



End-Stage Renal Disease Network of New York
1979 Marcus Avenue
Lake Success, NY 11042-1072
(516) 209-5578
esrd.ipro.org



Would you like to help other patients learn more about kidney disease?

If you're interested in speaking with other patients about kidney care choices, consider being a part of our Patient Advisory Committee.

The Patient Advisory Committee (PAC) provides an opportunity to patients, transplant recipients and care partners for the purposes of lending perspective and assisting in the promotion of patient, family and care partner engagement in ESRD care, as well as promoting positive relationships between patients, provider staff, ESRD stakeholders and the Network. The PAC consists of three separate levels of involvement: Members, Representatives and Chairpersons. The Patient Advisory Committee is for individuals who are interested in:

- **Member Level:**
 - Educating themselves on kidney disease and ways to be a healthier patient living with ESRD
 - Becoming an empowered patient by being an active participant with your personal care team
 - Learning more about the patient advocacy and quality improvement activities
- **Representative Level:** (Must be nominated by their social worker or another facility representative and complete a certified peer mentor training course)
 - Developing and Expanding their advocacy skills and become more involved with their Dialysis Facility and ESRD Network
 - Speaking with their ESRD peers and sharing advice and experiences
 - More education and training surrounding ESRD and other kidney diseases
- **Regional Chairs:** (must serve a PAC Representative for at least 1 year before consideration)
 - Assist supporting patients and activities in your region and talking with other patients and care team members to obtain their perspectives.
 - Provide feedback on the effectiveness of the Network's patient related activities and assist in developing resources and tools that will support reaching quality improvement goals
 - Review and make recommendations regarding patient related health care messages, materials and activities planned by the Network.

Once involved in the PAC a patient may be interested in serving as a Subject Matter Experts (SME). SMEs are individuals who are able to devote more time each month to be involved in planning quality improvement activities with the Network and other Federal agencies including participating on national conference calls.

Patient Subject Matter Expert Application Form

Please complete the following information for consideration to participate on the Network Patient Advisory Council (PAC) and/or as a Network Patient Subject Matter Expert.

To complete the process of joining PAC, each individual must review and complete the below Patient SME Application form and PAC Agreement form.

Patient Advisory Committee (PAC) Participation and Confidentiality Agreement

The Centers for Medicare & Medicaid Services (CMS) has contracted with the End Stage Renal Disease (ESRD) Network of New York (Network 2) to promote education and resources to the ESRD patients and providers.

In order to support this endeavor, Network 2 maintains a PAC comprised of members, representatives and chairpersons for the purposes of lending perspective and giving feedback to the Network. The committee will be represented by peritoneal dialysis patients, hemodialysis patients, and transplant recipients, Care Partners and/or Family Members that represent all regions of Georgia, North Carolina and South Carolina. The Network's Community Outreach Coordinator will coordinate and supervise the committee.

While serving on PAC, I may have access to confidential and proprietary information, as well as protected health information (PHI). This may include information related to patients and their treatment. I must safeguard the confidentiality of PHI which is subject to Federal and State laws as well as certain privacy and security regulations pursuant to the Health Insurance Portability and Accountability Act of 1996 (HIPAA) and the Health Information Technology for Economic and Clinical Health Act (HITECH).

I understand that I must keep this information in strict confidence and can only access this confidential and proprietary information to the extent required to participate in the PAC. I will not retain such information or any copies thereof or disclose it to third parties or use it for any purpose other than the authorized function, service or activity assigned to me. I also agree that I will not now or at any time in the future, either directly or indirectly divulge, disclose, or communicate in any manner whatsoever to any person not employed or affiliated with the PAC any confidential or proprietary information that I obtain during the course of my participation without the prior written consent of ESRD Network 6.

I understand that violations of confidentiality requirements may, under Federal law, lead to a fine from \$100 per violation to \$1,500,000 and up to ten years imprisonment.

In the event I breach this participation and confidentiality agreement, I understand that IPRO may terminate my participation in the PAC, which does not limit IPRO's right to seek any other remedy under the law.

