

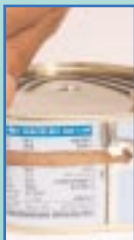
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Inside this issue:

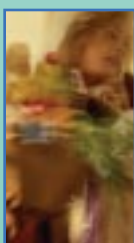
EMERGENCY MEAL PLANNING



It is important to plan for your nutritional needs in case of an emergency.

—Page 6

LESSONS LEARNED FROM DISASTERS: A GUIDE FOR EVERYONE



This guide will help you be ready if disaster strikes.

—Pages 8–9

THE ROLE OF THE ESRD NETWORKS DURING DISASTERS PAST AND PRESENT



The efforts of the ESRD Networks help to ensure care for people on dialysis during a crisis.

—Page 14

NEXT ISSUE QUALITY



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Summer/Fall 2006

DISASTER PREPAREDNESS

When DISASTER STRIKES

By Preston A. Englert, Jr., CAE
Director, NKF's Gulf Coast Assistance Initiative

We are defining the necessary steps and creating plans and systems to help people become prepared and ready to take action when the next disaster strikes.



IN SEPTEMBER 2005, I WAS HONORED THAT JOHN DAVIS, CEO OF THE NATIONAL KIDNEY FOUNDATION (NKF), asked me to serve as Director of the Gulf Coast Assistance Initiative for the NKF.

This appointment came just days after Hurricane Katrina destroyed the Gulf Coast. Having been raised in New Orleans and with family still living in the affected area, this assignment was of particular significance to me.

The NKF, I am proud to say, took action immediately after the storm. Within 24 hours, they created an e-mail list (listserv), making it possible for the medical community, government, large and small dialysis organizations and professional and voluntary organizations to communicate with one another for the first time since the storm hit. We all rely on cell phones, e-mails, landlines and even daily mail delivery, none of which were available following the storm. Outside of the immediate storm area, that listserv allowed instant communication and became a lifeline—a way to

share problems, needs and solutions, as well as the status of what was a rapidly changing situation.

The Centers for Medicare and Medicaid Services (CMS) set up daily conference calls with as many as 75 to 100 individuals participating. On these calls reports were made on the number of units that were damaged in each state, with updates given on those likely to re-open and when, and those expected to stay closed. We discussed the need for supplies, such as dialyzers, monitoring devices for diabetes, and scales; securing

additional dialysis unit staff to help overburdened units; how to locate missing patients and how the various organizations could work together to resolve these critical concerns.

Shortly afterward, I flew to Houston, Texas and met with leaders in the NKF of Southeast Texas and the Houston dialysis community to learn how the NKF could help. We visited the Astrodome and Reliant Center to talk with people on dialysis and to ensure they were receiving the necessary treatment. Here we saw both large and

Continued on page 3

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

Although it wasn't planned, ironically, as we complete this issue of *Family Focus* on disaster preparedness, once again we are in hurricane season. The thoughts of facing yet another hurricane are frightening, as many of the horrendous aftereffects of hurricanes Katrina and Rita still remain and will be with us for some time to come.

Living in the Midwest, I have never had to face a hurricane, but heading to the basement after a tornado siren is something I have been accustomed to doing since childhood. Regardless of the type of disaster, be it a hurricane, tornado, fire, earthquake or flood, being prepared for it can make the difference between death and survival. This is true for every person confronted with a disaster.

Having chronic kidney disease and being on dialysis, however, further complicates any of these situations. Not only would individuals have to deal with the same issues that might face anyone, such as securing housing, food and transportation,

they must also assure that they can get life-sustaining medications, medical care and dialysis treatment. Even obtaining food and transportation takes on added importance; a person on dialysis cannot necessarily eat whatever is available and transportation to dialysis is imperative. If someone is dialyzing at home, whether on peritoneal dialysis or hemodialysis, additional issues must be addressed. Is the home still a suitable location to perform treatment? Is the structure where an individual dialyzes safe and does it have plumbing and electricity? How does a person get the supplies necessary for treatment? How does one contact dialysis staff in the event of questions or problems?

It is our hope that none of our readers will ever face these types of situations. However, if you do, we believe that reading this issue of *Family Focus* carefully and following its advice



Karren King


will assure that you are prepared.

Sadly, I want to acknowledge the death of David Jones, a remarkable individual who was our Patient

Editor and had served on the Executive Committee of the National Kidney Foundation's Patient and Family Council. David's wisdom and gracious personality will be greatly missed.

Josephine Mahi has joined us as Patient Editor. Josephine has chronic kidney disease and has been on in-center hemodialysis since 2000. She has a long

history in the field of communications and health writing. She has also done health radio advice spots on an FM radio station in South Dakota. Josephine serves on the National Kidney Foundation Patient and Family Council Executive Committee.

Also, it is that time of year when your Editorial Board will meet and plan the *Family Focus* issues for 2007. Please let us hear from you about the topics you want addressed. We will continue to strive to bring you timely, important information that gives you the **knowledge** you need to be in **control** of your health and life. 

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



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

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John Harris, 59

New Orleans, Louisiana

JOHN HARRIS, 59, SUFFERS FROM CHRONIC KIDNEY DISEASE AND IS USED TO LIFE PRESENTING HIM WITH CHALLENGES.

John's brother, Paul, traveled to New Orleans to visit, and both went to sleep early that Sunday night because John had a dialysis treatment the next day. But neither of them was prepared for what would happen a few hours later.

"I remember waking up, and all of a sudden there was water throughout the first floor of the house," John said. "I kept hearing my brother yelling to get my attention because he was being dragged out of the window by the current of the water—trying not to get dragged under the water."

John fell off the bed and remembers panicking, not knowing if his brother was hurt, fighting to avoid being pulled out the second-story window by the current.


"I couldn't see the floor," he says of the sight that greeted him as his bed floated in six feet of water toward a newly broken window in his bedroom. John tried to get out of the house but found his front door blocked by a 30-foot fishing boat that had landed on his porch. So he kicked through the window and swam to the nearest roof, where his brother stood. Paul pulled John to safety.

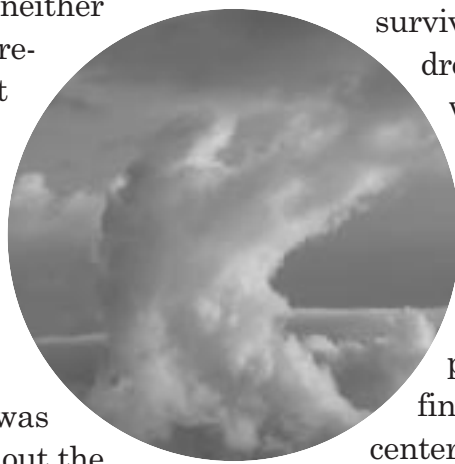
"We spent the night clinging to the roof in complete fear of falling asleep and drowning as the flood waters swept past

us," Paul remembers. "Throughout I was terrified for my brother, who was getting weaker because of dehydration and a fever, and he was missing his dialysis treatment on top of it all."

Three days later, the brothers were found still hanging on that rooftop by a neighbor who was canvassing the area for survivors. The neighbor dropped them off with a Coast Guard boat, which then delivered them to the Superdome. The problem, then, was finding a dialysis center. "When we first got to the Superdome, we didn't know what to do or where to go for help. John needed medical attention, and the Superdome was pure chaos."

Luckily, Paul found Rachel Wilson, a registered nurse who was volunteering at the Superdome, and told her of John's medical needs. "She immediately got on the phone with some organization, which I found out later was the National Kidney Foundation, that provided her with a list of out-of-state dialysis centers that could help my brother," Paul said. "Through the help of our family members, John was able to get a flight out of the area, and made it to a hospital, where they gave him his treatments."

After a week of relocating from one city to another, Paul joined his brother in Baton Rouge where John received his medication and treatments. "Without my neighbor, the Coast Guard, the volunteers, doctors and nurses, we probably wouldn't be here today." 



Disaster Strikes...

Continued from page 1

small dialysis units working hand-in-hand to give patients the best care possible under the most difficult conditions. We saw major accommodations being made by units—such as the addition of weekend shifts—to ensure that dialysis treatments were available for all those who needed it. We saw people who came prepared with copies of their medical records in plastic bags, which protected vital treatment information.

