



## KCER: KIDNEY COMMUNITY EMERGENCY RESPONSE COALITION

### ATTENDEES

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

### KCER MEETING MINUTES

|                       |                          |                                  |                                 |
|-----------------------|--------------------------|----------------------------------|---------------------------------|
| <b>Date: 10/21/08</b> | <b>Time: 12 noon EST</b> | <b>Location: Conference Call</b> | <b>Team: Patient Assistance</b> |
|-----------------------|--------------------------|----------------------------------|---------------------------------|

| 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 <a href="http://www.kidney.org">www.kidney.org</a> 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<br><br>Continue working with NKF IT Department   | All<br><br>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)<br><br>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<br><br>Vernon will check with Darlene to see the feasibility of each Network contributing to the production of the video - to get | Anna<br><br>Vernon | 11/18/08 |

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|---|--|--|-----|----------|
|   |  | her thoughts on whether the idea would fly...  |     |          |
| What are the specific plans for transplant patients | <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> | 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 |     | Ongoing  |
| National Disaster Preparation Month.                | <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>   | Complete   |     |          |
| Patient Cards                                       | <p>Patient Cards:<br/>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>        | Sherilyn is getting the counts form the Networks on how many and where to send them.   |     | 11/18/08 |
| Patient Assistance Charter                          | It is time to review and update the Patient Assistance Response Team Charter   | Please review the Charter and send suggested changes to Jim or Sherilyn  | All | 11/18/08 |

|                 |   |   |               |  |
|-----------------|---|---|---------------|--|
|                 | <p>The two items in the Charter that we should focus on are:</p> <ul style="list-style-type: none"> <li>• Identify sources of financial assistance for kidney patients in the event of a disaster;</li> <li>• Promote awareness of the resources available to kidney patients within the kidney community;</li> </ul> | <p>We should plan in advance and see if we can line up potential sources of support. Sheila will take on the task of writing the first draft of this.</p> | <p>Sheila</p> |  |
| 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><b>NEXT CALL: Tuesday, November 18<sup>th</sup>, 12pm Eastern Time</b><br/> Please note that this is a date change from the normal 2<sup>nd</sup> Tuesday</p>   |   |               |  |