2007 Summit – Final Report

This report summarizes activities and accomplishments of the meeting of the Kidney Community Emergency Response (KCER) Coalition, held on March 1, 2007 in Baltimore, MD. The structure of this report follows the outline of the Summit agenda.

KCER 2007 Summit / Welcome

James "Randy" Farris, MD (Centers for Medicare & Medicaid Services)

- The 2007 Summit was opened by Dr. Randy Farris, the CMS Regional Administrator from the Dallas Regional Office. Dr. Farris recognized and thanked the kidney community of care specialists, providers, beneficiary representatives, industry, ESRD Networks, professional organizations, and the federal, state and local agencies for their work on the Kidney Community Emergency Response Coalition. He noted that the kidney community has demonstrated its commitment to assisting state and local responders in meeting the life saving medical needs of individuals with kidney failure under all circumstances and that they know the true meaning of collaboration.
- Dr. Farris also stated that the KCER Coalition has contributed to the work of CMS in ensuring that the needs of individuals with ESRD are met in the event of an emergency and/or disaster, including a possible flu pandemic. CMS activities targeted towards individuals with kidney failure include those conducted in conjunction with the kidney community, such as formation of the Coalition, and those that are being conducted through contractual and/or regulatory venues.
  - ✓ The ESRD Conditions for Coverage, which are under revision with an Autumn 2007 target date for final rule publication, will include emergency preparedness and response language.
  - ✓ The new ESRD Network contract includes clear requirements for every Network to have in place plans for disaster response (including a flu pandemic plan) and to assist individuals with kidney failure, patients, providers, as well as federal, state and local responders.
    - ➢ In preparation for an emergency or disaster, Networks are required to facilitate and assist providers in developing plans for local disasters. This includes the sharing of lessons learned and best practices, hosting local meetings and forming local coalitions as appropriate, and distributing helpful materials 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 affected area, including specialty services offered. Additionally, Networks are tasked with tracking where patients are receiving services and

coordinating activities. This includes hosting inclusive, collaborative calls with providers, emergency workers, and other essential persons to ensure coordination of efforts and that the needs of individuals with ESRD are being met.

- For individuals with kidney failure, the ESRD Network responsibilities include distribution of educational materials and tools on how to prepare for a disaster and what to do in a disaster. Additionally, Networks are responsible for 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 the location of individuals and the exchange of critical medical information.
- As part of the CMS emergency/disaster planning process, ESRD Networks assist CMS by distributing CMS materials and resources to ESRD providers, facilities (transplant and dialysis), and individuals with kidney failure.

- Lastly, Dr. Farris communicated the continued need for improved processes; and expressed that it was CMS's pleasure to participate in the KCER Coalition Response Teams, the Strategic Planning Committee, and to lead the Federal Response Team, in partnership with CDC.

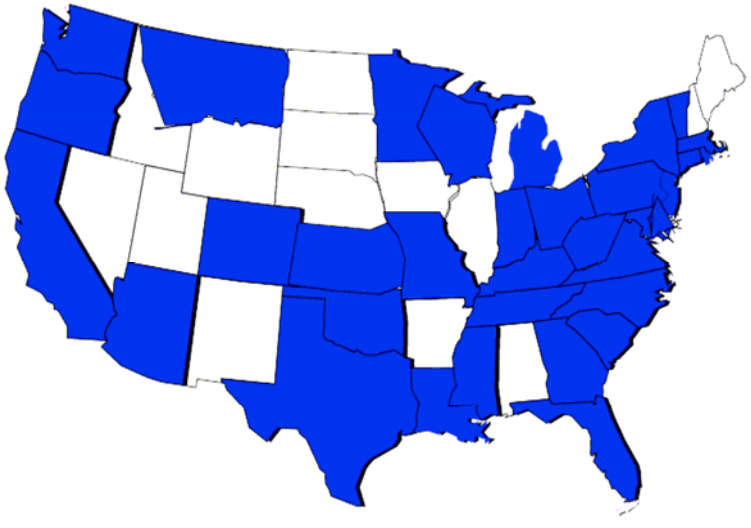
Opening Remarks

Kelly M. Mayo (FMQAI: The Florida ESRD Network – Network 7)

- KCER Phase I was initiated when the National Disaster Summit was convened on January 19, 2006 in Washington, D.C. The purpose of the National Disaster Summit was to review disaster response in the ESRD community, to plan for the future, and to explore interest in the formation of a national coalition.
- During the Disaster Summit, eight response teams were established, including:
  - ✓ Patient Assistance
  - ✓ Coordination of Volunteers
  - ✓ Physician Assistance
  - ✓ Communications
  - ✓ Patient and Facility Tracking
  - ✓ Facility Operations
  - ✓ Federal Response
  - ✓ Industry Supplies / Services
- A leadership/coordination committee (Strategic Planning Committee) was also formed with representatives from each Response Team.
- Phase I of KCER included the development and initial dissemination of tools and resources to help patients, facilities, emergency responders, and coalition members plan for, and respond to, emergencies and disasters.
- As KCER moved into Phase II**,** Network 7 assumed the lead for administrative support. In this capacity, Network 7 is tasked with:
  - ✓ Coordination and scheduling of Coalition meetings/calls
  - ✓ Maintaining a national website

- ✓ Maintaining a toll-free number
- ✓ Incorporating CQI and lessons learned
- ✓ Serving as central contact during emergencies, to include hosting and facilitating national calls, activating response teams and providing updates to KCER/CMS/Networks and others
- ✓ Providing technical assistance to affected Networks

- The second KCER Summit convened on March 1, 2007 in Baltimore, MD. There were 120 Summit participants, residing in 32 states. Organizations represented included:
  - ✓ 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
  - ✓ ESRD Networks
  - ✓ Hospital Healthcare Systems
  - ✓ Vendors
  - ✓ 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
  - ✓ Network Coordinating Council
  - ✓ Office of Inspector General
  - ✓ Physician Medical Groups & Independent Physicians
  - ✓ Renal Physicians Association
  - ✓ State Survey Agencies
  - ✓ Transplant Centers
  - ✓ Universities
  - ✓ Other Strategic Partners

- Summit Objectives:
  - ✓ Identify KCER accomplishments and goals;
  - ✓ Assess current status of national response strategy to assist federal, state and local efforts in the event of an emergency and/or disaster;
  - ✓ Develop a plan for raising public awareness of the critical needs of individuals with kidney failure and the providers that serve them;

- ✓ Plan for the promotion and dissemination of tools and resources for individuals with kidney failure, dialysis facilities, transplant facilities and key partners in emergency response at the federal, state and local level; and
- ✓ Plan for a possible flu pandemic.

2006 Regional Disaster Experiences

Glenda Payne (CMS) – Moderator

New York: Susan Caponi (ESRD Network of New York – Network 2)

- What Occurred
  - ✓ On October 12, 2006, the Great Lakes and Buffalo areas of New York experienced a record-breaking snowstorm – an extremely rare event for this early in the season.
  - ✓ The Governor declared a state of emergency and 350,000 utility customers were without power in the Great Lakes and Buffalo areas.
  - ✓ The storm closed a 100-mile stretch of the New York Thruway from Rochester to Dunkirk southwest of Buffalo.
  - ✓ Tree branches were falling due to the weight of the snow and trees and power lines were down, blocking the streets.
  - ✓ Officials in Amherst ordered a driving ban for the entire town, as 80 percent of the roads were impassable.
- Length of Emergency
  - ✓ The snowstorm lasted two days and many were without power for more than five days.
  - ✓ On day two, the National Weather Service issued a flood watch for several western New York counties. This was due to warming temperatures combining with melting snow, creating the potential for flooding in urban and low-lying areas.
- Number of Patients and Facilities Affected
  - ✓ Two units in Western New York were closed due to electrical outages, as neither had emergency generators. A third unit was operating on a generator for several days.
  - ✓ Other dialysis units in the affected area were hospital-based and had access to emergency generators.
  - ✓ Some patients were transported by ambulance to dialysis units.
- Interventions
  - ✓ Network 2 received reports from the closed facilities that all patients had been notified of the closures and were successfully rescheduled.
  - ✓ Contact numbers for the regional vice-president and regional office area manager of the closed facilities were provided to Network 2 staff.
- Lessons Learned

- ✓ At the time, Network 2 did not have a written internal disaster plan in place.
- ✓ The Network now has a coalition for disaster preparedness. Their first meeting was held on February 13, 2007.