In spite of the dedicated efforts of the kidney community, problems remained. Many people on dialysis were moved from shelter to shelter and received dialysis at different units for each treatment. When they were moved, their special needs often were not taken into account. For example, when transferred from a large shelter (Astrodome) to a smaller church shelter, the need for transportation to and from a dialysis unit was not planned. Additional problems for those on dialysis included lack of eligibility for Texas Medicaid for non-Texas residents, which also added to transportation problems.

The great difficulty I had in traveling into the storm-damaged areas was a minor example of the circumstances people living there were coping with daily. How could the doctors who had evacuated be reached? Where could dialysis be done? Was there electricity? Could hospital emergency rooms cope with the needs of people on dialysis? The NKF of Louisiana offices had been hit by the storm and staff members were without homes and resources, too.


Meanwhile, the NKF continued to respond. A special Web site was created as a source of information for professionals, people

on dialysis and their families and the public. An emergency message system was added to the NKF toll-free number where people could find and offer help.

As the Gulf Coast and its citizens have struggled to rebuild, the NKF has continued to address the problems that arose during the awful days of Katrina and Rita, and is working with CMS, organizations and industries throughout the kidney community in the Kidney Community Emergency Response Coalition, which represents the broad spectrum of organizations committed to assisting in the event of a future emergency or disaster. We are defining the necessary steps and creating plans and systems to help people become prepared and ready to take action when the next disaster strikes.

The NKF's National Organization continues to support the NKF Gulf Coast Affiliates' patient services programs for those affected by the 2005 emergency. The NKF's National Organization also continues to provide leadership and support for the Kidney Community Emergency Response Coalition as well as serving as the chairman for the Communication Response Group and providing members for the Federal Response Group and Patient Assistance Response Group.

We would like to thank Amgen, Satellite Healthcare, Inc. and the many individuals who contributed to the NKF's Patients Hurricane Fund.

Preston A. Englert, Jr. serves as the president and CEO of the NKF of the National Capital Area and is originally from New Orleans, LA. 

HURRICANE KATRINA WAS ON HER WAY, AND AS OF AUGUST 26 AND 27, 2005, despite mandatory evacuation orders, 50 percent of people on dialysis from metropolitan New Orleans were still in the city. Many of them arrived at the Louisiana Superdome. There was nowhere else for them to find shelter, and there were no available vehicles for evacuation. There was no water to drink, and of course, no access to water for either peritoneal dialysis (PD) or hemodialysis.

When they arrived at these shelters, those individuals who were able to travel were lucky enough to move on to the open arms of other dialysis unit staff in surrounding areas. These welcoming arms were mainly those of staff located in End Stage Renal Disease (ESRD) Network 13 units—covering Arkansas, Louisiana and Oklahoma—although units around the country were also involved. ESRD Network 13 and the small and large

KATRINA WATER: The Good, the Bad and the Ugly

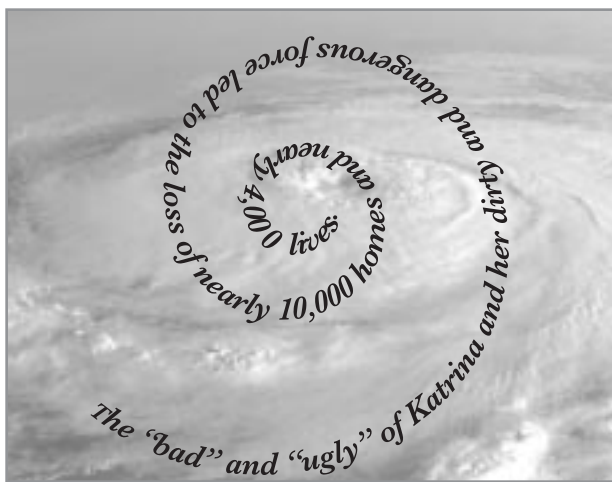
By Jill Linberg, MD, FACP

The damaging effects of Hurricane Katrina taught us to prepare for the future.

dialysis providers went above and beyond the call of duty to welcome and treat all people on dialysis who escaped the flood waters of Hurricane Katrina.

Those who stayed in metropolitan New Orleans spent many tortuous, hungry and thirsty days and nights. They had to walk through polluted water, and some lived on rooftops. Eventually, the luckier ones were brought to a triage center at the New Orleans International Airport, where they were later sent to appropriate medical and dialysis facilities. Our role at East Jefferson

General Hospital (Metairie, LA), was to receive these individuals from rooftops and from contaminated homes and waters of the New Orleans metropolitan area. East



Jefferson was fortunate to have electricity and clean, filtered water during the entire storm and its aftermath. I am proud to have been a part of

the dialysis team, who slept on stretchers for two to three weeks, worked long hours and found one Hot Pocket meal a most delicious dinner. As a team, we created an oasis for those rescued. What in the past had seemed so simple: a clean dry bed and clean water to drink and for dialysis had become a luxury. The “bad” and “ugly” of Katrina and her dirty and dangerous force led to the loss of nearly 10,000 homes and nearly 4,000 lives. With that fact in our minds, hearts and souls, we as a health care providing community strive to continue to do our best. We plan to do better “next time.”

Unfortunately, the next time is now, as the hurricane season has been underway since June. Wish us luck and keep us in your prayers!

Jill Lindberg is the director of the Metabolic Bone & Stone Clinic in Metairie, LA.

F a m i l y F o c u s V O I C E S



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?

By Mary Beth Callahan, ACSW, LCSW

MANY IMPORTANT THOUGHTS WERE RECEIVED in response to this question that can be useful whether the emergency is a flood, hurricane, tornado or earthquake. One of the important comments shared relates to “ICE” meaning “In Case of Emergency.” ICE is your emergency contact’s phone number that should be stored on your cell phone. Another person discussed rotating food supplies that could last three days in case of emergency and keeping prescription data in print and on a CD in a plastic bag in the car. Several individuals also spoke of the importance of knowing exit routes from their homes, locations of hospitals in areas that are protected from the potential disaster and friends with four-wheel drive vehicles.

One dialysis and transplant recipient of 33 years and a lifelong surfer and waterman,

spoke about paying attention to weather conditions and being prepared. He noted that keeping a stash of emergency medication in an extra heavy-duty plastic bag that can take a beating is a good idea.

Several people also spoke about keeping two to four weeks worth of important medications stashed away as well as having a large generator, bottles of water, batteries, flashlights, candles and matches. Another person spoke of the importance of keeping bandages and hand wash readily available. One person related the importance of realizing that if you are a dialysis patient, the poison in your body will accumulate if you are not able to receive dialysis because of a disaster. She noted the importance of controlling fluid intake, storing nutritious food, avoiding food with too much salt and

keeping a list of important telephone numbers including your doctors and pharmacies.

Another person shared that important papers such as your Social Security card, insurance card, birth certificate and deeds should be kept in a plastic bag and taken with you if you need to leave your home.

Thinking of needing to leave your home because of an emergency can be a very scary thought. However, planning as much as you can before an emergency happens can make a big difference in how much you worry if something does happen.

Mary Beth Callahan works as a transplant social worker at the Dallas Transplant Institute in Dallas, Texas.

The following list has been put together to help you in the event of an emergency.

