

HSAG: ESRD Network 15

Patient Councils, Patient and Family Support Groups, and New Patient Adjustment Support Groups



Why Are These Groups So Important?

- Peer support can provide personal connections and help patients better understand their health.
- Support groups teach coping skills.
- Getting together in a group helps people realize they are not alone and provides opportunities to discuss shock, anger, and the feelings of helplessness commonly associated with renal failure.

Tips for Establishing a Group

- Consider who will make up your group.
 - Will you include patients, caregivers, healthcare professionals, social workers, and/or friends of patients?
 - People will inspire and motivate each other, as well as teach through their own experiences.
- Establish a goal for each meeting.
- Engage interested staff and patients in the planning phase.
- Determine a consistent meeting place, day, and time.
- Create flyers and a poster for the dialysis center bulletin board.
- Consider how to provide information about the benefits of the support group, what a renal support group is, and information about confidentiality.
- Promote the group during every clinic visit.
- Call to remind individuals who expressed interest.
- Keep the group going.
 - Attendance may be sparse at first but will grow as word spreads.

Tips for Running a Group

- Bring food, journals, and other informative/pertinent information to share.
- Provide structure.
 - Structure could be provided by a book you follow or educational materials you bring to each group.
- Have different patients take turns running the group.
 - Encourage group leaders to bring informational/educational materials that are interesting to them.
- Make sure everyone has a chance to speak.
- Never interrupt a person who is speaking.
- Listen to each other.
- Keep an open mind.
- Respect the opinions of others.
- Avoid telling people how to do something.
 - Instead, offer friendly advice on how you approached or handled a similar situation.

RENAL SUPPORT GROUPS

The exchange of information and important patient-to-patient collaboration that occurs within a support group is one of the most valuable elements of patient participation. See the list of Renal Support Groups below listed by state.

- **American Association of Kidney Patients (AAKP)**
www.AAKP.org
 - Arizona
 - Phoenix
Contact: Risa Simon
risa@transplantfirst.org
Second Saturday of each month
 - Tucson
520.693.7365
Second Thursday of each month
(for kidney and liver transplant patients)
 - Nevada
 - Las Vegas
Contact: Richard Blaine
kidneykid2006@gmail.com
702.419.2438
Second Sunday of every month @ 1 p.m.
Refreshments are served!
 - New Mexico
 - Las Cruces
Contact: Susan Brown
susan.brown311@aol.com
575.496.2627
- **National Kidney Foundation (NKF) Peers**
www.kidney.org
 - Speak with a trained peer mentor who can share experiences about dialysis, transplant, and living kidney donation by calling 855.653.7337.
 - Join an online community at
www.kidney.org/online-communities

POPULAR GROUP DISCUSSION TOPICS

- Modality Choices
- Minimizing Problems of Long-Term dialysis
- Going Back to Work
- Coping with the Renal Diet
- Learning How Others Have Successfully Lived with ESRD
- Communicating with your Physician
- Programs on Renal Vacations
- Holiday Recipes
- Travel tips

CONTACT THE NETWORK

If you need more direction or assistance with organizing or running your groups, please contact the Network at:

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<https://www.hsag.com/en/esrd-networks/esrd-network-15/>