I also consent to and authorize ESRD Network 2 to use my name and image on their website: esrd.ipro.org, in Network social media, in materials and other forms of communications. I understand that I will not receive any compensation for this. I give permission for my name, e-mail address and telephone number to only be given to my Regional PAC representatives, whom I serve as advisor to for direction. It is understood that the Network will not share any further information without my consent.

By signing this participation and confidentiality agreement, I agree to actively participate in the PAC as a PAC Chairperson, Member or Representative, and I agree to all of its terms and conditions.

Signature

Print Name

Date

Patient Subject Matter Expert Application Form

Please complete the following information for consideration to participate on the Network Patient Advisory Council (PAC) and/or as a Network Patient Subject Matter Expert.

About You			
I am (check one):	<input type="checkbox"/> Patient <input type="checkbox"/> Family/Caregiver <input type="checkbox"/> Stakeholder		
Name (First, Last)			
Address			
City, State, Zip			
Primary Phone			
Email Address			
I identify as:	<input type="checkbox"/> American Indian or Alaska Native <input type="checkbox"/> Asian <input type="checkbox"/> Black/African American <input type="checkbox"/> Native Hawaiian or Other Pacific Islander <input type="checkbox"/> White <input type="checkbox"/> Other		
Ethnicity: I identify myself as	<input type="checkbox"/> Hispanic/Latino <input type="checkbox"/> Not Hispanic or Latino		
I mainly speak:	<input type="checkbox"/> English	<input type="checkbox"/> Spanish	<input type="checkbox"/> Other: _____
About Your ESRD Experience			
Dialysis Facility Name			
Dialysis Facility Phone Number			
Name of Referring Staff Member (must be included if staff members is referring candidate)			
Referring Staff Member Phone / Email Address			
Number of Years as a Dialysis Patient			
Current Treatment Type: (check one)	<input type="checkbox"/> In-Center Hemodialysis: <input type="checkbox"/> M/W/F or <input type="checkbox"/> T/T/S <input type="checkbox"/> Peritoneal Dialysis <input type="checkbox"/> Home Hemodialysis <input type="checkbox"/> Transplant, if yes, number of years as a transplant recipient _____		
Previous Treatment Types: (check all that apply)	<input type="checkbox"/> In-Center Hemodialysis <input type="checkbox"/> Peritoneal Dialysis <input type="checkbox"/> Home Hemodialysis <input type="checkbox"/> Transplant		
Are you on a transplant waitlist?	<input type="checkbox"/> Yes <input type="checkbox"/> No		
Connecting With You			
Preferred Method of Contact	<input type="checkbox"/> Phone <input type="checkbox"/> Email <input type="checkbox"/> Mail		
How often do you check your email (check one):	<input type="checkbox"/> daily <input type="checkbox"/> 2-3 times/week <input type="checkbox"/> only when expecting important messages <input type="checkbox"/> don't have email		

Patient Subject Matter Expert Application Form

Please complete the following information for consideration to participate on the Network Patient Advisory Council (PAC) and/or as a Network Patient Subject Matter Expert.

Are you able to travel out of state for face- to-face meetings?	____ Yes ____ No
Are you able to attend 2 or more meetings by phone per year?	____ Yes ____ No

Please read the following statements (*all must be checked to be considered*):

- ☐ I have read the PAC member responsibilities and participation/membership policy and agree to fulfill them to the best of my ability.
- ☐ I authorize the Network ____ and my dialysis center (*if applicable*) to utilize my name and email address for specific PAC and SME communications.
- ☐ I further authorize my Network to use my name where necessary in PAC and SME meeting minutes and in listing PAC and SME members in reports to the Centers for Medicare and Medicaid Services (CMS) and other business documentation.

Applicant Signature _____ **DATE:** _____

Staff Signature (if Applicable): _____ **DATE:** _____

Submit completed form to IPRO ESRD Network of New York, Network 2. You may fax it to 516-326-8929 or mail it to:

Attention: Patient Services Department
1979 Marcus Avenue, Suite 105
Lake Success, NY 11042

If you have any questions, please contact us at toll free number at 1-800-238-3773 or 516-209-5626.