



PAC Chairs Speak

A NEWSLETTER FOR PATIENT ADVISORY COMMITTEE REPRESENTATIVES

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Talking to your Doctor about Anemia Management

By James Martinez, PAC Chair for Nassau County

I have been a patient on hemodialysis for the last four years. There are many adjustments we have to make. Fluid restrictions, dietary restrictions and of course a sense of loss after our kidneys have failed. With that being said, anemia which is a serious condition to patients on dialysis adds to our burden of not feeling well.

Without getting too technical, anemia basically is a condition that affects patients on dialysis. Our kidneys sometimes can no longer secrete the hormone that stimulates red blood cell production in our bones; therefore without having medication to substitute for this hormone we can become anemic.

One of the measures for anemia is Hgb (hemoglobin) if your hemoglobin is below 10, and you are on dialysis, you are considered anemic. The medication that we usually get for anemia is called an "ESA" (Erythropoiesis-Stimulating Agent) usually the brand name Epogen or Procrit or Darbepoetin alfa, called Aranesp. All of these medications substitute for the hormone that our bodies no longer produce when our kidneys fail.

For these medications to work, you also have to have enough iron, folic acid and Vitamin B12 in your blood stream. Together with iron, folic acid and Vitamin B12; over time ESAs can raise your Hgb.

I can tell you from personal experience that I know when my hemoglobin is low.

Some signs of low hemoglobin are:

- chronic fatigue and loss of energy,
- shortness of breath,
- chest pain,
- palpitations.

Red blood cells carry oxygen to your body, when your hemoglobin is low your heart is working harder, which also over the long term is damaging to the heart muscle.

ESRD Network of New York PAC Chairpersons

Albany.....	Kathe LeBeau, Osmond Adams
Bronx.....	Vivian Davis
Brooklyn.....	Wendy Rivers, Warren Edmonds
Buffalo.....	Shane Deitz, Frank Ireland
Hudson Valley.....	Brenda & Ron Maeder
Manhattan/Staten Island.....	Larry Wilson, Nelson Nunez
Nassau County.....	James Martinez
Queens.....	Monica Richter, Elizabeth Credle
Rochester.....	open
Suffolk.....	Pete Savage
Syracuse.....	Sue Burns, Richard Atkinson
PAC Chair Advisor.....	Dawn Edwards

These PAC Chairpersons oversee the activities of the PAC Representatives in local facilities. PAC Chairs are happy to come out (schedule permitting) to Patient Meetings as guest speakers.

If you would like a PAC Chairperson to be the guest speaker at your next meeting, contact the Network Community Outreach Coordinator, Anna Bennett at (800) 238-ESRD (3773) ext. 474.

Please contact the Network at least one month before the meeting to allow time to work out schedules.

James Martinez, PAC Chair, Nassau County



My name is James Martinez and I started hemodialysis in September 2007.

I am currently a patient at Port Washington Dialysis in Port Washington NY.

My background is over 25 years of working as a licensed Radiographer, caring for sick and injured patients. Now that I have changed roles from being a caregiver to a patient, I feel that I can offer a different perspective to patients undergoing or commencing treatment.

It is my goal to visit with each patient at my center every treatment day, even if it's just a brief hello and how are you doing today? Being a PAC rep is not just hearing complaints, but you are an active member of the health care team, providing a friendly ear to patients undergoing the same treatment as I am and to steer them in the right direction when advice is needed.

I truly enjoy visiting sites and giving advice to PAC reps, helping them to recruit new members and trying to make other centers within my district a more pleasant environment for patients. I am an active member of the DPC (Dialysis Patient Citizen) a Washington DC grass root organization advocating for dialysis patients' rights.

I am very happy to be involved in all these patient advocacy roles, it leaves me with a great deal of satisfaction, and I hope to continue to serve the patients of the renal community for years to come.

Things you can do if you think you may have low hemoglobin:

1. Advocate for yourself. If the patient is not able to, the caretaker for that person has to step up. Do not depend on your healthcare team alone to make sure you are being treated properly.
2. Tell your nurse and doctor how you are feeling, and what you are experiencing
3. Ask questions. How are they treating your anemia at your center? What is the anemia protocol?
4. Which ESA does your center use? Epo, Aranesp, Procrit? How much are you receiving? And how often do you get it?
5. Know when blood work is being taken and get the results on the next treatment day.
6. Ask your nurse what they plan on doing to make your anemia better if the results come out low.
7. Trend your results. Document for your own use what your hemoglobin is from month to month and the dose of medication you get to treat anemia. This way you will see at what level of hemoglobin you feel best at and try to have them keep you at that level.
8. Ask your dietitian or physician about Folic Acid. If you need it, make sure you are prescribed a Folic Acid supplement and are taking it.
9. Ask your physician if you have acceptable Iron stores (levels) and if you need supplemental Iron. Iron helps carrying oxygen in your red blood cells to all tissues throughout your body.

Doing these few things and getting involved in your own care not only make you feel better and will show your healthcare team that you are taking an active part in your own care. It will make for a better outcome for you & your family and you'll feel better too!