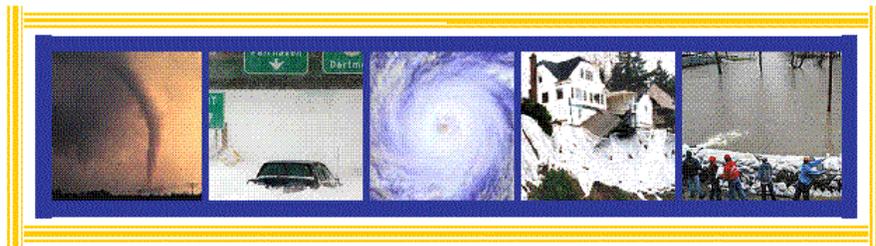


Kidney Community

Emergency Response Coalition



Final Report of the Eight Response Groups Created at the January Disaster Summit

July 1, 2006

Compiled by the National Kidney Foundation, Inc.

Introduction

In the recent past, there have been a record number of natural disasters in the United States. These disasters have ranged in magnitude from loss of electricity to a few thousand people to destroying one of our nation's greatest cities. Unfortunately, even a disaster that only cuts off electricity for a short period of time can greatly affect the kidney community and dialysis patients. In places without sufficient electrical back-up, dialysis machines are disabled, and when kidney patients are forced to even temporarily leave their homes, it is often difficult for them to find transitory care. The greater the disaster, the more difficult it becomes for kidney patients to get the care they must have. When an entire city is without clean drinking water and thousands are homeless, it has been demonstrated that special needs populations – in particular dialysis patients – are often overlooked. Those in the kidney community plan to change that.

In January 2006, the Kidney Community Emergency Response Coalition had its genesis in a meeting, the Disaster Summit: 80 people from 25 states and the District of Columbia participated in the Summit, with representatives from organizations including:

- American Association of Kidney Patients
- American Kidney Fund
- American Nephrology Nurses' Association
- American Society of Nephrology
- Centers for Medicare & Medicaid Services
- Centers for Disease Control
- Computer Services Corporation
- Departments of Health
- ESRD Network Organizations
- Food and Drug Administration
- Forum of ESRD Networks
- Hospital Healthcare Systems
- Independent Dialysis Centers (Free-Standing & Hospital-Based)
- Large Dialysis Organizations
- National Association of Nephrology Technicians
- National Institutes of Health
- National Kidney Foundation
- National Renal Administrators Association
- Office of Inspector General
- Physician Medical Groups & Independent Physicians
- Renal Physicians Association
- State Survey Agencies
- Transplant Centers
- Universities
- Vendors
- Other Strategic Partners

The Coalition arising from this Summit was formed to create a shared emergency response system for individuals and organizations and to help build local strategies into a national preparedness and response plan. In order to address the tasks at hand, the Coalition divided into eight response groups with initial administrative support provided by the Centers for Medicare and Medicaid Services (CMS) and, subsequently, by the National Kidney Foundation (NKF). The work of the Response Groups from February through July was coordinated by the Coalition Planning Committee chaired by Dolph Chianchiano, Senior Vice President for Health Policy and Research, at the National Kidney Foundation.

During the January Disaster Summit, the Coalition and Response Groups determined to focus on the following issues:

- **Patient Assistance Response Group** will work to educate patients on all available services before an emergency occurs; they will be the direct link to the patients for whom help is being developed.
- **Coordination of Staff and Volunteers Response Group** will establish volunteer databases for response to emergencies, educate volunteers who are deployed to emergency areas and investigate licensure issues.
- **Physician Assistance Response Group** will help displaced physicians register and/or be moved to a place where they can resume practice during and following an emergency.
- **Vendor (Industry) Services Response Group** will help dialysis providers quickly access the supplies and services they need in order to continue patient care.
- **Facility Operations Response Group** is collecting information from physicians and other health professionals who have been through disasters in order to create a template to help dialysis facilities make their own emergency plans.
- **Patient Provider Tracking Response Group** will create a database of all dialysis patients and will update it frequently as to the status of the given patient so that during a disaster, health providers will be aware of exactly which patients need what type of care and where patients are located.
- **Federal Response Group** is working to make organizations at the federal and state levels and first-responders aware of the special needs of the dialysis population in times of disaster.
- **Communications Response Group** is working to institutionalize a national email listserv, a national toll-free hotline number, an emergency resource website and make location-specific conference calls standard practice post-disaster.

The Summit generated enthusiasm and collective energy both within and outside the Coalition. Many individuals labored tirelessly to help ensure that the disastrous experiences of Hurricane Katrina dialysis patient victims would not be repeated.

This report of the Response Groups summarizes the work of the Coalition through June 30, 2006.

Respectfully Submitted,

Dolph Chianchiano, Senior Vice President for Health Policy and Research
National Kidney Foundation, Inc.

Suzanne J. Wyckoff, Executive Vice President
National Kidney Foundation, Inc.

Kidney Community Emergency Response Coalition

Report of the Communication Response Group

Group Leader: Preston A. Englert, Jr.
National Kidney Foundation

Goals:

1. Improve or enhance the use of communication technologies:
 - a) Institute Emergency Hotline
 - b) Create Emergency Preparedness and Response website
 - c) Create email listserv for activation during emergencies
2. Communicate / educate the needs of the kidney population to appropriate entities.

Communications Response Group Final Report

Workgroup Members:

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Workgroup Objectives:

With the need for redundant technologies recognized and taken into account, the following objectives were addressed:

1. Institutionalize a national email listserv
2. Develop a National toll-free number
3. Develop an emergency resource Web site
4. Institutionalize conference calls/standard practices post disaster

Process:

The workgroup met in person at the initial coalition meeting in Washington held in January 2006. In addition, the workgroup held two conference calls with its membership along with an additional conference call with all other work group leaders.

The workgroup objectives, listed above, were both well defined and very clear to the members of the workgroup who concentrated on the objectives. Three of these objectives were assigned to the National Kidney Foundation for execution, items 1, 2 and 3.

Additional items such as the use of ham radio operators, solar powered technology and satellite radio were introduced during the conference calls as items that needed to be added to future discussions. The need to include these items in a second phase of discussion using experiences of the Katrina disaster and communications groups in Louisiana and those led by the network were highlighted. (The role of ASN in added communications support was discussed as well.)

Communications in disasters using the best and newest technology will continue to evolve and it is recommended that review of the initial recommendations be ongoing and reviewed after each disaster.

