

The 2008 Patient Survey – what you told us

By Joyce F. Jackson, President and CEO



Every three years, we formally reach out to listen to those we serve. We do this by sending a patient feedback survey to all of our dialysis patients. Our last survey was conducted in 2005. This April, we used the same written survey as before.

Our overall response rate was 33 percent, which was lower than last time (421 patients responded compared to 574 who participated in 2005). We extend our thanks to those of you who took the time to complete the survey. Special congratulations to the units with the highest response rates: Port Angeles Kidney Center, Snoqualmie Ridge Kidney Center and Lake City Kidney Center!

The results remain very positive overall, consistent with the feedback from three years ago. We asked 27 questions and on 22 of them, our patients gave us an average score of 4.5 or higher on a 5-point scale (1 is low and 5 is high). On every question except one, the majority of patients gave us a score of 5 (the highest score possible).

“Would you recommend your Northwest Kidney Centers (NKC) dialysis center to someone who needed dialysis?” Yes, definitely, said 91 percent of the people who filled out the survey.

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Coping with kidney disease



Adapted from a book chapter written by Nancy Spaeth, BE, RN. Nancy started dialysis in 1966, has spent 15 years on dialysis and had four successful kidney transplants.

Coping:

- a. To struggle with, usually on even terms or with success.
- b. To deal with and attempt to overcome problems and difficulties.

So, you've been diagnosed with kidney disease recently or in the past. You want to deal with your health and life challenges as best you can. Finding hope and gaining knowledge are ways to get through this difficult time.

Disbelief, anger, fear, depression and denial are all common and normal reactions to big changes or losses in our lives. Over time, you will find that you are able to accept this disease. This important step is the key to moving forward in your life. There's no going back, but you can feel better.

First, you have to want to be as healthy as possible and then be willing to work for it. You can be a healthy person with a kidney problem. You're reading this article so you must be willing to try.

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What are the “Conditions for Coverage” and why should I care?

All dialysis programs in the US are regulated by federal rules. These rules are called the “Conditions for Coverage.” If Northwest Kidney Centers (NKC) or other dialysis units want to stay open, serve patients and be paid, we must comply with the Conditions. The government can literally shut down a dialysis unit if they believe it is not following the Conditions.

The federal government agency that makes the rules is called CMS – Centers for Medicare and Medicaid Services. They haven’t changed the Conditions for 32 years. New Conditions were released in the spring and they will be effective October 14, 2008. In mid-August, we received the 300-page “Interpretative Guidelines” that tell us exactly what CMS expects. Now, we must move quickly to make specific changes.

Our major goal this year is to adapt to the new Conditions. We must partner with our patients to do this. We’re in this together! In its press release, CMS stated “The rules focus on the importance of patient rights, patient safety and patient’s participation in the development of his or her own plan of care.”

We’ve compared what we do today to the new rules and we need to make changes in collaboration with you. For instance, you – the dialysis patient – or your designee, will be invited to give input on your care plan. Your doctor will be involved in the assessment and plan process and will lead the team of your dietician, social worker and nurse who will complete the plan together and share it with you.

The Conditions require us to have documentation in our medical record that your physician sees you every month, in the dialysis unit or in the office. Please keep your appointments with your nephrologist! These

rules apply to home, as well as in-center, patients. For the most part, while the rules are very strict, we anticipate that patient safety and quality throughout the U.S. will improve. We’ll be working together with each of you to adapt to the Conditions. We will try out new processes, listen to you as to how they are working, and then make modifications, if the Conditions allow us. We will use our best listening and communication skills to adapt to change together. It may be hard for you and for us to change. We’ll have to be patient with each other.

Thank you for working together with your dialysis unit staff and your doctors to adapt to the new Conditions for Coverage.



Results from the patient survey told us that your satisfaction is most closely related to how you are treated as a person by all NKC staff.

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What is most important to you? Just as in 2005, your satisfaction is most closely related to how you are treated as a person (respect, concern) by all NKC staff. Eighty-seven percent of you told us we were “Excellent” or “Very Good” at this.

What are the concerns?

The lowest rated question was “The dialysis chair is comfortable enough during my treatment.” Clearly, NKC patients are not satisfied that the NKC dialysis chair is comfortable enough.

Also, on five questions, you gave us slightly lower marks (for example, 4.7 instead of 4.8) compared to last time relating to: protection of privacy, your involvement in treatment, being treated with respect, feeling listened to,

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and being given information. We are taking this feedback very seriously, and will respond to this slight dip in satisfaction.

In the last three years, we've focused on improving needle-puncture skills of unit staff. The responses about this showed steady results compared to 2005. Fifty-seven percent of you told us the staff are always skilled and competent in inserting needles.

