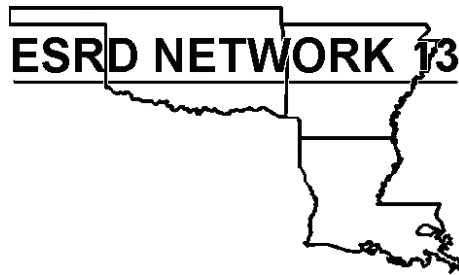


**ESRD Network 13
Kidney Community Gathering
Planning Manual For Dialysis and
Transplant Facilities**



Background

Network 13 began the Kidney Community Gathering (patient and community workshop) outreach project in 2009 as an avenue to provide information and education to individuals with end-stage renal disease, their caregivers and the community. In an effort to grow the project and provide more opportunities for educational outreach throughout the Network 13 service area, the Network has begun assisting dialysis and transplant facilities interested in hosting an “independent” Kidney Community Gathering in their area. The Network does not provide on-site staff support for the event, but it provides extensive technical assistance and planning support leading up to the event, including identifying professional and patient speakers and event location, educational materials, marketing and invitations for the event, and various other support to promote a successful educational event.

This document will assist those interested in organizing a Kidney Community Gathering. Once you decide to host an event, Network staff will work closely with the program organizer to extensively discuss and help prepare details of the event.

Process

Event date:

The Network has identified Sunday afternoon as an optimal day to host the event, as this allows those on the in-center hemodialysis modality an opportunity to attend on a non-treatment day.

Patient Contacts:

The Network suggests working with local Network Patient Representatives or local kidney support group members to establish a community patient connection and to identify potential speakers for the event and patient panel. In the event that there is not an NPR or support group in the selected area, then identify exemplary patients in the treatment facility. Often the Network staff providing planning support will be able to assist with identifying patient speakers or panel members.

Event Venue:

The Network has hosted the events in hospitals, churches and libraries with success. It is useful to find a venue with a built-in sound system and projector screens. Free Internet capabilities are also useful. The Network has had the best logistical experiences with public libraries, due to ease of access (sometimes a problem in large hospitals) and usually user-friendly built-in technology.

Suggested Agenda:

The Network has developed the following program agenda, with adjustments made as needed per location. The facility providing the Kidney Community Gathering is free to provide any topic of need or interest to its community, however the Network asks that the session about *all* ESRD treatment modalities stays on the agenda, along with the patient panel.

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|------------------|--|
| 1:00 – 1:15 p.m. | Registration and 3 question pre-test |
| 1:15 – 1:30 p.m. | Welcome, Introductions and Explanation of Network and Services |
| 1:30 – 1:45 p.m. | What is CKD? (Video from NIDDK – available online) A dialysis nurse is available for questions following the video. |
| 1:45 – 2:00 p.m. | Entertainment (Local singing groups/choirs/bands/etc.) |
| 2:00 – 2:30 p.m. | Keynote Address – (usually a CKD patient discussing their journey and how to maintain quality of life) |
| 2:30 – 3:00 p.m. | Treatment Options:– a dialysis nurse gives a very brief overview of ALL modality options before the video Dialysis Patients Speak (Video about importance of AV fistulas), refreshing patients about what options there are for treatment of ESRD. Afterward, the nurse explains the “buttonhole” cannulation technique and answers any audience questions about fistulas. |
| 3:00 – 3:30 p.m. | Food Demonstration and Taste Testing (Local dietitian gives presentation and passes out samples of renal friendly foods) |
| 3:30 – 4:00 p.m. | ESRD Patient Panel Discussion/ Q&A (Panelists are representative of all treatment modalities and share their reasons for choosing each modality and their experience with kidney disease. A dialysis nurse is also a part of the panel to answer clinical questions.) |
| 4:00 p.m. | Evaluation (Post –test), Closing and Good byes |

If an urban area is not struggling with fistula rates, the Network has brought in a local volunteer dentist to address oral hygiene as it relates to transplantation, instead of showing the fistula video.

Registration and Evaluation Forms

In an effort to measure learning of program attendees, the Network provides the facility hosting the event with copies of a “pre-test” (registration form) and a “post-test” (evaluation form) that is three questions about the material presented. The Network assembles and ships this information to the facility

to distribute to the program attendees and provides postage and materials for the return of these materials. The Network will analyze the data and share the results with the facility.

Educational Materials Available:

The Network provides various educational materials and exhibits for patients and caregivers to peruse and take home. Materials reflect the above mentioned topics as outlined in the statement of work. Additionally, the Network provides “goodies” such as letter openers, plastic bags for materials, Network 13 pens, etc. as available.

Speakers Needed:

- **Emcee:** To welcome, introduce other speakers and coordinate moving topics along
- **Dialysis nurse:** To discuss treatment modalities and answer clinical questions
- **Patient Keynote**
- **Renal Dietitian:** To discuss topic related to renal diet, or to give basic overview of renal diet
- **Patient Panelists:** transplant, in-center hemodialysis, home hemodialysis, peritoneal dialysis

Materials Needed

- Laptop
- Projector (try to find location which has this built in)
- Speakers (try to find location which has this built in)
- Dialysis Patient Speak DVD (available from ESRD Network 13)
- You Have the Power to Prevent Kidney Disease video (available online at <http://www.youtube.com/watch?v=Jw3jSDsiMJA>)
- Camera – if you would like to document this fun event!
- Educational Materials (available from ESRD Networks, Renal Support Network, American Association of Kidney Patients, and other organizations)
- If providing renal friendly refreshments: cups, ice, food items, cutlery, plates, napkins

Contact Heather Binkley at ESRD Network 13 if you would like more information about planning a Kidney Community Gathering.

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