

Support Groups

The Network frequently receives calls from people in search of a renal support group. Unfortunately, there aren't many. Why? Transportation is one of the most common problems for many people. Another is not wanting to spend extra time at the dialysis unit, or coming back on their "off" day. Support groups provide an invaluable service to its participants. They help patients and family know they are not the only ones with these challenges. They help problem-solve, offer hope, inspire, educate, and they empower.

Gloria, of Baltimore, MD, started a support group herself. "Everyone needs support, someone with an ear to listen and maybe answer some questions. No matter what you are experiencing in life someone else has already come through it. What you came through will help others come through... We can be there for one another." Gloria has the right idea! You do NOT have to be a trained professional to run a peer support group. You just have to have the heart.

Tips

There are many resources available to help get you started. Gloria's approach is to have materials on different subjects available to help get people talking. Other ideas include:

- Introduce 10 minutes of material to chew on that brings up feelings and experiences. Prepare questions to encourage discussion among participants just in case they're shy and slow to start talking.
- Get guest speakers such as a social worker, nurse, dietitian, doctor, ESRD Network, local National Kidney Foundation, transplant center.
- Be creative.
 - ◇ Have a holiday party and ask everyone to bring a finger food (renal friendly!) to share.
 - ◇ Celebrate spring by having a picnic meeting. Everyone can bring their own food or you can make it a renal friendly potluck.
 - ◇ Have a "share your hobby" meeting, asking members who have a special craft or a unique hobby to come and share it with the group.
 - ◇ Have an awards night. If certain individuals or businesses in your community have been supportive of your group in some way, devote one meeting to thanking them and recognizing them with certificates of appreciation.



If you want to join a support group, there are agencies that can help you locate one. If there isn't one convenient to you, consider starting one yourself! See the other side of this page for information.

More Tips

- Have a set day, time, and place. There are many places that offer free meeting space such as the library or hospital. If you are going to start a group, make it convenient for yourself!
- Plan topics ahead of time for several months or a year. This will save time and allow you to choose speakers and gather any materials.
- Try to arrange any speakers as far in advance as possible. The more notice a person has the more likely their schedule will be free. Also give them a call about a week before hand to remind them!
- Market with posters or fliers on the bulletin board, unit newsletter, word of mouth, AAKP, NKF, or the ESRD Network.
- Meetings ebb and flow. Sometimes you have a ton of people, sometimes you don't. Do NOT get frustrated. Keep track of what topics seemed to have the most interest for people and the ones that bomb. Build off the successes!

Resources

For Help Identifying Local Support Groups:

American Association of Kidney Patients (AAKP)

www.aakp.org/outreach

1-800-749-2257

AAKP has information on how to start your own group and will post its information on their national website listing for free.

National Kidney Foundation (NKF)

www.kidney.org

1-800-622-9010

You can contact your local NKF office for information about groups they may be sponsoring.

Alternative Groups:

Renal Support Network (RSN) offers a toll-free call line and an on-line support group:

HOPEline 1-800-579-1970 (Speak with other kidney patients)

www.kidneyspace.com (On-line support group) This on-line group is now available in Spanish!

To find out if there are other support groups closer to you, or for ideas on how to start your own support group, contact Renée at the Mid-Atlantic Renal Coalition (Network 5) at **1.866.651.6272**.

Meeting Topic Ideas

Adjusting--What makes it easier for some, harder for others?

Depression and kidney disease

Sleep and kidney disease

Sex and kidney disease

Options

What is the Network?

Diet stuff (try recipes from renal cook books)

Pain management

New research

Understanding your medications

Communicating with your doctor or staff more effectively

Nutrition and supplements

Safe exercise

Self-help strategies

Relaxation and visualization techniques

Taking charge of your healthcare