



KCER: KIDNEY COMMUNITY EMERGENCY RESPONSE COALITION

2008 KCER SUMMIT REPORT

**February 21, 2008
Baltimore, Maryland**

Under contract with CMS, FMQAI: The Florida ESRD Network (Network 7) serves as the lead for administrative support of the Coalition. Contract Number HHSM-500-2006-NW07C



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Introduction

The Kidney Community Emergency Response (KCER) Coalition is the leader in providing emergency and disaster preparedness and response information for stakeholders in the kidney community. Since 2005, the KCER Coalition has collaboratively developed, disseminated, implemented, and maintained a coordinated preparedness and response framework for the kidney community in the event of any type of emergency or disaster.

The 2008 Summit celebrated a third year of KCER's successful annual meetings. This year's Summit was held on February 21 in Baltimore, Maryland. There were over 120 registered attendees from End Stage Renal Disease (ESRD) Networks, the Centers for Medicare and Medicaid Services (CMS), dialysis and transplant providers, National Institutes of Health, city and state health departments, industry supply and service organizations, kidney-related organizations, patients, and emergency management agencies.

Summit Objectives

The 2008 Summit Meeting aimed to display Response Team achievements and present recent and future Coalition activities. This year's Summit organized a broad mix of stakeholders to network and discuss recommendations to promote and improve KCER planning and response mechanisms. Summit activities engaged stakeholders in collaborative activities to evaluate the efficiency of resources and identify and address any gaps.

Technical Assistance

KCER is available to provide technical assistance to ESRD Networks, CMS, and other organizations. Technical assistance can be requested at any time, not just when faced with a potential emergency or after a disaster strikes. Information and resources can be provided before a disaster to supplement existing preparedness measures. KCER resources include:

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| Toll-free information hotline | KCER hosts a kidney community toll-free emergency hotline for patients / providers at 888-33KIDNEY. In the event of a disaster, this hotline will serve to connect dialysis patients, their families, and healthcare providers with kidney care resources. |
| Emergency email distribution lists | In the event of a large-scale emergency/disaster, Networks can request that this resource be activated so that kidney community responders can exchange critical status information via email. The Listserv is tested and updated quarterly and also provides occasional announcements. |

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| Kidney community conference calls | <p>The KCER Coalition is available to host conference calls for national emergencies and disasters. Notices and dial-in information will be posted on the website and on the KCER Hotline.</p> <p>The KCER Hotline is 866-901-ESRD (866-901-3773). During non-emergency times, a recorded message is available.</p> <p>This conference line is also available for use by individual Networks for coordinating pre-disaster preparedness, emergency response and recovery activities.</p> |
| Open / Closed facility status | <p>KCER is available to help Networks post the open / closed status of facilities to www.dialysisunits.com.</p> <p>KCER can also assist Networks in communicating provider operational status to State Agencies, CMS and other appropriate stakeholders.</p> |
| Additionally, KCER is available to | <p>Help identify “lessons learned” and share best practices.</p> <p>Provide assistance with continuous quality improvement.</p> <p>Address and update internal and community practices for disaster readiness and response.</p> <p>Provide emergency management education and training.</p> |

Every Disaster is Different

Hazards can vary by city, state, and time of year. Each disaster has its own unique characteristics that present new and sometimes challenging issues to the kidney community and emergency responders. KCER possesses the flexibility and resources to assist in a variety of emergencies. For example,

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| <p>A Network office may have to close due to inclement weather, such as a snowstorm or tornado warning. KCER is able to assist with back-up Network coordination and relay important information to other Networks, CMS, and other key organizations.</p> |
| <p>Recent California wildfires drew great national interest. There was widespread news coverage of the events, drawing a high level of public attention. Wildfires also pose significant and lasting public health concerns.</p> |
| <p>Severe ice and winter storms in the Midwest involved multiple states from Arkansas to Nebraska. Ice and freezing rain caused power-outages and severe travel limitations and made for a lengthy response and recovery.</p> |

