-year-old adopted daughter of one of my friends. I had known Amy, my donor, since she was six months old. I now refer to her as “my Hero!” I think a scripture in the Bible expresses my feelings to my donor best of all. Jesus said: “Greater love hath no man than this that he lay down his life for his friend.” (John 15:13) That is what she did for me!

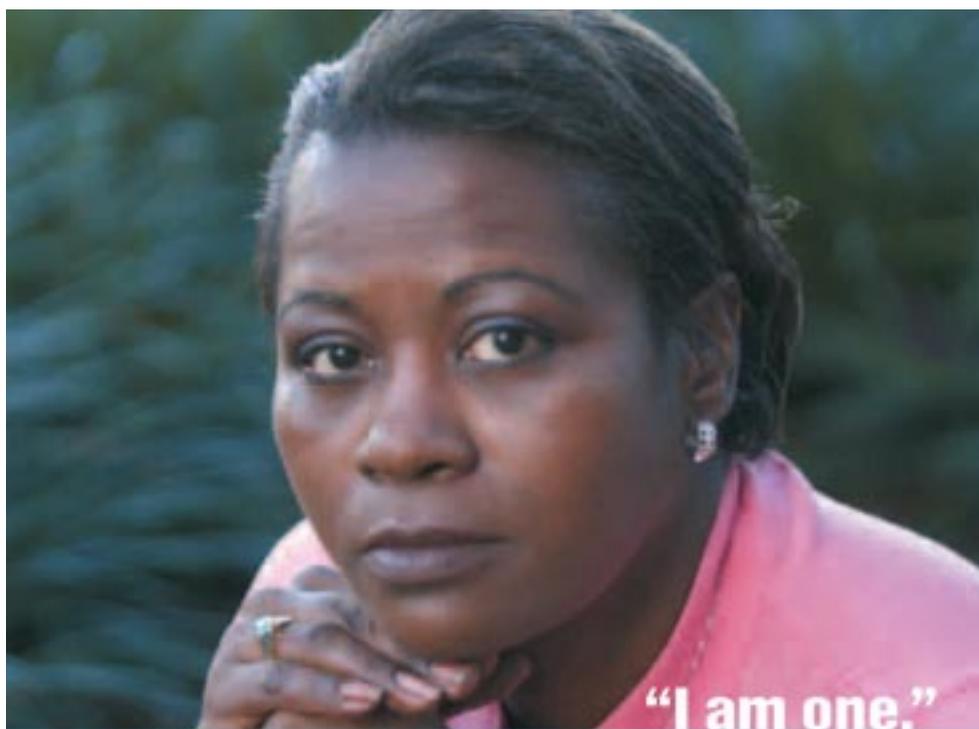
My life after transplant has not been perfect but it has been good. My kidney is working great but occasionally I will have a little “bobble” as I call them, with my meds that we transplant

patients know all about! I’m just really one “happy camper” these days.

I hope my story can be of encouragement to someone out there reading *Family Focus*. I’m a grateful 3 1/2 years, post-op-transplant patient. I will be going back to work with the blind in China, God willing.

Dialysis and transplant have truly been one of my life's greatest blessings. Not only have they extended my life, but they have changed my heart in so many ways. May I take this opportunity to thank the great medical people who spend their lives caring for dialysis patients. You are appreciated!

Ms. Morgan lives in Dallas, TX. 



"I am one."

One in nine Americans has chronic kidney disease.

"Are you?"

Like me, most people with chronic kidney disease don't even know they have it. If you have high blood pressure, diabetes or a family history of kidney disease, you are at risk. But early detection can prevent chronic kidney disease from turning into kidney failure.

March is National Kidney Month. Support our efforts to reach every American at risk by making a gift today. Visit us online or contact us at (800) 822-9010 for free screening and information.



National Kidney Foundation

www.kidney.org

Hurricane Relief Aid



THOUSANDS OF VICTIMS OF HURRICANES

KATRINA, RITA and WILMA face homelessness and devastation, but kidney patients without access to dialysis treatment face life-threatening danger in addition to loss of property.

To help people with chronic kidney disease (CKD) in the affected areas get the services they need, the NKF has created a relief resource network posted on www.kidney.org, offering dialysis locations and treatment information, other direct patient assistance and information for health care professionals interested in volunteering for the effort.

"We are very gratified by the terrific cooperation we have seen by everyone involved in helping patients deal with this disaster. National Kidney Foundation Affiliates, other kidney organizations, the large dialysis organizations and the kidney-related industries have all worked hard and closely together on behalf of the people who are suffering," stated John Davis, CEO of the NKF.

To contribute to the Foundation's Patients' Hurricane Relief Fund, visit www.kidney.org or mail checks to the National Kidney Foundation Patients' Hurricane Relief Fund, 30 E. 33rd Street, New York, NY 10016. One hundred percent of funds contributed to the Relief Fund will go directly towards patient assistance.



THERE'S ONLY ONE WAY TO FACE DIALYSIS.

TOGETHER.

No one should have to face dialysis alone, and thanks to Amgen, no one has to. Because Amgen—the world's largest biotech company—is dedicated to helping you deal with the many issues that can go along with kidney failure and dialysis.

For example, many people with chronic kidney disease on dialysis develop *anemia*, a shortage of red blood cells. Anemia can make you very tired and unable to complete routine daily tasks. Anemia may also lead to more serious problems like heart disease.

An important gland called the *parathyroid* can also be affected by kidney disease, leading to a condition called *secondary hyperparathyroidism (secondary HPT, for short)*—which can cause serious problems in your bones and blood vessels.

Amgen offers an entire family of products and services to help support people on dialysis and the people who love them. Because we're not just dedicated to improving the lives of people with kidney failure, we're dedicated to protecting them.

AMGEN

Find out more about our work at www.amgen.com.

© 2004 Amgen. All rights reserved. MC24291