Missouri: Sarah Yelton (Heartland Kidney Network – Network 12)

- What Occurred
  - ✓ On July 19, 2006, the National Weather Service provided an alert that a thunderstorm complex had produced straight-lined winds and downbursts, with wind speeds up to 80 miles per hour in Eastern Missouri.
  - ✓ Over 500,000 people were left without power.
- Length of Emergency
  - ✓ The emergency lasted one week, with the greatest impact occurring during the first two to three days.
- Number of Patients and Facilities Affected
  - ✓ Forty-two dialysis facilities within a 25-mile radius of St. Louis, MO were affected.
  - ✓ Thirty-four of the units were located within Network 12's service area, serving 2,605 patients.
  - ✓ Eight of the units were located in Network 9/10's service area.
  - ✓ Twenty-four facilities lost power, water, or a combination of both (for one to eight days).
- Interventions
  - ✓ Network 12 contacted local government officials to advocate for power and water restoration to the affected dialysis facilities.
  - ✓ The Missouri State Agency helped contact facilities to check operational status and needs and to offer assistance. Each facility was successfully contacted.
  - ✓ A coordinated effort with CMS was initiated, including tracking of displaced patients, answering billing questions, and providing regular updates.
  - ✓ A Large Dialysis Organization (LDO) provider offered generators to independent facilities.
- Lessons Learned
  - ✓ Several of the affected facilities had recently participated in the June 16, 2006 ESRD Network mock disaster drill and reported that the drill had helped them to prepare for an actual emergency event.
  - ✓ Network 12 did not have success in their request for press releases or Public Service Announcements (PSA). However, they have since established new contacts through the Department of Health to accomplish this.
  - ✓ Network 12 was unable to engage city and state government leaders in post-emergency follow-up.
  - ✓ Network 12 achieved mixed success with utility companies.
  - ✓ Network 12 made adjustments in their preparedness planning and coordination with facilities and other responders.

Oklahoma: Patricia Philliber (ESRD Network Organization #13)

- What Occurred
  - ✓ On January 11, 2007, a weather advisory was generated warning that 100% of Oklahoma and Northwest Arkansas would be impacted with an ice storm of 3-8 inches. The storm was to arrive on Friday, January 12, 2007.
- Length of Emergency
  - ✓ The emergency lasted one week. All facilities were operational by January 19, 2007, though one was still running on a generator.
- Number of Patients and Facilities Affected
  - ✓ There were 22 facilities and 1,228 patients within the affected region.
- Interventions
  - ✓ January 12, 2007 – Network 13 sent an alert notice to all facilities in the identified area.
  - ✓ January 12, 2007 – A broadcast fax was sent to all nurse managers in Oklahoma and Northwest Arkansas. The fax provided the following instructions and information:
    - ➢ Implement disaster plans
    - ➢ Communicate plans with patients
    - ➢ Ensure patients have their medical records
    - ➢ Reinforce emergency diet and fluid restrictions
    - ➢ Back-up facility may not be available due to scope of storm
    - ➢ Network 13 office affected/closed; cell phone contacts shared; access to voice mail would be available from offsite
  - ✓ January 12, 2007 – An email notice was sent to the Oklahoma State Agency and CMS.
  - ✓ January 15, 2007 – The Network contacted the Director of the Office of Emergency Management in Oklahoma and maintained contact until normal operations were restored (coordinated transportation, etc.).
  - ✓ January 15, 2007 – A broadcast fax was sent to facilities in eastern Oklahoma with the following information:
    - ➢ Offered help with challenging travel/transportation issues
    - ➢ Coordination with the Office of Homeland Security Office of Emergency Management (OEM)
    - ➢ Provided American Red Cross Shelter locations
  - ✓ January 16, 2007 – Network 13 addressed transportation barriers with Medicaid contractor.
  - ✓ January 17, 2007 – A broadcast fax was sent to all units in Oklahoma and Northeast Arkansas with the contact information for transportation providers.
- Lessons Learned
  - ✓ Weather monitoring, pre-storm preparedness activities, and relationships with key responders helped to facilitate successful outcomes.

Texas: Geli King-Brown (ESRD Network of Texas, Inc. – Network 14)

- What Occurred
  - ✓ Network 14 experienced several natural emergencies in 2006, including:
    - ➢ Wild fires
    - ➢ Wind storms
    - ➢ Tornadoes
    - ➢ Ice storms
    - ➢ Severe flooding
- Length of Emergency
  - ✓ The length of the emergency varied by incident.
- Number of Patients and Facilities Affected
  - ✓ The number of patients and facilities affected varied by incident.
- Interventions
  - ✓ Each emergency was handled locally and did not interfere with continuity of care.
  - ✓ Facilities affected were able to log onto Texas' EMSystem and comment on the status and location of patients. Facilities were also offered assistance through EMSystem.
  - ✓ Many patients were sent to other facilities to get them out of the affected areas.
  - ✓ Network 14 and the Texas ESRD Emergency Coalition (TEEC) were in constant communication regarding how best to handle each situation.
- Lessons Learned
  - ✓ The EMSystem is a 'real time' data base system that allows for the tracking of critical information from facilities regarding access to care issues.
  - ✓ The Coalition was pleased to see the efficient response from the community through EMSystem.

Hawaii: Allison Kregness (Western Pacific Renal Network, LLC – Network 17)

- What Occurred
  - ✓ A sudden fire broke out in a hemodialysis facility in Hawaii. The third shift of dialysis patients began with 5 patients and 3 staff members. A large bang was heard in the facility followed very quickly by smoke. Staffed immediately called 911 and proceeded to cut and clamp patients from their dialysis machines. All patients and staff were safely removed from the dialysis facility within 7 minutes of the initial emergency. The brick two-story building was completely leveled and destroyed in 45 minutes, leaving 50 patients without a facility to dialyze.

- Length of Emergency
  - ✓ The facility management set up a command center in a hotel room. Although the unit was destroyed, a larger problem was presented due to the regional office was located on the second floor of the building. The fire destroyed all patient and staff records. The facility contacted the Network office for patient phone numbers because their corporate office in

Seattle was not currently open and no one knew of the disaster.
    - ✓ The Network helped the facility management make phone calls as necessary and find facilities to accommodate the 50 patients. Five facilities in the area graciously took patients by creating extra shifts. Facility staff volunteered to go with the patients to the facilities and continue with their care on the extra shifts. The Network provided the facility management with copies of the emergency employment and patient record forms from the CMS Emergency Handbook and staff was directed to bring their licenses to the facility for verification.
    - ✓ SIMS provided the 2728 documentation and patient information for emergent transfer and Medical Directors were on hand at every facility to write basic dialysis orders to accommodate patients until a thorough assessment could be accomplished. All patients were placed by day two and all staff assigned to clinics accordingly.
- Number of Patients and Facilities Affected
    - ✓ Fifty patients from the destroyed facility were dialyzed at five surrounding facilities.
    - ✓ Facility staff volunteered to follow the patients to the new facility to continue with their care.
- Lessons Learned
    - ✓ It took approximately one year to rebuild the facility and restore all the destroyed records. Regional Offices are no longer located in the facility building. Patients were invited back to their new facility grand opening 11 months after the fire and most grateful to be back home. Emergency preparedness and fire drills have become an enormous part of the in-service programs.
    - ✓ The facility staff acted bravely and quickly, without second-guessing, and evacuated their patients immediately. Ten minutes after evacuating the facility, it was completely engulfed in flames. ESRD Network 17 was instrumental in organizing and facilitating the safe transfer of patients and staff.

Pandemic Preparedness

Sherline Lee (CDC)

- The current healthcare system is operating without the capacity to meet increased demand for services, or "surge."
    - ✓ A 2002 General Accounting Office (GAO) survey suggested that urban hospitals lacked capacity to respond to a major biological event.
    - ✓ In 2004-2005, one-third of hospital emergency rooms had to divert patients due to inadequate staff or overcrowding.
- A "bad" season of regular influenza can result in shortages of beds, staff, and diagnostic kits, resulting in the diversion of patients from healthcare facilities (APIC Influenza Survey 2003-2004).
- Healthcare sector planning is limited:
    - ✓ HRSA/CDC Bioterrorism Cooperative Agreements.
    - ✓ Sector Infrastructure planning in incipient phase.
    - ✓ Planning is isolated and current JCAHO required exercises are facility-based, not community or regionally coordinated.