We asked, "As a new patient, I learned about my kidney disease and treatment from NKC unit staff." The average score was 4.3, which is lower than most questions.

We received comments from 218 people who gave feedback. You gave our staff many compliments about their care, attention and skill. Your concerns included chair comfort, being treated with respect, how clean the unit is, how much control you have over your care, and communication issues with staff.

We added a question about how you feel about your overall health. The results are that 61 percent of you said your health is "excellent," "very good," and "good." Thirty-nine percent said "fair" or "poor."

What are we going to do with this?

Our board, managers, doctors and staff are reviewing the results right now for NKC overall and for their own units. They appreciate the positive scores and are seriously reviewing the concerns. We will report in the next issue of *Output* our "Action Plan" that will respond to your feedback. Each unit will prepare an action plan tailored to the feedback from that unit.

Thank you very much for taking the time to complete this survey. We value your input very much.

Kidney Research Institute one of the first in U.S. dedicated solely to kidney disease research studies



"Never has there been an era with so much scientific data. But how can, how should, those data be applied to the treatment of a disease that afflicts more than 26 million Americans," wonders

Jonathan Himmelfarb, MD. Himmelfarb arrived in Seattle in June to begin directing of innovative research studies conducted by a new research institute, the Kidney Research Institute (KRI) – a partnership between Northwest Kidney Centers and the University of Washington Division of Nephrology. Himmelfarb hopes the results from multiple upcoming studies will translate ultimately to better care, a higher quality of life and lower mortality rates for those suffering from kidney disease.

"Data have confirmed a very high rate of kidney disease in our society, and that there are a multitude of problems that kidney patients face, including an uncommonly high mortality rate," Himmelfarb said. "It is time to aggressively seek new approaches to identifying kidney disease early and preventing its progression; discover better predictors of kidney-disease associated risk; find new, effective treatments for advanced kidney disease through relevant research; and then translate these discoveries back into direct and improved care for the patient."

More than twenty-seven percent of Medicare's budget is spent on patients who have kidney disease. It is, Himmelfarb believes, an under-appreciated public health issue in our time. He is particularly concerned with the connection between kidney disease and

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We can choose our own road

By Sonja Coffman, Community and Patient Relations Coordinator



In 1920, poet Robert Frost wrote these lines at the end of a famous poem –

“Two roads diverged in a wood,
and I –

I took the one less traveled by,

And that has made all the difference.”

I was reminded of this poem today when I was talking to a woman who dialyzes at NKC. She’s a very inspirational person with a long history of living with kidney failure. She has experienced many difficult things the rest of you have – and more than some.

Though growing up in her family was not a happy or loving experience, this woman was determined to make different choices for her life. She decided to choose a road “less traveled by” – a new direction compared to her childhood.

What choices led her down this different road?

- She vowed that her own family would always be a place of unconditional love and warmth.
- She knew that every minute of every day, she had a choice about how she’d live her life. It could be a negative experience or it could be the choice of kindness, love, positive energy and faith. She chose the latter road, and that has made all the difference.

We may not have a choice of what befalls us, but we do have choices about how we look at and think about them, and how we cope with them. I hope the message of this woman’s life choices can give you encouragement when making your own choices. She certainly is a wonderful role model to me.

NKC volunteers are Seafair royalty

By Syrenka Slettebak, Manager of Community Health Education Programs



Ashley Nonato (left) is Miss Filipino Community, and Mika Kusumi is Miss Japanese First Princess.

Seafair is Seattle’s unique summer celebration. It is a series of ongoing festivities that occur over a period of two months, from June through August.

Every summer, Northwest Kidney Centers (NKC)

takes part in several Seafair events. This year, NKC was an

exhibitor at Hispanic Seafair, the Chinatown-International District Summer Festival, and Pista sa Nayon: Filipino Seafair. NKC’s mascot, Sidney, and outreach volunteers regularly attend these community events in order to raise awareness about kidney disease.

This summer, for the first time ever, two NKC volunteers were appointed Seafair princesses! Ashley Nonato is Miss Filipino Community, and Mika Kusumi is Miss Japanese First Princess.

Ashley Nonato volunteered at NKC’s Elliot Bay Kidney Center for several months, and then recently became a community outreach volunteer. She was inspired to volunteer because of her beloved grandfather who was a dialysis patient. Mika Kusumi first volunteered at Lake City Kidney Center when her mother worked there as a nurse. Now, Mika volunteers for NKC events, such as the Fest and Expo, and does community outreach with her family.

Both young women are dedicated NKC volunteers, wonderful community representatives, and highly deserving of their Seafair titles.

Coach's Corner

Come laugh with me

By Sharon Pahlka, Kidney patient and life coach



“Will you come laugh with me,” my friend asked. She invited me to a “laughter club,” a new trend for achieving better health. Many of us are learning the key role laughter plays, especially as we get older. I remember a dinner with two

close friends, when I started describing a bummed date. Somehow, my description and timing were just right and we all began laughing hysterically.