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You Matter

- We are all impacted by emergencies and disasters. Emergencies can range from blackouts, flood warnings, tornadoes, earthquakes, hurricanes, and hazardous materials spills. A disaster can happen anywhere at any time.
- We all have a role in preparedness and response. Each stakeholder brings a unique and valuable perspective to preparedness and response in the kidney community. Everyone has a role in personal / family preparedness. Additionally, stakeholders may play a role in preparing their workplace and their patients.
- We can all make positive changes in the kidney community. Each activity that promotes disaster preparedness in the kidney community strengthens knowledge and relationships that can save lives.

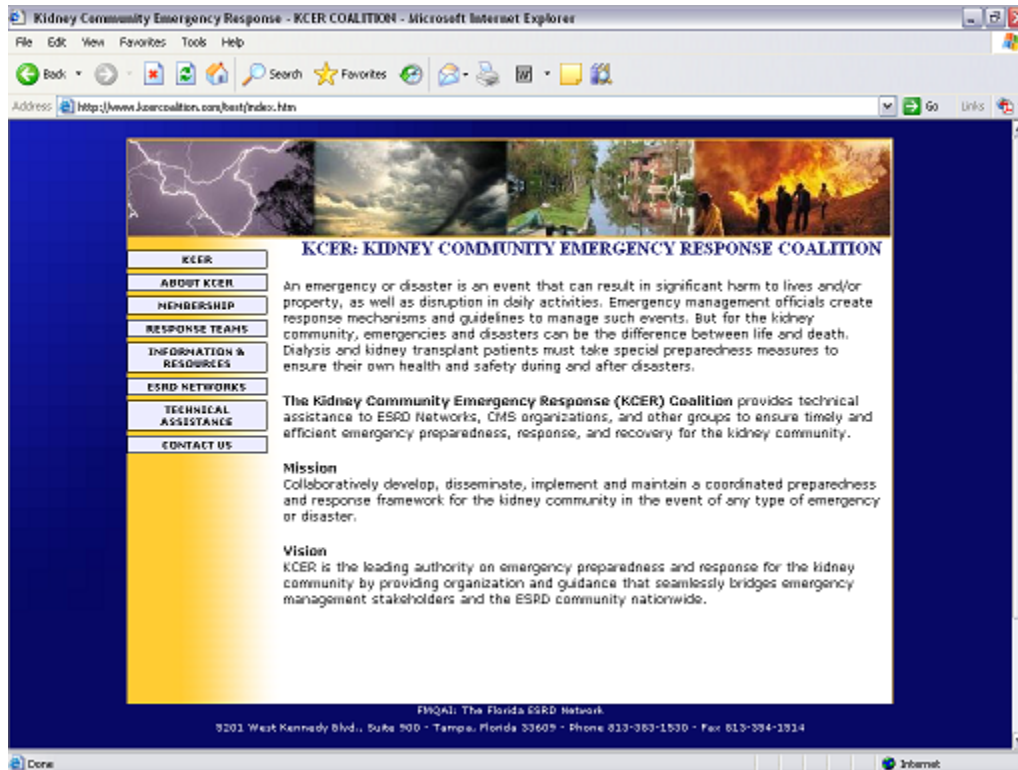
Save A Life

The KCER Federal Response Team developed the “Save a Life” document to promote the importance of disaster preparedness in the kidney community. ESRD patients on dialysis require unique planning and resources that must be addressed at the local, state, and national level. This educational tool is designed for all organizations; especially emergency management decision makers who may not be aware of dialysis and kidney transplant patients’ special requirements. This tool describes the basic requirements for dialysis treatment, and how patients, dialysis providers, and emergency responders can plan ahead. A copy of this document can be downloaded from the KCER website at www.kcercoalition.com/SaveALife.pdf.

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KCER Website

The updated KCER website is set to launch in April 2008. Aside from a new graphic design, features include an easy navigation menu to access information.