- Hospital pandemic planning:
  - ✓ A small percentage stated they were well-prepared and requested increased guidance and assistance in planning.
  - ✓ Hospitals are concerned about the implementation of plans and the procurement of potentially lifesaving equipment, such as ventilators, Personal Protective Equipment (PPE), and antivirals.
- Federal pandemic plans:
  - ✓ National Strategy for Pandemic Influenza
  - ✓ Homeland Security Council Implementation Plan for the National Strategy for Pandemic Influenza
  - ✓ Heath and Human Services (HHS) Pandemic Influenza Plan
    - ➢ Strategic Plan
    - ➢ Public Health Guidance for State and Local Partners
    - ➢ HHS Operational Plan (includes continuity of operations)
- Goals of the federal response:
  - ✓ Stop, slow, or otherwise limit the spread of a pandemic to the U.S.
  - ✓ Limit the domestic spread of a pandemic and mitigate disease, suffering and death.
  - ✓ Sustain infrastructure and mitigate impact to the economy and the functioning of society.
- The three pillars of national strategy encourages planning to occur at all levels – federal, state, and local community, as well as by individuals:
  - ✓ Preparedness and communications
  - ✓ Surveillance and detection
  - ✓ Response and containment

	Federal	State/Local	Private	Individual
Preparedness	Develop and exercise federal agency plans Facilitate State/ Local planning Advance international planning	Develop and exercise state and local-level plans, include non-health entities	Establish contigency systems in partnership with other sectors to maintain delivery of essential goods and services	Make plans to support selves for several days if necessary by keeping supplies at home; Discuss how a household would respond to potential issues
Communications (Guidance)	Provide guidance to the private sector and the public • Community and workplace measures • Social distancing • Infection control	Provide public education campaigns Identify key spokespersons	Promote an ethic of infection control and establishing mechanisms to allow workers to provide services from homes (where possible)	Be prepared to follow public health guidance on containment measures (i.e., stay at home, avoid travel, hand hygiene)
	Operationalize measures to limit spread			
Surveillance	Develop systems and form partnerships to enhance situational awareness			
Countermeasures	Establish stockpiles, promote production capacity, develop allocation and distribution plans	Establish stockpiles, distribution plans and systems	Plan distribution of countermeasures to promote health and safety of clients and workers	

- Key Considerations for Healthcare Delivery
  - ✓ Healthcare delivery may be stressed or may need to be transformed in order to meet the needs of those who become ill and those who are chronically ill.
  - ✓ The cardinal determinants of public health and healthcare responsibility are:
    - ➢ The pandemic's severity and the availability of vaccine and antiviral medications.
    - ➢ The availability of healthcare staff.
    - ➢ The availability of adequate supplies and medical materials.
    - ➢ Dependencies on other critical infrastructures such as power, water, and financial.
    - ➢ Coordination beyond the healthcare facility level and across normal boundaries – with the community, other delivery sites, and with public and private partners.
  - ✓ Interrelated decisions will include:
    - ➢ Prioritization and distribution of medical countermeasures.
    - ➢ Defining essential healthcare services and essential healthcare providers.
    - ➢ Application of healthcare, workplace, community and household infection control measures.

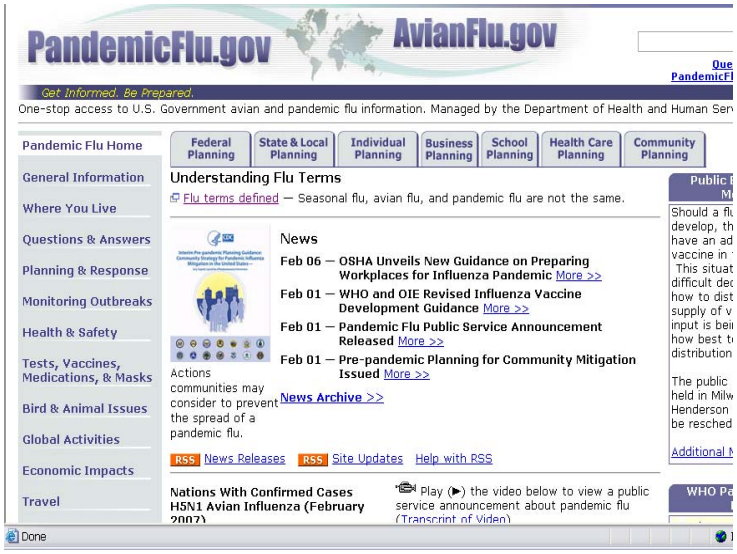
- Content of risk communication campaigns.
- Whether and when to make adjustments in the way care is delivered, known as implementing altered standards of care.

✓ Depending on the severity of the pandemic, certain requirements may be waived or revised to facilitate efficient delivery of healthcare services. Examples include EMTALA, HIPAA, Medicare, and Medicaid requirements.

✓ In order to maintain situational awareness, resource tracking should be performed in real time to inform adjustments in delivery of care.

✓ The need to deliver antiviral prophylaxis before symptoms begin, or to provide therapy to infected patients within 48 hours after symptom onset, presents significant unresolved logistical challenges.

- Pandemic Influenza Federal Interagency Healthcare Steering Committee (HHS, DHS, DOT, VA, HIS, and DOD and HHS daughter agencies: CDC, AHRQ, HRSA, FDA, CMS, and NIH):
  - ✓ Collaborate and inform work on Homeland Security Actions. Each agency brings different expertise and partners into the mix.
  - ✓ Coordinate and develop guidelines (e.g. "Community planning guide on providing mass medical care with scarce resources," home health guidance).
- Healthcare Sector Planning Workshop:
  - ✓ Workshop is intended to develop sector-specific pandemic planning guidelines.
  - ✓ Outreach is scheduled to begin in mid March 2007.
  - ✓ Planning for the first workshop is to begin in April or May 2007.
- Second CDC/AMA National Preparedness Conference – This was a National forum initiated to highlight roadblocks and solutions in pandemic planning for healthcare delivery/surge capacity. It also addressed non-pharmaceutical interventions and community mitigation strategies:
  - ✓ Solicit best practices from communities and local planners.
  - ✓ Emphasize innovative planning that includes all sectors.
  - ✓ Publish best practices to be shared as a resource.
  - ✓ Identify roadblocks to preparedness as grounds for future efforts.
- Important Resources:
  - ✓ Home Health Guidance and Tools
  - ✓ Pandemicflu.gov
    - Community Planning Guide for Providing Mass Medical Care with Scarce Resources
    - Community Strategy for Pandemic Influenza Mitigation
    - HHS Implementation Plan Healthcare and



Infection Control Supplements
- Preparedness Checklists
- Mask / Respirator Guidance for Healthcare Workers
- Community Guidance for Mask / Respirator Usage

Jim Curtis (KCER Project)

- A Pandemic Preparedness Response Team was added to the current 8 Teams, forming the 9th Response Team.
- The goals of the Pandemic Preparedness Team include:
  - ✓ Develop and disseminate plans to help the kidney community maintain its ability to care for patients in the event of pandemic flu.
  - ✓ Work with federal, state, and local agencies to assure that the KCER plan fits into the overall pandemic preparedness plans.

Testing and Refining the National Response Strategy – Tabletop Mock Disaster Drill

Jim Curtis (KCER Project) and Sally Gore (Network 7)

- Purpose of the Drill:
  - ✓ Analyze feedback from the Response Teams as to how they may act in response to a given situation.
  - ✓ Evaluate how Response Team answers *complement* or *interfere with* or *duplicate* efforts of other Response Teams.
  - ✓ Develop a list of tasks for the Response Teams to work on in order to develop a viable kidney community emergency response.
- Scenario Overview
  - ✓ A wide area is affected by a severe storm. It is a three state area with metropolitan areas and rural/suburban areas. Within the three state area there are:
    - 100 dialysis facilities
    - 8,000 dialysis patients
  - ✓ A 24-hour warning to prepare is provided.
  - ✓ After the storm sweeps through there is significant damage to the affected area:
    - Power outages affect 30% of the area
    - 30 dialysis facilities are inoperable initially
      - 15 recover after four days
      - 10 take three weeks
      - 5 have to be rebuilt from scratch
    - 2,400 patients need to find a place to dialyze
      - 1,200 need a new location for at least 3 weeks
      - 700 of these will be displaced from their homes
    - 10 nephrologists have been displaced
    - 100 nurses and technicians are needed to help in local dialysis facilities for 3-4 weeks
  - ✓ The storm arrives on a Tuesday morning. Patients that were not brought in after the warning on Monday will already have gone two days without dialysis.

