

End Stage Renal Disease Network of New York Patient Advisory Committee Training Presentation

2009

Who is the ESRD Network of New York and what do they do?



“The Mission of the End Stage Renal Disease Network of New York is to promote Health Care for all ESRD patients that is safe, effective, efficient, patient-centered, timely and equitable.”

The History

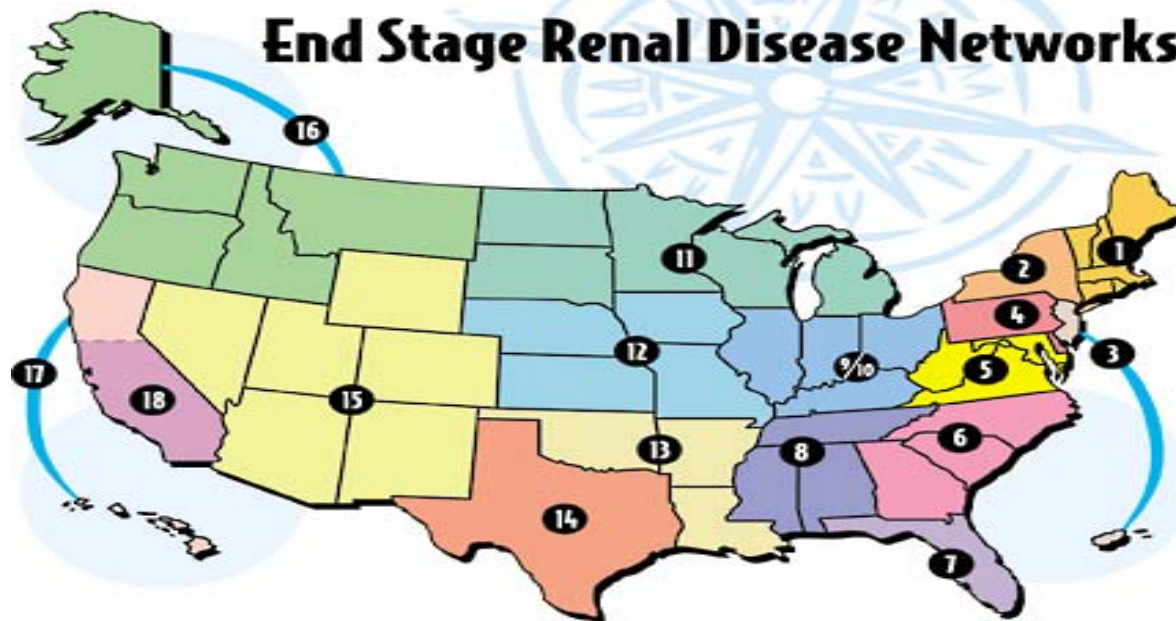
The End Stage Renal Disease (ESRD) program is a national health insurance program (Medicare) for people with irreversible kidney disease and was established in 1972 – before 1972, patients with ESRD were selected by a committee to receive dialysis treatments. Those who were not selected died.



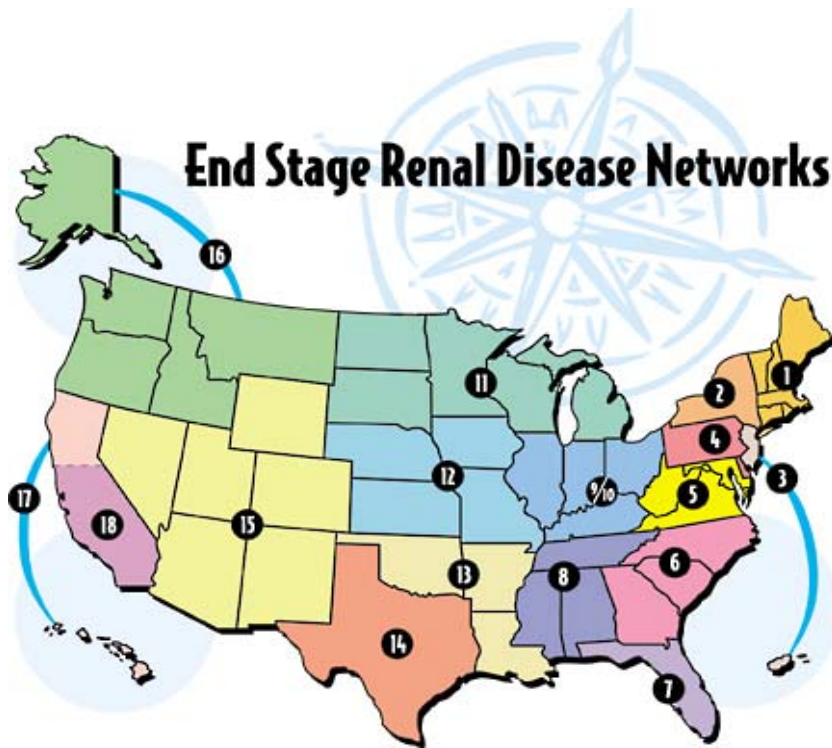
In 1978 congress authorized development of network organizations to oversee the quality of care in ESRD treatment facilities and thirty-two networks were established nationwide