Essential information for people on dialysis and transplant recipients

Kidney Community
Emergency Preparedness and Response:
888.33KIDNEY (335.4363),
www.kidney.org/help

Help getting dialysis in an emergency

The Forum of End Stage Renal Disease (ESRD) Networks: 804.794.2586
Nephron Information Center:
www.dialysisunits.com

Planning for an emergency: brochures, checklists, and other publications

National Kidney Foundation (NKF): 800.622.9010,
www.kidney.org
■ *Planning for Emergencies: A Guide for Kidney Patients*
■ *Planning for Emergencies: A Guide for Dialysis Facilities*
■ Fact sheets: *Emergency Meal Planning, Emergency Meal Planning for Diabetics*

American Association of Kidney Patients (AAKP): 800.749.2257, www.aakp.org
■ Emergency Guide
■ Patient Emergency Information sheet

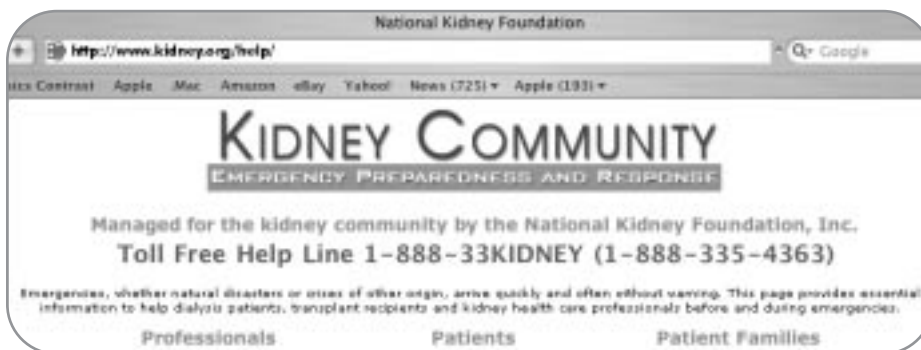
Centers for Medicare and Medicaid Services (CMS): 800.MEDICARE,
www.medicare.gov

■ *Preparing for Emergencies: A Guide for People on Dialysis*, Publication # CMS 10150 (available in Spanish)

Federal (Department of Health and Human Services) emergency checklist:
www.pandemicflu.gov/planguide/emergencycontacts.pdf

The Nephron Information Center:
www.dialysisunits.com

EMERGENCY RESOURCES For People With Chronic Kidney Disease



www.kidney.org/help

- Meal plan for disasters and emergencies

Helpful organizations in an emergency

American Red Cross: 202.303.4498,
www.redcross.org
Federal Emergency Management Agency (FEMA): 800.621.FEMA (3362), 800.462.7585 (TTY);
www.fema.gov

Food and Drug Administration (FDA): 888.INFO.FDA (888.463.6332), U.S. hurricane site: www.fda.gov/cdrh/emergency/hurricane.html

National Hurricane Center:
www.nhc.noaa.gov

National Weather Service:
www.weather.gov

U.S. Department of Housing and Urban Development: 202.708.1112, TTY: 202.708.1455;
www.hud.gov/katrina

Emergency financial grant information

American Kidney Fund (AKF): 800.638.8299, 301.881.3352, 866.300.2900 (Español); www.akfinc.org

AAKP: 800.749.2257, 813.636.8100,
www.aakp.org

American Red Cross: 202.303.4498,
www.redcross.org

Caregiver Emergency Respite Fund: 317.713.2979,
www.caregiveremergencyrespitefund.org

FEMA: 800.621.FEMA (3362), 800.462.7585 (TTY);
www.fema.gov

NKF: 800.622.9010, 212.889.2210;
www.kidney.org or

Kidney disease organizations

NKF: 800.622.9010, 212.889.2210;
www.kidney.org or

AAKP: 800.749.2257, 813.636.8100; www.aakp.org

AKF: 800.638.8299, 301.881.3352;
www.akfinc.org

The Forum of ESRD Networks: 804.794.2586,
www.esrdnetworks.org

The Nephron Information Center: www.dialysisunits.com

Mental health resources

American Association of Retired Persons (AARP): 888.687.2277,
www.aarp.org/griefandloss
American Academy of Child and Adolescent Psychiatry: 202.966.7300,
www.aacap.org

Anxiety Disorders Association of America: 301.231.9350,
www.adaa.org

Centers for Disease Control and Prevention (CDC): 800.CDC.INFO, 888.232.6348 (TTY); www.bt.cdc.gov/mentalhealth

Department of Health and Human Services: 800.789.2647, www.mentalhealth.samhsa.gov/disasterrelief

Depression and Bipolar Support Alliance: 800.826.3632,
www.dbsalliance.org

GriefNet.org:
www.griefnet.org

Growth House: www.growthhouse.org

National Association of the Mentally Ill: 800.950.NAMI (6264), www.NAMI.org

National Institute of Mental Health: 866.615.6464,
www.nimh.nih.gov

NKF's *Family Focus* Summer 2006 issue: www.readfamilyfocus.org

National Mental Health Association: 800.969.NMHA (6642), www.nmha.org

Posttraumatic Stress Disorder Alliance: www.ptsdalliance.org

Stress Anxiety and Depression Resource Center: www.stressanxiety-depression.org

U.S. Department of Health and Human Services: www.hhs.gov/emergency or www.mentalhealth.samhsa.gov/disasterrelief/psa.aspx

U.S. Department of Veterans Affairs—National Center for Post-Traumatic Stress Disorder:
www.ncptsd.va.gov

Thanks to Lisa Drossos, MSSW, LCSW and the Florida ESRD Network for their help in compiling this resource list.



EMERGENCIES, SUCH AS EARTHQUAKES, HURRICANES OR OTHER NATURAL DISASTERS, CAN HAPPEN WITHOUT WARNING. An emergency plan specific to your unique chronic kidney disease (CKD) needs could very well save your life.

One very important matter to consider is how to meet your nutritional needs during an emergency. In the event of an emergency, you may not be able to get to your dialysis treatments. For example, some reports in the wake of Hurricane Katrina suggested that only 50 percent or more of the people on dialysis had been located 10 days after the hurricane. These individuals, many of whom missed more than a week of dialysis treatments, often had multiple health problems, such as extra fluids and dangerously high potassium levels (1). Following a strict diet will help control the buildup of toxins and fluids in your body. To prepare for an emergency, it is crucial to have kidney-friendly, nonperishable foods (ready-to-eat goods that do not need refrigeration, such as dried or canned foods) and menu plans set aside at home.

Electricity or water may not be available during an emergency, limiting your food choices and meal preparation. Without electricity, food in your refrigerator will keep safely for up to 12 hours and in the freezer for one to two days if these appliances are opened only when needed for meal preparation. Using a refrigerator thermometer is a more accurate guide. To keep foods safe, the temperature should be below 40 degrees Fahrenheit or 5 degrees Celsius. If your refrigerator temperature is above 40 degrees F, food will only be safe for four hours. After that, the food should be thrown away, as eating it may lead to food poi-

Emergency Meal Planning

By Kristin Roach, RD, LD

You can plan to meet your special nutrition needs in an emergency.

soning. If perishable items meet these temperature guidelines, it is recommended you eat them first before using nonperishable, shelf-stable foods. Grocery lists for emergency planning are available to help you stock your supply with the right nonper-



If an emergency event should last more than three days, the menu plans can be repeated.

ishable foods. Ask your dietitian or contact the National Kidney Foundation (NKF) for the list, then pick up listed items as you can when grocery shopping. Set aside these foods specifically for emergencies to ensure you will have them if needed. Remember to regularly check expiration dates of these items and replace as needed. It is also a good idea to keep distilled water (which doesn't contain minerals that bottled water may) and disposable plates and utensils in stock. Other items to consider for your emergency plan are measuring cups, a scale, a hand-operated can opener, candles, matches and a refrigerator thermometer (2,3).

In addition to keeping a stock of food supplies, you should have emergency meal plans for at least three days. These menu plans are stricter than your usual nutrition plan, particularly for protein, sodium, potassium and fluids. For

your emergency plan, fluid intake should, in general, be limited to two cups or 16 ounces a day (4). As mentioned before, following a strict menu plan is key to keeping toxins and fluids from building up in your body. You can get these menu plans though your dietitian, kidney health care staff, or the NKF's *Emergency Meal Planning* fact sheet, which contains sample menus. If needed, the menus can be changed according to your preferences or special health needs. Your dietitian can help create menus that are right for you. If an emergency event should last more than three days, the menu plans can be repeated.