Letting our mischievous inner kid come out to play is not only fun, it's good for our health, especially those of us with a chronic illness. Laughter is nature's multi-purpose medication.

- It relieves stress and tension, improves breathing and helps digestion.
- Researchers believe that humor may cause chemical changes in the brain that help our body's resistance to illness.

Some hospitals are so convinced of the benefits of laughter they have started “humor programs,” including a “Laughmobile” full of funny audio tapes, books, and toys, and laughter workshops to encourage staff to add humor to their work and lives.

Choosing humor to approach life's problems, rather than anger and hostility, helps me take my situation and myself less seriously and give my faults less weight. Here are some ideas:

- Make your own laughmobile: put funny movies, cartoons and books in a basket where you can find them.

- Send a silly note, balloons, or funny item to a friend who needs cheering. (I love to send silly singing cards.)
- Most important, adopt an attitude of playfulness. Let others know you are a person who knows how to laugh.
- Invite a friend to come laugh with you. You figure out how to make it happen.

Coaching Question: When was the last time you laughed so hard you cried?

Coaching Tip: Try to laugh at least once a day. (Twice is better!)

Quotes: “Were it not for my little jokes, I could not bear the burdens of this office.”
Abraham Lincoln

“A merry heart does good like medicine.”
Proverbs 17:22

“If I had no sense of humor, I should long ago have committed suicide.” *Mahatma Gandhi*

Coping with kidney disease

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I've heard over the years that people are in denial. This means that they are unwilling to accept their kidney disease, follow their diet, take their medicines or stick to their dialysis schedule. They may lie around the house and complain to their family and friends.

These are self-defeating emotions and can lead to a downward spiral into a deep hole of sadness and depression. It's hard to climb out of holes when you feel weak, hopeless or sorry for yourself. The more depressed you are, the harder it is to crawl out. Although depression is very understandable in this situation, I suggest that you keep the hole as shallow as possible. The keys are activity and information – to stay active physically, mentally and emotionally. This is how you keep your spirit and body in balance.

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I am going to suggest another type of denial. You can also deny your kidney disease the chance to pull you down into a hole or distract you from taking good care of yourself. Choose to be thankful that dialysis and transplants are available now when they weren't 50 years ago. Make the most of your life. People choosing to look at life this way see dialysis, their diet, medications, and physical activity as tools to help build a better life – to keep them out of the hole. This is called coping well!

You might start by setting goals, both short term and long term. Keep your goals realistic and don't set yourself up to fail. Long-term goals might be to continue to work or go to school, to raise your children, or learn to dance, or to volunteer or travel.

Whatever your goals are, write them down and put them in a place you see every day, such as the bathroom mirror.

Long-term goals might feel too big for you right now. So, also set some short-term goals that will get you and keep you in shape. Then you can pursue the long-term goals later. Put these on the mirror, too.

A few examples are:

1. Get up every day and get dressed.
2. Walk for 10 minutes today and add 1 to 2 minutes every day or two.
3. Always take medicine on time every day.
4. Stay within salt and fluid guidelines.
5. Get as much dialysis as you can.
6. Rethink your angry thoughts. Instead of thinking, "I'm upset with that dietitian for telling me what not to eat," I will think, "I don't like my new diet limits, but I will follow them for better health. "

Now you're cooking. You are staying out of the hole or beginning to climb out. Thinking of life as a journey can be very helpful. There are rough roads, storms and unexpected barriers. You will weather the trek if you are at your strongest and your best. And, you can better enjoy the beautiful views and fun along the way.

Exercise, activity and good sleep are wonderful tools to ward off depression. Sometimes you may need help. Talk with your doctor about depression, pain or sleep problems. There are non-addicting medicines to help with these problems. Your doctor may be able to solve other health problems that are making it difficult to sleep. Talk with your dialysis center's social worker if you feel you need help with counseling.

It's important that you learn:

1. Everything you can about your disease and treatments.
2. To ask your doctor questions and be partners in solving problems.
3. What you can and can't do physically.
4. To break big problems down into smaller tasks, making them easier to solve.
5. To keep moving forward every day.

Inch by inch, and day by day, you can climb out of the hole. Learn about all the tools you can and put them to use to improve your life.

You are still *you*. *You* are valuable. Most important, *you* are the manager of your body and your life. Your doctor, nurse, dietitian, social worker, vocational counselor and others can give you advice on what to do and maybe even how to do it. But, **YOU** are the only one who can actually do it! Good habits and a number of tools make good "copers."

