



RENAL OUTREACH

ESRD Network 9/10

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What Is Independence When It's Not The Fourth of July?

By Fonda Setters, M.S.W.,
Patient Leadership Committee Member

The new catch phrase in the dialysis community is "patient independence." The Center for Medicare and Medicaid Services (CMS) encourages the promotion of independent functioning in the patient population.

Few of us can fault the theory behind this thought. Most human beings wish to make their own decisions and live their lives as they see fit. Patients should be involved in their medical care. It is incredibly difficult to buy into something that you do not understand or want. Any of us taking medication should know what it is supposed to do, what the potential side effects are, and how to know if it is not working. Dialysis patients should know what treatment options are available to them personally and then choose the modality that best fits their lifestyle.

But at the end of the day, whether patients are pulling their own needles because their home hemodialysis treatment is finished, or they are connecting to the cyclor to start their nightly peritoneal dialysis treatment, the question still needs to be asked, "What is patient independence?"

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Princess for a Day A Community Event in a Blessed Life

by Martinlow V. Spaulding

Despite having lived the past 14 years with kidney failure, my life has been blessed in countless ways. Because of this, I want to give back to my family, community, and other people with chronic kidney disease. My greatest blessing has been to be a "Daddy" to my six amazing children (one boy and five girls!), so I welcome any opportunity to be involved in their activities. I was diagnosed with kidney failure in 1992 and was started on peritoneal dialysis (PD). The following year, my brother, Paul, gave me the "gift of life," a kidney. Following that kidney's rejection 10 years later and another stint on PD (CCPD), my sister, Rita, gave me one of her kidneys. These precious gifts made me aware that family was the greatest gift of all, and I was determined to do all I could to enhance the lives of not only my own family, but the lives of others as well.

Do Dads Club

As a member of my children's Do Dads Club at Heather Hills Elementary School in Indianapolis, I have the joy of organizing events for the students and their families. My goal is, "Leave them with an experience!"

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What Is Independence (con't)

Independence is not “one size fits all.” It varies with our personalities, our circumstances, our strengths and our fears. The person who spent their toddler years saying, “I can do it” may be the patient on home hemodialysis. The person who is wary of sticking themselves with needles will more likely be on in-center dialysis. This does not mean that the second patient is any less independent. It simply means that the patient made a different choice depending on personal needs. That is true independence. Independence may mean staying within the fluid restrictions to avoid stress on the heart so that there is more time to spend with the children. Independence may mean properly administering one’s immunosuppressive medications to maintain a transplanted kidney. Independence may mean asking your physician questions and getting answers because you respect the doctor’s knowledge who in turn respects your autonomy. Independence is when a person is diagnosed with ESRD and told that dialysis is needed and a choice is made to start treatment, or knowing the consequences, the informed choice is made not to receive treatment.

Independence in the world of ESRD and its treatment does not go strictly by the dictionary definition that says independence means to be free from the influence, guidance or control of others. Patients influence each other based on the information and support they share with each other. Physicians give guidance to patients on how best to take care of themselves. And yes, sometimes, some measure of control must be given up in order to get what is wanted or needed. Independence, in the dialysis setting, is not letting dialysis become your life, but making the choices you need to make sure that the treatment just becomes a thread in the tapestry of your life and not the whole picture.

Patient Lifestyle Meeting

“Health, Happiness & Hope”

Hosted and Organized by



Martinlow Spaulding, MA, BAA
(Chronic Kidney Disease
Patient - Since 1992)

Sponsored by the Renal Support Network (RSN) and supported by The Renal Network, Inc. (ESRD Network 9/10).

Sunday, September 9, 2007
10:00 am - 4:30 PM
Crowne Plaza North
Columbus, OH 43229

FREE Brunch & Patient Education for
CKD Patients & One Guest.

Registration is required.

Please contact Renal Support Network (RSNHope.org to download registration forms), 818-543-0896 or toll-free 1-866-903-1728 for FREE registration forms.

The Do Dads Club grew out of All Pro Dad, a part of the Family First Foundation led by Tony Dungy, head coach of the Indianapolis Colts football team. Tony wanted to raise awareness about dads who participate in the lives of their children. As a way of giving back through the Do Dads Club, I organized a "Princess For a Day" gala at the school, allowing dads to show their daughters how very special they are to them. (Not to leave out the sons, "princes" were also welcome to attend.)