In 1988 Centers for Medicare Services (CMS) reduced the number of networks to 18. Each black dot represents the location of a Network. We are Network 2, we serve the entire state of New York



Some networks represent several states



- This is due to the amount of ESRD patients in a specific region.
- There are more ESRD patients on the east coast than the west coast so there are more networks in the east

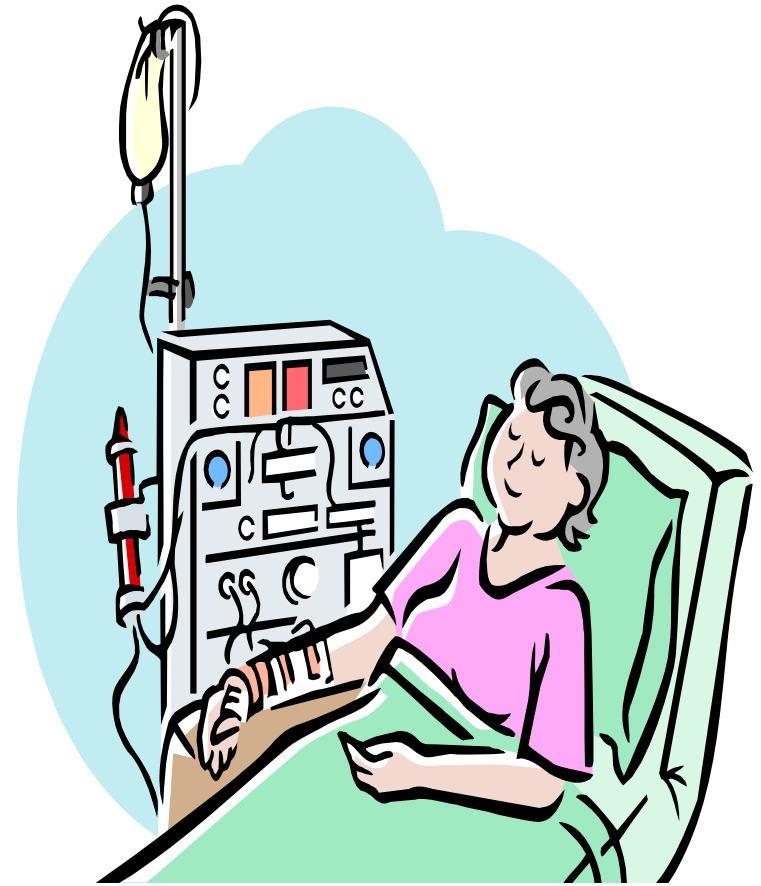
ESRD in NYS



- General NY state population of 19,254,630
- There are currently 23,000 ESRD patients receiving dialysis treatment in NY
- 254 dialysis and transplant facilities in NY State

What Do WE Do for You?

- ✓ Develop quality initiatives to improve outcomes –Fistula First, phosphorus management
- ✓ Provide education
- ✓ Community resources
- ✓ Grievance committee
- ✓ Provide patient “voice”



What Do I Do If I Have A Problem at My Center?



Good Practices Get Better Results!