- Question One - You have been given a 24-hour warning that there is a major storm coming that ***will*** disrupt many essential services. What are the five most important things a facility should do during the 24-hour preparation time? How do the Response Teams assist?
    - ✓ Notify patients of facility plans
    - ✓ Provide your patients with treatment orders and medication lists
    - ✓ Ensure PD patients have supplies and contact numbers for vendors
    - ✓ Dialyze as many patients as possible
    - ✓ Contact back-up facilities
    - ✓ Look for communications from the Network
    - ✓ Make contact with utility companies
    - ✓ Assess your staffing and supply situation
    - ✓ Ensure patients and staff have appropriate ID for passing security checkpoints
    - ✓ Response Teams monitor the situation as needed, prepare for potential response
- Question Two – On Tuesday morning at 8:00 am the storm hits the area. By 10:00 am there are 30 facilities without power. You are in dialysis facility "Y" when the power goes out. The first shift of patients has just come off. There are 18 patients who have not dialyzed since Saturday, and four of those are in your waiting room now. What should facility "Y" do? How are the Response Teams involved?
    - ✓ Tell patients to stay in side the facility
    - ✓ Secure the building
    - ✓ Access your supply of drinking water, food and blankets
    - ✓ Listen to the radio
    - ✓ Perform a physical assessment of patients
    - ✓ Feed your staff and patients
    - ✓ Turn off your electronics to prevent surge damage
    - ✓ Make contact with radio station to send out a PSA
    - ✓ Response Teams monitor status of facilities to identify potential issues, coordinate assistance and resources as needed
- Question Three – Dialysis facility "X" did not lose power. It normally dialyzes 120 patients, but a facility that has a back-up agreement with facility "X" has sent an additional 40 patients. Now, 10 more patients show up unexpectedly from surrounding facilities. What should facilities do? What action is taken by the Response Teams?
    - ✓ Determine how long your on-hand supplies will last and if the back-up facility will be sending extra supplies
    - ✓ Determine if the back-up facility will be sending extra staff and how you will help care for their needs
    - ✓ Consider how you will locate medical records for temporary patients
    - ✓ Assess the status of community transportation and the ability to transport patients form facility to home/shelter
    - ✓ Determine how you will communicate with the rest of the kidney community
    - ✓ Response Teams assist with coordinating staffing and supplies as requested
- Question Four – The area has lost power and the roads are littered with debris. The local utility company will not have power restored for ten days. Facility "Y" has a back-up generator and a 3-day fuel reserve. It has a contract with a local fuel company to deliver fuel every two days in the event of a power outage. However, because wind has knocked

trees and power lines down, the fuel supplier will not be able to make their first delivery for at least 4 days. How should facility "Y" respond? What should the Response Teams do?

- ✓ Contact the Network and neighboring facilities to determine potential the extent of the power outage
- ✓ Notify Network of your status
- ✓ Evaluate patients, reduce treatment time and/or frequency
- ✓ Contact the local EOC and inquire about resource support
- ✓ Send your patients and staff to your back-up facility prior to fuel source running out
- ✓ Meet with your response team to set up a timetable for alternatives

- Question Five – Another facility has been without power for three days. It is in the process of trying to locate patients and check on their health and safety. The facility has tried contacting the neighboring dialysis facilities and the Network. However, despite these extensive efforts to account for patients, 15 still are missing. If a facility is down and it is trying to locate missing patients, what should it do? What about the Response Teams?
  - ✓ Contact local law enforcement agencies and search and rescue teams
  - ✓ Contact the local relief shelters
  - ✓ Check the patients' home and emergency contact numbers
  - ✓ Send a runner to try and reach the patients at home
  - ✓ Check the local hospitals
  - ✓ Check the morgue
  - ✓ Facility and Patient Tracking Response Team advises the impacted networks on how to track missing patients via DPAR (disaster patient activity report)
- Question Six – It is now five days post-storm and the power and water to facility "Z" has been restored. Immediately post-storm, the area had been closed to the public because of high water and trees down. The facility is now accessible to the public and the staff is sent to evaluate the damage and prepare to reopen the facility. Power is restored and the facility status needs to be assessed. What should the facility do? How can the Response Teams assist?
  - ✓ Assess damage to building and dialysis equipment
  - ✓ Clear debris from parking lot and sidewalks
  - ✓ Test dialysis machines
  - ✓ Discard medications that may have been compromised
  - ✓ Check inventory and replace supplies as needed
  - ✓ Disinfect the water system
  - ✓ Response Teams provide technical assistance to the provider community as needed
- Mock Drill Wrap-Up – The Response Teams worked independently to identify issues, priorities, and gaps in response mechanisms. The mock drill prepared them for the next task of planning for future Response Team activities.

Response Team Planning / Next Steps

- Team Selection was initiated. For each Response Team, a correlating poster was displayed throughout the day, listing the Team objectives and their accomplishments to date. Attendees were invited to self-select the Response Team they were most interested in joining, if they were not already part of a Team.
- Brainstorming ensued among the Coalition members. Response Teams met together to review their Team's objectives and accomplishments, and to plan for future activities.
- A Stop/Start/Continue (SSC) Grid (*See Appendix A*) was utilized as a planning tool for each Team. Teams recorded current KCER activities they would like to "stop," activities they felt had not been addressed and would like to "start," and current KCER activities they would like to "continue." The SSC Grid for all Teams is included on the following pages.
- View open/closed facility status per KCER mechanism on www.dialysisunits.com. A spokesperson for each Team provided a report to the entire Coalition on their Team's plan for moving forward.

Partnership for Success

Lisa Hall Drossos (KCER / Network 7), Stephen Fadem, MD (Nephron.com), Susan Larsen (CMS) and Kelly M. Mayo, MS (Network 7)

- One of the KCER tasks is to promote and disseminate tools and resources to individuals with kidney failure, dialysis facilities, transplant facilities, and key partners in emergency response (federal, state, and local).
  - ✓ Means for the dissemination of tools and resources include:
    - ➢ National journal articles – The Physician Response Team and Coordination of Staff Team have already submitted articles related to KCER activities for publication and others are planned.
    - ➢ Web-based materials – www.KCERCoalition.com was viewed by Summit attendees. The home page provides links to Coalition resources that are required for disaster response. The Response Team page lists team objectives, accomplishments, links to Team tools/materials and Team meeting minutes. The ESRD Network page links to each ESRD Network, lists the states in their territory, and links to individual state disaster coalitions. A resource page provides links to each organization represented by KCER, and other key stakeholders in emergency response.
    - ➢ Distribution via ESRD Networks – ESRD Networks can disseminate key KCER information and materials via facility mailings, fax-blasts, newsletters, Network websites, and educational meetings.
    - ➢ www.dialysisunits.com - Dr. Steven Fadem provided a demonstration of how to view open/closed status of facilities via the Nephron website.
  - ✓ The nine Response Teams were encouraged to think about other methods of distributing information as they move forward with their planning.
- Another key KCER task is that of raising public awareness about the critical needs of individuals with kidney failure and the providers that serve them; and the need to plan ahead to ensure life-saving services are available and obtainable.
  - ✓ Opportunities for collaboration with CDC, State Agencies, State Departments of Health, Emergency Management Organizations, and other key stakeholders were emphasized.

- ✓ KCER Outreach was also emphasized. Attendees were asked to participate in outreach and assist with the review and development of KCER materials. A KCER poster was displayed at the meeting and offered to Coalition members to exhibit at national meetings. Abstracts have already been submitted for NANT, ANNA, NKF National Clinical Meetings, and ANA. The following handouts were included in the Summit binders (*See Appendix B1-B5*):
  - *Save a Life*
  - Key contact information for disaster/emergency response
  - Response Team overview
  - Facts regarding kidney disease
  - Summit Q & A

- Susan Larsen provided a CMS Emergency Preparedness Planning Update. The Centers for Medicare and Medicaid Services Survey and Certification Group (S&C) is currently developing an improved health care provider emergency planning process. S&C has established several internal workgroups who have been developing recommendations for robust and effective planning for responding to all hazards (e.g., hurricanes, tornados, fires, power outages, pandemic flu, nuclear/biological terrorist attacks, etc.). These workgroups and their objectives include the following:

S&C Emergency Preparedness Workgroups	
Work Groups	**Objectives**
Interagency Roles & Integration	✓ Determine appropriate emergency preparedness role, responsibilities & functions of: ✓ CMS Central & Regional Offices ✓ State Survey Agencies ✓ Other Federal & State agency partners ✓ Develop updated policies, guidelines, checklists to assist SAs develop effective emergency preparedness plans
Provider Standards, Policies & Guidance	✓ Develop robust emergency planning policies & requirements that apply to all provider types ✓ Develop improved guidance to providers regarding supplies, equipment, evacuation, shelter in place, etc. ✓ Develop improved policies & guidance for State & Federal surveyors
Information Infrastructure	✓ Determine CMS Data Team's appropriate role & functions during a emergency ✓ Determine critical & essential data functions, including contingencies, during an emergency ✓ Analyze State's capability to track provider status & capacity
Monitoring & Enforcement	✓ Determine appropriate adjustments to health care provider monitoring & enforcement during an emergency and/or public health disaster, including 1135(b) waiver & CMS suspension polices ✓ Determine critical & essential Regional Office functions, if SA staff are unable to perform essential business functions due to emergency

Communication & Outreach	✓ Develop effective emergency communication strategies for CMS Central & Regional Offices, SAs, provider associations & other partners ✓ Determine the communication modes CMS will use to relay information to SAs, providers & other partners, including utilizing a CMS Emergency Preparedness Website ✓ Provide timely, accurate & helpful information to partners, media & public during an emergency
Education & Technical Assistance	✓ Develop & adapt training materials for SAs, Central/Regional Offices to assist with emergency plans ✓ Determine appropriate training & assistance needs for providers, SAs, & S&C Central & Regional staff. ✓ Determine appropriate use of CMS Website to disseminate training & technical assistance information.