Disaster Communications and Redundant Technology: The priorities assigned to NKF were accomplished by partnering with the NKF CyberNephrology Center at the University of Alberta in Edmonton, Canada. Both the staff of the NKF and the staff of the CyberNephrology Center are capable of providing management and control services. The use of identical or very similar tools, software, and hardware make contingency planning very simple. The CyberNephrology Center's expertise when combined with its location near the other coast of North America and in a different country, make it extremely unlikely that both control centers would be unable to operate and manage these services.

Accomplishments:

1. Kidney Community Emergency Listserv

A listserv has been established at the address ER@listserv.kidney.org. In ordinary times, the listserv is an "announce only" communication tool which will update itself automatically from time to time. The initial names on this listserv were those who were on the Hurricane listserv in September 2005 and those who attended the Coalition's meeting in January 2006. During an emergency, the list will become interactive and all members will be able to talk with all other members. *The listserv will be activated by NKF upon notice from CMS headquarters -- Gina Clemons or her designee.*

Backup: Identical listservs have been established in two places, running on both listserv.kidney.org and mailman.srv.ualberta.ca. Additions, deletions, and changes will be made in parallel so that either list can be activated in time of disaster. In the event that listserv.kidney.org becomes unavailable, the Edmonton server will be available to provide identical functionality.

2. Kidney Community Toll Free Emergency Hotline

The toll-free number is for the "Kidney Community" and will be used for general reference to the media as a resource for the public.

The number is **888-33KIDNEY** or **888- 335-4363** and is called the Kidney Community Emergency Hotline.

Backup: The hotline number can be referred to any call center should the New York location of NKF become disabled during an emergency.

3. Kidney Community Emergency Response/Preparedness Web Site

The website www.kidney.org/help is divided into professionals, patients/families and people who want to help. Feedback from all Response groups was obtained and is included in the web site design and organization. The site was created with a large list of resources available as well many helpful links. It contains a wealth of information supplied by other Coalition Response Groups, as well. In emergencies, the web site will address the current situation and be updated frequently on an as needed basis.

Backup: As was done for the Katrina disaster, a web site has been established which will normally provide information on disaster preparedness and general resources on this subject. The site is hosted in New York City by one of the larger web hosting services in the U.S. and is mirrored in Canada as well, providing multiple redundant paths.

During a disaster, the NKF web services team will substitute ready-made pages for the general pages normally on the site and will begin adding relevant information as it is reported. In the event that no members of this team are able to access the host server, the staff in Edmonton, Canada will be able to step in and perform this same function.

In the unlikely event that the host of www.kidney.org might become unavailable, the pages of the site will be copied to CD and distributed both to Edmonton and to Kansas City, Missouri where NKF has a Field Office. Should kidney.org go dark, both the staff in New York and in Edmonton will have the capability to load the content on a functioning web server and redirect the domain name to point to the functioning server. In this way, the web site will be always available to provide needed resource information.

4. Kidney Community Conference Calls During an Emergency

Conference calls will again be instituted by CMS as needed during an actual emergency. Individuals on the listserv will be notified of the calls and the calls will be disaster specific.

Kidney Community Emergency Response Coalition

Report of the Coordination of Staff/Volunteers Response Group

Group Leader: Sue Cary
ANNA

Goals:

1. Identify, organize and mobilize nurse volunteers – inclusive of hospital based, freestanding, home based and long term care settings.
2. Identify, organize and mobilize non-nursing facility volunteers e.g. social workers, dietitians, patient care technicians, biomedical technicians – inclusive of hospital based, freestanding, home based and long term care settings.
3. Develop training modules for professional and technical disaster responders.

Coordination of Staff/Volunteers Response Group

Team Members: Sue Cary (ANNA) Chair Suepreu@cox.net
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Jeff Harder (CNSW) Jharder@u.washington.edu

Conference Calls: February 7, 2006
March 15, 2006
May 2, 2006
May 23, 2006
Next call: June 13, 2006

Goals:

1. Establishment of volunteer databases for response to disasters

Actions:

- a. On American Nephrology Nurses' Association (ANNA) web site there is a link for nurses, patient care technicians, and social workers to sign up to become part of a database of volunteers for response during disasters. There will be a link for dieticians to sign up soon.
- b. Links to ANNA's web site are going up on National Kidney Foundation (NKF), Nurses and Nephrology Technicians (NANT), Council of Nephrology Social Workers (CNSW), Council on Renal Nutrition (CRN), Council of Nephrology Nurses and Technicians (CNNT), ESRD Network 7 and NRAA web sites.

- c. There will be lead people who will have access to the complete database information from their discipline.
Access to nurse and technician data base information: Sue Cary, Norma Gomez, Marianne Newmann, Lynda Ball, Fran Rickenbach
Social Worker: Surveen Klein, Teri Browne, Camille Yuscak, Jeff Harder
Dieticians: Paula Frost (more will be named)
PLAN: Gary Green is working on creating on NKF Web site a link for dialysis units in need of volunteers during a disaster can click on and it will bring them to a form to fill out asking their contact information. This will then be emailed to the lead people of Team 2 listed above. On June 13th conference call team 2 members will decide the order of who will respond to those in need as far as giving them information from the database.
PLEASE NOTE: VERIFICATION OF LICENSE WILL NOT BE DONE BY ANNA WHEN VOLUNTEER INFORMATION IS COLLECTED. THIS WILL BE THE RESPONSIBILITY OF THE DIALYSIS UNIT IN NEED OF VOLUNTEERS.
- d. ANNA will be creating a news release announcing the Disaster Preparedness section on ANNA web site and the link for volunteers to sign up.

2. Education of volunteers who will be deployed to disaster areas.

Actions:

- a. Educational handout titled "Packing for Deployment" was provided by Michelle Braun. This is available to go on web sites.
- b. ANNA web site has an educational section in the Disaster Preparedness section. This area refers to the reader to the CDC web site.
- c. Link to sign up to volunteer for disasters also refers the volunteer to CDC web site on Emergency Preparedness & Response.
- d. Team members also discussed the Community Emergency Response Team (CERT) web site. They agreed this site is a good resource for volunteers to review.

2. Investigate licensure issues.

- a. Spread sheet has been created with RN licensure contact information for several states.
- b. Spread sheets will be created with Social Worker and Dietician licensure information will be created by members of Team 2.
- c. ANNA web master is considering placing spread sheet on web site.

