Network of New England

PATIENT PAGE

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Taking Care Of Business: Notes From A Patient's Wife

Hello, my name is Judy Paige; I am a member of the Network of New England's Patient Advisory Committee known as the P.A.C. It is our job to bring to the attention of the Network the things that are important to patients and families, so that they can take the steps necessary to better serve the Renal Community.

I am **not** a renal patient but my husband Charles Paige, Sr. is and he is also a member of the PAC. He is on Hemodialysis and gets his treatments 3xs a week at Mary Mahoney Dialysis Center in Roxbury, MA, a Fresenius Clinic. He shared his testimony in one of these newsletters some time ago about dry weight and how God had taken him off dialysis for 4 years before he had to return to treatments. He has an AV Fistula and it has lasted him with no problems for 17 plus years.

I wanted to share with you 2 things today:

1. The importance of partnering up or better yet, becoming a partner with your health care team. I'm not talking just a yes or no kind of partner, but an **Actively Participating** partner.
2. The importance of having someone you trust (husband, wife, family member or friend) participate with you in strategy sessions with your staff and doctors.

You are the only one who knows how you feel. If you participate in your care, you may find that some of your difficulties may be alleviated by changes to your care and added advice for you to follow.

There are so many things that a dialysis patient has to keep track of:

- What you eat
- How much you drink
- How much rest/sleep you get
- Your Spiritual/Religious well being
- How you play
- The quality of your new life
- What all those chemical analysis mean to your treatment

So with a husband, wife, family member or friend at your side, perhaps they can help jog your memories about things you wanted to ask about or let your team know about. They may have noticed something you experienced or something you told them during one of these sessions that will give your team hints to ways that they can help you. One of the best old sayings that I have found to help us along the way is "**TWO HEADS ARE BETTER THAN ONE".**

Don't wait for your team to ask you, if you haven't had a session in a while, make an appointment **now**. Bring your support and talk, talk, talk about your condition. Find out how really important you are to your team, they are there to help you.

The circumstances of our lives as people change all the time. The important thing is what we do about the changes. Getting all the knowledge and understanding we can by ask, ask, asking questions helps you make right decisions. The more you know the more you can be in control.

You are **not** just a statistic. Join in with your health care team, because the life you improve and the life you save may be your own.

Health care professionals get your patients involved in their care and urge them to bring in support. Sometimes we get intimidated by you, not because of you but because of our own fears and hesitations. Teamwork is Good. Teamwork works.

If you would like to have your support person on yourself talk to me about how to encourage you. Ask your clinic to call the Network of New England they have my number. Charles and I are available to you.

God bless you and I pray that you will have a wonderful rest of your life.

Rev. Judy Paige, PAC Member since 2002.

Many Opportunities For Kidney Patients To Learn More!

If you are new to dialysis or kidney transplant, or if you have been on treatment for some time, there are many opportunities to learn more about kidney disease and it's treatment. You can learn more by attending kidney focused educational events and conferences, self educate using the wonderful world wide web (the internet) or participate in local organization meetings. Here are a few of the educational opportunities open to you and your family.

American Kidney Fund

The American Kidney Fund (AKF) is our nation's # 1 source of direct financial assistance to kidney patients, and is a leader in providing education to those with and at risk for kidney disease. Our programs address all stages of kidney health, including kidney disease awareness and prevention; community outreach to individuals at high risk for kidney disease; and treatment-related support for those requiring renal dialysis or transplantation.

The following financial assistance programs are offered by the American Kidney Fund to needy dialysis and kidney transplant patients:

- The Individual Grants Program provides financial assistance to qualified dialysis patients who are referred by their physicians and social workers. Grants are provided for treatment-specific expenses such as transportation, over-the-counter medicines, medication co-payments, kidney donor expenses and other necessities such as dentures.
- The Pharmacy Grant Program enables qualified renal patients to receive urgently needed medications, nutritional products, and durable medical supplies. The Kidney Fund has contracted with ECHO Pharmacy®, a mail order pharmacy, to provide medications and supplies at discount prices, thereby increasing the purchasing power of patients' grants.
- The Disaster Relief Program helps ESRD patients get back on their feet when catastrophic events strike their communities. This program provides funds to assist patients replace medications, food and household items and pay for other necessities lost because of natural disasters such as flooding, hurricanes, etc.
- The Sherer Travel-Related Dialysis Program assists eligible dialysis patients to afford treatment while traveling. Patients or facilities may be reimbursed for the 20% of treatment costs not covered by Medicare or any other source for emergency transient dialysis. Grants are limited to travel necessitated by death or serious illness in the family or for the purpose of kidney transplant workup only. The Sherer Program is funded through a bequest from the Estate of Vera L. Sherer. For further information about these and other programs please call the Patient Services Department toll-free at 1-800-638-8299 or contact the social worker at your dialysis center.

RSN Renal Support Network

The Renal Support Network (RSN) is a great new organization devoted to kidney patients and their families. The vision of the RSN is to instill health, happiness and hope through education, advocacy and awareness to the kidney community.

The RSN is a nonprofit, patient-focused, patient-run organization that provides non-medical services to those affected by chronic kidney disease (CKD). RSN strives to help patients develop their personal coping skills, special talents, and employability by educating and empowering them (and their family members) to take control of the course and management of the disease. A vital role of RSN is to provide lawmakers and policymakers with the patients' perspective on the needs and capabilities of people with CKD. The Renal Support Network values people with kidney disease and helps them become self-sufficient through education, advocacy, and hope for a better tomorrow.

Specially the RSN can help patients find resources to manage their disease, offer materials and activities that make their lives more enjoyable, offer patients and family education on life enhancement and illness-related issues, showcase the talent and untapped potential of people with CKD, teach patients how to advocate for themselves with legislative partnering.

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