



Quality  
Insights

Renal Network 4



# Network 4 Patient Representatives

## August Monthly Meeting

August 1<sup>st</sup> 2:00 PM

August 2<sup>nd</sup> 2:00 PM

Add valuable information to your Patient Representative Tool box!!

**Question:**

Did you know that Support Groups are valuable and can be helpful??

# What is a Support Group Format?

- Support groups vary, but the basic format is a small group of people (maybe no more than 10) meet on a regular basis to discuss their experiences and provide mutual support.
- Unlike formal group therapy, the meeting is often led by a lay person or group member with some training in facilitating group discussions. The group leader may act as a moderator.
- Support groups define when and where they meet

# What is an Kidney Support Group?

- More specifically, Kidney Support Group consists of a group of kidney patients, family members, caregivers and/or interested individuals.
- They provide the opportunity to discuss topics related to kidney disease and dialysis, share information and experiences as well provide and receive support.

# Success of Support Groups-Are they helpful?

- Over the years, support groups have proven to be a successful intervention to help patients cope with a new or existing diagnosis.
- **Kidney Support groups have helped patients to:**
  - Learn more about CKD and how to manage their kidney disease
  - Adjust to lifestyle changes
  - Stay physically active and socially engaged
  - Understand that other patients share the same challenges and have successfully overcome them
  - Become more engaged in their treatment
- **Additional benefits for families and care givers:**
  - Family members and caregivers can be positively affected by being part of the kidney support groups.
  - Directly or indirectly, family members and caregivers gain knowledge, implement problem solving techniques, receive support, and gain strength to help support their loved one.

# Benefits of Support Groups

- Probably the biggest advantage of support groups is helping a patient realize that he or she is not alone; there are other people who have the same problems.
  - This is often a revelation and a huge relief to the person
- Being in a support group can also help you develop new skills to relate to others. The members of the group who have the same problems can support each other and may suggest new ways of dealing with a particular problem.
- When joining a support group, people may be uncomfortable at first when it comes time to discuss problems in front of strangers. However, the fact that others are facing the same type of situation may help members open up and discuss their feelings.
  - Everything that takes place within the support group should be kept confidential providing a safe environment
- Do On-line support groups work?
  - Although there has been relatively little research on the effectiveness of online support groups, there is some evidence that online support groups can be beneficial. More research is needed to discover if this venue is effective,

# What actually happens at Support Groups?

- Members provide each other with various types of support.
- Usually personal experiences are shared, usually related to:
  - Success stories and milestones
  - Burdensome issues, characteristics or situations
  - Frustrations and sorrow
- Members with the same issues come together for sharing coping strategies, to feel more empowered and for a sense of community.
- The help shared at Support Groups may take the form of providing and evaluating relevant information, relating personal experiences, listening to and accepting others' experiences, providing sympathetic understanding and establishing [social networks](#).
- A support group may also work to inform the public or engage in advocacy.

# The ultimate purpose of a kidney disease support group

- Receive emotional support in a safe, welcoming environment
- Share thoughts, feelings and concerns
- Learn from one another's knowledge and experience
- Problem solve
- Establish friendships and gain a sense of belonging
- Become educated and informed
- Develop skills needed for personal growth and development



# Finding a Support Group

- A researcher from [University College London](#)
  - lack of qualitative directories
  - many support groups are not listed by search engines can make finding an appropriate group difficult.<sup>[4]</sup>
  - medical community needs "to understand the use of personal experiences rather than an evidence-based approach... these groups also impact on how individuals *use* information.

# Best Strategies in Finding a Support Group

- Talk to your Social Worker at your facility
- Visit the QIRN4 Website
  - Guide on “How to start a Support Group”
- Google Search “ESRD Support Groups”
  - [National Kidney Foundation \(NKF\)](#)
  - [American Association of Kidney Patients \(AAKP\)](#)
  - [Renal Support Network \(RSN\)](#)
  - [Kidney & Urology Foundation of America \(KUFA\)](#)
  - [Dialysis Patient Citizens \(DPC\)](#)

# American Association of Kidney Patients

- AAKP
  - Support groups for patients dealing with kidney disease are a growing need in many communities.
  - 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
- <https://aakp.org/support-groups/>

# National Kidney Foundation

- Interested in being a peer mentor? [Click here to complete a brief application.](#)
- **About NKF Peers**
  - A national, telephone-based peer support program from the National Kidney Foundation (NKF)
  - Connects people who want support with someone who has been there
  - Helps people adjust to living with chronic kidney disease, kidney failure, or a kidney transplant. Also offers support to those considering living kidney donation or who have been living kidney donors.
- **How do participants interact with each other?**
  - Participants are connected through a toll-free, automated telephone system. No one discloses personal phone numbers or incurs long-distance charges.
  - The automated telephone system allows participants to leave voicemail messages for their partners and block calls at certain hours.
  - Telephone services are provided free-of-charge by the NKF.
  - To learn more: Call **855-653-7337 (855-NKF-PEER)** or email [nkfpeers@kidney.org](mailto:nkfpeers@kidney.org)

# 1:1 Support through NKF

- Patient Information Help Line, NKF Cares, offers support for people affected by kidney disease, organ donation or transplantation.
- Designed just for patients, family members and caregivers.
- Speak with a trained professional who will answer your questions and listen to your concerns. We speak Spanish, too (Hablamos Español).
- NKF Cares is available Monday - Friday from 9:00 am - 5:00 pm Eastern Time.
- Call toll-free at 1.855.NKF.CARES (1.855.653.2273) or email [nkfcares@kidney.org](mailto:nkfcares@kidney.org).

# Renal Support Network (RSN)

- Renal Support Network (RSN) is a nonprofit organization that provides non-medical services to those affected by chronic kidney disease (CKD).
  - Call our [Hopeline](tel:8005791970) (800) 579-1970 M-F from 10-4pm (PT) to talk to a person who has lived with kidney disease.

# Time to discuss and share

- Has this been helpful?
- What is your experience with Support Groups?
- Do you feel better equipped to talk about support groups to patients at your facility after this presentation?

# Next Patient Rep Meeting:

- Topic: **How can I help with Quality Improvement at my facility**
- Choose the best time for you to attend!
  - Tuesday; September 5<sup>th</sup> at 2:00 PM
  - Tuesday; September 5<sup>th</sup> at 7:00 PM
  - Wednesday September 6<sup>th</sup> at 2:00 PM
- Call in information:
  - Each meeting will have a separate web link to view the presentation on your computer
  - Each meeting will have the same phone call in number
- All information will be sent to you one week before the meeting