



RENAL OUTREACH

ESRD Network 9/10

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2006 Robert Felter Award Winners

Facility Award

Provena Saint Mary's Dialysis Center Kankakee, IL

Amy Wiley, LSW, facility social worker and primary contact for the "Healing Hopes" project accepted the award on behalf of Provena Saint Mary's Dialysis Center.

The facility used the following quote by Allan K. Chalmers as the basis of its project's development:

"The grand essentials of happiness are something to do, something to love, and something to hope for."

This project offers the facility an opportunity to bring hope into the lives of its patients and their families by showing that hopes can come true.

Too often the disease process and dialysis treatment become the central focus in the lives of chronic kidney disease patients and their families - medically, socially, and financially.

This award will be used to provide assistance to patients and one of their family members to attend a local community event, such as the



Amy Wiley (l.) and Barb Gronefeld (r.)

Patient Award

Barb Gronefeld Centerville, OH

My name is Barb Gronefeld and I was diagnosed with polycystic kidney disease at the age of 32. I wasn't too surprised since my father suffered from this disease: the difference being that he didn't know he had kidney disease until he went into kidney failure at the age of 55. I myself went into kidney failure at the age of 52.

I tried hemodialysis and then I heard about peritoneal dialysis and within a few months was doing very well with this type of dialysis in my home. I then was evaluated for the transplant list and after three years of being on dialysis, I received a kidney transplant June 13, 2003. As kind of a footnote to this, my younger brother, who also has this same hereditary disease, got a kidney transplant in March of 2005.

I have been on the Patient Leadership Committee (PLC) of The Renal Network for the past four years, and I am very glad to have the privilege of serving on this committee with so many dedicated professionals and patients.

Rehabilitation Starts With A State of Mind

by Terry Carter, Sr
Renal Care Group, Austintown, OH

It's devastating to hear that your kidney is going and is working at 50%, then 30%. I believe that everyone who has heard this news starts with denial that says "I won't have to take dialysis", but inevitably we end up three times a week, hooked up to the machine that gives us life and we thank God for it. But what happens to our mindset? Do we give up or do we step up?

Adjustments, adjustments, adjustments, they are the cycle of life, but this adjustment can turn your whole world around. The tiredness that accompanies this

adjustment is unreal and the sick days are more than low ebbs; they are earth-shattering statements

that our lives will never be the same. One wonders from day to day, is it possible to carry your weight on the job or even at home?

Renal failure is all consuming and dealing with one's emotions one day at a time until we reach a plateau where solid decisions can be made is all one can do to make it.

I can't speak for everyone, but as for me and my sanity, I'll take a job any time over sitting and thinking about my physical condition. Maybe this is a form of denial but I prefer to think of it as a form of rehabilitation.

Part-time, full-time, half-time work; volunteering once a week, twice a week or everyday; contributing to life extends my own. If I do no more than make a call to encourage someone or if I mail a card, or write a letter, I have stepped out of myself and into my purpose – productivity.

When you become productive, the illness is no longer controlling you; you are controlling your destiny.

Remember the old gospel song that said something like "if each one would win one?" Just think if each renal client reached out and touched just one other person in a positive way and then they touched one or two and so on and so on. Why not make a difference?

Healing starts in the mind, if not one's kidney, than healing of one's mindset. If I think I can make a difference, make a change, be a spokesman, walk a mile a day, then I can. If I make this small positive step, it can have a ripple effect in my life. I can let

it ooze over into my marriage and my relationship with my children and my extended family. It can change the way I

invest in my future and it can cause me to reevaluate what is really valuable and what is not. It may cause me to become closer to God, or to change my diet or learn to swim. It could also compel me to listen to Mozart or read a poem or start a journal.

My teacher used to say, "in this hurried world, don't forget to stop and smell the roses." I really didn't understand it at the time, but her words have been made resoundingly clear.

Step one to healing and rehabilitation is just a simple positive thought.

Step two is reevaluating one's "valuables" and understanding that we have the power to make our own worlds work for us, and we can make a difference along the way.

“When you become productive, the illness is no longer controlling you; you are controlling your destiny. “

Step three is contact with our Creator. The scripture says in Philippians 4:13, "I can do all things through Christ which strengtheneth me." If you, a dialysis client, never before thought about the power of God in your life, now is the time to give God a try.