If you have CKD and diabetes, there are other recommendations. Avoid sugar and sweets as usual. Also, keep instant glucose tablets, sugar, hard candy,

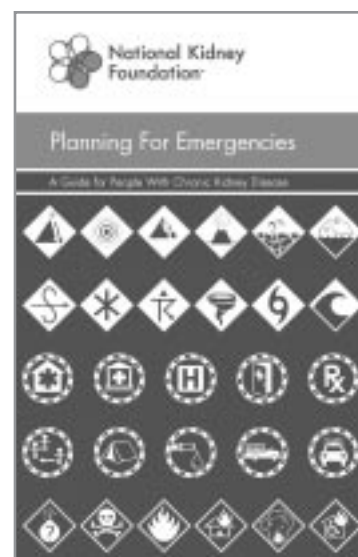
or low-potassium fruit juices in supply to treat low blood sugars. You should also have at least a two-week supply of insulin and/or other diabetes medications on hand. Other diabetic supplies, including extra batteries for your glucometer, should also be set aside.

Being prepared will pay off should you face an emergency event. Although emergencies may be unpredictable, a proper nutrition plan can help you make it through a difficult time.

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Kristin Roach is a registered and licensed dietitian. Currently, she serves as a Right Start case manager for Fresenius Medical Services. She has been practicing as a renal dietitian for more than five years.



Planning for Emergencies: A Guide for People With Chronic Kidney Disease is available for order

by calling the NKF at 800.622.9010.

AS WE BEGIN THE 2006 HURRICANE SEASON, WE KNOW ALL TOO WELL THE RUIN HURRICANES KATRINA AND RITA HAD ON THE GULF COAST, including the impact on homes, neighborhoods, businesses, property and lives. We see the destruction with our own eyes as we go about getting the materials we need to begin the repairs. Other issues that are not so easy to see are of concern to many people with chronic kidney disease and the staff who work with them in the southern Gulf region.

In the face of disaster, big or small, essential basic human needs must be met quickly. Basic needs include physical safety, security, food, water, medical and mental health care, housing, clothing, stable and consistent emotional support and accurate information about post-disaster surroundings. A survivor's well-being may be negatively affected if these initial basic needs are not met and maintained over time.

Mental health trauma and emotional turmoil that individuals, families and children endure may feel overwhelming, especially when there is not enough help to go around. Confusion, hopelessness and fear are common emotional reactions following catastrophes. Feeling victimized, helpless, frustrated and angry about what has happened is normal. Distress about what is to come may become severe and may affect an individual's ability and desire to perform routine daily activities, such as getting out of bed, eating or socializing with friends and family. Experiencing these and/or other changes, such as lower motivation, crying spells or disinterest in what is happening around you may be signs of depression and may require professional help. Stagnation (inactivity), lack of support and increased concerns may lead to

In The Face of Disaster

By Surveen K. Klein, MSW, LCSW-BACS, MPH

Emotional reactions are common after a disaster.

anxiety disorders, feelings of depression, post-traumatic stress disorder (PTSD; ref. 1) and even thoughts of harming oneself or others. If you think someone is in danger of harming him or herself or someone else, contact your emergency response number immediately.

Individuals may also experience varying stages of grief:

1. DENIAL about what happened
2. ANGER toward the situation, circumstances, losses, and costs
3. BARGAINING in an attempt to make the situation better
4. DEPRESSION, which others may recognize as changes in mood or behavior
5. ACCEPTANCE and looking toward the future (2).

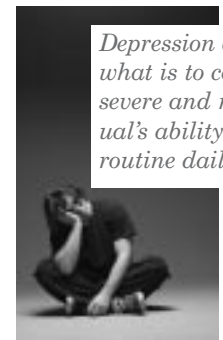
We are unique individuals, and no one person moves through these stages exactly the same way. Someone may move through the grief process smoothly, while another person may feel stuck in a certain stage. Individuals may move through one stage quickly and another more slowly, or even fluctuate between stages depending on factors such as prior coping skills and ability to cope in such an extraordinary situation. What happens in the environment, household and inside a person can affect where a person is in his or her healing process. By accepting the reality of the situation and your losses, you can then begin to move through the many emotions and feelings, including hurt, loss and grief. Continuing through this process, you may begin to experience new feelings of

renewal, restoration, healing and recovery.

If you have been through a disaster, express yourself as much as you can by talking about your experiences. Allow others to support you during this challenging time. Know that there is help available and ask for it when you need it. Encourage others to do the same. Find out about what progress is being made in your neighborhood and community.

Identify what gives you personal strength. Then draw on your strengths as you move through the healing process. Remember: There are professional mental health care providers who can help. Talk to the social worker in your dialysis unit or ask your doctor, social worker or health care provider for a referral if you think you need one.

Understand that you are not alone. You may witness an outpouring of support and desire from others who want to assist, who may or may not have firsthand knowledge of the disaster you have experienced. The process of healing and repair



Depression and anxiety about what is to come may become severe and may affect an individual's ability and desire to perform routine daily activities...

may seem scary and overwhelming. Strong support systems,

making use of available resources and knowing you CAN move forward during a very difficult time will help you as you steer a pathway to recovery.

Remember, a very important part of your support system is your medical team. Be sure to

inform your dialysis unit and transplant medical teams of your new location and new contact information if you are involved in an emergency evacuation or disaster. It is important to work with your local health care providers to help you continue access to your medical treatments and health care. If you have an emergency health care need, go to the nearest hospital emergency room in your area.

If you know people who have been through a disaster, one of the most important things you can provide is support, which includes listening and encouragement. Listen carefully and let them know you truly care about their safety and well-being. Assist them with following up with their health care treatments. Remind survivors there is hope. You may want to offer to help them understand the available resources. Do not feel as though you have to fix every problem. Chances are your assistance alone will not be a "fix-all" solution; however, the positive impact you have can be huge. Be consistent, because people you know will likely experience ups and downs during healing and recovery. Obstacles can be expected along the way. Be prepared to provide additional periodic support during their courageous road to self-restoration and recovery.

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FROM THE HURRICANES THAT HIT THE GULF COAST REGION TO A LARGE DIALYSIS FACILITY BURNING TO THE GROUND, the year 2005 has changed the way many of us think and act. What would you do if your dialysis unit disappeared? Where would you go? Who would you call? We have all heard about disaster preparedness, but many of us do not know what to do to plan for a disaster, and those who know may not have taken the time and effort to plan. Being prepared does not cost a lot of money nor does it take much time. Here are a few simple things learned from the 2005 disasters.

In July 2005, disaster struck the University Dialysis Clinic in Sacramento, California. Located in an older wooden building, the unit was one of the first to offer dialysis in Sacramento. The building housed a hemodialysis unit, a peritoneal dialysis (PD) clinic, administrative offices and two doctor's offices. Late in the afternoon someone smelled smoke, but looked and found nothing. In the hemodialysis clinic, nurses, technicians and people receiving dialysis were just settling in for the last shift. The building's offices were closed for the day. Suddenly a loud explosion rocked the building. Smoke began to come into the unit. Getting everyone out became a top priority. Teammates began to return blood, but quickly realized it was necessary to "clamp and cut" (i.e., stop the blood pump, clamp both the arterial and venous bloodlines, then cut the lines without returning the blood in order to immediately free the patient from the machine). Patients who were able to walk out to the parking lot. Others were assisted. In less than six

LESSONS LEARNED FROM DISASTERS: A Guide for Everyone

By Julie Weiss, RN

We can prepare for future disasters by looking at past events.

minutes the entire building was engulfed in flames. The five-alarm fire was the largest in Sacramento history.

Having those who had been on dialysis meet in the parking lot allowed the group to know where everyone was and that all were safe. The unit staff was able to take care of the patients while the fire department fought the blaze. Word spread far and wide. Others offered to help. A coordination center was set up at a nearby hotel. So much had to happen very quickly. More than 100 people who dialyzed at University Dialysis had to be relocated. Dialysis treatment schedules had to be created, phone lines had to be rerouted from the burned facility to another unit close by, and other patients who dialyzed at the burned facility had to be contacted. By 11:00 pm that night, nearly every person due the next day for treatment had been called. The message was simply, "Everyone is okay. Stay by the phone and you will be called back with further directions for tomorrow."

The technical difficulties during the first few hours and into the next couple of days taught us two key lessons:

1. **KEEP** your contact information up to date. It was difficult to reach several individuals with out-of-date or missing phone numbers and emergency contact information.

