



National Disaster Coalition

Preparedness & Response for the ESRD Community

Disaster Summit – Final Report

This report summarizes activities and accomplishments of the initial meeting of the National Disaster Coalition. This meeting, called the Disaster Summit, was held on January 19, 2006 in Washington, DC. The structure of this report follows the outline of the Summit agenda.

Opening Remarks / Background

Gina Clemons (Centers for Medicare and Medicaid Services)

- The collective and collaborative response from the renal community is critical to ensuring that individuals in need of dialysis receive care.
- There is always room for improvement and we applaud and encourage on-going efforts.
- Recent hurricanes had a significant impact on the renal community and continue to affect facilities and patients today.
- The hard questions asked regarding disasters included:
 - ✓ Is the renal community prepared to respond?
 - ✓ What is the goal for the national “response?”
 - ✓ Is the renal community committed to develop this response?
 - ✓ Are there sufficient, collective resources for the response?
 - ✓ What role will each organization play?
 - ✓ Will each organization commit the resources (staff, funds, other) to fulfill this role?
- The role of CMS is not to administer the National Disaster Coalition; however, it will play a leadership role in the following areas:
 - ✓ Policy
 - ✓ Billing
 - ✓ Network
 - ✓ Survey & Certification

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

- At the request of CMS, Network 7 was pleased to host the initial meeting of the National Disaster Coalition, which focused on the preparedness and response for the renal community.
- Preliminary work included research on resources, as well as a pre-Summit survey. This work identified consensus among the renal community regarding facility operations, patient tracking, state collaboration, volunteer support, and communication.
- The Coalition intent is to develop a “national-state-county-local” model.

- Hurricanes drove many attendees to participate in the Summit, but the Coalition worked to address all types of emergencies – both natural and man-made.
- With limited time – but achievable goals – the attendees were tasked with building the foundation for the Coalition and implementing a comprehensive national response mechanism.

Introductions

- Eighty individuals participated in the Summit representing the following organizations:

<ul style="list-style-type: none"> ✓ American Association of Kidney Patients ✓ American Kidney Fund ✓ American Nephrology Nurses' Association ✓ American Society of Nephrology ✓ Centers for Medicare & Medicaid Services ✓ Centers for Disease Control ✓ Computer Services Corporation ✓ Departments of Health ✓ ESRD Network Organizations ✓ Food and Drug Administration ✓ Forum of ESRD Networks ✓ Hospital Healthcare Systems ✓ Independent Dialysis Centers (Free-Standing & Hospital-Based) 	<ul style="list-style-type: none"> ✓ Large Dialysis Organizations ✓ National Association of Nephrology Technicians ✓ National Institutes of Health ✓ National Kidney Foundation ✓ National Renal Administrators Association ✓ Office of Inspector General ✓ Physician Medical Groups & Independent Physicians ✓ Renal Physicians Association ✓ State Survey Agencies ✓ Transplant Centers ✓ Universities ✓ Vendors ✓ Other Strategic Partners
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- These participants resided in twenty-five states and the District of Columbia.

General Objectives

- Develop a shared plan for national strategic responses in the event of a disaster that includes clear roles and responsibilities for developing and implementing these responses.
- Create priority action areas for the National Coalition that includes a plan for disseminating best practices and strategies at the state and local level.
- Build the foundation for formalizing a National Coalition and action plans.

Coalition Building

- A coalition is a group of individuals and/or organizations with a common interest that agree to work together toward a common goal.
- Collaboration is defined as exchanging information, modifying activities, sharing resources, and enhancing the capacity of another for mutual benefit and to achieve a common purpose by sharing risks, resources, responsibilities and rewards.

- The factors affecting a coalition’s capacity to create change include:
 - ✓ Having a clear vision and mission
 - ✓ Action planning for community and systems change
 - ✓ Developing and supporting leadership
 - ✓ Documentation and ongoing feedback on programs
 - ✓ Technical assistance and support
 - ✓ Securing financial resources for the work
 - ✓ Making outcomes matter

First Steps

Fortifying Our National Response Mechanism

- The Coalition began its planning process by building upon the outstanding national response strategies that agencies and organizations implemented over the past years in response to disasters. Many of these strategies combined preparedness work with direct response during and after an actual disaster.
- Based on previous experience and expertise, eight key response areas were identified. (See Strategic Map below)
- Individuals from agencies/organizations who, along with others, played a lead role in developing and implementing these strategies provided a short overview of what these strategies were, how they were implemented and what some of the key challenges were in making them happen. All items were documented in the form of a “Strategic Map.”
- Attendees were invited to add missing key elements, including strategies, partners and challenges. The initial responses and the other added elements combined to form the Coalition’s “Strategic Map.”

STRATEGIC MAP

Patient Assistance & Response
<ul style="list-style-type: none"> ▪ Created a system for accepting, warehousing and distributing donations and supplies from corporate partners and other donors ▪ Provided direct support to patients through monetary grants ▪ Established an organization-wide donation effort that was matched dollar for dollar ▪ Obtained grants to support technicians volunteering their services ▪ Administrated a grant from pharmaceutical companies ▪ Provided social services, housing, patient shelters, pet shelters, gasoline and diesel, generators, education materials for emergency preparedness. ▪ Offered support with coping mechanisms ▪ Develop a pre-established evacuation plan with a “partner center” to go to during/post disaster ▪ Address the special needs of recent transplant patients relating to risk of infection and rejection ▪ Care of LifeSite vascular access ▪ Mechanism to identify patients as ESRD to first responders (T-shirts, bracelets, water proof sign) ▪ Prepare patients in advance: education, identification, transportation, communication

- Involve National Guard in airlifting patients
- Voluntary patient phone number registration with Networks
- How to obtain access to patients in shelters. Tracking patients as they move between shelters