A Special Guest...

Lieutenant Robert Maloney, Baltimore City Fire Department, Office of Emergency Management presented a special welcome from Baltimore Mayor Sheila Dixon. Mr. Maloney expressed thanks to KCER Coalition members for their efforts in disaster planning for the kidney community.

Collaboration

“Opportunities for Collaboration, Next Steps” worksheets were provided in the meeting materials packet. These worksheets first outlined each Response Team and their focus, then asked the following questions for each Team:

1. What do you think is the most important activity of this Response Team and why?
2. What are some additional activities and resources that could be created or utilized by this Response Team (other organizations with similar goals, new audiences or methods, new types of documents or outreach, etc)?

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3. What do you think is an area where this Team may have gaps? How can the Team address those gaps?

After the Response Team updates, individual tables were instructed to work together to produce an evaluation of each activity and create recommendations to bridge any identified gaps. KCER Coalition members volunteered to assist in facilitating table discussion and ensure that the worksheets were completed.

Response Teams

Each Response Team Leader presented a brief Power Point outlining their recent activities, achievements, and future needs. Teams used this opportunity to educate the Coalition and other meeting attendees about their endeavors and discuss possible collaboration with other Teams.

Communications Response Team

Team Leadership - Gary Green

The Communications Response Team goals are to 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. Recent Team activities include:

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| Reviewing information on www.kidney.org/help | The content is being evaluated for appropriateness to main subject audience, which is the public and patients. The Team recommends that professional resources be moved to the KCER website, www.kcercoalition.com and also that the site be redesigned. |
| Maintaining the KCER Emergency Listserv | The listserv (er@listserv.kidney.org) is now up to 363 members. This list is tested periodically to determine deliverability. The Team plans to use test mailings to obtain voluntary demographic data on list members. Additionally, the Communications Team established a Listserv, or email distribution list, for each of the eight Response Teams. |
| Develop a Communications “Best Practices” | The Team formed a subcommittee to develop information to advise facilities on communications issues relating to emergencies and disasters. The target date for completion is second quarter 2008. |

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The KCER Collaboration determined these areas as important Response Team activities

- ✓ KCER Listservs
- ✓ National hotline
- ✓ Websites

The KCER Collaboration developed these recommendations:

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| Provide public service announcements (PSAs) | Provide pre-written Public Service Announcements (PSAs) to standardize messages across the renal community in coordination with emergency management language and practices. |
| Develop and disseminate non-electronic (hardcopy) information to patients and providers | How do people access information if communications systems are unavailable (no electricity, phone, mobile phones, computers, or Internet access)? Explore the use of radio, television, and newspapers to disseminate information. Utilize patient and provider newsletters to provide information. |
| Differentiate between www.kcercoalition.com and www.kidney.org/help | Differentiate between the two websites in terms of their purpose and intended audience. It is confusing having two “KCER websites.” Possibly refer to the www.kidney.org/help site as the “Patient Help website” instead of calling it the “KCER site.” |

Coordination of Staff and Volunteers

Team Leadership - Norma Gomez

The Coordination of Staff and Volunteers goal is to develop a means that professional dialysis staff, to include nurses, technicians, social workers and dietitians, can be made available and deployed to assist patients during a disaster. Recent Team activities include:

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| Establishing an emergency Volunteer Database | A link is provided on the ANNA web site for professionals to sign up to volunteer during disasters (www.annanurse.org). The current list of volunteers includes: <ul style="list-style-type: none"> ➤ 113 Nurses and Technicians ➤ 2 Dietitians ➤ 26 Social Workers |
| Establishing a Team email distribution list | A Team email distribution list ensures the Team leadership and members can communicate efficiently. |
| Contacting all registered volunteers and encouraging | This would allow them to be hired before the emergency as intermittent Federal employees and, when needed, |