Kidney Community Emergency Response Coalition

Report of the Facility Operations Response Group

Group Leaders:

Bill Numbers, Fresenius Medical Care
Tony Messana, National Renal Administrators Association
Tom Bradsell, DaVita
Jim Curtis, Northwest Renal Network

Goals:

1. Minimize the disruption of services to the dialysis patients
2. Re-establish services to the dialysis community as possible.

Facility Operations Response Group Final Report

Committee Leaders:

Tom Bradsell, DaVita
Jim Curtis, Northwest Renal Network
Anthony Messana, St Josephs Hospital and NRAA
Bill Numbers, Fresenius Medical Care

Committee Members:

Deborah Brouwer, Renal Solutions Inc.
Rita Clymer, DaVita
Danilo Concepcion, St Josephs Hospital and NANT
Russell Dimmitt, Fresenius Medical Care
Linda Duval, ESRD Network 13
Mary Fenderson, DaVita
Gail Frederick, Satellite Healthcare
Bonnie Freshly, Forum of ESRD Networks
Gema Gonzalez, FDA
Brenda Lepley, National Renal Alliance
Tamara Lujan, Better Water Company
Condict Martak, CMS
Rita McGill, West Pennsylvania Allegheny Health System
Maureen Michael, Central Florida Kidney Centers
Carolyn Neuland, FDA
Stuart Redpath, Dialysis Clinics, Inc
Byron Roshto, Fresenius Medical Care
Kathleen Smith, Fresenius Medical Care
Cindy Toombs, Fresenius Medical Care

The Facility Operations Committee has accomplished several things as our part in the National Disaster Coalition. We hope that these efforts will serve the greater dialysis community when we face our next disaster.

We have developed a document titled “Four Keys to Being Prepared for a Disaster” which is an abbreviated disaster planning tool focusing on the four main topics (each with several steps to take) that our committee felt were the most important.

We have added several important items to the CMS Manual “Emergency Preparedness for Dialysis Facilities”. As a committee, we extend a hearty *Thank You* to the original authors, and did not feel that this manual needed any kind of significant overhaul. The additions to the manual are important considerations based on the experience of our committee members. We made an appendix to this manual which simply consists of all of the forms contained in the original manual, to be distributed in MS Word format for adaptability and ease of use by the dialysis facility. As an additional preface to the manual, we have put together some reports of disaster experiences that will help the reader understand the importance of having an effective disaster plan.

We developed a “Dialysis Facility Disaster Planning Template” to help guide individual facilities through the disaster planning process. This template combines several checklists that were submitted by committee members.

We searched for useful documents from any source we could find, and have identified a few that will be of use to the dialysis community.

Respectfully submitted,

Jim Curtis

For these attachments, please refer to the separate file of Attachments to the Coalition Report:

1. CMS Manual *Emergency Preparedness for Dialysis Facilities* (As edited)
2. Forms Appendix to CMS Manual
3. Four Keys To Being Prepared For A Disaster
4. Dialysis Facility Disaster Planning Template
5. Facility Generator Survey (for Network use, from Network 13)
6. FEMA Business Recovery Plan
7. LA-DEEP Coalition Patient Needs Assessment
8. FEMA Preparing for Disaster for People with Disabilities and other Special Needs (PDF)
9. CDC Bring Up Your Dialysis Water Treatment System (PDF)

10.

Kidney Community Emergency Response Coalition

Report of the Federal Response Group

Group Leader: Glenda Payne
CMS

Goals:

1. Establish and build communication channels within the Federal agencies that are critical in emergency situations (FEMA, CDC, etc.).
2. Develop an education packet with key materials to be used to educate personnel across Federal and State agencies, JCAHO, etc. regarding the unique needs of the dialysis and transplant populations.

Federal Response Group Final Report

Team Members: Deborah Levy, CDC; Dolph Chianchiano, NKF; Doug Marsh, NW 18; Efrain Reisin, Nephrologist, New Orleans; Gina Clemons, CMS, Baltimore; Condict Martak, CMS, Baltimore; Glenda Payne, CMS, Dallas; Janet Crow, Forum of ESRD Networks; Jeff Kopp, Nephrologist, NIH; Judith Kari, CMS, Baltimore; Kenneth Lempert, Nephrologist, PHS; Lee Hamm, Nephrologist, New Orleans; Steve Egger, MS State Agency; Susan McDevitt, FL State Dept. of Health.

Actions of the Team: Major efforts have focused on identifying critical contacts within the state and federal agencies charged with responding to disasters and educating them on the unique needs of individuals with ESRD. An educational piece (attached) was developed and distributed to aid these individuals in understanding the particular needs of kidney patients. An initial phone conference was held on May 8 to address questions and concerns of these partners, and to identify further opportunities for collaboration. Efforts continue to identify and educate partners who will be active participants in emergency response efforts. A list of currently identified national contacts is attached.

Additional Federal Actions:

- **ESRD Conditions for Coverage** - The ESRD Conditions for Coverage (currently under revision with a spring 2007 target date for final rule publication by CMS) include proposed language related to emergency preparedness. While actual requirements will not be known until publication of final rule, comments were submitted on behalf of the Federal Response Team, Kidney Community Emergency Response Coalition, recommending that based on "lessons learned," the final rule includes the following requirements:
 - Annual contact with a local disaster management representative to assess the facility emergency plan and to ensure local agencies are aware of the dialysis facility, its provision of life-saving treatment, and the patient population served.
 - A proposed written evacuation plan including identification of back-up dialysis facilities; patient and staff education; patient information packets which includes identification card, current treatment orders, latest treatment records; plan of care, current lab reports, guidance to obtain care, and emergency diet guidance; provisions for protection of medical records; plan for obtaining emergency power and a potable water supply; and reporting facility status to the ESRD Network and State agency, including contact information for critical staff.
 - Also proposed is that each staff member must be able to demonstrate their role or responsibility in implementing the facility's disaster preparedness plan.