Kidney Research

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heart disease. "Kidney patients are far more likely to die prematurely from cardiovascular-related illness rather than developing end-stage kidney disease requiring dialysis or kidney transplantation. If end-stage kidney disease does develop, then the cardiovascular risks are further multiplied."

Active planning for several studies is already under way at the new Institute. One study centers on improving vascular tolerance to dialysis; the second contrasts the effects of two common heart medications in patients with kidney disease.

In addition to his directorship of the KRI, Dr. Himmelfarb has been appointed a professor in the University of Washington Department of Medicine, Division of Nephrology, and is the first holder of the Joseph W. Eschbach, MD, Endowed Chair in Kidney Research at the UW. Before coming to Seattle, Dr. Himmelfarb served as Chief of the Maine Medical Center's Nephrology Division, Director of the kidney transplant program and as Associate Chair of the Department of Medicine for research. He serves on the editorial boards for Kidney International and the Journal of the American Society of Nephrology.

For information regarding the Kidney Research Institute, go to:

www.nwkidney.org, or call Jane Pryor, Vice President of Development, at (206) 292-2771, ext. 5354.

The *Output* is published bi-monthly for kidney patients and interested persons by the Northwest Kidney Centers. It is available on our Web site at www.nwkidney.org.

The *Output* provides general information and is not intended to serve as a treatment guide. Patients must never change their treatment unless directed to do so by their doctor or transplant team.

Values: Service • Excellence • Integrity • Teamwork • Stewardship
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PKD Walk, September 20

Calling all patients, families, caregivers, friends and anyone else that wants to join the fun

By Fredrika McQueen, NKC Team Captain for the PKD Walk

Join the Northwest Kidney Centers (NKC) team for the 2008 Walk for PKD (Polycystic Kidney Disease)! Our team goal is to raise as much money as possible for PKD research and spread knowledge about kidney disease. Eighty-five cents of every dollar raised will go toward PKD research and patient education. We will also use the walk to raise awareness of NKC and continue our outreach and education mission about all types of chronic kidney disease.

Help us raise money and awareness! Support our team and get us closer to the finish line - a CURE for PKD!

Every penny helps and is greatly appreciated by all parties involved, so thank you in advance for your help and support. If you'd like to join the NKC team, we'd love the company; if you just want to donate to show your support, we won't complain about that; and if you'd like to volunteer at the walk either for NKC or for the Seattle Friends Chapter of the PKD Foundation, that's great too.

This year's walk is Saturday, September 20, at Magnuson Park in Seattle. Check-in and registration start at 9 a.m.; the walk begins at 10 a.m. For more information or to join the NKC team, check out our team page at: http://walk.pkdcure.org/site/TR/Events/SeattleChapter?team_id=31620&pg=team&fr_id=1857, or you can contact me directly at: fmcqueen31@comcast.net or (206) 920-3375.

Thanks to everyone past, present and future who provides such great support.

2008 COMMUNITY CALENDAR



Sunday, September 14 Cascade TRIO Softball Game and Picnic

Time: 1:00 p.m. – 4:00 p.m.
Location: Tibbetts Park,
Issaquah

Are you waiting for a transplant? Join transplant recipients, living donors, donor families and friends at this fun and special event. Contact Irwin Etter at (206) 364-0813 or etterir@comcast.net.



Saturday, September 20 PKD Walk

Time: Registration begins
at 9:00 a.m.; Walk begins at
10:00 a.m.

Location: Magnuson Park in northeast Seattle
Join the NKC Team and walk with us or
volunteer at the NKC information table!
Contact Fredrika McQueen at (206) 920-3375
or fmcqueen31@comcast.net.



Saturday, September 20 Olympic Peninsula Health Fair

Time: 10:00 a.m. - 3:00 p.m.

Location: Sequim High School gymnasiums
For information, contact Brigid at
(360) 417-6765 or brigidwoodland@aol.com.



Wednesday, September 24 Scribner Courage in Health Care Award Program

Time: 6:00 p.m. – 8:00 p.m.
Location: Harborside on Lake
Union

The Scribner Courage Award is given to health care professionals who have made an extraordinary contribution through the exhibition of personal courage. For tickets and information, contact Marcie Wirtz at (206) 292-2771, ext. 1107, or wirtzm@nwkidney.org.



Saturday, September 27 Chinese Information & Service Center's Health Fair

Time: 10:00 a.m. - 3:00 p.m.

Location: CISC's International Family Center
in Seattle's Chinatown.

For more information, view the CISC's Web
site at www.cisc-seattle.org.



Saturday, October 4 Start! Puget Sound Heart Walk

Location: Qwest Field, Seattle

For information, view the American Heart
Association's Web site at www.americanheart.org.



Saturday, October 11 Step Out: Walk to Fight Diabetes

Location: Seward Park,
south Seattle

For information, view the American Diabetes
Association's Web site at www.diabetes.org.