Coordination of Professional Staff: Nursing & Technical Volunteers

- Organized nurse volunteers
- Organized technician volunteers
- Develop training modules for the nurses and technicians to be first responders
- Implement rapid immunizations for front line healthcare professionals
- Improve cooperation between providers to avoid the monopoly of resources
- Identify if area truly needs the volunteers before sending entire staffs
- Develop a common scope of practice for patient care technicians (PCTs) — all must be certified
- Add renal dieticians/renal social workers
- Implement crisis intervention programs for volunteers
- Develop plan for staffing acute dialysis units
- Ensure that dialysis professionals are recognized as first responders so they will not be stopped at checkpoints
- Investigate multi-state compact endorsement by all states for Registered Nurses (RNs)
- Develop a national registry for RN/PCT volunteers that are willing to travel
- Establish vendors that are ready to supply housing and food for volunteers
- Initiate a standardized temporary RN license application
- Address liability issues
- Investigate ways to manage competition from outside industries for healthcare workers post disaster
- How to transport volunteers into disaster areas
- Establish funding sources to volunteers
- Train volunteer nurses in LifeSite protocols

Physician Placement & Assistance

- Organized Physicians
- Network for placing nephrologists months after storm
- Database that lists location of displaced physicians
- Pre-identification of vascular access support
- Standardized protocols for emergency dialysis treatment
- A listing of physician volunteers with their specialties and contact information
- Address liability issues on behalf of physicians treating influx of “unknown” patients
- Prepare/educate nephrology community for influx of acute dialysis needs (ie disaster injuries have caused the renal failure)
- Set up a Doctors Without Borders type program in the U.S
- Generate symposium report for dissemination of resource info with publication and web based information (re: nursing and physician journals)
- Consider having ESRD Networks keep on file individual patient’s dialysis prescriptions (with patient consent)
- Coordinate nephrology services with other physician groups

- Develop a physician/education relief fund
- Emergency reciprocity of licensure

Communications

- Established an e-mail listserv to facilitate 24-hours a day / 7-days a week communication
- National conference calls as needed with key partners
- Solar powered communication technology
- Use of TV/radio to recruit volunteers
- Translate excel spread sheets re open/ closed units to dialysisunits.com
- Use of HAM radio systems
- Categorize the listserv by topic
- Have standardized national emergency levels, similar to terrorist threat levels
- Develop a dialysis patient disaster data profile kept on a distant server and updated quarterly
- Develop a website listing available resources and links to agencies / companies / organizations that provide resources
- Improve communication with FEMA
- Designate a primary person on each ESRD related website that is a contact for disasters
- “Amber” alert type signs on evacuation routes for critical information for dialysis patients
- Satellite radio/TV/phones
- Add an established agenda to focused conference calls and allow for question and answer period
- Initiate daily physician conference calls
- Mechanism for speaking with one voice to federal government

Patient & Facility Tracking / Database

- Developed a website that provided a listing of dialysis units closed and developed software that would read MS Excel files into the database
- Established emergency toll-free 800 number for patients
- Established emergency toll-free 800 number for employees
- Develop standardized tracking forms for patient and facility status
- Tracking of patients needs to be communicated to attending nephrologists not only to the provider
- Utilize Global Positioning System (GPS) technology
- Develop back up plan for Networks to get data
- Define “open” unit with capacity and staffing numbers
- Tuberculosis after Katrina: difficulty in trying to identify all patients that came through a receiving unit where staff later converted to positive skin test
- Expand from open/closed spreadsheet to a map on the website
- Flash drives for all patients with medical information that can be updated monthly at the facility
- Reporting all displaced patients to a specific website even if only one treatment was given

Facility Operations & Services

- Played key role in developing the CDC guideline on bringing water systems back on-line

after storms

- Helped in mobilization of water systems
- Provided research information regarding a movable (sorberent) dialysis machine that requires only 1.5 gallons of potable water per treatment
- Coordinated with Emergency Operation Centers (EOCs)
- Provided pre-disaster education to patients and staff and provided pertinent supplies
- Developed a comprehensive Hurricane Policy & Procedure Manual that addresses facility operations
- Staged emergency generators and fuel at regional hubs
- Developed a process for trucking in emergency food, water, and clothing to patients and teammates
- Developed a standard “patient card”
- Established communication tiers

Federal Response

- Processed requests for expansion of stations immediately
- Approved requests for Special Purpose Dialysis Facilities immediately
- Suspended usual surveys in the affected areas at the time of the immediate crisis
- Health Insurance Portability and Accountability Act (HIPAA) relaxed to supply patient information to receiving facilities and to help facilities and family find missing patients
- Patient deaths during the disaster not attributed to the facility
- Allowed ESRD facilities to bill for services provided at temporary off-site locations
- Interacted with state agencies to facilitate services (water, fuel, electricity)
- Patient education information
- Public service announcements
- Patient identification cards for ESRD evacuees
- Work through DHHS-ESF (emergency support function) to obtain better coordination and assistance
- Involve CDC and the ASTHO (agency for state and territorial health officials) to reach state and local health departments
- Raise awareness of communicable diseases such as TB, NORO, RSV, VIRRIO
- Direct the contact with FEMA
- Engage AHFQ and HRSA in coalition
- Model best demonstrated practices
- New conditions for coverage
- Consider higher reimbursement for treatments of displaced patients
- Develop quick turn around for reimbursement issues
- Develop national disaster drills

Industry Supplies & Services

- Medications
- Laboratory services
- Temporary housing
- Water, fuel, clothing
- Medical equipment/supplies
- Nutritional supplements