- **ESRD Network Contract** - The new ESRD Network contract, effective July 1, 2006, includes clear responsibilities for every Network in the area of disaster planning and response for ESRD providers, patients, and to CMS. In June 2006 a mock emergency drill was conducted with all of the ESRD Networks to ensure they were prepared to satisfactorily fulfill their responsibilities.
 - In preparation for an emergency or disaster, Networks are required to facilitate and assist providers/facilities in developing plans for local disasters to include sharing of lessons learned and promising practices; hosting local meeting and forming local coalitions as appropriate; and distribution of material created by CMS or as directed by CMS.
 - In the event of local disasters, ESRD Networks must track and make available to the public the open and closed status of the facilities in the effected area, including specialty services offered; track where patients are receiving services; and coordinate activities, including hosting inclusive, collaborating calls with providers, emergency workers, and other essential persons to ensure coordination and that the needs of individuals with ESRD are being met.
 - For patients, the ESRD Network responsibilities include distribution of educational material and tools on how to prepare for a disaster, and what to do in a disaster; assisting patients in identifying dialysis facilities that can provide ESRD services; and as directed by CMS, providing information to family members and treating facilities on where a patient previously/currently is receiving services to assist in location of individuals and the exchange of critical medical information.
 - As part of the CMS emergency/disaster planning process, ESRD Network assist CMS by distributing CMS materials and resources to ESRD providers, facilities (transplant and dialysis), and beneficiaries.
- **CMS ESRD Activities Flu-Pandemic** - From early efforts, it is apparent that individuals with ESRD will present a challenge to the dialysis facilities as well as the hospital system in the event of a flu pandemic. The National Coalition is working with CMS is planning for a flu pandemic.
 - As part of the contract with CMS, all 18 ESRD Networks are distributing education and preparation material to all facilities in their Network area, including references to federal tools and resources that are available to assist with preparation for a flu pandemic.
 - Each Network has included information on their website specific to flu pandemic preparedness, including the state plan and federal tools, and has ensured that it can readily be used as a vehicle to distribute information, to track outbreaks, and posted status of affected and open facilities.
 - All 18 Networks have identified a contact within the state for flu pandemic efforts and are working to be updated and included in state planning efforts, with the goal of having a plan at the state and local level that recognizes the unique needs of the ESRD population and the system burden that will be caused in an outbreak (e.g., increased dependency on hospitals for dialysis services).

Disaster Response Contact List for State and Federal Agencies

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Brad Austin was referring to HHS Office of Disability - <http://www.hhs.gov/od/>

Save a Life - What You Need to Know About

Emergency Preparedness for Individuals with Kidney Disease

Kidney failure is a life threatening condition. As of March 2006, there were over 448,500 individuals with kidney failure in the U.S. Patients with kidney failure will die if they do not get either regular repeated dialysis treatments or medications to prevent rejection of a kidney transplant. Subsequent to Hurricanes Katrina and Rita, the community of individuals, facilities and patients involved in kidney disease recognized the need to improve planning and preparation for any disaster. While each group has a responsibility in these actions, federal, regional and state agencies are critical in these efforts.

What Dialysis Patients Need in Disasters

Repeated dialysis treatment: Being without dialysis as few as three or four days could result in illness or even death for these patients. Dialysis requires:

- Space to do the treatment;
- Electricity to run the equipment;
- Dialysis machines;
- Potable water for use in the treatment (each treatment requires a minimum of ~100 gallons of pressurized water);
- Water treatment equipment (Carbon filtration and either reverse osmosis or deionization);
- Supplies (dialyzers, blood lines, saline, medications, etc.);
- Personnel qualified to perform dialysis; and
- Medical records including the prescription for dialysis.

How you can help:

- Include dialysis clinics in the list of high priority locations to have power, water and phone services restored if these services are interrupted.
- Assist in providing emergency generators, fuel, and tanker water to dialysis clinics if these are needed.
- Facilitate delivery of supplies to dialysis clinics.
- Include dialysis personnel on lists for priority access to gasoline if supplies are limited.
- Recognize security assistance may be needed to protect emergency generators and fuel used to run the dialysis equipment.
- Encourage early evacuation of kidney patients with appropriate family members, as warranted. They need to get to a safe place near available dialysis services as soon as possible.
- Allow patients and staff with appropriate identification to cross roadblocks and travel during curfews to get to and from dialysis clinics.

- Work with dialysis providers, state agencies and the End Stage Renal Disease Network organizations (www.esrdnetworks.org) to provide alternate sites for treatment if dialysis clinic operations are impacted by the disaster.
- When individuals seek shelter in disasters, routinely screen for kidney failure. Add: “Do you require dialysis?” and “Do you have a transplanted organ?” to the screening tools in use.
- Recognize that individuals with failed kidneys will need to limit fluid intake and use caution in consuming foods high in salt and potassium (such as MREs) during periods of limited access to dialysis: public service announcements may need to be edited to recognize these restrictions.
- Ask shelters to group individuals needing dialysis in a specific area of the shelter, and to consider arrangements for transportation to dialysis in transferring these individuals to another shelter.
- Designate a few shelters as the “go to” locations for dialysis patients to make transportation to dialysis treatment easier. These shelters can be used for other evacuees as well.

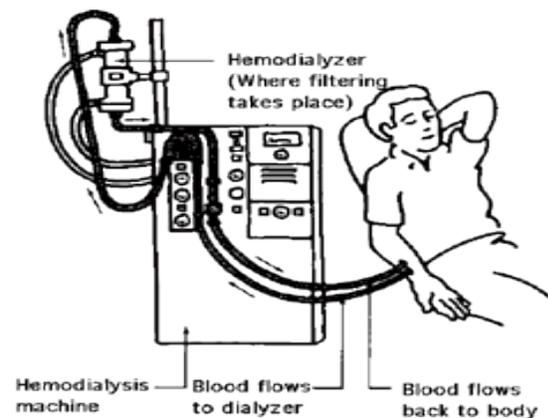
Basic Facts about Kidney Disease and Treatment

Here are some basic facts about kidney disease, how it is treated, and what you may need to do to help kidney patients access life-saving/sustaining treatments, which require electricity, safe water, specialized equipment and specially trained personnel.

Kidneys perform crucial functions. When kidneys fail, the blood must be regularly cleansed of toxins and extra fluids by using either an artificial kidney (**hemodialysis**), by introducing a cleansing solution into the abdomen (**peritoneal dialysis**), or by using a healthy, donated kidney to replace the patient’s failed kidney function (**kidney transplant**). If patients do not receive dialysis within 3 days they will become critically ill and may potentially die.

Many patients suffer kidney failure due to either diabetes or high blood pressure (hypertension). Both of these conditions may also require special attention and available medications in the event of disasters.