2. **KEEP** a copy of your health history and dialysis treatment prescription. The individuals who received dialysis in this unit were fortunate; their medical treatment information was stored electronically. This allowed other units to get the needed treatment information for people who were being relocated.

In addition, there are several important steps that can be taken NOW, before a disaster strikes.

Before a disaster or emergency:

- ✓ **GET COPIES** of the National Kidney Foundation's booklet, *Planning for Emergencies: A Guide for Kidney Patients and Preparing for Emergencies: A Guide for People on Dialysis* published by the Centers for Medicare and Medicaid Services (CMS; publication #10150) from your dialysis unit. If your unit does not have a copy, contact the National Kidney Foundation in your area or toll-free at 800.622.9010 or online at www.kidney.org. To obtain CMS publications, call 800.MEDICARE.
- ✓ **ASK YOUR DIALYSIS** team for any local disaster preparedness resources. Your local End Stage Renal

Disease (ESRD) Network will have disaster information. Your city government and state department of emergency services should also have information. Check out resources at your local library and the local American Red Cross.

- ✓ **LOOK IN YOUR LOCAL** telephone book. Most have several pages of what to do in an emergency and give local phone numbers for more information.
- ✓ **MAKE A COPY** of your health information. This should include a medication list, a list of allergies, your doctors' contact information, insurance information and your dialysis prescription. Keep this list in a safe place to take with you. Give a copy to a friend or relative in case you are hurt and unable to speak.
- ✓ **OBTAIN AND WEAR** a medical alert bracelet. This will provide important information if you are hurt or cannot talk. Your local pharmacy or dialysis unit nurse or social worker may be able to provide more information on companies that provide this jewelry and ordering it at low or no cost to you.
- ✓ **UPDATE YOUR CONTACT** information at your unit. Be sure to provide a mobile phone number if you have one. Add contact information for a friend or relative who lives out of town.
- ✓ **CREATE AN EMERGENCY** kit. A fanny pack or soft lunch bag works well. Include three to five days' supply of medicine, a

Continued on next page

To find this issue or past issues of Family Focus on the Web, go to www.readfamilyfocus.org

copy of your telephone contact list and your health information. Be sure to take it with you if you travel or have to leave home in bad weather. Put a copy of your insurance (health, home, car) information in the bag.

- ✓ **LEARN YOUR UNIT'S** disaster plan. Practice emergency evacuation. Where will everyone meet if you have to leave in a hurry? Learn how to get off the dialysis machine. Find out where your "back-up" facilities are. Identify two alternative dialysis facilities, one in your immediate area and one further away. Your social worker can help you.
- ✓ **CREATE AN EMERGENCY** food kit. Include food and supplies to last five to seven days. Ask your dietitian for a copy of your three-day emergency diet. A general shopping

list is available from your renal dietitian or can be found in the CMS pamphlet *Preparing for Emergencies* or the National Kidney Foundation fact sheet *Emergency Meal Planning*.

- ✓ **IF YOU ARE ON PD**, be sure to assemble a PD supply kit. A picnic or food cooler with wheels works well and moves easily. This should include five to seven days' worth of supplies and solutions. Take care to rotate your supplies every six months to ensure that all supplies are fresh with no expiration dates exceeded.
- ✓ **FILL YOUR CAR** with a full tank of gas at the first sign of bad weather. Always try to keep the tank at least half full. If disaster strikes there may not be power for the gas stations.

- ✓ **IT MIGHT HELP** to remind you to check your emergency supplies if you do it when you change your clocks each spring and fall and the batteries in your smoke detectors.
- ✓ **DESIGNATE A MEETING** place that is safe and well known by each family member. Knowing where everyone is to meet limits the stress of trying to contact and find each person.

During a disaster or emergency:

- ✓ **STAY CALM.** Remember that you have a plan. Following your plan is your blueprint to staying safe.
 - **MOVE TO A SAFE** place if you are in danger.
 - **GET OUT** of the building if it is on fire.
 - **MOVE TO HIGHER** ground if flooding is expected.
 - **MOVE AWAY** from windows or falling objects in an earthquake.
 - **MOVE TO A TORNADO** shelter when alerted.

Sometimes staying at home is the safest place.

- ✓ If you have to leave home, remember to take your emergency kit and supplies.

✓ If you are on dialysis, follow directions. Your team knows what to do and will provide information.

After a disaster or emergency:

- ✓ Get to and stay in a safe place. Stay near a phone and listen to the radio or television for directions.
- ✓ Call your dialysis unit and tell them where you are. You may need to call the company headquarters. Be sure to put that number on your phone list.
- ✓ Tell everyone that you have chronic kidney disease and that you require dialysis. This is important if you go to a shelter.
- ✓ Protect your dialysis access. Make sure it is used only for dialysis.
- ✓ Start your emergency diet.

Disasters and emergencies are stressful. Being prepared and having a plan will protect you and your family. Remember: The best defense is offense.

Julie Weiss is the regional operations director for DaVita in Northern California.

Disaster planning checklist

Get copies of the National Kidney Foundation's booklet, *Planning for Emergencies: A Guide for People With Chronic Kidney Disease* and *Preparing for Emergencies: A Guide for People on Dialysis* published by the CMS.

Read the Disaster section in your local phone book.

Make a medication list.

Ask for a copy of your dialysis prescription and health information.

Get and wear medical alert bracelet.

Update your personal contact information at your dialysis unit.

Request a copy of your three-day emergency diet from your dietitian.

Create your personal emergency kit.

Create your emergency food kit.

Fill out the phone list and contact information sheet (see template).

Learn about and practice your disaster plan at your dialysis unit.

Emergency kit checklist

Medication for three to five days

Phone list

Copies of insurance cards

Copy of emergency diet in case you cannot get to your food kit

Emergency contact list Phone number and/or address

Your dialysis unit

Your local back-up dialysis unit

Your out-of-town back-up dialysis unit

Dialysis company headquarters

Doctors' offices

Hospital

Family or friends

Health insurance

IN THE SPRING ISSUE OF *FAMILY FOCUS*, WE TALKED ABOUT “STAYING STRONG.” In this issue on disaster planning, we talk more about how to get stronger.

There are several ways you can prepare for disaster situations. Because people with chronic diseases are often weaker and have less stamina (energy) than healthy individuals, it is especially important that they make an effort to keep up their strength and stamina in order to be prepared for the extra physical demands a disaster situation might bring. Even if a disaster never happens, making the effort to keep up your strength and stamina is particularly important for people on dialysis because kidney disease and the dialysis process can make you prone to losing muscle and becoming weak.

Here are some basic guidelines for doing any type of strength exercises in which you lift or push weights (dumbbells, soup cans, resistance bands, machines at the gym, even your own body weight), taken from the National Institute of Aging Exercise Guide, available for free online (www.nia.gov/publications.org) or by calling 800.222.2225.

How Much, How Often

- ❑ DO strength exercises **at least twice a week** for each specific muscle group. Do not do exercises for the same muscle group two days in a row. Allow at least one day in between.
- ❑ USE the **minimum amount of weight, or no weight at all the first week or two.** This will prevent injuries by allowing your tendons and ligaments to get stronger first.
- ❑ In order to build your strength, **gradually INCREASE the amount of weight** over a period of weeks and months.

Let's Talk About Getting Stronger

By Patricia Gordon, RN, PhD

Gaining strength can help you prepare for the physical demands of a disaster.

Starting Out

- ❑ When you **START OUT**, choose a weight (or resistance) that you can lift or push 8–15 times in a row.
- ❑ Your effort **SHOULD FEEL** hard to very hard, but **not** very, very hard. When you start out, if you cannot lift or push a weight (including just your own body weight) eight times in a row, then it is probably too heavy for you. If you can lift or push it **more** than 20 times, it is probably too light.
- ❑ **TAKE** at least three **seconds to lift or push the weight; hold for one second, then take at least three seconds to lower the weight.** This is very important. Do not let the weight (even your own body weight) drop back down into place—lower slowly.