- Internal Quality Control (IQC) is a critical component of disaster preparedness and response activities. For KCER these activities include:
  - ✓ Regional Mock Drills – Network 7 announced plans to conduct four (4) initial mock disasters – one in each CMS regional office territory (Dallas, Boston, Kansas City and Seattle). Each following year, the drills should be repeated to encourage readiness and improvement. The type of emergency or disaster will vary in each region. Following the mock disasters, Network 7 will work with the entire renal community from each area to assess the response and conduct CQI to determine opportunities for improvement and next steps.
  - ✓ IQC tools will be developed for measuring preparedness and response in emergencies/disasters. Coalition expertise and participation is crucial to this effort. With each emergency situation, learning occurs quickly and can be applied to the next event.
- An overview of the Roles / Responsibilities of Coalition participants was provided, including:
  - ✓ KCER
  - ✓ Response Teams
  - ✓ FMQAI
  - ✓ Other
- The next step for KCER communications include:
  - ✓ Network 7 will develop the KCER 2007 Summit Report. The Report will be posted on the KCER website: www.KCERCoalition.com.
  - ✓ The Strategic Planning Committee will meet via an in-person meeting.
  - ✓ The Response Teams will continue their planning and activities. They will communicate by way of bi-monthly conference calls.

Adjournment

- All participants were thanked for their time, energy, and continued commitment to KCER. It was agreed that all of the effort put forth by Coalition members would serve to improve the quality of care and access to treatment for the ESRD population, especially during times of emergencies and disasters.

Evaluation Summary

FMQAI received favorable feedback from the Summit participants. Of the evaluations received:

- 97.20% strongly agreed that the teaching methods were appropriate and effective.
- 98.20% strongly agreed that the program was well organized.
- 97.20% strongly agreed that the physical facility was adequate.
- 98.8% strongly agreed that the content helped add to work skills and knowledge.
- 98.8% strongly agreed there was opportunity to network with colleagues.

Comments Regarding the Meeting

- ✓ Very good orientation to a vast issue that crosses many different situations and state policies.
- ✓ Good speakers: very good topics/subjects.
- ✓ Very well organized and informational.
- ✓ Handouts were extremely useful, especially the "Save a Life."
- ✓ The overview of the KCER status and working group discussions were helpful.
- ✓ The website availability was helpful.

Opportunities for Improvement

- ✓ Mock drill needs more time.
- ✓ Mock drill packed too much information into one day,
- ✓ Mock drill needed more specific instructions; room set up should be more conductive to networking.
- ✓ Handouts were in small print and were difficult to read.

Recommendations

- ✓ Add a brief overview of each work group at beginning of mock drill to help newcomers understand and find a starting point. Prepare an exercise orientation to better explain the purpose and procedures of a mock drill. Create future mock drills with additional resources, instructions, and downsize the scope of the exercise to better suit time limitations.
- ✓ Readjust the font size and layout of handouts so they are easier to read.
- ✓ Continue to utilize the website to promote and disseminate information.
- ✓ Use the same organizational format for future similar meetings.

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Appendix A: Stop/Start/Continue (SSC) Grid

The attached grid is based on the KCER Response Team tasks. Your review should consist of 2 basic steps:

1. A review of the current KCER Response Team Tasks to comment on what you believe is working well and what areas you believe could be improved or removed.
2. Addition of new tasks – areas that are not currently being addressed or other tasks that could be implemented to fulfill the goals of the KCER.

Review of the Current KCER Committee

1. Review each work group, and the tasks they are working on to identify those processes and tasks that will lead the coalition towards a useful work product, those that are duplication of efforts with other work groups, and those that are not providing a useful outcome.
2. Add comments in the appropriate column for these tasks:

STOP	Record items you would like to discontinue for KCER Phase II. This may include tasks that are no longer appropriate or tasks that are consuming resources that could be better spent elsewhere.
START	Record items you would like to see added to current tasks to strengthen them. Also record items you would like to see modified to better achieve KCER goals.
CONTINUE	Record items that you would like to continue into KCER Phase II. This would include any tasks or projects that you believe are especially effective and productive.

Addition of New Tasks

1. In the space provided at the end of the grid, add any tasks you would like to see added to Phase II. These should be new tasks, not currently assigned a Response Team.
2. In the left-hand column, record a general description of the new task. In the right hand-column, record specific details/steps for this new task. Be as specific as possible to ensure the final document represents your idea.

FACILITY OPERATIONS: Sue Rottura (Chair), Tom Bradsell, Deborah Brouwer, Sue Caponi, Rita Clymer, Danilo Concepcion, Jim Curtis, Russell Dimmitt, Linda Duval, Mary Fenderson, Gail Frederick, Bonnie Freshley, Gema Gonzalez, Brenda Lepley, Tamera Lujan, Condict Martak, Rita McGill, Tony Messana, Maureen Michael, Carolyn Neuland, Bill Numbers, Lawrence Park, Stuart Redpath, Byron Roshto, Kathleen Smith, Cindy Toombs, June Chronic Hugn, Andree Gardner, Susan Kelley, Tiffany Washington, Renee Bova-Collis, Danielle Daley, Katrina Dinkel, Teresa Casey

	STOP	**START**	**CONTINUE**
	Note things you would like to see eliminated from the KCER Response Team Tasks.	***Note things you would like to see Added to or Changed in the KCER Response Team Tasks.***	***Note things you especially like about the current KCER Response Team Tasks.***
OBJECTIVES:			
Facilitate cooperative planning among the wide variety of dialysis facilities, ESRD Networks and community disaster planners and assist with facility preparation, response and recovery efforts.		Include utilities Recruit appropriate divisions for diversity of input Make KCER posters for every dialysis unit Develop a best practice template Start toolkit ideas Add materials to KCER website	
ACCOMPLISHMENTS:			
The document "Four Keys to Being Prepared for a Disaster"			Continue
Revision of the CMS Manual "Emergency Preparedness for Dialysis Facilities"			Continue
Forms appendix in Word format			Continue
Dialysis Facility Disaster Planning Template			Continue
Facility Generator Survey Tool			Send
"Bring up your Dialysis Water Treatment System"			Distribute

COORDINATION OF STAFF AND VOLUNTEERS: Norma Gomez (Chair), Lynda Ball, Michelle Braun, Teri Browne, Sue Cary, Lisa Drossos, Paula Frost, Jeff Harder, Surveen Klein, Marsha Lisk, Susan McDevitt, Marianne Newmann, Mike Paget, Stuart Redpath, Fran Richenback, Kim Schroeder, Robert Walker, Camille Yuscak, Christie Hurley, Liz Howard, Lana Kacherova, Sandie Dean, Dean Morris, Geli Brown

	STOP ***Note things you would like to see eliminated from the KCER Response Team Tasks.***	**START** ***Note things you would like to see Added to or Changed in the KCER Response Team Tasks.***	**CONTINUE** ***Note things you especially like about the current KCER Response Team Tasks.***
OBJECTIVES:			
Develop procedures so that professional dialysis staff, to include Nurses, Technicians, Social Workers and Dietitians, can be made available and deployed to assist patients during a disaster.		Add administrative assistants, biomedical personnel, administrators and transplant providers	Updating process: 1. How often 2. Who will update 3. Educate field staff 4. Advertise and recruit Networks 5. NKF links
ACCOMPLISHMENTS:			
Established emergency volunteer databases. Provided a link on the ANNA web site for professionals to sign up to volunteer during disasters.		Test process Coordinate with LDOs and American Red Cross	
Reviewed and posted an educational handout titled “Packing for Deployment.		Review Material	Training/ Education
Investigated licensure issues in an effort to assure that the process of deploying professional volunteers does not slow the Kidney Communities response in a disaster.		Other disaster organizations	NDMS Identify points to coordinate with other response teams