HEMODIALYSIS (HD): This treatment involves cleaning the patient’s blood of harmful toxins and excess fluids using an artificial kidney (dialyzer) and a hemodialysis machine. Treatment requires specially trained personnel, electricity, and safe water. Hemodialysis must be done at least three times a week, for about 3 to 4 hours each time. The public water supply can be used for dialysis, but the water must be specially treated with electrically operated equipment to

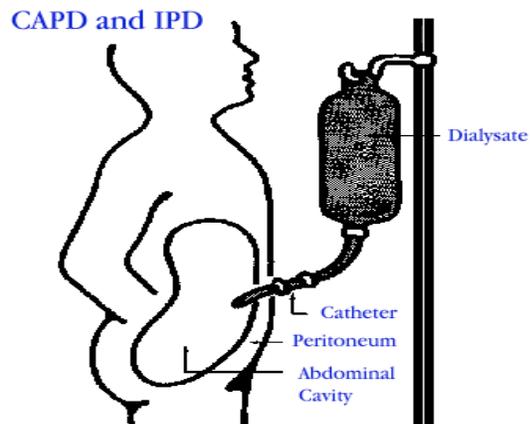


remove substances (such as chlorine, aluminum and fluoride) that would harm patients during dialysis. Most dialysis clinics do not have emergency generators, so restoring electricity will be critical. Those dialysis clinics with emergency generators would need a re-supply of fuel should the emergency situation last longer than one day. It takes more time and resources to set up temporary units than to restore existing units, if those units are not severely damaged. If dialysis cannot be provided in an outpatient setting, kidney patients will overload those hospitals that provide dialysis, [impair access to patients needing hospital care](#) and present a greater challenge in areas where the hospitals that do not provide dialysis. **More patients each year choose to do their own treatments at home. Should a disaster affect a home dialysis patient's residence, making restoration of services (water and electricity) a high priority will restore the patient's ability to perform life sustaining treatment. Home patients have been encouraged to notify their utility suppliers about their status as home dialysis patients. In emergencies of extended duration, these patients would need deliveries of dialysis supplies.**

PERITONEAL DIALYSIS (PD):

Peritoneal dialysis uses the patient's peritoneal membrane, which surrounds the intestines, to act as a filter. A tube (catheter) is placed into the peritoneal cavity and then a special solution (dialysate) flows through the catheter into the abdomen, where harmful toxins and excess fluids move from the blood to the dialysate. The solution is then drained out and discarded. Done at home, the

treatments are continuous, with 4-6 exchanges of fluid being done daily. While some PD techniques use machines and electricity, in a disaster situation, these patients would use manual techniques that do not require electricity. They would need replenishment of supplies and an environment that protects them from infection. As with hemodialysis patients, being without treatment would lead to illness and death for these patients.



TRANSPLANT: *Kidneys for transplant can come from either deceased or living donors. Patients who have received a transplant must have special drugs to prevent rejection of the kidney and avoid exposure to infections (i.e., those that could be spread by crowds in a shelter) since the drugs they take to prevent transplant rejection also diminish the body's ability to fight infections.*

***Thank you for your time and interest.
We look forward to working with you and your agency.***

Kidney Community Emergency Response Coalition

Report of the Patient Assistance Response Group

Group Leaders:

Kris Robinson, American Association of Kidney Patients
Phylis Ermann, American Kidney Fund

Goals:

1. Improve the identification and tracking of patients pre-disaster (work with the Patient and Facility Tracking Group for consistency).
2. Improve patient preparation for any/all disasters (i.e. education and resources)
3. Develop a central coordination system for financial aid (to decrease duplication, ease burden on patients and facilities looking for information, centralized tracking of donations and disbursements).

Patient Assistance Response Group Final Report

Education

The workgroup identified and reviewed existing patient education materials on emergency preparedness. There are 40-50 resources with excellent publications from CMS, NKF and the Networks and no need to reinvent the wheel.

The group determined there is a need for some more concrete tools for patients immediately ahead of a disaster which could include:

1) A toolkit in a plastic box or bag with

- emergency medical instructions (diet, etc.)
- a waterproof bag for medicines
- a placard or T-shirt identifying the individual as a dialysis patient
- medical history, insurance #'s
- dialysis unit and telephone #
- a list of local emergency resources and contact information

Lists of emergency resources and contact information could be maintained online, updated and printed as needed. These might include:

- Dialysis providers to find open units
- FEMA and other Federal programs
- Red Cross and other relief agencies
- Resources for financial aid, housing, medication, transportation, mental health and coping tools, pet rescue

2) A laminated wallet card (similar to the one on the NW 7 website) for patients to carry with them at all times, identifying them as dialysis patients and basic medical information.

Questions regarding the above include:

1. Is there a source of funding for these items?
2. How would they be distributed—by providers, Networks, etc?

Direct Patient Assistance

The following needs for direct support to patients through monetary grants were identified:

- replacement of lost medications
- transportation
- housing
- replacement of household items
- utilities
- food
- nutritional supplements
- clothing
- replacement of dentures, eyeglasses and other necessities

The next steps will be to:

- Conduct a survey on how well these needs were met following Katrina/Rita (perhaps using information from CNSW)
- Identify gaps
- Identify needs for better coordination of direct patient resources

Kidney Community Emergency Response Coalition

Report of the Patient/Facility Tracking Response Group

Group Leader: Glenda Harbert
Network 14

Goals:

1. Implement a patient tracking system to ensure accessibility.
2. Develop tracking forms for patients and facilities:
 - a) Mechanism for Patient Identification/medical information that travels with the patient
 - b) Determine the appropriate routes for tracking National/Regional Level data and Facility specific data ongoing to gather patient tracking information
 - c) LDO System access for tracking with link to current Patient Registry
 - d) Mechanism for reporting patients by UPIN
3. Implement a Facility Tracking System -- Definition of Open Unit/Closed and Expand Open and Closed Units to Mapping.
4. Receiving units to report displaced patients even for only treatment is one.
5. Surgeon General's Public Health Database – linked to ESRD Registry.
6. 800 number for patients.

Patient/Facility Tracking Response Group Final Report

Workgroup Members

Glenda Harbert/NW14 gharbert@nw14.esrd.net - 972-503-3215, Leader
Michael Kennedy/CSC mkennedy@esource.net - 919-767-7371, Leader
Margo Joyner/NW6 mjoyner@nw6.esrd.net - 919-855-0882
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Paul Muntner/Epidemiologist – Study/Follow Up on Disaster – Tulane – pmuntner@tulane.edu 504-988-1047
Amanda Hyre/Tulane – How patients move – database management ahyre@tulane.edu 504-988-3855
David Holst – RCG/Nashville - dholst@renalcaregroup.com - 615-315-5599
Steve O'Bryan- FMC- Steve.O'Bryan@fmc-na.com

Workgroup Objectives

1. Develop and implement methodology for tracking displaced patients during an emergency.
2. Develop and implement a system to track open and closed facilities during an emergency.