Rehabilitation, like faith, is a daily process.

In order to be rehabilitated, one must constantly work at keeping it alive by applying these steps and determining that one's goal can be reached. By applying these simple principles to my own life, I am in the eighth month of returning to work part-time. I love golf and go as often as my schedule allows. I continue to have ministerial speaking engagements and have a closer relationship with my wife of over 31 years than I ever had before. I am also a pretty good fisherman and I have just purchased a boat. All of this was accomplished with the help of God, a caring dialysis center, and a new attitude. No man can do it alone. Reach out to God, surround yourself with positive people, and as Nike says, "Just Do It."

Finally, I implore you to take your first step into rehabilitation. You will find it just the beginning of an earth-shattering positive experience!

(Terry has been on hemodialysis for over five years now. He initially took a leave from his position as a car salesman, but has returned to work in the last year with the goal of going back to full-time employment. He continues to inspire others with his calling as an Apostolic Pentecostal minister. In addition, he shares household duties with his wife who is employed full-time as a teacher. Of course, he especially enjoys his hobbies of golf and fishing.)

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Patient Concerns Expressed to the Network

During 2005, the Network's Patient Services Department received 533 calls (total of grievances, patient complaints and facility concerns) of which 116 were primarily complaints from patients and family members.

The type of issues expressed by patients and family members to the Network included: the quality of care received during dialysis; staff professionalism and other staff-related issues; being inappropriately discharged from a unit; and concerns about not being able to find placement in a dialysis facility.

The Network staff members who receive these calls assist patients by 1) working with them to develop a plan of action for their concern; 2) suggesting different ways to talk to staff about their concerns; 3) providing additional resources; 4) helping them understand federal and facility guidelines and policies; and 5) contacting the facility staff, as needed and requested. If the Network is requested to contact the facility, your name is used ONLY with your permission.

If you have a complaint regarding your dialysis treatment, we encourage you to work with your facility staff, if possible. Each facility has a grievance process and also has information about how to contact The Renal Network and the Department of Health.

If you prefer to contact the Network initially or if you are not satisfied with the facility's response to your grievance, you are welcome to call the Patient Services Department at (1-800-456-6919) or visit our patient Web site, Kidney Patient News (www.kidneypatientnews.org), to learn more about our Grievance Process.

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Frequently Asked Questions about Arterial Venous Fistula's (AVF)

1. Why should I get an Arterial Venous Fistula (AVF)?

It is widely accepted among the majority of nephrologists and other dialysis professionals that an AVF is the preferable access type by which to receive your dialysis. AVFs, with proper care tend to be the longest lasting type of dialysis accesses and require fewer interventions, such as de-clotting, which can be very painful. With an AVF, it is also likely that you will experience fewer infections, fewer days in the hospital, and receive more adequate dialysis, which in turn will improve the way you feel and improve your quality of life.

2. How do I get an AVF?

There are several members of your healthcare team who can provide you information about obtaining an AVF, but you might want to initiate this discussion with your physician or a nurse in the dialysis clinic. Prior to talking with your healthcare provider you would probably benefit from educating yourself about the benefits of having an AVF. Several sources of educational information regarding AVFs (some of which are included at the end of this document) are available.

3. Who is a candidate for an AVF?

There are very few instances where a fistula is not indicated. Nowadays, in the majority (including those with diabetes or who are “older”) of patients a “mapping” study of the blood vessels in the arm is conducted, which will help select the best veins for a fistula and decrease the chance for an unsuccessful surgery. Be persistent; if the mapping study was not done, asking for a second opinion is quite reasonable.

4. I don't like needles, how do I cope with this fear?

There is no denying that having an AVF requires the insertion of two needles into the access site. However, there are many options for dealing with the needles. Many patients report that by learning to place their own needles, they are focusing more on the needle placement than the pain associated with the needles. Additionally, your clinic might have a topical or subcutaneous anesthetic available to numb the area prior to the needle sticks. There are relaxation techniques such as breathing and imagery exercises, which might help reduce the anxiety often related to a fear of needles. You might also ask your clinic or MD if smaller needles might be appropriate or if other ideas for dealing with the pain exist.