INDUSTRY SERVICES AND SUPPLIES: Ken Chen (Chair), Steve Neighoff, Bryan Sheehan, Charlie Sandora			
	STOP ***Note things you would like to see eliminated from the KCER Response Team Tasks.***	**START** ***Note things you would like to see Added to or Changed in the KCER Response Team Tasks.***	**CONTINUE** ***Note things you especially like about the current KCER Response Team Tasks.***
OBJECTIVES:			
Establish a process to proactively educate Federal/State officials and Providers/Networks of critical patient needs during an emergency. Develop a plan to assure that essential supplies and equipment are available to meet the needs of kidney patients during a disaster.		Educate emergency planners and agencies at the local level Operationalize specs developed for website Bring in NNI supplies and services web template Push for system to do needs assessment – priority needs? Beyond everyday capacity Contract distribution process / back-up capability for emergency supplies / corporate policy? Develop criteria to launch notification • Regional / State • National Policy to determine management of established depot (coordination with Facility Operations Team)	Continue to brainstorm Identify points to coordinate with other Response Teams Recruit more members
ACCOMPLISHMENTS:			
Developed criteria for a one-stop resource for dialysis providers requiring vendor support during disaster situations. Defined the need for a database to ensure information is readily available by the Internet and other means. Worked with NKF to develop resource database and means of keeping it maintained.			

FEDERAL RESPONSE: Glenda Payne (Chair), Dolph Chinchiano, Gina Clemons, Janet Crow, Steve Egger, Lee Hamm, Judith Kari, Jeffrey Kopp, Kenneth Lempert, Deborah Levy, Doug Marsh , Condict Marsh, Susan McDevitt, Efrain Reisin, Sherline Lee, Kathleen Egan			
	STOP	**START**	**CONTINUE**
	Note things you would like to see eliminated from the KCER Response Team Tasks.	***Note things you would like to see Added to or Changed in the KCER Response Team Tasks.***	***Note things you especially like about the current KCER Response Team Tasks.***
OBJECTIVES			
Develop and distribute educational material for Federal, State and Local agencies on the needs of ESRD patients in an emergency situation. Develop plans and criteria for the utilization of Federal resources during a disaster.		Revisit different agencies FEMA contact needed State and territorial health office contacts needed Disseminate materials when listed, utilizing key contacts with CDC, HRSA Transplant - what materials does UNOS have?	
ACCOMPLISHMENTS			
An educational handout was developed and distributed to aide federal, state, and local emergency responders in understanding the particular needs of individuals with kidney failure an the need to plan ahead.			Continue, review and revise?
Contacts have been identified and phone conferences have been held with federal partners to address questions and concerns of federal partners, and to identify further opportunities for collaboration.			Continue engaging federal agencies
CMS made contractual changes to clarify / enhance the responsibilities of ESRD Networks and strengthened the assistance available through state survey agencies.		Networks with Special Needs Shelters should educate them on ESRD and needs Non-English speaking patients – communication, assistance, education Develop a list of key players at State Agencies	Continue to strengthen communication processes with state survey agencies and between SSAS and Networks. Utilize CMS Regional Offices

PHYSICIAN PLACEMENT AND ASSISTANCE: Andrew Cohen (Co-Chair), Robert Kenney (Co-Chair), Sarah Yelton, Kenneth Lempert, Gene Freund			
	STOP	**START**	**CONTINUE**
	Note things you would like to see eliminated from the KCER Response Team Tasks.	***Note things you would like to see Added to or Changed in the KCER Response Team Tasks.***	***Note things you especially like about the current KCER Response Team Tasks.***
OBJECTIVES:			
Provide chronic kidney disease (CKD) expertise, and the management of dialysis and transplant patients during a large-scale crisis. Provide assistance to physicians that are displaced by disasters.			Continue to provide assistance for academic programs NIDDK / NIH
ACCOMPLISHMENTS:			
Work has begun with Federal representative of DHHS to establish a specific team of kidney specialists that would be mobilized to provide assistance in the areas receiving kidney patients from the disaster area under the National Disaster Medical System of DHS.			NDMS roster has been developed for physicians, nurses, and dialysis technicians to be federalized and deployed. Add social workers and nurse practitioners.
Training sessions on provider responsibilities and expectations have been conducted during national training sessions.			Possibly develop a training video / possibly interactive web program
Tools have been developed to help physicians prepare and respond.			Displaced MD website / RPA / Articles / CJASN

COMMUNICATIONS: Gary Green (Chair), Bridget Carson, Tony Englert, Nora Fascenelli, Jackie Harley, Paul Miller, Kim Ramsey, Meryl Slowik, Susie Stark, Suzanne Wyckoff, Aaron Herold			
	STOP	**START**	**CONTINUE**
	Note things you would like to see eliminated from the KCER Response Team Tasks.	***Note things you would like to see Added to or Changed in the KCER Response Team Tasks.***	***Note things you especially like about the current KCER Response Team Tasks.***
OBJECTIVES:			
Improve or enhance the use of communication technologies to assure that information is available to assist the kidney community provide continuity of care during the response and recovery phase of a disaster.			Continue, but change "disaster" to "emergency".
ACCOMPLISHMENTS			
Developed a Kidney Care Emergency web site www.kidney.org		Develop information ("best practices") regarding the types of communications technologies available, strengths and weaknesses, recommendations. Review issues surrounding confidentiality and privacy of PHI during emergencies and disasters.	Additional discussion is necessary to streamline and clarify how an emergency is declared and from where information regarding the event is to come. A flowchart will be developed to provide a procedure for the future. With the advent of additional websites to deal with emergencies, additional discussion appears necessary to clarify roles, to avoid duplication, and to minimize confusion during an event
Created the Kidney Community Emergency list serve for activation in emergencies at ER@listserv.kidney.org. Set up toll-free line (888-33KIDNEY) to serve as the central number for use in public service announcements for patients, family members, providers and the renal community at large. Established a second toll-free line (866-901-ESRD) to provide key information to ESRD Networks KCER web site under development www.KCERCoalition.com. Target or tentative completion date is March 1, 2007.			The members of the listserv need to be reviewed. Current members should be polled to ensure that they still wish to be part of the list. It is recommended that certain constituencies (Networks, CMS, etc.) be added to the list as a matter of course. Additional discussion is necessary to streamline and clarify how an emergency is declared and from where information regarding the event is to come. A flowchart will be developed

			to provide a procedure for the future. Continue toll free line (866-901-ESRD) Issues regarding site availability, site management, and redundancy during emergencies should be reviewed.

PATIENT ASSISTANCE: Phyllis Ermann (Co-Chair), Kris Robinson (Co-Chair), Troyce Crucchiola, Brenda Dyson, Steve Fadem, Tracy Fortson, Darlene Rodgers, Rick Russo, Linda Schacht, Virna Elly, Vernon Silva, Sheila Weiner, Dawn Edwards

	STOP	**START**	**CONTINUE**
	Note things you would like to see eliminated from the KCER Response Team Tasks.	***Note things you would like to see Added to or Changed in the KCER Response Team Tasks.***	***Note things you especially like about the current KCER Response Team Tasks.***
OBJECTIVES			
Provide educational resources for patients in preparation for emergencies / disasters. Establish a Central coordination system for financial aid to patients.		Gather current check lists / resources and review for completeness or gaps Standardize checklists/ toolbox: Networks/ RSN/ AAKP / others Review suggestions provided to CMS for update of patient education booklet Look at ways to disseminate educational information e.g. patient and professional publications and professional meetings	

ACCOMPLISHMENTS			
Identified the need for more concrete tools for patients immediately in advance of a disaster. Developed education material on reinforcing that vital medical information and emergency contact information be readily available in a disaster. A laminated identification card for patients to carry with them at all times, identifying them as dialysis patients and basic medical information. Identified the need for direct support to patients through monetary grants.			
PATIENT AND PROVIDER TRACKING: Glenda Harbert (Chair), Kelly Brooks, Melinda Hayes, David Holst, Amanda Hyre, Tiffany Washington, Michael Kennedy, Paul Muntner, Steve O'Bryan, Chris Lovell, Tom Scheidel, Cathy Long, Marie Merenda, Carol Logan, Leah Skrien, Donna Swenson			
	STOP ***Note things you would like to see eliminated from the KCER Response Team Tasks.***	**START** ***Note things you would like to see Added to or Changed in the KCER Response Team Tasks.***	**CONTINUE** ***Note things you especially like about the current KCER Response Team Tasks.***
OBJECTIVES			
Develop a system to keep track of patients and dialysis providers to ensure patient accessibility to needed medical services. Develop a mechanism for Patient identification/medical information that travels with the patient.			
ACCOMPLISHMENTS			
A standardized, basic medical record has been developed. This will initially be a paper system, work will continue toward a web-based record.		Involve CROWNWeb in planning to incorporate some of the core data elements we've established for portable medical record Need to ensure that these tools are disseminated to all facilities via Networks with understanding that these are the "official" tools to be used during emergency event (will possibly require some sort of directive from KCER/CMS?)	