Progressing

- ❑ It is crucial that you gradually **INCREASE** the amount of weight that you lift or push. This is an important part of building muscle. However, too much weight will injure muscle and cause it to break down.
- ❑ When you **CAN LIFT** or push a weight 8–15 times, you can increase the weight the next time. However, it is best to gradually build up from 8 to 15 repetitions, and then add another one or two sets of 8–15 repetitions before increasing the weight. Remember to wait at least one minute between sets.

Safety

- ❑ **Do not HOLD your breath** while lifting or pushing the weight (including your own body weight). Breathe out while you do the hardest part of the exercise (usually the lifting or pushing part) and breathe in as you lower or relax.
- ❑ **AVOID jerking the weight into position.** If you have to jerk the weight into position, it is too heavy for you.
- ❑ **Do not LOCK the joints** (elbows and knees) in your arms and legs. When doing leg exercises, tighten your thigh muscles when straightening your knees. This will protect your knee caps by lifting them.
- ❑ **You SHOULD NOT experience pain** when you are doing the exercises, and the range of motion in which you move the weight should never hurt. If you do experience pain, stop doing the exercise and let the muscle and/or joint rest for a

few days. If you have severe pain, or continue to have pain for more than a few days to a week, you should call your doctor. When you first start out, you may have some muscle soreness for about 24 hours after you exercise. This is called delayed-onset muscle soreness and should go away within a couple of days. This is caused by microscopic injury to the muscle fibers and is very common when people begin an exercise program.

- ❑ **TALK to your doctor** for guidelines about weight lifting and your particular type of dialysis access.

Getting stronger is just one more thing that you can do to help yourself in everyday life and to be better prepared to meet its physical demands, including those in any disaster you might face.

Patricia Gordon, an exercise physiologist, is on the faculty of the Department of Physiological Nursing at the University of California, San Francisco. Her research specializes in muscle function and kidney disease.

Family focus



“It is crucial that you gradually increase the amount of weight that you lift or push. This is an important part of building muscle.”

Exercise FOCUS

Better Walking With Stronger Legs



To strengthen the calves and feet:

- ▶ Stand behind a straight back chair or in front of a counter.
- ▶ Slowly raise the heels as far as possible and hold.
- ▶ Slowly lower heels to the floor.
- ▶ Work up to 3–5 sets of 8–15 repetitions.

To make this exercise harder:

- ▶ Do it without holding on to chair or counter.
- ▶ Raise up on one foot at a time.

- ▶ Wear ankle weights.
- ▶ Hold dumbbells in each hand.
- ▶ At the gym, do this exercise on the seated or standing calf raise machine.



To strengthen back of legs and buttocks:

- ▶ Stand behind a straight back chair or in front of a counter.
- ▶ Slowly raise one foot, bending the knee until the foot is level with the knee.
- ▶ Slowly lower the foot to starting position.
- ▶ Repeat 10 times for each leg.
- ▶ Work up to 3–5 sets of 8–15 repetitions for each leg.

To make this exercise harder:

- ▶ Wear ankle weights.
- ▶ At the gym, do this exercise on the leg curl machine.
- ▶ At the gym, do this exercise on the seated or standing calf raise machine.

To strengthen inner and outer hip muscles:

- ▶ Stand with side to chair, holding on to chair back for support.
- ▶ Slowly raise leg out to the side, as high as possible, keeping the body upright and the knee straight.
- ▶ Pause, then slowly lower leg to starting position.
- ▶ Continue the motion by crossing the leg in front of the standing leg as far as possible while keeping hips and shoulders facing front.
- ▶ Do not twist the body.
- ▶ Return to starting position.
- ▶ Turn around to work other leg.
- ▶ Work up to 3–5 sets of 8–15 repetitions for each leg.



To make this exercise harder:

- ▶ Wear ankle weights.
- ▶ You can do these exercises on the hip abductor/abductor machines at the gym.

To strengthen front thigh muscles:

- ▶ Sitting straight in chair so that the edge of the seat does not cut into the back of the knee
- ▶ Keep feet together on floor.
- ▶ Slowly straighten leg and hold (do not lock knee).
- ▶ Lower slowly to starting position.
- ▶ Repeat with other leg.
- ▶ Repeat 10 times for each leg.
- ▶ Work up to 3–5 sets of 8–15 repetitions for each leg.



To make this exercise harder:

- ▶ Wear ankle weights.
- ▶ At the gym, do this exercise on the leg extension machine.

TIPS

- ▶ Do each exercise no more than every other day, but at least twice a week.
- ▶ Stop if you feel pain.
- ▶ Remember to breathe while performing the exercises; holding your breath raises blood pressure unnecessarily. Generally it is recommended to take a breath, then breathe out while doing the lifting or pushing, or the most strenuous part of the exercise. This also insures that the working muscles will get plenty of oxygen.
- ▶ Plan to do an exercise every time a television commercial comes on, or take a break in the office and do them at your desk.

Thank God for P.D.

By Steve Gideon

I'm a man who started out with kidney cancer.
They took out the kidney, I thought that was the answer.
But come to find out I had a disease in my other kidney,
And at first I thought this was gonna be the end of me.
But after my doctor talked to me about dialysis
It didn't sound so bad,
when I began dialysis I began to feel very glad.
For my kidney disease there is no cure,
But thank God for PD that's for sure.
What eases my mind are the people who take care of me.
Because if I didn't have the staff and my wife
I don't know where I would be.
If you are a candidate for Home PD
I'd think about it and say that's for me.

All you have to do is want to live,
this is what PD will give.
At first I shed a lot of tears
But after a while I overcame all my fears.
With PD I can live a long time,
This is a thought I always keep in my mind.
I pray for dialysis people every night
And one day we'll be alright.
I thank God for giving me life every day,
And I pray for many years on earth to stay.
All I have to do is believe
And for 20 or 30 years I won't have to leave.

Steve Gideon dialyzes in Springfield, MO.

WHETHER YOU LIVE IN AN AREA THREATENED BY EARTHQUAKES OR IN AN AREA THAT FEELS THE THREAT OF HURRICANE OR TORNADO SEASONS, being as prepared as possible is the ultimate goal. When a natural disaster or other kind of emergency strikes, everyone—including transplant recipients—benefits from the same good preparation. In addition to preparing for a large-scale disaster, a transplant recipient should also prepare for what could be called the “mini” disaster. An example of a “mini” disaster might be a delay in the delivery of your mail-order medications, causing your supply of immunosuppressive (anti-rejection) medications to run dangerously low. Good planning can help with disasters large or small!

Although a transplant recipient needs to take the same basic steps as everyone else for disaster preparedness, some additional steps will help you be prepared for situations particular to the special needs of a kidney transplant recipient. The following are some tips for transplant recipients to help prepare for any type of emergency.

GENERAL TIPS

- **KEEP** bottled water on hand for drinking. Hydration is very important to a transplant recipient.
- **HAVE** a list of your insurance information and the names and telephone numbers of your doctors and transplant center. Keep two copies: one at home and one with a family member or at work.
- **WEAR** a medical emblem, such as a MedicAlert or other brand of medical identification bracelet or neck-

lace. Your social worker or your local pharmacy will have information on how to get this bracelet or necklace.

MEDICATIONS TIPS

- **KEEP** a current list of your medications with you. Give a copy to a family member. This is crucial if you need to replace medications after an evacuation.



“In addition to preparing for a large-scale disaster, a transplant recipient should also prepare for what could be called the “mini” disaster.”

- **KEEP** an extra supply (at least seven days’ worth) of your medications. This is important even without a disaster. You never want to run out!
- **IF YOU USE** a mail-order pharmacy, always allow for extra time for processing and mailing.
- **CONSIDER** keeping a small supply (two to three days’ worth) of your medications at an alternate location from your home (e.g., work place or a family member’s home). Watch your expiration dates and remember to rotate this stock.

DISASTER Preparedness for Potential and Current Transplant Recipients

By Nancy Swick, RN, BSN, CCTC

Being aware of your daily needs is important when readying for an emergency.

- **WHEN TRAVELING**, keep your medications with you! Do not pack or ship your medications. Carry them with you in your carry-on luggage.