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| <ul style="list-style-type: none"> ▪ Distribution process of supplies ▪ Emergency list in database of supplies ▪ Security for transport and storage ▪ Priority clearance procedures ▪ Compensation after crisis ▪ Support and education on use of medications and equipment that may have been damaged in disaster ▪ Central supply depot for all providers ▪ Identification signs for supply trucks ▪ Post priority needs on website for FEMA and state agencies |
|--|
- Other areas the group felt were important to address in the future, included:
 - ✓ Process for repopulation
 - ✓ Self-determination of patients to decline treatment
 - ✓ Total pandemic: process to obtain staff/supplies internationally
 - ✓ Working to allow families to stay together during disasters. Giving priority to keep family systems intact
 - ✓ Triage coordination
 - ✓ Have a dialysis representative in each state Office of Emergency Preparedness in order to have access to state officials involved in decision making
 - ✓ Establishment of dialysis shelters
 - ✓ How to service quarantined areas
 - ✓ Educating and empowering patients to pre-plan
 - A list of roadblocks and challenges were also created.
 - ✓ Working with multiple organizations
 - ✓ Unity among coalition members
 - ✓ Working through bureaucracy
 - ✓ Deciding where to “end” and how to prioritize
 - ✓ Dealing with various multi-state disasters, terrorism, and pandemics
 - ✓ Ability to incorporate “practice” drills of a plan
 - ✓ Developing effective working relationships with FEMA, state, and local EOCs
 - ✓ Competing for ESRD patients
 - ✓ Communicating during and post-event
 - ✓ Funding for planning and implementation of strategies

Creating Response Teams

- Based on the eight key response areas discussed, all attendees were invited to self-select the “Response Team” they were most interested in joining. National organization representatives served as Response Team Leaders. A complete list of participants by Response Team is included in the appendix on page 27.
- Each team utilized a set of planning worksheets in order to refine and develop the strategic response, emphasizing the model of “National – State – County – Local.”
- This process provided each team with some very clear groundwork for how the Coalition can begin to enact critical national strategies. The Response Team worksheets for all areas have been listed on the following pages. These include each Team’s goals, actions/activities and action plans.

✓ Patient Assistance and Response	pages 9-10
✓ Coordination of Nursing and Technical Volunteers	pages 11-12
✓ Physician Placement and Assistance	pages 13-14
✓ Communication	pages 15-16
✓ Patient and Facility Tracking / Database	pages 17-18
✓ Facility Operations and Services	pages 19-20
✓ Federal Response	pages 21-22
✓ Industry Supplies and Services	pages 23-24

RESPONSE TEAM WORKSHEET – PATIENT ASSISTANCE

KEY RESPONSE AREA: Patient Assistance and Response

Group Co-leaders: Kris Robinson and Phyllis Ermann
 Group Members: Steve Fadem, Linda Schacht, Tracey Fortson, Rick Russo, Brenda Dyson and Darlene Rodgers

Part I:

Please begin your planning work with a team discussion around the Goals of your response strategy. Some of these may be found in the language on the Strategic Map. What is it you want/need to accomplish through this Response Strategy?

GOAL(S) OF RESPONSE STRATEGY:

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

Part II:

After you have finished your discussion on goals, move on to identifying the specific Activities that will make up the Response Strategy. Some of this language may already be on the Strategic Map. Be as specific as you can about the wide variety of actions and activities that will need to be taken in order to accomplish the goals you have identified above. Remember to also focus on how these activities will impact/address needs and issues at the state and local level.

ACTIONS/ACTIVITIES

- Tool kit
- Educational tools for patients, providers and others
- Posters
- DVD/CD/Paper resources
- Identification by some method-t-shirt, medic alert bracelet, band, microchip
- Resource list
- Mechanism of dissemination
- Train-the-trainer

Part III:

Now, work as a team to prioritize the activities above. Which ones can/must be implemented in the Short-Term? Long-Term? Use this as your guide to prioritizing. When you have finished, move on to Action Plan

RESPONSE TEAM ACTION PLAN – PATIENT ASSISTANCE

KEY RESPONSE AREA: Patient Assistance and Response

ACTIONS/TASKS	BY WHOM	WITH WHAT OTHER SECTORS	BY WHEN	RESOURCES & SUPPORT NEEDED/AVAILABLE	POTENTIAL BARRIERS OR RESISTANCE	MILESTONES
<i>What needs to be done?</i> Improving patient preparedness for any/all disasters.	<i>Who will take this action?</i>	<i>What other sectors will work with you?</i>	<i>Action due date?</i>	<i>What financial, human, political, and other resources are needed?</i> <i>Are available?</i>	<i>What individuals and organizations might resist?</i> <i>How?</i>	<i>How will you know you have been successful?</i> <i>What will have occurred?</i>
Gather and review all current patient focused disaster preparedness educational materials.	All	None at this point	02/05/06	Time-yes Conference call scheduled for 02/21/06 to review information gathered NW15 will host the first call Call-in Number: 800-605-5167 Participant Code: 772749	Proprietary information...will folks "share"?	Send all information to Dr. Fadem. He will collate and distribute
"Fill in the blanks"	All	Will depend on what is gathered in step #1	Call on 02/21/06	Time-design, testing, review Clerical support Design and printing		Focus group to look at the information...pilot any newly created materials
Financial Resources						
Implementation						

Source: Adapted from Fawcett S. et al., *Preventing Adolescent Pregnancy: An Action Planning Guide for Community Based Initiatives*, Work Group, University of Kansas, 1992.

Mock-up of a "tool kit", testing, duplication, training, distribution, etc.
Train-the-trainer

RESPONSE TEAM WORKSHEET – VOLUNTEER COORDINATION

KEY RESPONSE AREA: Coordination of Professional Staff: Nursing and Technical Volunteers

Group Leaders: Sue Carey
 Group Members: Lisa Drossos, Kim Schroeder, Norma Gomez, Marsha Lisk and David Smith

Part I:

Please begin your planning work with a team discussion around the Goals of your response strategy. Some of these may be found in the language on the Strategic Map. What is it you want/need to accomplish through this Response Strategy?

GOAL(S) OF RESPONSE STRATEGY:

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

Part II:

After you have finished your discussion on goals, move on to identifying the specific Activities that will make up the Response Strategy. Some of this language may also already be on the Strategic Map. Be as specific as you can about the wide variety of actions and activities that will need to be taken in order to accomplish the goals you have identified above. Remember to also focus on how these activities will impact/address needs and issues at the state and local level.

