



Better healthcare,  
realized.



**About Me: Renee Minor,**  
*PAC Chair North Carolina,*

My name is Renee Minor and I have had chronic kidney failure all my life. I am happily married with a son, and have spent my time getting myself involved within my community at my dialysis clinic. I started dialysis 5 years ago and have been a Patient Advisory Committee (PAC) Chair for Network 6 since 2016.

## Support Groups: Creating Community

As told by Renee Minor, Winston Salem, NC

Dialysis is time consuming. I arrive at the clinic at 6:45 a.m., by 7:15 a.m. my vitals have been checked, and I am hooked up to the machine. I'm headed home by 10:30 a.m. When I get home, I usually take a nap so I have enough energy to have family time when my husband and son get home. My family has always been a great source of support. My mom, who has since passed, was on dialysis at the same time as me, but for different reasons. I think this gave me a different perspective as not only a dialysis patient, but also a family member. I know my mom thought of herself as a burden to my father and I, and I realized that if that's how she felt, than it must be how a lot of other people are feeling. There are a lot of patients at my facility, and they all need support and understanding. Deciding to start a support group seemed like a great way to fill this need.

When I first approached my clinic managers about starting a support group, they were hesitant. They told me that they could not help to fund my events, and that I would have to run the group completely separate from the clinic. As the support group became more popular and successful, the clinic became more lenient and supportive. I also started a Bingo Night, and a Ladies Night Out. Everyone loves our Bingo Nights, and all the men are jealous of our Ladies Nights! I just tell them that they should organize a boy's night! Our ladies night started with three attendees and has grown to about 15! Recently, I have become more involved with the Network and the PAC, which I enjoy because now, I have more one-on-one conversations with other patients.

I am passionate about creating community within the clinic. As a patient, I feel that programs like this would have helped me when I first started, and as a family member of someone on dialysis, it is something I would have wanted for my mother. It is a very depressing life if you are just living for dialysis. Getting involved keeps me going and gives me a positive outlook on life.



### Tips for getting involved:

- Take your treatment a day at the time. Don't let a couple rough treatments get you down.
- Ask for the support you need. Your social workers and nurses are here to help.
- Do not withdraw from your family and friends. Do not feel like a burden- the people in your life want to help you.
- Make time to live your life and do fun things- Dialysis keeps you alive, but you do not live to do dialysis.



If you want to join or start a support group, speak with your dialysis social worker to discuss your options. Support Groups take many different forms – in person, in center, on line or via phone. Below is a list of ESRD Organizations that offer support groups:

**American Association of Kidney Patients (AAKP)**

<https://aakp.org/support-groups/>

**National Kidney Foundation (NKF)**

**Website: [www.kidney.org](http://www.kidney.org)**

**Renal Support Network (RSN)**

**Website: [www.RSNhope.org](http://www.RSNhope.org)**

**Call the HOPEline**

(800) 579-1970 (toll-free)

Monday through Friday from 10am to 6pm  
(Pacific Time)

### Tips for Starting a Support Group:

- Assess your community to identify the different needs from people in your area before beginning to form the group
- Begin recruiting people who are interested in helping you form a group
- Create a goal or mission for the support group based on what you have learned from your community
- Brainstorm on a location and when meetings will be held that will work best for the group
- Once details are confirmed, begin publicizing and inviting individuals to your group

For more information on starting a support group in your area visit [aakp.org](http://aakp.org) or call 1-800-749-2257

Please note: If you're looking to start a group at your dialysis facility, please contact your social worker for support and guidance.

If you have a concern, but you are uncomfortable talking to a facility staff member, you may call your ESRD Network at:

#### **IPRO End Stage Renal Disease Network of New England (CT, MA, NH, RI, VT)**

1952 Whitney Avenue, 2nd Floor  
Hamden, CT 06517

Patient Toll-Free:

1 (866) 286-ESRD (3773)

Fax: (203) 389-9902

E-mail: [info@nw1.esrd.net](mailto:info@nw1.esrd.net)

Web: [network1.esrd.ipro.org](http://network1.esrd.ipro.org)

#### **IPRO End Stage Renal Disease Network of New York**

1979 Marcus Avenue, Lake Success,  
NY 11042

Patient Toll-Free: 1 (800) 238-3773

Fax: (516) 326-8929

E-mail: [info@nw2.esrd.net](mailto:info@nw2.esrd.net)

Web: [network2.esrd.ipro.org](http://network2.esrd.ipro.org)

#### **IPRO End Stage Renal Disease Network of the South Atlantic (GA, NC, SC)**

606 Aviation Parkway, Suite 30  
Morrisville, NC 27560

Patient Toll-Free: 1 (800) 524-7139

Fax: (919) 388-9637

E-mail: [info@nw6.esrd.net](mailto:info@nw6.esrd.net)

Web: [network6.esrd.ipro.org](http://network6.esrd.ipro.org)

#### **IPRO End Stage Renal Disease Network of the Ohio River Valley (IN, KY, OH)**

3201 Enterprise Parkway, Suite 210  
Beachwood, OH 44122

Patient Toll-Free: 1 (844) 819-3010

Fax: (216) 593-0101

E-mail: [info@nw9.esrd.net](mailto:info@nw9.esrd.net)

The Network will accept grievances by phone, fax, email or postal mail.



This material was prepared by the IPRO ESRD Network Program, under contract with the Centers for Medicare & Medicaid Services (CMS), an agency of the U.S. Department of Health and Human Services. The contents presented do not necessarily reflect CMS policy. CMS Contract Number: HHSM-500-2016-00019C