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| <p>them to also register for the NDMS</p> | <p>would be deployed as active Federal employees to include salary, travel, housing, subsistence, and licensing.</p> <p>Nephrologists, nephrology technicians and nephrology nurses are eligible to register with NDMS. The National Disaster Medical System is a section within the U.S. Department of Homeland Security, Federal Emergency Management Agency, and is responsible for supporting Federal agencies in the management and coordination of the Federal medical response to major emergencies.</p> |
| <p>Testing and refining the Response Team's Activation Plan by participating in the September 2007 KCER Disaster Exercise.</p> | <p>The drill helped identify the need for:</p> <ul style="list-style-type: none"> ➤ Phone tree ➤ Alternate 1-800 number for Team Conference Calls in times of emergency (ANNA did provide an 800 number for back-up) ➤ Communication with other Response Teams and Large Dialysis Organizations (LDOs) to coordinate staffing in times of emergency ➤ State practice act information – need to investigate the ability to gain waiver or extension of timeframes during and post disasters for nursing licensure. Addressing this concern with the Federal Response Team and the CMS Survey & Certification Team. |
| <p>Dialysis DMAT</p> | <p>The Team has discussed the merits of establishing a Dialysis Disaster Medical Assistance Team (DMAT). There are currently issues with funding of the equipment and staff.</p> |

The KCER Collaboration determined these areas as important Response Team activities:

- ✓ Efforts to coordinate with the National Disaster Medical System (NDMS).
- ✓ Recruiting and maintaining a database of volunteers.

The KCER Collaboration developed these recommendations:

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| <p>Define volunteer roles and expectations</p> | <p>What are the qualifications and expectations of a patient care technician, nurse, and other staff positions? Define expectations and the timeframe in which volunteers should respond/deploy (12-24 hours?).</p> |
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| Provide training to volunteers in order to expedite the deployment process | How will volunteers be mobilized/transported, how will they maintain communications? |
| Establish standard job protection for volunteers, clarify licensure issues, insurance, HIPAA | Standardized procedures, roles, and liability coverage should be provided before the volunteers register. |

Facility Operations

Team Leadership - Larry Park and Sue Rottura

The Facility Operations Response Team's goal is to 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. Recent Team activities include:

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| Revising the first edition of the "CMS Emergency Preparedness for Dialysis Facilities Disaster Manual" | Revision has been completed. This includes useful updates such as placing all the forms in one section of the manual for ease of use/reference and making the forms available in Microsoft Word documents for easy editing to assist in developing facility-specific plans. This document will be distributed to dialysis facilities and placed on the KCER website. |
| Participating in the 2007 KCER Disaster Exercise | The drill assisted the Team in assessing preparedness levels. |
| Reviewing other available tabletop exercises | Reviewed exercises for Networks, counties, and providers. Plan to conduct/participate in another drill prior to the Atlantic Hurricane Season, which starts June 1, 2008. |

The KCER Collaboration determined these areas as important Response Team activities:

- ✓ Revision of the CMS Emergency Manual and putting the forms in a Microsoft Word format.
- ✓ Developing relationships with vendors and the Industry Services/Supplies Subcommittee and having vendors develop their own response plans to move supplies in an emergency situation.
- ✓ Drills and tabletop exercises.

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The KCER Collaboration developed these recommendations:

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| Develop minimum requirements for facility disaster preparedness | Recommend minimum standards including how to disaster-proof a facility and surrounding area (mitigation against trees too close to the roof/windows, keep records off the floor, etc). |
| Develop a template for tabletop exercises | Monitor facility drills or be able to provide a grading scale and recommendations for improvement. |
| Clarify who/how to update www.dialysisunits.com | Clarify the roles and responsibilities of Networks and providers when updating the facility open/closed status on www.dialysisunits.com . |

Federal Response

Team Leadership - Glenda Payne and Renee Dupee

The Federal Response Team’s goals are to develop and implement a coordinated response for the kidney community in the event of any disaster, and educate the emergency response community, allowing them to respond more effectively and efficiently and ensure the care individuals with kidney disease require is available. Recent Team activities include:

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| Presenting information and materials (KCER brochures, “Save a Life”) on the national conference calls | <ul style="list-style-type: none"> ➤ CMS Survey and Certification Emergency Preparedness Stakeholders Call, September 19, 2007, ➤ CDC State and Local Call (CDC Division of State and Local Readiness), December 19, 2007, and ➤ HHS Regional Emergency Coordinators Call, February 13, 2008. |
| Reviewed / Revised Statement of Work (SOW) and ESRD Manual | Revisions to clarify expectations of Networks in emergencies. |
| Clarifying issues which are barriers to enrolling volunteers in the National Disaster Medical System (NDMS) | Barriers and issues include costs and level of interest in using this resource if it available. |
| Engaging other Federal Partners through connections with the emergency preparedness and response activities being done for all provider types | The Federal Response Team continues to foster relationships with government agencies. |

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The KCER Collaboration determined these areas as important Response Team activities:

- ✓ Addressing potential legal issues and barriers to staffing during disasters. Addressing issues with HIPAA and exploring barriers to deploying volunteers.
- ✓ Communication among Federal agencies to raise awareness and promote the needs of the kidney community to other Federal agencies to overcome barriers.

The KCER Collaboration developed these recommendations:

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| Assist in the publishing and dissemination of the CMS Emergency Guide for Dialysis Facilities | Develop a method to promote the updated version and assist organizations in locating the new manual. Be available to answer questions about the updates. |
| Acquire and maintain DHS/FEMA relationships | Relationships with emergency management officials will assist the Team in advancing their goals and strengthening their activities. |
| Assist in or promote pre-positioning dialysis assets | Identify resources that would be needed in an emergency. Coordinate with FEMA and state emergency management logistical staging areas (LSAs). |

Pandemic Preparedness

Team Leadership – Wendy Schrag and Larry Park

The Pandemic Preparedness Team goals are to develop and disseminate plans to help the kidney community maintain its ability to care for patients in the event of pandemic flu. The Team works with Federal, state and local agencies to assure that the KCER plan fits into overall pandemic preparedness plans. Recent Team activities include:

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| Providing web resources | These materials are obtained from multiple resources and revised. The Team posts the highest quality, most pertinent information for the kidney community on the Team webpage. This information is further categorized into user-friendly sections and additional links are provided to other organizations. So far, there is no easy step-by-step plan for pandemic preparedness planning for dialysis providers or dialysis patients. |
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| <p>Developing information and resources (posted on the Team webpage)</p> | <ul style="list-style-type: none"> ➤ Anti-Viral Decision-Tree: developed decision-tree on processes needed to determine stockpiling of anti-viral medication, ➤ OSHA Mask Recommendations: researched and summarized OSHA mask recommendations in a pandemic emergency, and ➤ Patient Preparedness Checklist: developed pandemic preparedness checklist for dialysis patients. |
| <p>Assessing ESRD Networks & Dialysis Providers</p> | <p>Team provided questionnaires to all ESRD Networks & Dialysis Providers that are members of the Kidney Care Council to assess their current level of pandemic preparedness planning. Results showed a need to develop kidney-specific pandemic preparedness resources for ESRD Networks, patients and dialysis providers. All were excited about resources our Team could provide to them.</p> |
| <p>Forming three new sub-Teams in December 2007</p> | <ul style="list-style-type: none"> ➤ Patient education/resources/information Team, ➤ Provider education/resources/information Team currently working on a pandemic preparedness checklist for dialysis providers, and ➤ Marketing Team. |
| <p>Currently in development</p> | <ul style="list-style-type: none"> ➤ Ethical Issues and Decision-Making: a document to assist dialysis providers in processing ethical issues related to resource allocation, personal protection, and civil liberties, ➤ Most Important Things to Know: a document which outlines facts for kidney patients and for providers, and ➤ Pandemic Preparedness Week: The first week of October 2008 will promote awareness for pandemics. Dialysis clinics will receive a fax blast from their ESRD Networks of resources to download from the Team webpage to promote pandemic preparedness education with staff and patients. ➤ Also, a Team drill will be conducted in 2008. |