Once Upon a Saturday Morning

The school gymnasium was decorated in the style of a fairy tale castle. Following a special breakfast fit for a king (or was it fit for a princess?), each girl—wearing a darling princess outfit and priceless smile—was escorted by her dad into the gym through a brightly lit entrance. The dads wore "king" crowns they had made with their girls, but it was the princesses who ruled the day, and the kings bowed to them and obeyed their royal commands.

Upon entering the castle, every princess received a royal makeover complete with colorful face makeup, beautiful hairdos with bright accessories, shiny fingernail polish with glitter, and sparkling jewelry. It surprised the dads a bit when the princesses "commanded" that the dads should have fingernail polish as well, but all complied and were actually showing off their dazzling nails.

Then a very special moment: The princesses and kings danced to fairy tale music. Afterwards they received a photo of the royal couple for an everlasting memory.



Martinlow and "Princess For A Day" daughter Olivia.

Everyone enjoyed the royal celebration and lived happily ever after.

Giving of Yourself: The Most Priceless Gift of All

"Leave them with an experience" is my philosophy when organizing a community event. Princess For a Day is an awesome experience (and now an annual event). It allows dads who would probably never think of doing something like that a chance to be more loving toward their daughters. My life is also blessed with other fulfilling "give back" activities.

One program I organize is the Child Care Exchange, providing parents with a monthly night off to share special time with each other. The Exchange parents take turns babysitting at the school while they and the kids enjoy dinner and a movie. I also co-chair the school's Talent

Showcase, which encourages dads to perform with their children.

Many dads choose to be a "provider" for their children by giving, giving, and giving things to them instead of giving the most priceless gift of all—their time! I believe the greatest gift that any dad can leave his community is not money or items, but legacies... his children. Live for others!

Reprinted with permission from the Renal Support Network (RSNhope.org). This article originally appeared in the Spring 2006 issue of RSN's *Live & Give* newsletter.

Author's Biography

Martinlow V. Spaulding, MAA, BA, weKAN Patient Activist & PEPP Speaker has been both a dialysis and kidney transplant patient since 1992. He is a recipient of The Renal Network's Robert Felter Patient Memorial Award. Martinlow, with his wife Elaine, a kidney/cancer nurse and their six children live in Indianapolis, IN.

FATHER KNOWS BEST

“Boy-Oh-Boy”

By Gary Owensby, Renal Patient

No 45 year-old black man wants to be called “boy.” Absolutely not. Except me. I really want to be called boy. Please. I NEED to be called boy. For 25 years, my dad affectionately called me boy. All of the time. I may have been 12 years old before he finally called me Gary. I loved my dad, and I miss him very much.

However, just because James Robert Owensby died in 1984 doesn’t mean he left me empty-handed. He taught me confidence and toughness; attributes that helped me survive the last 20 years.

Although my father had no formal education, he was easily the smartest man I’ve ever known. He knew so much about everything. He continuously told me that I could do anything I wanted, and I believed him. “Look boy, get your education so you won’t have to work in a factory like I do,” dad said. “If you go to school,” he promised, “I’ll always help you. But you have to do your part.”

When told of my kidney failure, my dad insisted I explain the disease to him. Once I did, he asked, “You want one of my kidneys?” I was stunned. What a guy, I thought. But I told him no. However, his incredibly unselfish gesture made me love him even more. Of course, I couldn’t take his kidney. Even if he hadn’t been 54 years old and dying from leukemia, I wouldn’t have taken it. Is this what he meant when he said he’d always be there for me? I thought of his offer as the ultimate act of love and sacrifice.

Though I was always sure my dad loved me, he never told me so. It wasn’t his style. But he told others. According to my aunts and uncles, my dad constantly bragged about me. “That

know that boy of mine made the honor roll again. You know that boy of mine is at Ohio State University.”

Small Potatoes. Because I was twice as proud of my dad as he was of me. He loved his family and sacrificed everything to support us. Fortunately, my first 10 years of dialysis were physically uneventful. My body felt no serious side effects from the three days a week, four-hour dialysis treatments.

Then things changed! Sometime around 1995 problems began. At various times, it was either pneumonia, hypertension, lung problems or thyroid ailments that landed me in the emergency rooms at Ohio State University Hospital. A number of people who know I’ve been on dialysis for more than 20 years occasionally marvel at my toughness. I’m not that tough. My dad was much tougher.