ACTIONS/ACTIVITIES

- National councils / organizations for each discipline to solicit and maintain a database list of potential volunteers.
 - Utilize existing professional councils and associations e.g. CNSW, ANNA, NKF.
 - Collaborate with governmental and private organizations e.g. CDC, Health Department, state boards.
 - Encourage volunteer language on key organization / council membership applications.
- Explore what is currently in place with state boards of nursing for out of state nurses that are deployed in disaster situations.
- Develop a list of volunteer potential roles in disaster areas and differentiate what requires licensure and what does not.
- Identify and address any liability issues.
- Coordinate shelter, transportation and expectations of volunteers.

Part III:

Now, work as a team to prioritize the activities above. Which ones can/must be implemented in the Short-Term? Long-Term? Use this as your guide to prioritizing. When you have finished, move on to Action Plan

RESPONSE TEAM WORKSHEET – VOLUNTEER COORDINATION

KEY RESPONSE AREA: Coordination of Professional Staff: Nursing and Technical Volunteers

ACTIONS/TASKS	BY WHOM	WITH WHAT OTHER SECTORS	BY WHEN	RESOURCES & SUPPORT NEEDED/AVAILABLE	POTENTIAL BARRIERS OR RESISTANCE	MILESTONES
<i>What needs to be done?</i>	<i>Who will take this action?</i>	<i>What other sectors will work with you?</i>	<i>Action due date?</i>	<i>What financial, human, political, and other resources are needed?</i> <i>Are available?</i>	<i>What individuals and organizations might resist?</i> <i>How?</i>	<i>How will you know you have been successful?</i> <i>What will have occurred?</i>
National organization for each profession to solicit and maintain a database list.	ANNA	NKF; CNSW; state agencies; NANT; NRAA; state boards of nursing	May 2006	<ul style="list-style-type: none"> ▪ Needed – a point person for each group ▪ Already available – websites; state agencies 	Possible difficulty in engaging state agencies	<ul style="list-style-type: none"> • Point person in each organization is identified • Database is initiated
Explore what is currently in place with state boards of nursing for out of state disaster response.	ANNA; Networks	National Council of State Boards of Nursing; state boards of nursing	April 2006	<ul style="list-style-type: none"> ▪ Needed – funding; clerical support; administrative support ▪ Already available – Existing listserves; Survey Monkey 	Funding	Initial contact made by the end of February
Develop a list of volunteer potential roles in disasters and differentiate what requires licensure and which does not.	All	NKF; CNSW; state agencies; NANT; NRAA; state boards of nursing	First conference call 2/7/06	Teleconference line	Funding for ongoing calls	Network 7 to host first call Tuesday, 2/7/06, 1:00 pm EST. Call-in number 866-262-1846 ; Room number *0007161*

RESPONSE TEAM WORKSHEET – PHYSICIAN PLACEMENT & ASSISTANCE

KEY RESPONSE AREA: Physician Placement and Assistance

Group Co-leaders: Andrew Cohen, MD and Robert Kenney, MD

Group Members: Sharon Adler, MD, Melanie McKnight, MD, Nauman Oureshi, MD, Jeffrey Kopp, MD, Sarah Yelton and Linda Ball

Part I:

Please begin your planning work with a team discussion around the Goals of your response strategy. Some of these may be found in the language on the Strategic Map. What is it you want/need to accomplish through this Response Strategy?

GOAL(S) OF RESPONSE STRATEGY:

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

Part II:

After you have finished your discussion on goals, move on to identifying the specific Activities that will make up the Response Strategy. Some of this language may also already be on the Strategic Map. Be as specific as you can about the wide variety of actions and activities that will need to be taken in order to accomplish the goals you have identified above. Remember to also focus on how these activities will impact/address needs and issues at the state and local level.

ACTIONS/ACTIVITIES

- Improvise
- Develop training protocol – web-based, present at ASN via ppt. – general, then disaster specific
- Journal articles – need to identify authors/speakers; perhaps have a separate supplement to Journal
- Consensus conference – prescription for preparing for disaster, timeline would change over time
- “Up to Date” program
- Crisis Team
- Include: International Nephrologists, MDs need to bring staff, seizmo-nephrologists (earthquake specialists)

Part III:

Now, work as a team to prioritize the activities above. Which ones can/must be implemented in the Short-Term? Long-Term? Use this as your guide to prioritizing. When you have finished, move on to Action Plan

Mission: In the event of a disaster: to provide uninterrupted Nephrologist-supervised medical care for patients with chronic and acute renal failure.
(Nauman Qureshi, MD)

Conference Call scheduled Friday, February 24th at 11:30 am ET

RESPONSE TEAM WORKSHEET – PHYSICIAN PLACEMENT & ASSISTANCE

KEY RESPONSE AREA: Physician Placement & Assistance

ACTIONS/TASKS	BY WHOM	WITH WHAT OTHER SECTORS	BY WHEN	RESOURCES & SUPPORT NEEDED/AVAILABLE	POTENTIAL BARRIERS OR RESISTANCE	MILESTONES
<i>What needs to be done?</i>	<i>Who will take this action?</i>	<i>What other sectors will work with you?</i>	<i>Action due date?</i>	<i>What financial, human, political, and other resources are needed?</i> <i>Are available?</i>	<i>What individuals and organizations might resist?</i> <i>How?</i>	<i>How will you know you have been successful?</i> <i>What will have occurred?</i>
Clinical symposium w/supplement in Journal on physician education	Sharon Adler, MD to speak to planning comm. for ASN fall mtg	ASN, RPA, NKF AJKD	By Feb 24 (next conf call) for mtg; 4-5 mos for publication	Make contact with authors/speakers; need to find funding	Time and dollars – won't reach all physicians (those who don't belong to ASN, some attend conf, some only read)	On the ASN program for fall; Printed publication
Voluntary physician database for those willing to volunteer to serve	Jeffrey Kopp, MD	Public Health Services database; ASN/RPA/NKF	Will contact PHS by Feb 24 th call; long term 6-12 months?	CMS involvement; may need tri-society involvement; Tap into LDO annual meetings	PHS – ad hoc; no resources; getting people to sign up Notices – state medical soc.	Have a database set up.
Develop a disaster fund for physicians.	Sharon Adler, MD to contact ASN; Robert Kenney to contact RPA	Council of Am. Kidney Society; vendors; each of tri-society	Contacts to be made prior to Feb 24 th conf call; long-term goal undetermined currently.	Vendor assistance (e.g., Amgen); loans/grants	No money – maybe could secure for training; need to develop a screening process for fund allocation.	An established disaster fund for physicians.