The KCER Collaboration determined these areas as important Response Team activities:

- ✓ Development of Sub-Teams to focus more on patient/provider education.
- ✓ Creation and/or dissemination of the pandemic preparedness checklist, stockpiling algorithm, antiviral decision tree, OSHA mask recommendations, and the ethical decision-making matrix.
- ✓ Pandemic Preparedness Week: email and fax-blasting facilities the available resources and patient checklist to create awareness.

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The KCER Collaboration developed these recommendations:

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| Pandemic Preparedness Day | Additional outreach / education / public service announcements about the October Pandemic Preparedness Day for the renal community. |
| Funding antiviral supplies | Explore the possibility of Federal government funding antiviral supplies for all facilities staff and patients. |
| Evaluate state and Federal pandemic plans | Evaluate state and Federal pandemic plans to determine how ESRD fits into the plans. Provide feedback to state pandemic planners on the importance of inclusion of ESRD patients into state plans. |
| Research | There is still an unknown impact to dialysis patients. More research is needed specifically on the kidney community during pandemic emergencies. |

Patient Assistance Response Team

Team Leadership - Brenda Dyson, Phylis Ermann, and Kris Robinson

The Patient Assistance Team goal is to provide educational resources for patients in preparation for emergencies and disasters; and to be the central coordination system for disaster financial aid to patients. Recent Team activities include:

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| Providing patient education and information | The Team identified the need for specific information to help patients prepare for an emergency. They developed education material reinforcing the importance of having vital medical information available in an emergency. The Team also reviewed identification cards for patients to use in an emergency. |
| Identifying the availability of resources | The Team identified reliable sources of financial assistance in an emergency, such as AAKP, AKF, and NKF. The Team is planning for the identification of disaster specific resources, linking patient disaster preparedness resources to the patient website, and translating some of the documents into Spanish with the assistance of ESRD Network 18. |

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| Proposing the kidney community designate the official color of lavender to identify ESRD patients | Proposing the kidney community designate lavender as the official color to identify ESRD patients and to make wristbands, identification cards, and fanny packs available. This identifying color should be communicated to local, state, and national emergency responders, health organizations, and lawmakers. An official color may assist patients and staff in crossing barriers and can also raise public awareness of the special needs of the kidney community in the event of a disaster. |
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The KCER Collaboration determined these areas as important Response Team activities:

- ✓ Developing a uniform method of patient identification: identification cards, the use of the color lavender, fanny packs. Creating awareness of the identification methods and building identity in the renal community.
- ✓ Patient education in multiple languages

The KCER Collaboration developed these recommendations:

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| Develop media alert messages for patients | Coordinate with the Communications Team to develop and disseminate Public Service Announcements. |
| Promote lavender as identifying color for dialysis patients | Inform State Emergency Management Agencies, State Departments of Health, Red Cross, and kidney organizations of the intent to use lavender to identify dialysis patients and the use of lavender-colored patient identification cards. |
| Target rural areas | Ensure inclusion of patients in rural areas, home patients, and independent facilities. |
| Use recognizable pictures, like a logo, for patients | Develop information in other languages, large print, audio/video, Braille. Use hardcopy dissemination methods, as not all patients or facilities have access to web resources. Develop education and resources for families and communities. |

Patient and Provider Tracking Team Leadership - Shane Perry

The Patient and Provider Tracking Team's goal is to develop a system to track patients and dialysis providers to ensure patient accessibility to needed medical services, and to develop a mechanism for patient identification and to facilitate transport of medical information with the patient. Recent Team activities include:

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| Re-Grouping | The majority of past members have continued interest in the Response Team. New Team leadership and KCER staff are working to strengthen Patient and Provider Tracking activities. |
| Brainstorming | There are three tasks, including: <ul style="list-style-type: none"> ➤ Task 1: Emergency Core Data Set: The purpose of the ESRD Emergency Data set is to support continuity of care and reduce fragmentation of care. The data set is comprised of important health record elements identified by nephrology professionals; ➤ Task 2: Tracking Open/Closed Status of Units by using www.dialysisunits.com. The purpose of provider tracking in a disaster situation is to ensure that accurate information regarding availability of dialysis is facilities is known publicly; and ➤ Task 3: Standardized communications and tools. |

The KCER Collaboration determined these areas as important Response Team activities:

- ✓ Open/Closed facility status on www.dialysisunits.com
- ✓ Core emergency data set

The KCER Collaboration developed these recommendations:

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| Stress the importance of backup patient records | Communicate the importance of facilities keeping current backup patient records. |
| CROWNWEB | Connecting the core emergency data set to the CROWNWEB system in development. |
| Locating patients and families after a disaster | Help locate family members by utilizing existing national resources like the Safe and Well site/telephone number (https://disastersafe.redcross.org). |
| Disaster Patient Activity Reports | Develop or provide a refresher course on the use of Disaster Patient Activity Reports (DPARs) and distribute emergency core data set. |

Physician Placement and Assistance

Team Leadership - Robert Kenney, MD and Kenneth Lempert, MD

The Physicians Placement and Assistance Team goals are to provide nephrology expertise, and a means for deploying them, for the management of dialysis and transplant patients during a large-scale crisis; and to provide assistance to physicians that are displaced by disasters. Recent Team activities include:

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| Website for displaced physicians | This site will be activated in response to disasters and allows physicians to enter their contact and other information. Patients, staff, hospitals, and areas in need can view the site: http://www.renalmd.org/publications/report.cfm |
| Educational resources and publications | The Team has developed these resources: <ul style="list-style-type: none"> ➤ “How to prepare a dialysis unit for providing treatments during a disaster,” by Robert Kenney, MD, ➤ “Disaster response: Role for nephrology volunteers,” by Jeffrey Kopp, MD, ➤ “Lessons from the hurricanes and earthquakes of 2005,” and ➤ “Kidney Patient Care in Disasters,” and “Emergency Preparedness Planning for Patients and Facilities.” |
| NDMS | Researching and defining the uses and limitations of the NDMS for the needs of the kidney community and sharing lessons learned on the NDMS. |

The KCER Collaboration determined these areas as important Response Team activities:

- ✓ Displaced physicians’ website
- ✓ Working through NDMS and other Federal regulations

The KCER Collaboration developed these recommendations:

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| Coordinate efforts | <ul style="list-style-type: none"> ➤ Coordinate activities with large dialysis organizations that may already have similar resources available, ➤ Clarify which provider groups have a centralized patient database system or physician’s help-line and how to access this in case of an emergency (limited or no electricity / internet / phone), and ➤ Collaborate with the Coordination of Staff and Volunteers and the Federal Response Team to provide a consensus or single method to register, confirm, train, and maintain a database of volunteers (doctors, nurses, social workers, dietitians, others). |
| Distribution of resources | Distribute resources in geographic areas (FEMA regions) |

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Summary

The 2008 KCER Summit was a success largely due to the dedication and continued efforts of kidney community stakeholders who volunteer their time and expertise as members of the Kidney Community Emergency Response Coalition. These collaboration activities not only encouraged recognizing important Response Team achievements, but also allowed kidney community members to learn about KCER, explore a variety of issues and share knowledge on available resources.

Response Team teleconferences, Strategic Planning Committee teleconferences and in-person meetings like the KCER Summit will continue advancing the Coalition's goals. The KCER continues to incorporate these important relationships, resources, and information into disaster preparedness and response for the kidney community. ESRD Networks, providers, volunteers, government agencies, industry representatives, and patients are all encouraged to use the KCER guidance, tools and resources, and to provide feedback so that the Coalition will continue to grow and strengthen.