Individuals who are awaiting a transplant also have special issues to consider. If you are waiting for a transplant when a disaster strikes and the transplant center where you are listed is affected, you may need to transfer to another transplant program. The transplant center where you are listed will need to request an emergency transfer because of the disaster. If the disaster is severe enough (such as with Hurricane Katrina) and you must relocate to a new area, you can transfer the waiting time you have built up to the new

transplant center. Once you have relocated, the new transplant center will ask for your medical records and ask that you complete a United Network for Organ Sharing (UNOS; organization that oversees the national list of transplant information and operates the computerized organ sharing system, matching donated organs to recipients) Transfer-of-Waiting-Time form. By signing this form, the time you have built up will be transferred to the new waiting list. This is the same process for any transfer of waiting time, regardless of the reason. More

information about transferring your waiting time can be found in UNOS’ brochure, *Questions and Answers for Transplant Candidates and Families about Multiple Listing and Waiting Time Transfer*. You can request a free copy by calling the UNOS Patient Services Department at 888.894.6361 or on their Web site at www.unos.org

Emergencies and disasters often strike quickly and without warning. Even those “mini” emergencies can happen when you least expect them. We all benefit from planning ahead and taking as many steps as possible to be prepared for a disaster, be it large or small.

Nancy Swick is a transplant coordinator at Northern California Kidney Transplant Center, Santa Rosa Memorial Hospital, Santa Rosa, CA.

“ATTENTION ALL YOU UNDER USED CARS!”

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A PPROXIMATELY 150 MEMBERS OF THE U.S. HOUSE OF REPRESENTATIVES, as well as 27 U.S. Senators, have endorsed the *Kidney Care Quality and Improvement Act*. In the House of Representatives, the bill number is H.R. 1298. In the Senate, it is known as S. 635. This legislation is the top priority of the *Kidney Care Partners (KCP)* coalition, of which the *National Kidney Foundation (NKF)* is a member. KCP membership includes dialysis companies, pharmaceutical manufacturers and organizations representing people with chronic kidney disease (CKD) and kidney doctors and nurses. There are several important features of the legislation:

THIS ACT WILL PROTECT AND EMPOWER PEOPLE WITH CKD

1. EDUCATING MEDICARE BENEFICIARIES about CKD can save Medicare money and improve patient outcomes.

- It has been shown that, in people with CKD, the addition of patient education, before a level of kidney failure that results in the need for regular dialysis treatments has developed, has lowered the rate of hospitalization and the number of emergency room visits and increased the likelihood of permanent vascular access placement. Permanent vascular access placement contributes to the reduction in hospital stays and visits.

- To meet this need for education, H.R. 1298/S. 635 calls for a new Medicare benefit that will pay health care personnel, such as social workers and nurses, for giving education sessions to people who are not yet on dialysis and who have Medicare Part B.

2. EXPANDING HOME DIALYSIS options will benefit people with CKD.

- Home dialysis therapies can lead to better health outcomes

Support Grows for Kidney Care Quality and Improvement Act

By Dolph Chianchiano, JD, MPH

New laws that may affect your care are currently being considered

for people who are thought to be good candidates and free patients from the limits of dialyzing in a clinic three times a week, making it possi-



Dolph Chianchiano, JD, MPH

ble for them to keep their jobs or return to work.

- H.R. 1298/S. 635 states that the Secretary of Health and Human Services must give incentives to improve the Medicare benefit for home dialysis, such as changing the way kidney doctors are compensated for monitoring individuals who dialyze at home.

The bill also states that the Institute of Medicine must examine the barriers to understand why more people who have Medicare do not use home dialysis treatments.

3. THE ROLE OF DIALYSIS TECHNICIANS in providing care should be recognized.

- H.R. 1298/S.635 specifies that dialysis care technicians working in dialysis units should have a minimum amount of training.

REIMBURSEMENT PROVISIONS WILL ADVANCE QUALITY OF CARE

- H.R. 1298/S. 635 calls for an experiment with the reimbursement system for dialysis care that would pay more based on quality of care delivered.

- H.R. 1298/S. 635 sets up a framework for annual adjustment of the Medicare

reimbursement rate for dialysis treatments.

This is necessary because:

1. DIALYSIS CLINICS ARE the only Medicare providers that do not have their payments adjusted for increases in costs, such as salaries, rents, etc.

- In other words, although the cost of living has gone up every year, what Medicare pays for dialysis care has pretty much stayed the same since 1983. Payments for other health care services have been adjusted for the cost of inflation.

- Therefore, dialysis facilities cannot compete in the marketplace for health professionals. For example, during 1990–2005, hospitals received a cumulative increase of 32.4 percent in reimbursement for inpatient care. During the same period of time, dialysis reimbursement was increased by only 5.2 percent.

- As a result, it is more and more difficult for dialysis providers to find and keep health care staff needed to provide quality services to people on dialysis, particularly registered nurses.

2. MEDICARE RATES do not compensate dialysis providers for cost of care.

- According to the Medicare Payment Advisory Commission, dialysis clinics will lose almost \$2 per treatment in 2006 on the Medicare reimbursement rate for dialysis treatments.

- The Medicare Payment Advisory Commission also estimates that the costs for running dialysis clinics will increase by 3.1 percent in 2007.

H.R. 1298/S. 635 INCLUDES PROVISIONS TO REDUCE COST OF THE LEGISLATION

1. MODIFICATION of surgical reimbursement.

- Hospitalization accounts for 35 percent of Medicare dollars spent for people on dialysis, with vascular access problems being the largest single cause of hospitalization.

Section 101 of H.R. 1298 calls for changes in payment for dialysis access procedures, for example, by increasing the use of services at vascular access treatment centers rather than hospitals to reduce the cost of care.

2. EXTENSION OF MEDICARE secondary payer provision.

- H.R. 1298 would extend the period of time during which Medicare is Secondary Payer for ESRD services from 30 to 33 months. (When Medicare is Secondary Payer, employer group health plans have primary responsibility for the cost of dialysis services needed by their employees.)

On June 12–13, 2006, a group of NKF “People Like Us” patient advocates traveled to Washington, D.C., seeking support from the U.S. Congress for S. 635/H.R. 1298. “People Like Us” activists visited the offices of congressional members from key states to discuss this legislation. Meeting with lawmakers is one of many ways through which “People Like Us” members are actively raising awareness about CKD, and becoming their own best advocates.

Family Focus readers who are interested in learning more about or joining this energetic group of patient advocates are encouraged to visit the “People Like Us” Web site www.nkfpeoplelikeus.org or e-mail us at peoplelikeus@kidney.org

Dolph Chianchiano is the senior vice president for health policy at the NKF National Organization in New York City.

SADLY, 2006 HAS ALREADY SEEN ITS SHARE OF DISASTERS.

There was record-breaking snow in New York's Central Park, and more than 100 tornadoes the same day in the Midwest. It is important that you, as well as your dialysis or transplant providers, have emergency plans in place. The facilities should review their plans at least yearly and make changes as needed. This article shares the efforts and role of the End Stage Renal Disease (ESRD) Networks during disasters past and present.

The ESRD Networks across the United States are required to help dialysis centers and transplant units with disaster planning. Helping units with disaster planning is placed into each Network's Statement of Work (SOW) with the Centers for Medicare and Medicaid

Services (CMS). The SOW is a contract between CMS and the Networks. It outlines what CMS expects each Network to do in the upcoming year. The Networks are surveyed each year to ensure they have met the expecta-

tions of the contract and, if so, a renewal contract is offered. In addition to planning for a disaster, when a disaster occurs, the Networks get involved.

During the 2005 hurricanes, four Networks were actively involved with the staff of dialysis centers and transplant units and the people who receive dialysis in each of the hurricane-affected areas—Network 7 (Florida), Network 8 (Mississippi, Alabama and Tennessee), Network 13 (Louisiana, Oklahoma and

The Role of the ESRD Networks During Disasters Past and Present

By Kimberly Thompson, RN, BSN, CNN

The ESRD Networks take an active role in helping people affected in a disaster.