Source: Adapted from Fawcett S. et al., *Preventing Adolescent Pregnancy: An Action Planning Guide for Community Based Initiatives*, Work Group, University of Kansas, 1992.

RESPONSE TEAM WORKSHEET – COMMUNICATIONS

KEY RESPONSE AREA: Communications

Group Leader: Preston (Tony) Englert

Group Members: Susie Stark, Roberta Bachelder, Meryl Solwik, Bridget Carson, Jackie Harley, Kim Rucker, Paul Miller, MD, Suzanne Wyekoff

Part I:

Please begin your planning work with a team discussion around the Goals of your response strategy. Some of these may be found in the language on the Strategic Map. What is it you want/need to accomplish through this Response Strategy?

GOAL(S) OF RESPONSE STRATEGY:

1. Create a national communication strategy
2. Improve or enhance the use of communication technologies
3. Communicate / educate regarding the needs of the kidney population to appropriate entities

Part II:

After you have finished your discussion on goals, move on to identifying the specific Activities that will make up the Response Strategy. Some of this language may also already be on the Strategic Map. Be as specific as you can about the wide variety of actions and activities that will need to be taken in order to accomplish the goals you have identified above. Remember to also focus on how these activities will impact/address needs and issues at the state and local level.

ACTIONS/ACTIVITIES

- Develop listserv
- Describe type, frequency, appropriateness of conference calls
- Incorporate emergency broadcast system announcements
- Utilize wire service
- Identify central clearinghouse
- Utilize media
- Investigate the use of solar power, satellite phones, ham radios
- Match the needs of disaster to appropriate technology
- Identify and utilize experts – logistics, communications
- Partner with first responder agencies
- Provide model disaster plans

Part III:

Now, work as a team to prioritize the activities above. Which ones can/must be implemented in the Short-Term? Long-Term? Use this as your guide to prioritizing. When you have finished, move on to Action Plan

RESPONSE TEAM WORKSHEET – COMMUNICATIONS

KEY RESPONSE AREA: Communications

ACTIONS/TASKS	BY WHOM	WITH WHAT OTHER SECTORS	BY WHEN	RESOURCES & SUPPORT NEEDED/AVAILABLE	POTENTIAL BARRIERS OR RESISTANCE	MILESTONES
<i>What needs to be done?</i>	<i>Who will take this action?</i>	<i>What other sectors will work with you?</i>	<i>Action due date?</i>	<i>What financial, human, political, and other resources are needed?</i> <i>Are available?</i>	<i>What individuals and organizations might resist?</i> <i>How?</i>	<i>How will you know you have been successful?</i> <i>What will have occurred?</i>
Institutionalize national listserv	NKF	Networks, CMS, LDOs, Coalition members	04/01/06	<ul style="list-style-type: none"> ▪ Cooperation of other groups ▪ 0.5 FTE 	Since disaster has passed, enthusiasm may be lessened	Once it's operational – after test
Institutionalize conference calls / Standard practice post-disaster	CMS	Networks, CMS, LDOs, Coalition members	1st call 2/23/06 4pm EST	<ul style="list-style-type: none"> ▪ Cooperation of other groups ▪ 0.5 FTE 		Focus group to look at the information...pilot any newly created materials
Develop National 800 / Website	NKF	Networks, CMS, LDOs, Coalition members	5/30/06	<ul style="list-style-type: none"> ▪ Cooperation of other groups ▪ 0.5 FTE 		

Source: Adapted from Fawcett S. et al., *Preventing Adolescent Pregnancy: An Action Planning Guide for Community Based Initiatives*, Work Group, University of Kansas, 1992.

RESPONSE TEAM WORKSHEET – PATIENT & FACILITY TRACKING

KEY RESPONSE AREA: Patient & Facility Tracking / Database

Group Co-leaders: Glenda Harbert and Michael Kennedy
 Group Members: Leigh Ann Sauls, Tom Smith, Kelly Brooks, Paul Munter, Amanda Hyre, David Holst

Part I:

Please begin your planning work with a team discussion around the Goals of your response strategy. Some of these may be found in the language on the Strategic Map. What is it you want/need to accomplish through this Response Strategy?

GOAL(S) OF RESPONSE STRATEGY:

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

Additional Topics of Conversation

- EMSSystem -- Utilitized by Emergency Operators; Used like SIMS; Web Bases; They list current service capabilities

Part II:

After you have finished your discussion on goals, move on to identifying the specific Activities that will make up the Response Strategy. Some of this language may already be on the Strategic Map. Be as specific as you can about the wide variety of actions and activities that will need to be taken in order to accomplish the goals you have identified above. Remember to also focus on how these activities will impact/address needs and issues at the state and local level.

ACTIONS/ACTIVITIES

- All to send in ideas of fields for the tracking form and information form by 2/10 to Glenda Harbert (gharbert@nw14.esrd.net)
- Future Dissemination of Information – patients, providers, LDOs, Networks and CMS

Part III:

Now, work as a team to prioritize the activities above. Which ones can/must be implemented in the Short-Term? Long-Term? Use this as your guide to prioritizing. When you have finished, move on to Action Plan