Sometimes, during dialysis the needle pain is excruciating. So what. My dad once missed only two consecutive days of work after a finger was accidentally amputated. I’ve had pneumonia five times and I’ve been admitted to intensive care twice.

Big deal. On a third grade education, my dad worked in a factory 34 years and raised nine children. Never mind that I once endured a head-pounding week without my blood pressure medication. More importantly, my dad went a year without work shoes so his children could have school clothes. Now, who’s tough?!

Around December 2000, my kidneys began to swell and hurt. My surgeons determined that both kidneys should be removed during separate operations. Additionally, a near fatal stomach bleed would require a third operation. One guy, three operations. My doctors were worried, so was I. Nevertheless before each operation, I called on God and James Owensby.

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I remembered my dad said he'd be there when I needed him. All three operations went fine.

My mother always said, "You think that Buick doesn't move without you in it, huh?" She was absolutely right. I tried to follow my dad everywhere. I wanted to be wherever he was. I listened to him. I watched him. I wanted to learn from him. And even today, 20 years after his death, it's my dad's positive influences that strengthen me. No way could I make it without my memories of him. I'm very grateful my dad taught me to be strong, moral and confident. He promised he'd be there for me; thusly, I still call on him when things get tough. I love him so very much. I'm so proud that he was my father. And I'm even more proud to be his boy.

(It is with great sadness to report that Gary died in October 2006 at the age of 47.)

The Joy of Being a Volunteer

By Lorraine Edmond

I am a kidney transplant patient. Lorraine Edmond is my name. Volunteering is my game.

As a mother, grandmother and active member of my church, I have always volunteered. Being diagnosed with End-stage Renal Disease just provided me with new volunteer opportunities. I hit the floor running and never looked back. A few weeks after starting dialysis, in 1992, I heard about The Renal Network (it was called Tri-State Renal Network back then). The Network asked dialysis facilities to appoint patient representatives to work with the Network and to share educational information with patients at their facilities. Well, in 1993, I became the patient representative for my dialysis unit and became a member of the Patient Advisory Council (PAC).

I also am a trained Patient-to-Patient volunteer. I provide encouragement and support to newly diagnosed patients referred by doctors or social workers. I keep an open line twenty-four hours a day for any who are in need of support. Upon learning that no support groups for kidney patient existed in 1992 in Northwest Indiana, I formed a support group for dialysis and transplant patients and their families. The name is SHARE and stands for sharing, hearing about renal experiences. Besides supporting each other, the group also receives educational information. We meet once a month over lunch. We started with twenty-five people in attendance and our activities have extended to hosting facility-wide parties and picnics.

In 1994 while on the PAC, I was asked to serve on the Patient Leadership Committee (PLC) Patient Education Subcommittee which conducted patient surveys, helped promote patient awareness of Chronic Kidney Disease (CKD) and worked to revise the Network statement of patient rights and responsibilities. I continue to serve on the PLC today. In 2003, I was appointed to The Renal Network Medical Review Board (MRB) as a member of their Patient Relations Subcommittee. This subcommittee deals with matters which directly affect patients, such as grievances, access to transplant and home therapies, as well as vocational rehabilitation.

Volunteering for me is a great and spiritual reward. I find comfort and immense joy, knowing I have helped a fellow renal patient. I have volunteered in many other community activities, at renal health fairs, in the school office for seven years before transplantation, church, senior activities and I am currently serving as vice president of the tenant's organization where I reside.

If you are looking for something new and rewarding, try **volunteering!**

THE RENAL NETWORK

The core purpose of The Renal Network (TRN) is to facilitate the achievement of optimal wellness for renal disease patients. The Network takes on a number of different roles to accomplish its purpose. It has three major functions: quality improvement, data collection and patient education/complaint resolution.

Quality improvement - The Network works in a variety of ways. It provides continuing education and timely patient outcomes feedback to help the dialysis healthcare team work with patients to achieve optimal wellness. The Medical Review Board (MRB) assesses the quality of patient care and the appropriateness of services delivered.

Data collection - To further promote quality care, the Network continually gathers information from member facilities on patient care. This data is compiled statistically, analyzed and reported back to renal professionals to help them manage their end-stage renal disease programs. The Network also uses this data to identify universal areas for improvement and to educate facilities in general on how to improve patient outcomes.