An on-line system to identify operational status of facilities has been established with direct facility data entry controlled by ESRD Networks.		Develop way to inform facility staff of when their facility is open and they can return to work Add message center / listserv to nephron.com where facilities could report capability to assist others Include link to ANNA's KCER page with volunteer info	
A process for tracking patient movement among dialysis facilities has been established, including a timeframe for facility reporting to ESRD Networks.		Develop consensus on data entry of patients being tracked in SIMS, as well as for reporting out of SIMS; include CROWNWeb in planning Need to ensure that these tools are disseminated to all facilities via Networks with understanding that these are the "official" tools to be used during emergency event (will possibly require some sort of directive from KCER/CMS?)	
PANDEMIC PREPAREDNESS: Rob Foreman (Co-Chair), Bill Numbers (Co-Chair), Deborah Levy, Bill Peckham, Kris Robinson, Lawrence Park, Judy Stevenson, Sue Kirschbaum, Jan Deane, Rick Russo, Virna Elly, Steve Fadem, Brenda Dyson, Steve Neighoff, Allison Kregness, Lynda Ball, Karen Strott, Robin Bender, Shirlene Lee, Matt Howard, Edwin Del Salto			
	STOP	**START**	**CONTINUE**
	Note things you would like to see eliminated from the KCER Response Team Tasks.	***Note things you would like to see Added to or Changed in the KCER Response Team Tasks.***	***Note things you especially like about the current KCER Response Team Tasks.***

OBJECTIVES			
This group will develop and disseminate plans to help the Kidney Community maintain its ability to care for patients in a pandemic event. The team will work with Federal, State and Local agencies to assure that the KCER plan fits into the over-all Pandemic Preparedness plans.		Local communication Office Emergency Management Recruit appropriate divisions for diversity of input Education of medical / lay people Goals Evaluate the work of other 8 response teams and adopt what is appropriate Identify gaps after assessment of Response Teams Educate emergency planners and agencies at a local level Resources, supplies, critical infrastructure Investigation of possibility of attaching Network dialysis pandemic plan to state plans ANNA National ESRD Education Day August 2007 / annually for legislative exposure Groups to invite: CMS, National Association of City County Health Offices, Council of State and Territorial Epidemiologists, Association of State / Territorial Health Officials, National Governors Association	
ACCOMPLISHMENTS:			
Committee is represented by ESRD patients, including home hemodialysis and transplant recipients; kidney patient and provider organizations.			

Appendix B1: *Save a Life*

What You Need to Know About
Emergency Preparedness for Individuals with Kidney Disease

Kidney failure, often called End Stage Renal Disease or "ESRD", is a life threatening condition. There are nearly half a million individuals with kidney failure in the U.S. Individuals with kidney failure require either medications to prevent rejection of a transplanted kidney, or regular repeated dialysis treatments to clean the blood supply, as frequent as three to four times a week, if they have not had a transplant. Missing even a few treatments can result in severe illness or even death for an individual with kidney failure needing dialysis.

A Kidney Community Emergency Response Coalition has been formed that includes public and private partners representing kidney care medical professionals, dialysis and transplant facilities, vendors that supply services and medications, patient representative groups, ESRD Networks, and federal, state, and local emergency responders. The Coalition created tools and resources to help providers and federal, state, and local emergency responders develop plans to help meet the life saving medical care needs of individuals with kidney failure.

You can access information on Coalition activities, and available tools and resources at **www.KCERCoalition.com. In the event of a disaster, call 1-888-33KIDNEY(1-888-335-4363) for information on how to obtain the service or assistance you need.**

Basic Requirements for Dialysis Treatment

- **Space** to do the treatment
    - **Electrical Power** to run the equipment (if electricity is not available, one machine would require a 1.65KW size generator – an average facility has 16-20 machines and a water treatment system will require at least a 50KW generator)
- **Dialysis machines**
    - **Potable water** for use in the treatment (each treatment requires a minimum of ~100 gallons of treated, pressurized water)
    - **Water treatment equipment** (Carbon filtration & either reverse osmosis or deionization)
- **Supplies** (dialyzers, blood lines, saline, medications, etc.)
- **Personnel** qualified to perform dialysis
    - **A physician's prescription** for dialysis and medical records to support the treatment
    - **A hospital** or other similarly equipped system and a means to transport a patient if complications occur while providing dialysis

DO YOUR PART – PLAN AHEAD

While the national emergency response plan can assist state and local efforts, because medical care and emergency response occurs locally, it is essential that a coordinated state and local emergency response plan is in place to meet the critical health needs of individuals with kidney failure. Waiting for an emergency or disaster to occur is too late! Dialysis is dependent on the availability of power, gas, supplies, and water – commodities that, without proper planning, are difficult to access in the event of an emergency or disaster. Individuals with kidney failure need to know ahead of time what they can do to maintain their health during an emergency and disaster, such as minimizing fluid intake and restricting their salt and potassium intake, eating an "emergency diet", and planning ahead so that they have the information they need and know how to find care. The following are a few suggestions and information on how to obtain more comprehensive information to assist in your planning.

Individuals With Kidney Failure Need To:

- **Make an emergency supply kit**.
- **Keep an updated medicine / allergies list** with you at all times.
- **Create a personal evacuation plan** - plan to evacuate early when warranted.
- **Talk to the health care team** about the facility emergency care plan, including how to contact facility staff in the event of an emergency or disaster, where back-up care can be obtained, and how to get copies of vital medical records. Many facilities have toll free numbers to call for assistance.
- **Keep a record of your facility's name** (make sure it is the official name because many facilities have similar names), physician name, and emergency contact information and keep them with all other important information.
- **Collect important personal information** and put it together in something water proof.
- **Give your kidney care team out-of-state contact** numbers (if available).
- **Get a copy of the emergency diet** and keep emergency supplies on-hand.
- **Plan for back-up transportation** to dialysis.
- **Get a list of dialysis facilities** in the area.
- **Follow your physician's advice** regarding diet & fluid intake during a disaster, when possible.
- **Follow the same frequency for dialysis services when possible**. Services may be harder to find so don't wait too long to start looking. Following the emergency diet can help if you can't get to services for a day or two.

For comprehensive planning information for individuals with kidney failure, visit: <<Medicare.gov/Dialysis/Static/Publications.asp>>.

Providers Need To:

- **Identify a leader**, and a back-up, who can head the facility's emergency preparation and response activities
- **Make a plan** to secure and protect your equipment, supplies, and records
- **Create and keep up to date a list of emergency phone numbers** for your staff and patients
- **Have an emergency plan for your patients** (as example, provide them with a copy of their last "run" sheet, a list of their medications, an emergency diet, and facility or corporate phone number(s) in a sealable plastic bag).

- **In the event of a disaster, report your facility's status to your ESRD Network:** if your facility is "open" (e.g., able to provide dialysis in a safe environment) or "closed." If you are unable to reach your local ESRD Network, call 866-901-ESRD (3773) for information on who to call and what help is available.