RESPONSE TEAM WORKSHEET – PATIENT & FACILITY TRACKING

KEY RESPONSE AREA: Patient & Facility Tracking / Database

ACTIONS/TASKS	BY WHOM	WITH WHAT OTHER SECTORS	BY WHEN	RESOURCES & SUPPORT NEEDED/AVAILABLE	POTENTIAL BARRIERS OR RESISTANCE	MILESTONES
<i>What needs to be done?</i>	<i>Who will take this action?</i>	<i>What other sectors will work with you?</i>	<i>Action due date?</i>	<i>What financial, human, political, and other resources are needed?</i> <i>Are available?</i>	<i>What individuals and organizations might resist?</i> <i>How?</i>	<i>How will you know you have been successful? What will have occurred?</i>
Develop a task group email list serve	Michael Kennedy (mkennedy@esource.net)		1/23/06			
Conference Call Call-in number 877-214-5010 ; Code 169364	Response Team Members	Networks, CMS, Dialysis and Transplant Facilities	02/15/06 2:30PM			
Develop a draft form for the Response Team to present and respond to...	Glenda Harbert (gharbert@nw14.esrd.net)		2/15/06			
Schedule a meeting with stakeholders to determine and define fields for the patient tracking and movement form	David Holst (dholst@renalcaregroup.com),	Networks, CMS, LDOs, Coalition members, other key stakeholders	3/1/06			

Source: Adapted from Fawcett S. et al., *Preventing Adolescent Pregnancy: An Action Planning Guide for Community Based Initiatives*, Work Group, University of Kansas, 1992.

RESPONSE TEAM WORKSHEET – FACILITY OPERATIONS

KEY RESPONSE AREA: Facility Operations and Services

Group Co-leaders: Bill Numbers, ony Messana and Tom Bradsell
 Group Members: Deborah Brouwer, Danilo Concepcion, Rita Clymer, Jim Curtis, Russell Dimmitt, Linda Duval, Mary Fenderson, Gail Fredrick, Gema Gonzalez, Brenda Leply, Condict Martak, Rita McGill, Maureen Michael, Carolyn Neuland, Stuart Redpath, Kathleen Smith and Cindy Toombs

Part I:

Please begin your planning work with a team discussion around the Goals of your response strategy. Some of these may be found in the language on the Strategic Map. What is it you want/need to accomplish through this Response Strategy?

GOAL(S) OF RESPONSE STRATEGY:

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

Part II:

After you have finished your discussion on goals, move on to identifying the specific Activities that will make up the Response Strategy. Some of this language may also already be on the Strategic Map. Be as specific as you can about the wide variety of actions and activities that will need to be taken in order to accomplish the goals you have identified above. Remember to also focus on how these activities will impact/address needs and issues at the state and local level.

ACTIONS/ACTIVITIES

- Standardize specific components to be required within dialysis
- Unit disaster planning
 - Providers
 - Patients
 - Community Resources

Part III:

Now, work as a team to prioritize the activities above. Which ones can/must be implemented in the Short-Term? Long-Term? Use this as your guide to prioritizing. When you have finished, move on to Action Plan

RESPONSE TEAM WORKSHEET – FACILITY OPERATIONS

KEY RESPONSE AREA: Facility Operations and Services

ACTIONS/TASKS	BY WHOM	WITH WHAT OTHER SECTORS	BY WHEN	RESOURCES & SUPPORT NEEDED/AVAILABLE	POTENTIAL BARRIERS OR RESISTANCE	MILESTONES
<i>What needs to be done?</i>	<i>Who will take this action?</i>	<i>What other sectors will work with you?</i>	<i>Action due date?</i>	<i>What financial, human, political, and other resources are needed?</i> <i>Are available?</i>	<i>What individuals and organizations might resist?</i> <i>How?</i>	<i>How will you know you have been successful? What will have occurred?</i>
Conference Call 877-988-3571 Code: 484454	Russel Dimmitt (rdimmitt@renalcaregroup.com)		2/7/06 12pm EST			

RESPONSE TEAM WORKSHEET – FEDERAL RESPONSE

KEY RESPONSE AREA: Federal Response

Group Co-Leaders: Glenda Payne/ Gina Clemons
 Group Members: Deborah Levy, MD, Lee Hamm, Dolph Cianchiano, Judith Kari, Janet Crow, Doug Marsh, Efrain Reisin and Steve Egger

Part I:

Please begin your planning work with a team discussion around the Goals of your response strategy. Some of these may be found in the language on the Strategic Map. What is it you want/need to accomplish through this Response Strategy?

GOAL(S) OF RESPONSE STRATEGY:

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

Part II:

After you have finished your discussion on goals, move on to identifying the specific Activities that will make up the Response Strategy. Some of this language may also already be on the Strategic Map. Be as specific as you can about the wide variety of actions and activities that will need to be taken in order to accomplish the goals you have identified above. Remember to also focus on how these activities will impact/address needs and issues at the state and local level.

ACTIONS/ACTIVITIES

- Pull together existing materials from organizations (providers, professional organizations, etc) that can be used as a basis
- Distribute information as the “right” opening for this education presents (e.g., pandemic flu preparedness)

Part III:

Now, work as a team to prioritize the activities above. Which ones can/must be implemented in the Short-Term? Long-Term? Use this as your guide to prioritizing. When you have finished, move on to Action Plan

Audience for this targeted education:

- Members of Congress
- State health agencies
- State Medicaid Directors
- State health officers (ASTA, National Assoc. of City and County Health officers; Council of State and Territory Epidemiologists, etc.)

RESPONSE TEAM WORKSHEET – FEDERAL RESPONSE

KEY RESPONSE AREA: Federal Response

ACTIONS/TASKS	BY WHOM	WITH WHAT OTHER SECTORS	BY WHEN	RESOURCES & SUPPORT NEEDED/AVAILABLE	POTENTIAL BARRIERS OR RESISTANCE	MILESTONES
<i>What needs to be done?</i>	<i>Who will take this action?</i>	<i>What other sectors will work with you?</i>	<i>Action due date?</i>	<i>What financial, human, political, and other resources are needed?</i> <i>Are available?</i>	<i>What individuals and organizations might resist?</i> <i>How?</i>	<i>How will you know you have been successful?</i> <i>What will have occurred?</i>
1. Develop an educational packet for Federal agencies/JCAHO re ESRD						
A. Identify audience	A. Deb Levy (CDC)	All the group	A. End of Jan	Time	None	Starter list developed; complete list available
B. Survey currently available materials	B. Dolph & Glenda	B. NKF	B. Feb 2006			
C. Identify gaps	All	ANNA and LDO's Networks				
D. Educate with materials						
E. Review ER plans for congruence with education provided.						
2. Find a Leader	Consensus	All	ASAP	Administrative	Time, \$\$, Resources	NKF has volunteered
3. Identify Federal policies/guidance that need to be addressed or amended to better respond to issues that arose in the emergency.						

