



## KCER: KIDNEY COMMUNITY EMERGENCY RESPONSE COALITION

### ATTENDEES

<i>Sheila Wiener</i>	<i>Peter Traub</i>	<i>Jim Curtis</i>	<i>Connie Lorenz</i>
<i>Amy Williams</i>			

### KCER MEETING MINUTES

<b>Date: September 8, 2009</b>	<b>Time: 12 noon EST</b>	<b>Location: Conference Call</b>	<b>Team: Patient Assistance</b>
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TOPIC	DISCUSSION	PLAN OF ACTION	RESPONSIBLE	DUE
<a href="http://www.kidney.org/help/">http://www.kidney.org/help/</a> website	<p>Team discussed the new and improved NKF website on Emergency Preparedness.</p> <p>Team will continue to suggest improvements to website when necessary and encourage patients to <u>share their stories and photos</u> about how they coped with an emergency or disaster</p>	At this point, there have not been any patient stories placed on the website.	Tonya will work with DPC to help find patient stories to post on NKF website.	10/13/09
Video for training patients and local emergency preparedness organizations	We will continue to persure ways to develop this video, as we believe that it is an important tool for encouraging patients to prepare for emergencies, and will be a helpful tool for them.	Jim has sent a request to Larry Park to see if there is support from his organization for this video.	Peter will resend the script to the team.  Sheila will ask	10/13/09

			at the NKF about the possibility of getting one of their celebrity spokespersons to participate in the video	
Identify sources of financial assistance for kidney patients in the event of a disaster;	Jim talked with Sherilyn, and it was decided that this concept would not work as we had planned.	Look for national contact numbers for some of the medication companies so that we can list them on the web site.	Jim	10/13/09
Coffee House Calls	Discussed promoting "People Like Us" Coffee House Conversations call " <b>Get Ready for an Emergency</b> " in September.	Jim participated in the planning call, and will be presenting on the actual call with Lisa Hall from NW 7 / KCER  <b>3. Actual Call:</b> Tuesday, September 15 7:00 p.m. - 8:30 p.m. ET call in: 1.888.603.9220 Pass code: KIDNEY		Will be complete on 9/15/09
September is Disaster Preparation Month	Sherilyn revised the poster from last year changing the dates of 9/13 to 9/19, 2009	The new poster, and other information has been distributed to dialysis facilities through the ESRD Networks		Complete
New Business:	Review of the NxStage "Are You Ready" material comments: <ul style="list-style-type: none"> <li>• Some language could be stated differently – "people affected by kidney disease" is preferred by some over "kidney patient", and "kidney" could be better understood by some than "renal"</li> <li>• On page 7, ESRD should be spelled out as End Stage Renal Disease</li> </ul>	These comments will be provided by Jim to Kay Deck of NxStage.  The group would be very interested in working on this document in the future to adapt it to other modalities and dialysis systems, with great credit given to NxStage for the original development.	Jim  Discuss further at the next meeting. Kay Deck will be invited to participate.	Done  10/13/09

	<ul style="list-style-type: none"> <li>• On page 9 there is a statement about pre-registering for special needs shelters, and the ability to do this is not available in many places</li> <li>• Some places have check marks in boxes, and it was felt that it would be better to leave those blank so a patient could check them off as they complete each item</li> <li>• General comments are that portions in all capital letters may be hard for patients to read, and that a larger font of would be better as recommended by the Association for the Blind. This organization also recommends sanserf or New Times Roman fonts as being easier to read by visually impaired individuals.</li> </ul>			
Next call	September 8 <sup>th</sup> , 2009 12:00 PM (EST).			