Facilities are Required to Have Their Grievance Policy Posted in Patient Waiting Areas

- ✓ Familiarize yourself with the policy
- ✓ Take note of your Facility Grievance Committee Members
(you may need to refer to it one day)



Step-by-Step Problem Solving Tips

- Be Calm – getting agitated only makes matters worse
- Make notes so that you will remember everything, details get fuzzy after leaving and coming back
- If it is a medical issue, speak to your Nurse Manager or Doctor first
- If non-medical, speak to appropriate staff member
- Do not be confrontational , state your complaint in a calm, professional tone

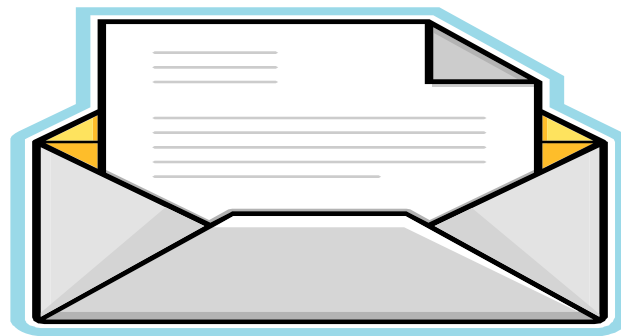
Step-by-Step Problem Solving Tips

- If it is not a personal issue, notify your PAC Representative; PAC reps can serve as moral support or as a representative in a complaint or grievance
- Always try to resolve the issue at your facility first by speaking to the involved parties getting others involved complicates matters - give your facility a chance to fix the problem; if your issue does not get resolved, go to the next step...



Step-by-Step Problem Solving Tips

Write a letter to your facility Grievance Committee – make copies and address them to each member. You should receive an answer in writing in a few days. If not, go to next step...



Step-by-Step Problem Solving Tips

Request a meeting with the Grievance Committee – agree on a time that is convenient for all members to attend. You may have a PAC representative with you if you desire. Refer back to your notes so that you don't leave any details out.

Call the Network – If you forget any of the steps or if the situation places patients in immediate jeopardy. The Network respects your privacy and confidentiality. You can file a formal complaint or grievance with us without fear of retaliation.



Remember! Disruptive Behavior and or Threats of Violence are Unacceptable

And could result in being sent home without treatment or discharged from the facility



Patient Representatives (PAC Reps)

Enable fellow patients to resolve issues themselves using these tips.
Do not interject your opinion.