Patient education - To educate staff and patients, the Network works through its Patient Services Department to provide an array of services. These free services include workshops, educational materials and publications such as the *Renal Outreach*, a newsletter for patients. Patients can subscribe to the newsletter or download current or past issues online at www.kidneypatientnews.org/RenalOutreach.html.

The Patient Services Department also handles complaints/grievances and works with both patients and their facilities to resolve issues. The staff will coach patients on how to initiate and participate in health care team meetings, how to advocate for themselves, and provide resources to help resolve their concerns.

In addition, the Network has a Grievance process that can be used when patients are either not satisfied with the results of their facility grievance procedure or prefer not to go through their facility's process.

A Grievance Form is on the patient Web site, www.kidneypatientnews.org or can be received by calling the Network toll free number at 800-257-8291. MRB members are responsible for evaluating patient grievances and serious complaints.

The Network also trends and keeps records of all complaints and grievances filed with the Network.

American Kidney Fund Medicare Part D Grant Program

This program offers qualified dialysis patients help with their prescribed bone disease medications.

Patients may receive up to \$2000 in grant assistance to help with their deductibles, co-pays, and coverage gap costs for their bone disease medications per year.

If you would like to find out if you qualify and want to receive an application in the mail call 800-638-8299 or e-mail patientservice@kidneyfund.org.

INTERNET RESOURCES

Medicare Web Sites that may be helpful:

If you want to compare dialysis facilities or locate dialysis facilities when you want to travel, visit Dialysis Facility Compare at www.Medicare.gov/dialysis.

Learn more about the Medicare Prescription Drug Program, Medicare Part D, and drug programs in your area by visiting www.Medicare.gov.

The Renal Network, Inc has two Web sites:

Kidney Patients News, www.kidneypatientnews.org, was created by the Network Patient Services Department to help patients, family and their friends find the resources needed to understand and cope with the many facets of kidney disease including Medicare Part D, how to be prepared for emergency situations, treatment options, diet and cookbooks.

The Renal Network Web site, www.therenalnetwork.org, is geared more towards the needs of facilities and staff. There you will find a copy of the Network's annual report, policies and procedures, as well as a variety of quality improvement and other resources.

Subscription Form for the *Renal Outreach*

Dialysis patients are eligible to receive free home delivery of the *Renal Outreach*. To receive the *Renal Outreach* patient newsletter at home, just complete and return the form below to our Patient Services Department. If you already have a subscription, feel free to give the form to a fellow patient or copy this page and distribute to patients on your shift.

HOME DELIVERY SUBSCRIPTION FORM FOR RENALOUTREACH

NAME: _____

FACILITY: _____

ADDRESS: _____

CITY: _____ STATE: _____ ZIP: _____

Mail to: **Renal Outreach**
 The Renal Network, Inc.
 911 E. 86th Street, Suite 202
 Indianapolis, IN 46240
FAX to: **317-257-8291**

Interested in being part of The Renal Network's Patient Leadership Committee?

We are looking for applicants for The Patient Leadership Committee (PLC) 2008-2010 term. This is a dynamic group of kidney and transplant patients, family members and professionals that helps the Network respond to patient needs and seeks ways to improve patient/staff relationships. It also acts as an advisory group to the Network Patient Services Department. Members on this committee need to have experience with kidney issues or have kidney disease and be able to travel to three meetings a year (travel costs are reimbursed). You can download an application for the PLC on the Network Web site at www.therenalnetwork.org or request one from the Network's office (800-456-6919).



Patient Leadership Committee - 10th Anniversary Celebration during the 2007 Nephrology Conference

1st Row - (sitting) Ed Lesser, Helen Kurtz, Dirk Combs, (standing) Dolores Perez (Communications Director)
2nd Row - (standing) Susie Stark (Executive Director), Lynn Winslow, George Aronoff, (Board President), Kathy Kirk-Franklin, Eric Gronefeld, Sonia Juhaz, Celia Chretien, Lorraine Edmond, Audrey Chengelis, Karen Habercoss
3rd Row - (standing) Guy Tibbels, Janet Schueller, Fonda Setters, Jim Dineen, Teri Browne, Ellen Newman, Craig Fisher, Barbara Gronefeld, Martinlow Spaulding, Kathi Niccum (Patient Services Director)

RENAL OUTREACH

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