Arkansas) and Network 14 (Texas). They provided important assistance to help people get their dialysis treatments and medicines. The goal of the Networks is to work as a partner in ensuring continued care for all people on dialysis after a disaster occurs.

Before and in preparation for the 2005 hurricanes, the Networks contacted all dialysis units and gathered information about their disaster plans as well as the steps that staff would take to activate the plan with the people on dialysis. (Each unit is required to have


units found to have poor or inadequate emergency plans. The SSA is another agency that CMS contracts with to provide oversight for the dialysis and transplant units. The Networks sent these units a toolkit of information and provided staff with support to help improve their disaster plans.

After the hurricanes struck, the Networks worked hard to communicate the special needs of people on dialysis and transplant recipients. The Networks advocated with state and federal emergency departments. They wanted to ensure that the people in charge at the local, state and federal offices of emergency management understood the special needs of the dialysis and transplant populations.

Following the disasters, the Networks set up a national toll-free 800 number for daily updates. These daily calls allowed information about

open and closed dialysis units and transplant centers, transportation needs, shelter and/or medication needs and much more to be shared. The Networks worked with the National Kidney Foundation (NKF) to set up an e-mail list (listserv) for people in the dialysis and transplant communities around the country to communicate with each other. The Networks worked with the CMS to help people affected by the hurricanes get services (financial grants, medicine, transportation) and units to restore dialysis services.

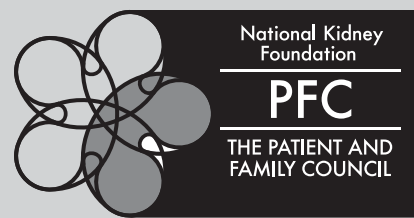
Network 7 has since led a national task force to standardize the best practices from the lessons learned from Katrina and Rita. As the next season of disasters is currently underway, the ESRD Networks encourage you to read the NKF booklet, *Planning for Emergencies: A Guide for Kidney Patients* to help you plan ahead and prepare in the event a disaster occurs in your area.

Kimberly F. Thompson is the ESRD Network Liaison for Family Focus. Currently, she is the patient services coordinator for ESRD Network 12 serving Iowa, Kansas, Missouri and Nebraska. 



“After the hurricanes struck, the Networks worked hard to communicate the special needs of people on dialysis and transplant recipients.”

a disaster plan and to make those plans available to you.) When the Networks reviewed the plans, they found that some units lacked a back-up dialysis facility. The Networks educated staff at the dialysis units about the need for two back-up units to provide care in the event of a disaster—one nearby and one farther away. Working with other agencies, such as the State Survey Agencies (SSA) and the local and regional Departments of Public Health, the Networks were able to focus on those



To find out about the many services and activities offered in your community or to join the Patient and Family Council at no cost,

contact us at **800.622.9010**

or visit us at **www.kidney.org**

**MEMBERS GET FAMILY FOCUS
DELIVERED DIRECTLY TO THEIR HOMES**

Rehoboth (Summer Camp at St. Anne, Ill)

For Annette
By Marjorie Love

There is certain friendliness
That stirs along the breeze,
It sends a happy greeting
That is whispered by the trees.

The birdies sing a welcome song
To all who come to stay
And little insects greet you
In their own familiar way.

The sunshine paints a picture
That is nature's pretty sight
And every star in heaven seems
To twinkle there at night.

Rehoboth, through your fellowship
God chose you to impart
His loving Words of Truth and Life
To every human heart.

When campfire days are over
And we leave Rehoboth's plain,
Already we anticipate
The time we'll come again.

Rainbows

By Marjorie Love

When storms of life
Bring grief or strife
God knows our heart
And does His part
To ease the pain;

He sends a rainbow after rain.

We watched His Beauty in the sky,
And knew he was standing by.

Marjorie Love receives dialysis treatment in Chicago, Illinois.



If I

By Thomas Strickland

If I lay down and go to
sleep, would I awake
to a better world or the
same betrayal?

If I close my eyes, will all
the turmoil and lies
subside?

If I cry for you, would you
cry for me? We can be
human when we want
to be.

If I am nice to you, would you
be nice to me? If so, I'm
pleased to meet thee.

If I give you love, would
I get a hand from
above?

If we give one another
a chance, the whole human
race could celebrate.
It's never too late.

Thomas Strickland dialyzes in Charlotte, North Carolina.

Awaiting Cancer Specialist

By Mary Anna Davis

Sitting here impatiently;
Waiting for the test
you see...

Praying I will be
cancer free,

I wait so impatiently.
If I claim cancer
free...

From the stripes
he bore for me

I'll not need to sit
here impatiently,
'Cause he healed me
completely.

Mary Anna Davis receives dialysis treatment in Portland, Oregon.

Voyage

By Thomas Strickland

If we take a voyage deep in
the cavern of our souls, we
could find something old,
something new.

If we take a voyage to find
our spirit, what could
become of it?

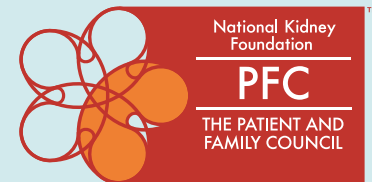
If we take a voyage to understand
our fellow man, we
could withstand all problems
at hand.

Take the voyage. You'll see it
could be a better person
inside you and me.

IF YOU HAVE DIABETES AND KIDNEY DISEASE, we want to hear from you about your experiences. Answer a brief survey about diabetes online at www.nkfkidneypatients.org Your responses will be kept confidential. Individual names will not be shared. The answers will be grouped together and used for education and in a *Family Focus* article. To request a copy of the survey, please call 800.622.9010.

Patient Family Council: Get Connected

By Duane Sunwold



YOU MAY HAVE HEARD OF THE NATIONAL KIDNEY FOUNDATION'S (NKF) PATIENT ORGANIZATION, Patient and Family Council (PFC). But you may not know that it is the largest and fastest growing patient organization dedicated to issues affecting people just like you with kidney disease and their families. The PFC's Executive Committee serves as the voice of more than 26,000 people with chronic kidney disease (CKD) and their loved ones.

The PFC is just one of the three constituent councils under the NKF's "People Like Us" advocacy initiative. "People Like Us" was started to empower, educate and enable people with CKD, transplant recipients, donors and family members to become effective advocates on issues that relate to them.

This year's PFC Executive Committee is a team of very talented and passionate individuals from all walks of life. They bring with them a personal understanding of how CKD affects the lives of people like you and me. As Chair of the Executive Committee and someone with CKD, I am honored to be working with such a dedicated group of individuals who has your best interests in mind. The PFC's Executive Committee has defined clear and exciting goals that will keep us very busy over the next two years:

FIRST, we will work to complete the important projects started by the previous Executive Committee, geared toward meeting the special needs of older adults with CKD. For example, the previous committee had begun a project to help people that are on dialysis who need long-term residential care. This will be one area of focus in the upcoming year.

SECOND, we will work on activities to help people with CKD become their own best advocate. This means, for example, creating the tools to help those with CKD learn the skills they need to become effective members of the health care team, to learn about and communicate with elected officials and government agencies and to speak out on behalf of others affected by kidney disease.

THIRD, we will work to make sure that the NKF's many useful programs and booklets reach those who need them the most—people with CKD, family members and caregivers.

As Chair of the PFC, I invite you to visit www.nkfkidneypatients.org to meet your new Executive Committee. Experience the PFC Message Board by going to "Get Connected" and clicking on "Message Board" to "talk" with others who may be having similar feelings or to share concerns and/or positive experiences related to kidney disease.

Every person with CKD has something of value to offer from his or her experience. Together, through the "People Like Us" Patient Family Council, we can benefit from your special experiences and talents to make important differences in the lives of people with CKD everywhere. E-mail us at pfc@kidney.org to let us know what is important to you. We look forward to hearing from you.

You can join the PFC free by calling the NKF at 800.622.9010 or visiting www.kidney.org

A chef and culinary instructor for more than 35 years, Duane Sunwold is interested and involved in dietary changes to improve kidney function and quality of life. Based on adherence to his nephrologist's health plan and dietary recommendations, Duane has succeeded in improving his kidney function. He serves on the NKF's People Like Us steering committee.



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.

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