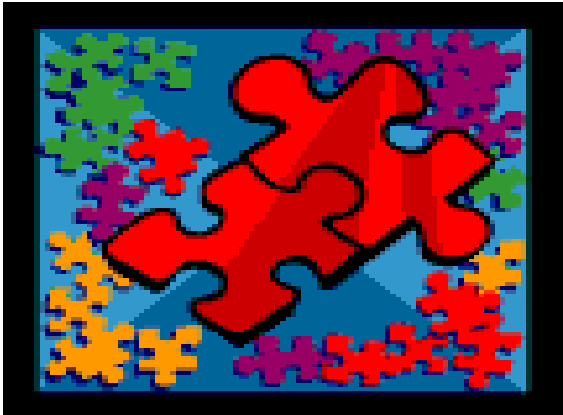


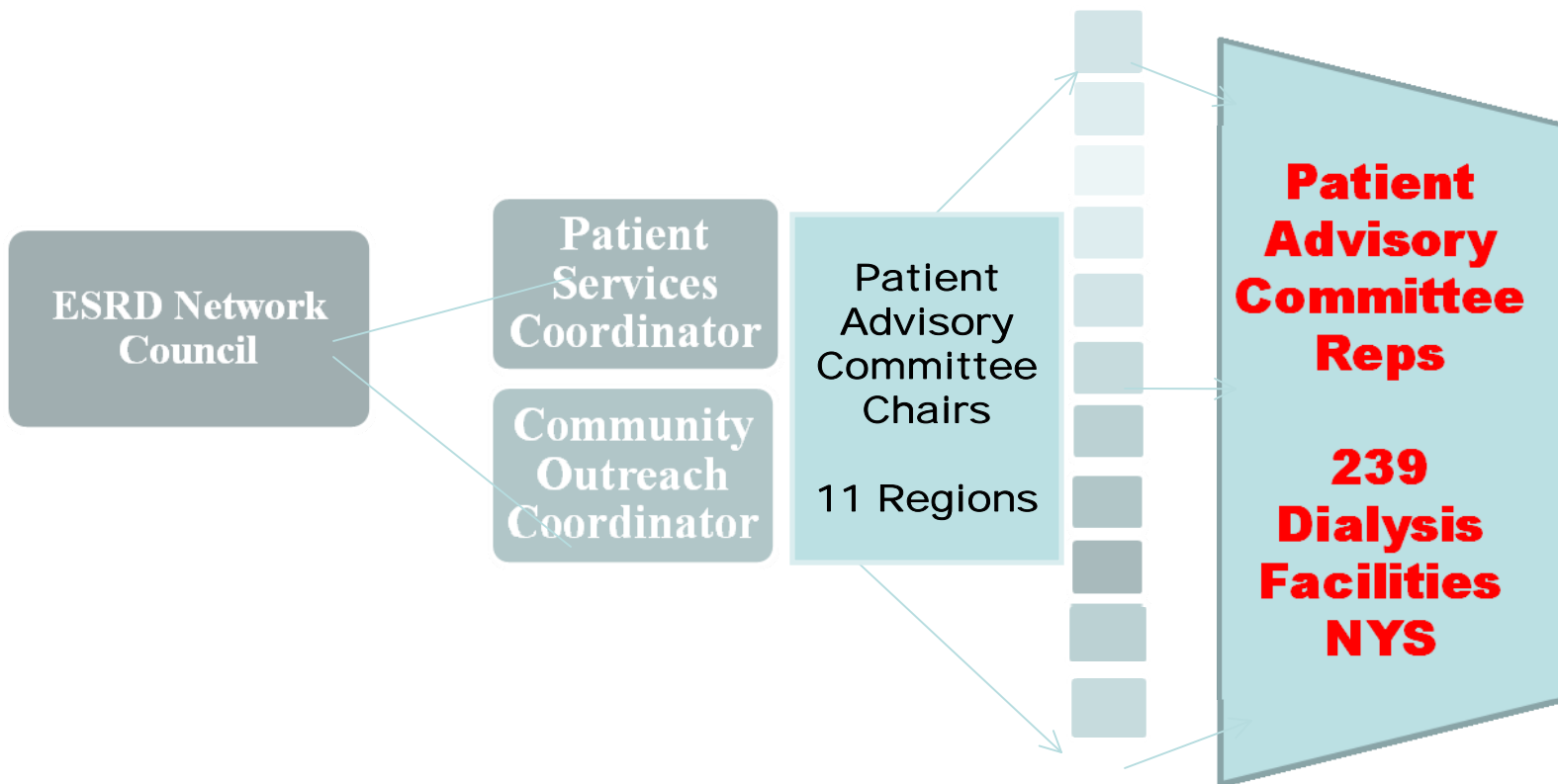
What Is The Patient Advisory Committee (PAC)



The PAC is a statewide organization of patients or family members who volunteer their time to represent the Network to their facility and their facility to the Network

Structure of the PAC





**ESRD Network of New York
Patient Advisory Committee
Organizational Chart**

PAC Coordinators

Dawn Edwards
Community Outreach Coordinator

Aaron Battle
Network Patient Services Coordinator

NYS is divided into 11 regions

- Rochester
- Albany
- Syracuse
- Hudson Valley
- Buffalo



- Manhattan/
- Staten Island
- Bronx
- Queens
- Brooklyn
- Nassau County
- Suffolk County

We currently have PAC Chairpersons representing the following regions

Manhattan/Staten Island

- ❖ Larry Wilson
- ❖ Aaron Battle

Bronx

- ❖ Vivian Davis
- ❖ Lorraine Langdon

Syracuse

- ❖ Hazel Parker
- ❖ Kelly Engel

Albany

- ❖ Kathe LeBeau

Queens

- ❖ Monica Richter

- ❖ Elizabeth Credle

- ❖ Joyce Jenkins-Barnes

Nassau County

- ❖ Michael Young

Brooklyn

- ❖ Warren Edmonds

- ❖ Wendy Rivers

Chairpersons Needed for 6 Regions

Suffolk County

Rochester

Albany (1)

Hudson Valley

Buffalo

Manhattan/Staten Island (1)



PAC Chair Goals 2008-2009

Recruit PAC Chairs – 2 Chairpersons per region

Visiting units without reps to recruit or initiate PAC representation

Chairpersons will encourage patient representatives to be sure patients are receiving issues of “PAC Notes”

