



KCER: KIDNEY COMMUNITY EMERGENCY RESPONSE COALITION

ATTENDEES

<i>Brenda Dyson</i>	<i>Jolene Bussiere</i>	<i>Sheila Weiner</i>	<i>Jim Curtis</i>
<i>Sammy Bailey</i>	<i>Vernon Silva</i>	<i>Ann Karanja</i>	

KCER MEETING MINUTES

Date: September 9, 2008	Time: 12 noon EST	Location: Conference Call	Team: Patient Assistance
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TOPIC	DISCUSSION	PLAN OF ACTION	RESPONSIBLE	DUE
Community Meeting on disaster preparedness.	This is complete	Post on website	Jim	11/18/08
Patient materials on the KCER or www.kidney.org websites	We have made a good start on this: there has been information added to the NKF website regarding some additional Network information	Review the website Continue working with NKF IT Department	All Sheila	11/18/08
Video for training patients and local emergency preparedness organizations	Vernon reported that he has received several letter from film schools. The gist of the letters was "Show me the money!" (my interpretation-JC) Anna was contacting Vernon via email after the call with an update on DaVita	We will check with DaVita about their in-house video team Vernon will check with Darlene to see the feasibility of each Network contributing to the production of the video - to get her thoughts on whether the idea would fly...	Anna Vernon	11/18/08

<p>What are the specific plans for transplant patients</p>	<p>We reviewed and discussed the document <i>Preparedness for Transplant Patients</i></p> <p>Patients who use Prograf <i>can</i> obtain individual foil pack wrap Prograf in 1 mg. from the pharmacy distributors. They are water resistant, small and portable.</p>	<p>There were a couple of suggested changes: the title should be changed to say “People with Transplant” or something similar , and remove the term “Transplant Patients”; The recommendation should be to have 2 weeks of transplant meds, with a link to a website that has potential resources to help patients with this; we may want to remove the pictures so it looks better when printed with a black and white printer</p>		<p>Ongoing</p>
<p>National Disaster Preparation Month.</p>	<p>The flyer and information from several response teams went out in September</p> <p>We like the idea of making this an annual practice</p>	<p>Complete</p>		
<p>Patient Cards</p>	<p>Patient Cards: KCER has developed information cards that will be given to patients to be used in emergency situations</p> <p>Vernon noted that after they sent cards out in his NW, they received several requests to have them printed in Spanish</p>	<p>Sherilyn is getting the counts form the Networks on how many and where to send them.</p>		<p>11/18/08</p>
<p>Patient Assistance Charter</p>	<p>It is time to review and update the Patient Assistance Response Team Charter</p> <p>The two items in the Charter that we should focus on are:</p> <ul style="list-style-type: none"> Identify sources of financial assistance for kidney patients in 	<p>Please review the Charter and send suggested changes to Jim or Sherilyn</p> <p>We should plan in advance and see if we can line up potential</p>	<p>All</p> <p>Sheila</p>	<p>11/18/08</p>

	<p>the event of a disaster;</p> <ul style="list-style-type: none"> • Promote awareness of the resources available to kidney patients within the kidney community; 	sources of support. Sheila will take on the task of writing the first draft of this.		
Disaster Relief	<p>Sheila reported that the NKF made 388 grants to help people who needed assistance to recent hurricanes, and they ran out of available funds. Transportation was the number one issue.</p>			
Next call	<p>The standing meeting will be the second Tuesday of each month at 12:00 Noon (Eastern Time).</p> <p>NEXT CALL: Tuesday, November 18th, 12pm Eastern Time Please note that this is a date change from the normal 2nd Tuesday</p>			