For comprehensive planning information for providers, visit:
<<www.cms.hhs.gov/ESRDNetworkOrganizations>> or
<<www.KCERCoalition.com>>

Federal, State, and Local Emergency Responders Need To:

- **Require State Emergency Management Associations** to include provisions for individuals with kidney failure in all plans, and involve ESRD Networks and dialysis facilities in all planning efforts.
- **List dialysis facilities as high priority locations for restoration of all services** such as power; water; and phone services.
- **Designate dialysis facilities as high priority for emergency services** such as generators; fuel; and tanker water.
- **Give priority to dialysis personnel** for limited supplies such as gasoline and housing.
- **Establish clear contacts** in each response area and make contact information known to ESRD Networks and dialysis facilities.
- **Encourage early evacuation** of individuals with kidney failure if they are on dialysis, with appropriate family members (where possible). Since services are needed on a frequent basis, the individual should be triaged, provided urgent care, and evacuated to a location where services can be provided repeatedly in a safe environment.
- **Facilitate delivery of supplies** to dialysis clinics.
- **Provide security assistance** to protect dialysis facility staff, emergency generators, and fuel used to run the dialysis equipment.
- **Allow patients and staff with appropriate identification to cross roadblocks and travel during curfews** to get to and from dialysis clinics.
- **Provide alternate sites for treatment** if dialysis clinic operations are impacted by the disaster - work with dialysis providers, state agencies and the End Stage Renal Disease Network organizations (www.esrdnetworks.org) to establish these locations.
- **Routinely screen for kidney failure** when individuals seek shelter in disasters. Add: "Do you require dialysis?" and "Do you have a transplanted organ?" to all screening tools.
- **Recognize that individuals with failed kidneys have unique medical needs** and 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; as example, 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 also be used for others.

Being without dialysis as few as three or four days could result in illness or even death for individuals with kidney failure.

Appendix B2: Key contact information for disaster/emergency response

DISASTER / EMERGENCY RESOURCE LIST

Kidney Community Emergency Listserv
ER@listserv.kidney.org

Kidney Community Toll Free Emergency Hotline 888-33KIDNEY or 888-335-4363

Kidney Community Emergency Response / Preparedness Web Site
www.kidney.org

Kidney Community Emergency Response Coalition (KCER)
- **Website www.KCERCoalition.com**
- **Toll-Free Line 866-901-ESRD (3773)**

Coordination of Staff / Volunteers
www.annanurse.org

Kidney Community Conference Calls During an Emergency:
- **Notices / dial-in numbers will be posted on the KCER website and on the KCER Toll-Free Line 866-901-ESRD (3773)**

Facility Tracking (open / closed status)
http://www.dialysisunits.com

Kidney Community Emergency Response (KCER) Coalition 2006 Summit Report
www.KCERCoalition.com

Kidney Community Emergency Response (KCER) Coalition 2007 Summit Report
www.KCERCoalition.com

Appendix B3: Response Team overview

RESPONSE TEAM OVERVIEW

The Kidney Community Emergency Response (KCER) Coalition is made up of dedicated members of the Kidney Community. All members of the community are represented from patients to physicians, from providers to industry to the government.

KCER has developed nine workgroups to work on individual parts of the overall plan. A steering committee that includes members from each of the Work Groups will put all of the pieces together into a comprehensive guide to emergency planning and response for the Kidney Community.

The Work Groups and area of focus are:

Patient Assistance:
- Educational resources for patients in preparation for emergencies / disasters
- Central coordination system for financial aid to patients

Communication:
- Toll-free emergency helpline for patients/community 888-33KIDNEY or 888-335-4363
- During emergencies: Email listserv and kidney community conference calls

Facility / Patient Tracking:
- Track and report open / closed status of dialysis facilities
- System to track displaced patients during an emergency

Federal Response:
- Educate Federal agencies and state partners in needs of ESRD patients
- Direct Federal resources for ESRD during a disaster response

Facility Operations:
- Assist facilities in disaster preparation / response
- Facilitate cooperative planning among independent and corporate facilities

Coordination of Staff / Volunteers:
- Develop and maintain a database of emergency / disaster volunteers
- Educate volunteers who will be deployed into disaster areas

Industry Supplies / Services:
- Assist in planning and emergency distribution of supplies for dialysis / transplant care

Physician Placement / Assistance:
- Provide nephrology expertise for the management of dialysis and transplant patients during a large-scale crisis
- Assist displaced physicians

Pandemic Preparedness:
- Ensure continuation of services in the event of a major pandemic
- Coordinate kidney community efforts with federal and state agency plans

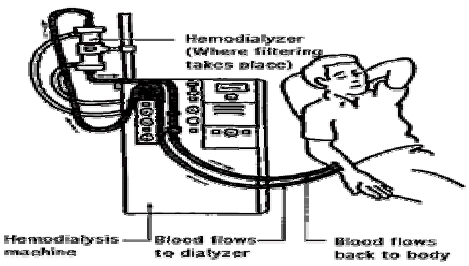
Appendix B4: Facts regarding kidney disease

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 individuals with kidney failure 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.

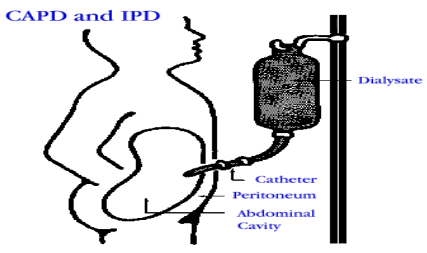
Many patients suffer kidney failure due to either diabetes or high blood pressure (hypertension). Both of these conditions may also require special attention and available medications that need to be taken regularly for the person to remain healthy.



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, fluoride and bacteria) 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 resupply 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 for hospitals that do not routinely 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 or may need to go to a dialysis facility for their treatments until they can resume home dialysis.

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.

Appendix B5: Summit Q & A

Kidney Community Emergency Response (KCER) Coalition Q & A's

July 26, 2006

Q.1. When was the Coalition formed?

A. CMS, through contract with the Florida ESRD Network, convened a National Disaster Summit on January 19, 2006 to review lessons learned post Hurricanes Katrina and Rita, promising practices, and to plan for the future. Eighty individuals, representing over 50 organizations across 25 states and the District of Columbia participated in the national Summit. During the Summit, a national "Kidney Community Emergency Response Coalition" was formed to assist state and local efforts in meeting the needs of individuals with kidney disease.

Q.2. Who is involved in the Coalition?

A. The Coalition is comprised of partners from the full kidney community representing patient and professional organizations; practitioners serving the patient with kidney failure such as nurses, technicians, dieticians, social workers, physicians and providers; independent dialysis and transplant facilities; large dialysis organizations; hospitals; suppliers; ESRD Networks; and state emergency and survey representatives; as well as the CMS and other Federal agencies such as the Food and Drug Administration (FDA), and the Centers for Disease Control (CDC).

Q.3. How is the Coalition organized?

A. The Coalition includes eight response teams addressing the areas of patient assistance, coordination of staff and volunteers, physician assistance, communication, patient/facility tracking, facility operations, Federal response, and vendor supply services with a coordinating committee composed of representatives from each of the response teams. The National Kidney Foundation was the administrative support lead for coordination of coalition activities during Phase I. CMS and the ESRD Networks have assumed the lead for coordination of coalition activities during Phase II, with strong support and participation from the practitioners, dialysis facilities, suppliers, beneficiary representatives, and other local, state, and Federal agencies.

Q.4. Who leads the Coalition?

A. All partners in the Coalition are active participants, and lead in their respective areas.

Q.5. What is the CMS role in the Coalition?

A. CMS, or an ESRD Network under contract with CMS, is participating on each of the eight response teams and the coordinating committee, and leading the Federal response area in partnership with CDC. CMS and the ESRD Networks have assumed the administrative support lead for coordination of Coalition activities during Phase II

with strong support and participation from the practitioners, dialysis facilities, suppliers, beneficiary representatives, and other local, state, and Federal agencies.

Q.6. What are the Coalition accomplishments?

A. A web site and 800 # for use by patients and staff during and following disasters has been set up; an on-line system for posting "open" and "closed" status of dialysis units is operational with access available to the public, including a system to map to the closest open facility; information on emergency planning based on lessons learned during recent disasters has been updated and distributed to individuals with kidney failure and dialysis facilities; an educational piece specific to the needs of individuals with kidney failure in an emergencies is being prepared and distributed to first responders and state and Federal response teams; public service announcements, bulletins, and other reference material has been developed and will be distributed to shelters; providers are finalizing a standardized basic emergency patient record; a database for listing patient care staff willing to volunteer in emergencies has been set up; and plans are underway to have trained kidney care professionals on stand-by for temporary federal employment if needed in the event of a disaster; and the vendors have developed a system to facilitate ordering and delivery of critical supplies.

Q.7. What happens next (Phase II) in Coalition activities?

A. The goal of Coalition activities in Phase II is to:

- Raise public awareness of the critical needs of individuals with kidney failure and the providers that serve them, and the need to plan ahead to ensure that life saving dialysis services are available and obtainable in the event of an emergency and disaster;
- Promote and disseminate tools and resources that are available to individuals with kidney failure, dialysis facilities, and federal, state, and emergency workers;
- Test and refine the national response strategy that has been put into place to assist federal, state, and local efforts in the event of an emergency and/or disaster; and
- Plan for a potential flu pandemic.