Source: Adapted from Fawcett S. et al., *Preventing Adolescent Pregnancy: An Action Planning Guide for Community Based Initiatives*, Work Group, University of Kansas, 1992.

RESPONSE TEAM WORKSHEET -- INDUSTRY

Key Response Area: Industry Supplies & Services

Group Leader: Ken Chen

Group Members: Wayne Bernard, Jenny Kitsen, Ralph Biddle, Brian Sheehan, Joan Solanchick, Walter Franz, and James Sweeney

Part I:

Please begin your planning work with a team discussion around the Goals of your response strategy. Some of these may be found in the language on the Strategic Map. What is it you want/need to accomplish through this Response Strategy?

Goal(s) of Response Strategy:

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

Part II:

After you have finished your discussion on Goals, move on to identify the specific Activities that will make up the Response Strategy. Some of this language may also already be on the Strategic Map. Be as specific as you can about the wide variety of actions and activities that will need to be taken in order to accomplish the goals you have identified above. Remember to also focus on how these activities will impact/address needs and issues at the state and local level.

Actions/Activities See action plan.

Part III:

Now, work as a team to prioritize the activities above. Which ones can/must be implemented in the Short-Term? Long-Term? Use this as your guide to prioritize. When you have finished, move on to Action Plan. [Information on the worksheet.](#)

Additional notes from Group Discussion:

- Distribution process for key depots needs to be integrated between central points and end users. Need coordination of location sites at national and region level.
- What level and content of education is needed, and to whom. First responders and others.
- Providers should be proactive in alerting and educating local agencies (fire, water, etc.).
- Networks need local resource list of vendors to help.
- Develop staging levels of critical services/equipment
 - Crisis needs
 - How to sustain delivery over weeks/months depending on the size of the disaster
- Security and clearance for transportation to move supplies/equipment in disaster area. How to get advance clearance?
 - Best practice: FMC printed signs to put on outside of trucks/vans identifying disaster supplies.
- Buddy system to help independent providers
- Financial compensation to industry for emergency supplies and deployment expenses.
- Best practice: CVS honored all prescriptions if patient produced bottle.

RESPONSE TEAM WORKSHEET -- INDUSTRY

Key Response Area: Industry Supplies & Services

Actions/Tasks	By Whom	With What Other Sectors	By When	Resources & Support Needed/Available	Potential Barriers or Resistance	Milestones
<i>What needs to be done?</i>	<i>Who will take this action?</i>	<i>What other sectors will work with you?</i>	<i>Action due date?</i>	<i>What financial, human, political, and other resources are needed? Are available?</i>	<i>What individuals and organizations might resist? How?</i>	<i>How will you know you have been successful? What will have occurred?</i>
Create list of critical dialysis needs by stage (immediate, mid-term, long-term)	Ken Wayne	Nephrologist(s), ASN, ANNA	2 months	People, time	Agreement on timing of stages	Coalition acceptance of list
Develop protocol for industry emergency coordination	Jim	LDOs, wholesalers, small providers, distributors	2 months – ID players. Month 3, create outline	People, time	“Don’t know who we don’t know” who should be involved	Outline accepted by Coalition
Develop framework for education	Bryan	Networks, state/federal organizations, Coalition Federal Response Team	3 Months	People, time, help line expenses?	Difficulty of engaging with numerous state/federal organizations and vendors	Plan judged reasonable and appropriate by internal group and Coalition

Next conference call February 13, 2006 at 10 AM EST, hosted by Network of New England.

Next Steps

Dissemination of Disaster Coalition Plans and Activities

- The Coalition brainstormed how to disseminate disaster coalition plans, while reinforcing the importance of distributing the information down to the local level.
- The following mechanisms were suggested / volunteered for dissemination of both the National Disaster Coalition's planning work, as well as any implementation plans or strategies:
 - ✓ Resource Guide
 - ✓ Journals
 - ✓ Meetings
 - Large Dialysis Corporations
 - American Society of Nephrology
 - ✓ National Kidney Foundation's Family Focus (patient-directed)
 - ✓ Networks (to social workers, then to patients)
 - ✓ CMS Information Strategy / Webpage
 - ✓ Nephron Information Center
 - ✓ American Nephrology Nurses' Association Website
 - ✓ American Association of Kidney Patients' Kidney Beginnings (patient-directed)
- The eight key Response Teams were encouraged to think about ways to distribute information as they move forward with planning.

Working Together as a Coalition

- The next step for moving forward as a National Coalition was to develop a mechanism for leadership. The National Kidney Foundation agreed to take on the responsibility of coordination, communication and other functions that are part of maintaining a coalition and moving this important planning work forward.
- Additionally, an interim "Planning Committee" was proposed and established with the following responsibilities:
 - ✓ Coordinating communication for the coalition including the Response Teams
 - ✓ Convening and coordinating follow-up meetings for the coalition and response teams
 - ✓ Identifying additional resources for the coalition
 - ✓ Recruiting additional members with a focus on creating a diverse membership
 - ✓ Managing the on-going work of the coalition
- The Planning Committee membership was agreed to be comprised of Response Team Leaders and representatives of other organizations that requested to be part of this group.
- The organizations serving as the interim Planning Committee are:
 - ✓ American Association of Kidney Patients
 - ✓ American Kidney Fund
 - ✓ American Nephrology Nurses Association
 - ✓ American Society of Nephrology
 - ✓ Amgen
 - ✓ Centers for Medicare and Medicaid Services
 - ✓ DaVita
 - ✓ ESRD Network Organizations
 - ✓ Fresenius Medical Care

- ✓ Miller Dialysis
 - ✓ National Association of Nephrology Technicians
 - ✓ National Kidney Foundation
 - ✓ National Renal Administrators Association
 - ✓ National Renal Alliance
 - ✓ Nephron Information
 - ✓ Renal Physicians Association
- The National Kidney Foundation, serving as the administrative lead for this Coalition, agreed to schedule the first meeting of the interim Planning Committee Meeting for March 2006.
 - Communication for the National Disaster Coalition, its Response Teams and Planning Committee will occur via e-mail, conference calls and in-person meetings when necessary .
 - Attendees made a motion, which was approved unanimously, to have the interim Planning Committee develop an official name for the Coalition.