Encourage regularly scheduled meetings with staff and patients



PAC Representatives

Represent dialysis and transplant facilities in their region



New York Patient Advisory Committee Mission Statement

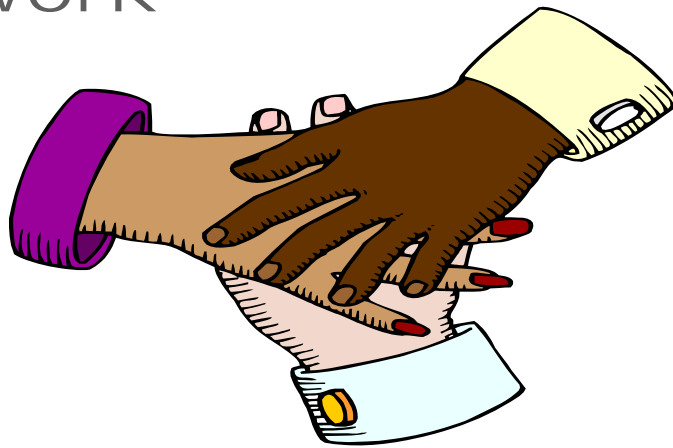
The Network Patient Advisory Committee, through its representatives in dialysis and transplant units, provides a link between patients and unit staff and opens opportunities for statewide communication for those in the renal community. Its mission is to identify and act upon issues of concern to ESRD patients thereby improving their quality of life.

Role of PAC Representatives

Promote communication between patients and staff

Inform patients about ESRD Network

Serve as a link between patients and ESRD Network



Responsibilities of PAC Representatives

- ✓ Inform appropriate unit staff members of patient concerns
- ✓ Encourage patients to be involved in their healthcare
- ✓ Empower patients to seek counsel from their health care team
- ✓ Gather and note ideas and suggestions from other patients
- ✓ Attend PAC meetings
- ✓ Help patients understand information provided by ESRD Network

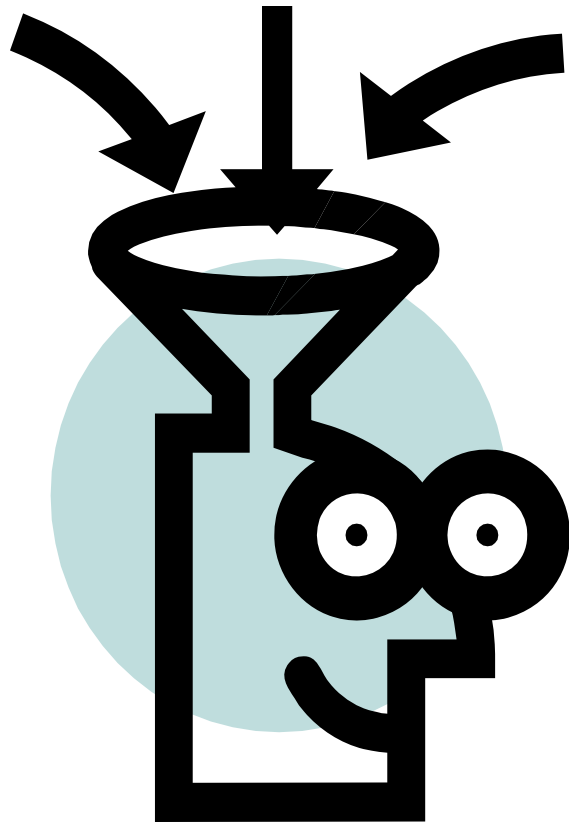
However, you must refrain from giving medical advice of any kind or commenting on specific orders of medical professionals



Requirements for PAC Representatives

- ✓ ESRD patient or Spouse
- ✓ Compliant to treatment
- ✓ Have a pleasant, positive attitude
- ✓ Be committed to improving the quality of life of ESRD patients
- ✓ Be willing to exchange information and ideas with patients and staff members in a friendly, professional manner

Things we want to be sure patients know...



- ✓ Grievance Policy
- ✓ Network contact information
- ✓ Treatment options
 - ✓ Where to go for information

Important Reminders...

- ✓ Make sure you know what you're talking about
- ✓ Refer to the Network or other professional staff members
- ✓ You may not be able to solve every problem
- ✓ Never, ever, give medical advice



We're Here For You At The Network! 800-238-ESRD (3773)

Dawn Edwards

Community Outreach Coordinator

Extension 549



Aaron Battle

Patient Services Coordinator

Extension 414