Accomplishments

- The Workgroup had one face-to-face meeting during the initial Coalition Meeting in Washington, DC in January 2006. Email and conference calls were utilized to accomplish the objectives and obtain renal community consensus.
- A set of recommendations regarding Patient and Provider Tracking and an Emergency Data Set were developed and consensus attained with FMC, DaVita and NRAA.
- The Coalition Physician Workgroup reviewed and approved the Emergency Data Set.
- A website for provider tracking housed on Nephron.com was established and is operational. This was made possible through partnership with Steve Fadem, MD and Brian Rosenthal's assistance and programming expertise of Nephron.com. A demo of this can be viewed at http://nephron.com/closing_units. ESRD Networks will be trained to utilize this system in June 2006.

A. Provider tracking

1. Definitions

- i. Open unit: Potable water and electricity from any source, supplies and staff sufficient to provide dialysis- performing dialysis.
- ii. Anything is less than open as defined is classified as “closed”.

2. Provider responsibilities

- i. Each unit should designate a disaster representative to the ESRD Network and provide off facility contact information. CMS should make accommodation in the Network Standardized Information Management System (SIMS) system for this element.
- ii. Each Network in the affected area should notify providers of contact information for the alternate Network should the Network be inoperable. A central 1-800 type number should be established and widely advertised to the community where backup Network information will be posted when needed.
- iii. Each facility in the affected area should contact the Network by telephone to provide a status update on a daily basis until the unit is reopened; unless the unit will not reopen for a prolonged period.
- iv. LDO facilities should report on a regional basis to the Network as directed or to CMS if available.

B. Patient Tracking

1. No reporting of patient movement should be required until the 5th post disaster day.
2. A Disaster Patient Activity Report (DPAR) with file specs should be created and utilized for this purpose to include patient first and last name, SSN, HIC number, and date of birth.
3. The DPAR should be submitted to the Network at Day 5 post disaster and then twice weekly on Tuesday and Friday. It is noted that some facilities operating in an affected area may not have the capacity to report; i.e. phone line to fax.
4. An Emergency Event should be created in SIMS to record these events.

C. Patient Health Record

1. An electronic patient specific personal health record is the ideal to ensure ready access by caregivers and to facilitate continuity of care across providers as patients move through a multi provider evacuation. The current reality does support swift adoption of this approach either from a resource or readiness standpoint. While the use of such a record may be the ideal it is not within the cope or the timeframe of the work of this coalition. It was discussed that creation of electronic PHR for all patients would require substantial investments for undetermined efficacy. The participants support the formation nationally of a Technical Expert Panel to critically explore the application, utilization and value of a PHR for this population in a disaster situation.
2. Emergency Data Set: Providers should produce a paper copy of the data set in any form from their databases annually for each patient and at the start of the Hurricane season & immediately in advance of a storm (if possible) for coastal areas. In areas subject to unpredicted disasters the information should be routinely produced twice a year. Patients should be instructed to carry the data set with them in the event of an evacuation.
3. Database Access: Neither opening Corporate databases for limited access or creation of a special database for use during disaster situations should be pursued due to concerns of misuse of data and privacy issues.

D. Other

- 1) It is strongly recommended that NKF develop a handheld version of disaster resources that can be quickly downloaded from the Coalition website to a cell phone. This should be a simple fact page with the essential phone numbers.
- 2) The definition of the incident that would activate these reporting systems should be established by the National Steering Committee in response to questions such as: *What is the required scope of a disaster to be a trigger* and *Who will give notice that the reporting systems are activated?* Suggestions include use of >10 facilities in a geographic region as a trigger criteria or that the Executive Director of the ESRD Network in the affected area make the determination based on local information of severity and scope. It was agreed that these questions be forwarded for resolution.

Kidney Community Emergency Response Coalition

Report of the Physician Placement and Assistance Response Group

Group Leaders: Andrew Cohen, MD
and Robert Kenney, MD

Goals:

1. Provide education for physicians affected by disasters and those that will be deployed to disasters.
2. Develop/revive national physician database with specialty of nephrology and nephrology extenders identified who would be willing to volunteer to serve during a disaster.
3. Develop a way to identify affected physicians: assistance in tracking.
4. Collaborate with other response areas to develop a patient tracking system.

Physician Placement and Assistance Response Group Final Report

Mission and Charge

The Physician and Placement Workgroup was charged by the Kidney Community Emergency Response Coalition (KCERC) to provide uninterrupted support by the nephrology community in the event of a disaster and to provide a means of assistance to physicians displaced by a future catastrophic event. The Workgroup developed the following charges:

Charge 1: Physician Deployment

- Define the roles for nephrologists and other physicians for the care of ESRD patients in disaster-stricken areas
- Define the roles for nephrologists in “receiving areas” of evacuees
- Define the roles of volunteer, emergency management, federally-allocated M.D.s

Charge 2: Physician Assistance

- Develop a temporary placement and deployment management plan for displaced physicians
- Availability of web-based and other information systems for physician management

Charge 3: Education

- Develop a nephrology-wide educational program regarding the management of ESRD patients during a large-scale crisis and the consequences of a disaster on this vulnerable population.

Physician Deployment

Largely through the efforts of one of our members, Jeffrey Kopp, MD, the Physician Workgroup established a working plan with the National Disaster Management System (NDMS) – currently administered by the Department of Homeland Security. After assessing the results of Hurricane Katrina, we determined two models for physician (and other health worker) deployment in the event of a disaster as follows:

Mission: A kidney responder network will provide clinical support to kidney patients in disaster settings, and in particular will ensure continuity of dialysis treatment following a disaster.

Operations: An NDMS program officer will oversee the program, including personnel database (including verifying licensure) and deployments. The Coalition will have a consultative role in developing the kidney responder network policies.

Personnel: Nephrology professionals will enter and maintain their records on a web-accessible database. These professionals will include physicians, physician assistants, nurse practitioners, nurses, dialysis technicians, social workers, and dietitians. The database will contain the following information: name, contact information, licensure (required update), certifications if available (e.g. BCLS and ACLS, required update), special skills if available (MD: central line placement, PD catheter placement; RN and dialysis tech: particular dialysis machine training), relevant health records (hepatitis B vaccine, annual PPD, annual influenza vaccine, tetanus vaccination, all with required updates), and documentation of web-based training completion (basic, advanced). Individuals will be deployed as temporary federal employees, providing transportation to the disaster theater, subsistence, and medical liability coverage. Web-based training will include both existing NDMS materials and to-be-developed disaster nephrology materials.