Summit Review

- The Coalition proposed a five-month timeframe be used for initial planning. The renal community must always be prepared for emergencies; however, since hurricane season begins in June, the group agreed to focus on completing our phase one work prior to June 2006..
- As part of its effort for the Disaster Summit, Network 7 announced that it would be collating all the action plans and notes from the meeting, developing a final report and distributing those materials via e-mail to all interested parties. This final report will serve as the draft strategic plan for the Coalition.
- Following completion of the report and its distribution to the community, the National Kidney Foundation will take over the administrative lead for the National Disaster Coalition. At that point, all questions may be directed to Dolph Chianchiano at dolphc@kidney.org.

Adjournment

- All participants were thanked for their time, energy and commitment. It was agreed that these efforts in the National Disaster Coalition would serve to improve quality care and access to treatment for our ESRD population, especially during times of emergency.

Appendix – Response Team Rosters

<i>Patient Assistance & Response</i>		
<u>Workgroup Leaders:</u>	American Association of Kidney Patients American Kidney Fund	
<u>Contact Information:</u>	Kris Robinson Phyllis Ermann	krobinson@aakp.org permann@kidneyfund.org
<u>Team Members:</u>	Steve Fadem, MD Tracey Fortson Brenda Dyson	Linda Schacht Rick Russo Darlene Rodgers
<u>Conference Call:</u>	February 21, 2006 2:00 PM (Eastern) Call-in Number: 800-605-5167 Participant Code: 772749	

<i>Coordination of Staff – Nursing and Technical Volunteers</i>		
<u>Workgroup Leaders:</u>	American Nephrology Nurses Association National Association of Nephrology Technicians National Renal Administrators Association	
<u>Contact Information:</u>	Sue Cary	Suepreu@cox.net
<u>Team Members:</u>	Lisa Drossos Norma Gomez David Smith	Kim Schroeder Marsha Lisk
<u>Conference Call:</u>	February 7, 2006 1:00 PM (Eastern) Call-in Number: 866-262-1846 Participant Code: *0007161*	

Physician Placement & Assistance

<u>Workgroup Leaders:</u>	American Society of Nephrology Renal Physicians Association	
<u>Contact Information:</u>	Andrew Cohen, MD ancohen@ochsner.org Robert Kenny, MD rkenney@renalassociates.com	
<u>Team Members:</u>	Sarah Yelton Melanie McKnight, MD Jeffrey Kopp, MD	Sharon Adler, MD Nauman Qureshi, MD Lynda Ball
<u>Conference Call:</u>	February 24, 2006 11:30 AM (Eastern) Call-in Number: 888-867-7084 Participant Code: 230714#	

Communication

<u>Workgroup Leader:</u>	National Kidney Foundation	
<u>Contact Information:</u>	Preston "Tony" Englert	penglert@kidneywdc.org
<u>Team Members:</u>	Susie Stark Meryl Slowik Jackie Harley Paul Miller, MD	Roberta Bachelder Bridget Carson Kim Rucker Suzanne Wyekoff
<u>Conference Call:</u>	February 23, 2006 4:00 PM (Eastern) Call-in Number: 410-786-3100 Participant Code: 136154	

*Patient Tracking / Facility Tracking Database*Workgroup Leaders: ESRD NetworksContact Information: Glenda Harbert gharbert@nw14.esrd.net
Michael Kennedy mkennedy@esource.netTeam Members: Leigh Ann Sauls Tom Smith
Kelly Brooks Paul Munter
Amanda Hyre David HolstConference Call: February 15, 2006
2:30 PM (Eastern)
Call-in Number: 877-214-5010
Participant Code: 169364*Facility Operations & Services*Workgroup Leaders: National Renal Administrators Association
DaVita
Fresenius Medical CareContact Information: Tony Messana anthony.messana@stjoe.org
Tom Bradsell tom.bradsell@davita.com
Bill Numbers bill.numbers@fmc-na.comTeam Members: Deborah Brouwer Danilo Concepcion
Rita Clymer Jim Curtis
Russell Dimmitt Linda Duval
Mary Fenderson Gail Fredrick
Gema Gonzalez Brenda Leply
Condict Martak Rita McGill
Maureen Michael Carolyn Neuland
Stuart Redpath Kathleen Smith
Cindy ToombsConference Call: February 7, 2006
12:00 PM (Eastern)
Call-in Number: 877-988-3571
Participant Code: 484454

<i>Federal Response</i>		
<u>Workgroup Leader:</u>	Centers for Medicare & Medicaid Services	
<u>Contact Information:</u>	Glenda Payne	gpayne@cms.hhs.gov
	Gina Clemons	gclemons@cms.hhs.gov
<u>Team Members:</u>	Deborah Levy, MD	Lee Hamm
	Dolph Cianchiano	Judith Kari
	Janet Crow	Doug Marsh
	Efrain Reisin	Steve Egger
<u>Conference Call:</u>	February 7, 2006 2:00 - 3:00 PM (Eastern) Call-in Number: 888-476-3757 Participant Code: 906409	

<i>Vendor Supplies & Services</i>		
<u>Workgroup Leader:</u>	Amgen	
<u>Contact Information:</u>	Ken Chen	kenc@amgen.com
<u>Team Members:</u>	Wayne Bernard	Jenny Kitsen
	Ralph Biddle	Brian Sheehan
	Joan Solanchick	Walter Franz
	James Sweeney	
<u>Conference Call:</u>	February 7, 2006 10:00 AM (Eastern) Call-in Number: 888-834-2663 Participant Code: 83963267#	