5. An AVF will change the looks of my arm, how do I cope with this?

The way we view our bodies is very important to the way we feel about ourselves. If you are uncomfortable with your physical appearance, it is more likely that you won't feel good about yourself in general. The repeated insertion of needles into an AVF can cause scarring and a change of appearance in your arm or wherever the AVF is placed. What is important to remember is that you have the choice to not let your feelings about yourself be defined by the look of your access site. By opening up and talking to other dialysis patients with AVFs you will learn the methods or coping mechanisms they have used in integrating these physical changes into their daily lives.

6. How is an AVF different from a catheter or a graft?

An AVF is created by connecting (usually in your forearm) one of your own veins and arteries together. Whereas a graft requires the surgical placement of a small flexible tube and a catheter requires the placement of a small tube into a large vein in your neck, chest, or groin. The AVF uses your own anatomy and requires no insertion of a “foreign” substance into your body. Since an AVF uses your own vein and artery, it is less likely to clot or become infected and tend to last longer than catheters or grafts.

7. What additional care will my AVF require?

The application of pressure to the site is necessary following the end of your treatment. This will likely need to be completed by you and it will add some additional time to your time in the clinic as the access stops bleeding. It will be important that you keep your access clean and wash it thoroughly prior to initiating your dialysis run. You will want to make sure anyone caring for or inserting needles into your access site is wearing clean gloves and observing infection control techniques.

You need to be very protective of the arm where your AVF is placed. This includes restricting others from inserting IV's, drawing blood, or taking your blood pressure in that arm. You will also want to check your access on a daily basis for any changes such as redness or swelling. You might be advised not to lift any heavy objects or put pressure on your access arm because this will limit circulation.

Additional Online Resources

1. www.kidneypatientguide.org.uk/site/contents.html
2. www.aakp.org
3. www.kidneypatientnews.org/VascularAccesslinks.html
4. <http://kidney.niddk.nih.gov/kudiseases/pubs/vascularaccess/>
5. www.ihf.org/IHI/Topics/ESRD/VascularAccess/Resources/
6. www.esrdnetworks.org
7. www.nephron.com/judy.html
8. www.lifeoptions.org
9. www.kidneyschool.org
10. www.cms.gov

This is a limited list to provide you with an initial list of resources to begin learning more about the benefits of having an AVF. Always speak with your physician, nurses, or other members of your healthcare team to discuss any questions or concerns.

*Frequently Asked Questions developed through a collaborative effort of
Patient Services Coordinators from the 18 ESRD Networks across the nation.*

Gronfeld cont'd

It is a wonderfully supportive group of great people who work on issues to help those on dialysis everywhere. I feel that anything I can do to help others with kidney problems or kidney failure I would be glad to do partly because it is my way of saying thanks to other people who have helped me. I've enjoyed working with all the people on this committee, and am grateful that I can continue to do so.

I was on the pediatric subcommittee for the first couple of years in the PLC, and this group was working to help the lives of children whose parents, siblings, or relatives were on dialysis. Currently I am on the vocational rehabilitation subcommittee and we are trying to encourage dialysis centers and patients to consider further education, or vocational training if they are interested in employment. I, myself, have taught preschool for the past 26 years.

I was also recommended by The Renal Network to apply for a position with the Advisory Group on Dialysis to the Ohio Board of Nursing, and I have served on this committee for one year. I have learned a lot about the other side of dialysis: the concerns of the staff at dialysis centers, especially the education of the staff to give the patients the best possible care. This has contributed to a different perspective for me, one that, I think will only enrich my position on The Renal Network.

I am interested in going to the Polycystic Kidney Disease Conference in June to learn more about current research, and ways to help other people in my situation. Not many people know that polycystic kidney disease is the most common hereditary life threatening disease in the world. Over 500,000 people in the United States alone have this disease. It can devastate families, because many times it affects more than one individual in a family.

The PKD foundation is especially interested in research to eliminate or at least control this disease. Attending this conference would give me the opportunity to meet with doctors and other professionals, and also patients who will broaden the scope of my knowledge, and give me resources to help others. I believe I will have lots of new information to bring back to The Renal Network.