Team functions: All providers will have a staff augmentation role. Providers can also choose to volunteer for a Kidney Medicine Assistance Team (KMAT). We envision ultimately having 3-4 teams, possibly located in the Northeast, Southeast, Gulf Coast, and West regions. When a sufficient nucleus of individuals has indicated an interest in forming a local KMAT, with a suitable mix of skills and clustered within designated region, a team leader will be designated and this individual will initiate discussion with a local DMAT about forming a partnership that would lead to joint training and joint deployment. An important additional resource is a US Army mobile dialysis unit located at the Walter Reed Army Medical Center in Washington DC; we will seek to encourage the Army to provide sufficient resources to make this team fully functional.

Table 1. Comparison of Staff Augmentation and KMAT functions.

	Staff Augmentation Role	Kidney Medicine Assistance Teams
Deployment environment	<ul style="list-style-type: none"> • Conventional social and medical environment • Example: support a functioning dialysis clinic or hospital that lies outside the immediate disaster area and has received a large influx of dialysis patients, at the request of the dialysis facility 	<ul style="list-style-type: none"> • Austere environment (central disaster area) • Examples: stand up a non-functioning dialysis clinic or support a reduced-function dialysis clinic in the immediate disaster area, or provide dialysis in a field hospital setting

Deployment teams	<ul style="list-style-type: none"> • Small multi-skill groups, DMAT not required • Staffing according to needs, deployment for up to 2 weeks 	<ul style="list-style-type: none"> • Deploy with DMAT for periods up to 2 weeks • Staffing according to need, e.g 2 team leaders, 6 physicians, 20 dialysis nurses and dialysis technicians, 6 social workers, 3 dietitians (numbers to care for 120-180 dialysis patients: 2-3 pts/nurse, 5 stations, 6 dialysis shifts) • Possibly with low-water consumption Redy dialysis machines
Web Training	Deployment and disaster nephrology topics, basic and advanced	Deployment and disaster nephrology topics, basic and advanced
Team training	Yearly, at selected professional meetings	<ul style="list-style-type: none"> • Yearly, at selected professional meetings • Four/yr required team training sessions Two with KMAT, two with KMAT+DMAT

Proposed (aggressive!) timeline, following possible program approval 5/06

6/1/06	8/1/06	9/1/06
	1/1/08 (earliest)	
NDMS program officer assigned	AKRN database up First KMAT up	>100 members in database
	with basic web training completed	Web training modules up Staff Augmentation response up

The affiliation with NDMS won wide support from the nephrology community and letters of support were provided by National Kidney Foundation CEO, John Davis, and American Society of Nephrology President Thomas Dubose Jr. MD. A discussion with NDMS Director, Dr. David Canton, led to an agreement to go forward with a staff augmentation model. The “KMAT” proposal was deferred due to issues of budgeting. The NDMS volunteers will be “federalized” at the time of a disaster and will assigned to existing Disaster Medical Assistance Teams (DMATS) by NDMS. The agreed-upon system is described as follows:

1) **Kidney provider staff database** to support operating in a Staff Augmentation Mode: Dr. Canton thinks that this could be accomplished via having kidney provider staff (physicians, nurses, dialysis technicians,

others) join NDMS-1 team, within the MST (Management Support Team). This team includes individuals with specialized skills who can be federalized and deployed in an emergency. Individuals register via an existing NDMS database and this database could be modified to capture specialty information (such as skill in placement of intravenous dialysis catheter or skills with particular dialysis machines). Medical licensure would be verified by the departmental Human Resources personnel; this is now performed by Department of Homeland Security (DHS) personnel and if the proposed move to Department of Health and Human Services (DHHS) occurs, would transition to that DHHS. License ascertainment can be a slow process, taking up to 6 months; whether this process can be speeded up for this initiative remains to be determined.

Activation process: In an emergency and upon request of particular dialysis facilities that faced a staff shortage, the disaster Incident Commander would contact NDMS, NDMS would put out a call for volunteers within NDMS-1 who have appropriate skills, volunteers willing to serve at that time would be identified, and these individuals would deploy as temporary Federal employees. As temporary Federal employees, these individuals are provided with transportation from home to the emergency site and back home, food and lodging, and liability coverage via the Federal Tort Claims Act. An important issue to discuss is whether the participation of these temporary federal employees in providing dialysis services would jeopardize the ability of dialysis units to bill for dialysis procedures. If so, how does this affect the feasibility of proceeding with this plan or any similar plan?

If we proceed with this option, a specific timeline would be established. A goal clearly would be to have a response capability by late summer 2006.

2) Kidney Medicine Assistance Teams (KMAT): A freeze on the creation of new teams (DMAT or other) has been in existence since NDMS was moved to DHS. It is unclear when this freeze will thaw. Further, once a decision to add new teams is made, a budget must be requested. Therefore, the KMAT project is at least 2-3 years away. We should put this idea on hold for now.

Several questions are as yet unanswered regarding the proposed system:

- Will the existing systems provide adequate professional staff and resources to kidney patients in future disasters?
- If not, what is the best way to provide such medical care?
- Will the NDMS-1 team approach to providing staff augmentation to existing facilities provide a significant improvement?
- Will large dialysis organizations (LDO) and other providers find this an acceptable approach?
- How will physician deployment be coordinated with other dialysis (or transplant) health care personnel, such as nurses and technicians?

Further details about the NDMS system can be seen in the FAQ section of a proposed website (Appendix 1.)

Physician Assistance

Through the efforts of one of our members, Robert Kenney, MD and the Renal Physicians Association (RPA) a web-enabled database for nephrologists, displaced by a disaster, has been developed. The elements of that database are shown in Appendix 2.

In addition the Workgroup investigated potential disaster and business insurance options with the RPA. It was suggested that a larger “at risk” pool could be developed with a program managed by the American Medical Association.

Education

The American Society of Nephrology, the pre-eminent scientific and educational organization for renal physicians and scientists, has agreed to sponsor several educational outlets for the Coalition.