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Provena Saint Mary's Dialysis Center cont'd

theater, a music concert or a sporting event that will allow the patients and their families to experience a sense of normalcy and increased sense of quality of life. The facility's goal is to demonstrate that patients are not defined by their chronic kidney disease but rather that they can successfully incorporate the management of their disease into full, productive, and satisfying lives.

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Beware Phone Scams

The Centers for Medicare & Medicaid Services (CMS) warns of a scheme that asks Medicare beneficiaries for money and checking account information to help them enroll in a Medicare Prescription Drug Plan.

This scheme is called the "\$299 Ring" for the typical amount of money Medicare beneficiaries are talked into withdrawing from their checking accounts to pay for a non-existent prescription drug plan. Consumers can report these cases to their local law enforcement agencies or 1-877-7SAFERX (1-877-772-3379).

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FLU Season

The Center for Disease Controls (CDC) advises that the flu season may extend well into May.

Although flu vaccine may no longer be available, the CDC reminds the public to practice “Good Habits For Health.”

These steps may help prevent the spread of respiratory illnesses such as the flu:

- **Cover your nose and mouth** with a tissue when you cough or sneeze—throw the tissue away after you use it.
- **Wash your hands often with soap and water**, especially after you cough or sneeze. If you are not near water, use an alcohol-based hand cleaner.
- **Avoid close contact with people who are sick.** When you are sick, keep your distance from others to help protect them from getting sick.
- **If you get the flu, stay home from work, school, and social gatherings.** In this way you will help prevent others from catching your illness.
- **Try not to touch your eyes, nose, or mouth.** Germs often spread this way.

Source: CDC FACT SHEET - Influenza Symptoms, Protection, and What to Do If You Get Sick

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In a May 2005 Primetime Live interview, Ann Serrano, wife of actor-comedian George Lopez, said of her decision to give him one of her kidneys, “There was no question. When you are put in that position where you could possibly lose someone you love, it’s a very easy decision.”

Double Kidney Transplants

A short-term study led by Dr. Robert Stratta, director of transplantation services at Wake Forest University Baptist Medical Center in North Carolina, found that transplanting two kidneys of limited function could be as good as giving one high-function organ. The double transplants were performed using kidneys that would otherwise be discarded.

The study population included 19 patients who received a pair of kidneys with limited function. The mean ages of the donors were 22 months for the pediatric kidneys and 65 years for the adult kidneys. Short-term follow-up revealed that the patients who received double kidney transplants had similar patient survival rates and kidney function outcomes to patients who received single transplants. The most significant aspect of the study was the use of donors younger than eight and older than 50 years of age and donors with conditions, such as high blood pressure, which would usually rule out participation.

About 67,000 people are on the national waiting list for a kidney transplant and only about 25 percent on the list receive a transplant each year. In 2001, the United Network for Organ Sharing (**UNOS**) developed the category of expanded criteria donors (**ECDs**) as a way of increasing sources for deceased donor organs. Although not a common procedure, double kidney transplants have been performed since the mid-1990. The use of kidneys of limited function make double kidney transplants a more possible option. Dr. Stratta’s study will help to define the ECDs standards to be used in the selection of suitable organs for transplant and of potential candidates for transplantation.

Stratta RJ et al. Experience with dual kidney transplants from donors at the extremes of age. Presented at the Central Surgical Association Annual Meeting, Louisville, Kentucky, March 9-11, 2006.

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A Gift for Rita

Today, I smiled and all at once
I thought of you.
How you shared with me
A precious part of you.

Today, I sang a memory tune
And felt my heart grow too.
Then I walked a happy mile
Along side with you.

Today, I did what I had to do
And I asked for no more.
Because I am blessed with so much
With thoughts of you at my door.

Today, I loved a little more
Thinking of thoughts of you.
And cherished twice amore
Of how much I love you.

A vibrant but unselfish thought
Lives within thoughts of you.
And in giving of yourself
Makes it fulfilling for me to do.



Martinow with sister Rita.

Rita, your simple smile is full of time
And everyday is full of more.
You bring such joy to mine
That I can only adore.

The act of love you gave to me
Is as priceless as thoughts of you.
My cup now overfloweth
With tears of love, just for you.

By Martinlow Spaulding

(Martinlow received a kidney from his sister Rita on June 2, 2004.)

April is National Donate Life Month - Celebrate the Gift of Life!

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