During its Annual “Renal Week” Meeting in November, the ASN will sponsor a President's Special Symposium: “ Disasters and Nephrology: Lessons from Katrina” on Sunday, November 19, 2006, 10:00 AM to 12:00 PM. The program will be as follow:

Moderators:
Robert Jay Alpern, MD
Sharon G. Adler, MD, FASN

- Speakers:
- 10:00 AM How to Prepare a Dialysis Unit for Providing Treatments during a Disaster - Robert J. Kenney, MD
 - 10:30 AM The Volunteer Physician: How to Interact with Providers and Deliver Care - Jeffrey B. Kopp, MD, FASN
 - 11:00 AM Disaster Outcomes: Follow-Up of the Katrina Dialysis Patients - Andrew J. Cohen, MD
 - 11:30 AM Salvaging Academic Programs: Recovering Research Programs with Lost Reagents and Looming Deadlines - Luis Gabriel Navar, PhD, FASN

The symposium will also be published in the Clinical Journal of the American Society of Nephrology.

Other Activities

Initially, the Physician Workgroup expressed interest in developing a web-supported database for evacuated dialysis patients. This, however, has largely been the task of the Patient and Facility Tracking Workgroup. After discussion with the Patient and Facility Tracking Workgroup Chair, Glenda Harbert, the Physician Workgroup agreed to participate in this project by reviewing the proposed data set.

The Physician Workgroup provided a revised version of the document, "Summary Recommendations, Considerations, and Resources For Treating Dialysis Patients In Disaster Areas." A revised version of that document is included with this report (Appendix 3.)

Kidney Community Emergency Response Coalition

Report of the Vendor (Industry) Services Response Group

Group Leader: Ken Chen
Amgen

Goals:

1. Establish process to proactively educate (a) Federal/State officials and (b) Providers/Networks of critical needs for emergency.
2. National coordination of manufacturers deployment plan.
3. Framework for standardized or coordinated emergency distribution process.

Vendor (Industry) Services Response Group Final Report

Concept / Requirements

- Provide a relevant one-stop resource for dialysis providers requiring vendor support during disaster situations
- Identify and make known specialized contact resources within vendor organizations to assist customers in disaster situations
- Maximize utility of the resource tool (database) by ensuring it is readily available via the internet and is efficiently maintained
- Establish clear lines of communication to key renal community stakeholders

Tool Development - Process

1. Work with NKF to determine underlying architecture, hosting, and maintenance plan for supply/equipment resource database
2. Establish relevant product categories most critical during disaster situations and draft database design concept
3. Populate tool with vendor support and quality check on a quarterly basis
4. Make tool available (with contingency for backup) on NKF emergency management website
5. Maintain and improve tool (with an annual “drill” to test implementation and check accuracy of information facilitated by CMS?)
6. Publicize existence of tool with periodic reminders for providers in collaboration with renal professional organizations and the renal networks

Questions to be Answered

1. What are the criteria / requirements for a company (and products) to be listed?
2. How will the list be developed and more importantly maintained on an on-going basis?
3. Who is responsible for continuous improvement / assessment of usefulness?

CONCEPT DRAFT

Product Category	Contact Information				
	Vendor	Disaster Coordinator	Phone	E-Mail	Web site
Dialysis Systems (Hardwired, Disposable)					
Hemodialysis Systems					
	Fresenius		800.662.1237		www.fmcna.com
	Gambro				www.usa-gambro.com
	etc...				
Hemodialysis Systems - "Waterless"					
	NxStage		866.697.8243		www.nxstage.com
	Renal Solutions Inc		866.774.6246		www.renalsolutionsinc.com
Peritoneal Dialysis Systems					
	Baxter				
	Fresenius				
	Medionics				
Water Treatment Systems - Portable					
Water Treatment Systems					
Portable Gas-Powered Generators					
Fuel					
Pharmaceuticals					
	Abbott Laboratories				
	American Medical Distributors, Inc				
	American Pharmaceutical Partners, Inc				
	American Regent, Inc				
	Amgen, Inc				
	Astellas Pharmaceuticals				
	AstraZeneca Pharmaceuticals				
	APPROXIMATELY 60 COMPANIES				
Disposable and Ancillary Equipment					
	Access Devices				
	Bandages, Dressings, Prep Kits				
	Chairs				
	Chemical Reagents / Tests				
	Concentrates				
	Conductivity Monitors				
	Diabetic Monitoring Equipment				
	Disposable Sets, Dialyzers				
	Equipment Parts, Maintenance, & Repair				
	Infection Control Products				
	IV Infusion Pumps				
	IV Solutions & Supplies				
	Oxygen & Defibrillators / Crash Carts				
	Protective Clothing & Accessories				
	Pyrogen Testing				
	Scales				
	Sterilants / Disinfectants				
	Sterilizing Devices				
	Test and Calibration Equipment				
	Used Equipment Resellers				
	Syringes & Needles				
Essential Services					
	Facility Design / Development				
	Group Purchasing Programs				
	Laboratory Services (Contract)				
	Medical Record Contacts				
	Temporary Dialysis Staffing Agencies				
National Organizations & Governmental Contacts					
	National Kidney Foundation (NKF)				
	Federal Emergency Management Agency (FEMA) Hotline				
	Center for Medicare & Medicaid Services (CMS)				

OTHER -- NOT CRITICAL AS SEPARATE CATEGORY FOR DISASTER SITUATION

Computer Hardware / Software

CRRT

Durable medical Equipment

Analytical Instrumentation

Dialyzer Reuse Systems

Dialysate Delivery Systems

Home Patient Services

IDPN Services

Management Services

Organ Perfusion / Transportation / Equip

Patient Transport Services

Pharmacy Services

Plasmapheresis

Vascular Testing

Discussion

Issues:

- 1 **How / where would this be hosted?**
- 2 **How is the list prepared and more importantly maintained?**
- 3 **What are the criteria / requirements for a company to be listed?**
- 4 **Are the categories sufficient / appropriate?**
- 5 **Agree that limiting marketing description is appropriate -- can receive through contact or website research vs in dbase?**

**ADDITIONAL MATERIALS SENT AS
SEPARATE ATTACHMENTS**

- CMS Manual, *Emergency Preparedness for Dialysis Facilities* (Revised)
- CMS Manual, *Emergency Preparedness for Dialysis Facilities* (As revised with the changes made by the Facilities Operations Response Group tracked)
- CMS *Emergency Preparedness* Manual Forms Appendix
- *Four Keys To Being Prepared For A Disaster*
- Dialysis Facility Disaster Planning Template
- Network 13 Facility Generator Survey
- FEMA *Business Recovery Plan*
- LA-DEEP Coalition's *Patient Needs Assessment*
- FEMA *Preparing for Disaster for People with Disabilities and other Special Needs* (PDF)
- CDC *Bring Up Your Dialysis Water Treatment System* (PDF)