US NETWORKING FOR YOU. . .

. . .YOU NETWORKING FOR US

ESRD 13 ESRD NETWORK ARKANSAS LOUISIANA OKLAHOMA

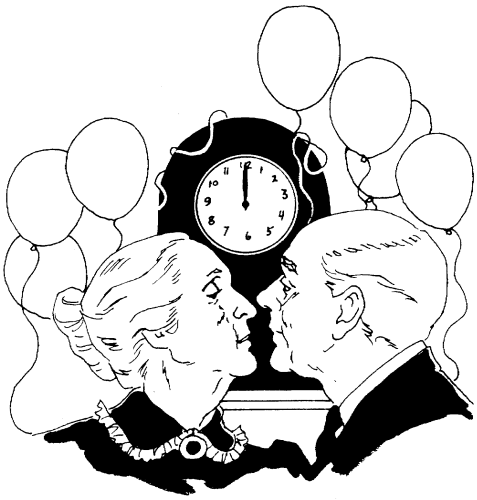
KIDNEY KONCERNS

WINTER/JANUARY ISSUE 31

HOLIDAY WISHES FOR A NEW YEAR

The Network 13 PAC and Staff would like to wish all patients and their families a wonderful holiday season. We hope the New Year continues to bring you the best possible care and quality of life that your center can provide. The New Year and the millennium provide us an opportunity to reevaluate ourselves and the directions we are taking. It provides us the opportunity to decide to improve or change a behavior that does not serve us well. The key to the success of any change is to start small and stay focused on one thing at a time. Most resolutions fail because we set unrealistic expectations or we try to change too many things at once and do not focus enough on one thing. So what can you do to improve your quality of life? Share your goal with your care team, family and support system so they can support and encourage your efforts. Do it for you so you can improve your outcomes. Make it a point to be here to celebrate the "real millennium" in the best health possible.

Network 13 is proud to announce that Penney Pilkington, chairperson of the Patient Advisory Committee (PAC), was one of 18 persons selected nationally to be on the New Patient Orientation Packet Committee. This committee has representation from the American Association of Kidney Patients, American Nephrology Nurses Association, Life Options Rehabilitation Advisory Council, National Kidney Foundation, National Renal Administrators Association, Renal Physicians Association, United Network of Organ Sharing, Forum of ESRD Networks and Health Care Financing Administration. This committee was formed to develop a standard educational information packet that will be utilized for all new ESRD patients. This committee will have its first meeting in January 2000 to begin the task of gathering, reviewing, modifying and developing the educational packet. Kidney Koncerns will provide updates on the progress of this committee.



Network 13 is proud that Penney is one of two patients on this committee. We felt it extremely important that the committee have patient representation to ensure the perspective of the patient educational needs be known. Penney was a transplant recipient for 33 years. She has battled chronic rejection the past several years and has just recently returned to dialysis. Dialysis has changed significantly since Penney had it first at age 12. She is becoming reeducated herself since her return. This will be a positive in her work on this committee. The committee will also allow Penney to be involved and active as she has decided to retire from her nursing position when she returned to dialysis. You can send suggestions to the Network and they will be forwarded to Penney so she can present the ideas to the committee. The Network contact number and address is on the back page.

"Glad You Asked That . . ."

QUESTION: Are you aware of the funds available from American Kidney Fund (AKF)?

ANSWER: **DID YOU KNOW THAT THE AMERICAN KIDNEY FUND WILL GIVE YOU CASH!**

I thought that sentence might get your attention. It's a cheap shot but it works and also happens to be true. The American Kidney Fund (AKF) has been helping end stage renal disease (ESRD) patients for nearly thirty years by providing cash assistance to those in need of a little help. Today, almost all Americans with ESRD have access to dialysis and transplantation. Yet a number or percentage of the costs associated with treatment remain the family's responsibility, a heavy burden for many. Since 1971 the primary mission of the AKF has remained constant: to provide financial aid for the urgent needs of people with chronic kidney disease. AKF grants help kidney patients when other sources of aid have been exhausted. In 1998 the fund provided $1,390,000 in patient aid grants, contributing to the quality of care and quality of life for over 14,000 patients.

The following is a summary of what the AKF can do for you. This information was reproduced from the AKF annual report and should be accurate and up to date:

AKF Pharmacy Grant Program: Sends vital prescription medications, nutritional products and medical equipment directly to patients in need. Our pharmacy program partner, American Prescription Providers, assures that our grants provide the maximum amount of product for AKF dollar.

AKF Emergency Funds: This fund has been established in almost 2,000 dialysis and transplant centers. The facility staff can provide immediate small cash grants for treatment emergencies with these funds.

AKF Disaster Relief Program: This program assists kidney patients get back on their feet when environmental crisis strike their communities. It assists with paying for clothing, food, household items and rent or utility bills as well as treatment necessities.

AKF Sharer Program: Covers the 20% of dialysis costs that are not covered by insurance when patients travel for family emergencies or transplant evaluation.

AKF Pediatric Campership Fund: Provides financial grants for children to attend summer kidney camps by assisting in camp tuition, transportation and camping supplies.

The question now is how do I get this help when I need it? The social worker at your dialysis or transplant facility is responsible for making a request to the American Kidney Fund. This makes it easier on you, Just Ask the Social Worker! If the social worker is not familiar with the American Kidney Fund programs they can contact the AKF national offices in Rockville, Maryland at (800) 638-8299.

This article was written by David Broach, PAC and Board of Directors for Network 13, Secretary of the National American Kidney Foundation.

If you have any questions for "Glad You Asked That", forward them to ESRD Network 13, 6600 N. Meridian, Suite 155, Oklahoma City, OK 73116-1411, or phone (800) 472-8664. Selected questions will appear in future issues of Kidney Koncerns.

PATIENT POETRY

Sherry Crabtree was awarded the Editor's Choice Award for Outstanding Achievement in Poetry from the National Library of Poetry for this poem dedicated to her son. Her son was killed in an auto accident. Sherry is a hemodialysis patient in Bastrop, LA.

FRIENDS FOREVER

There's a new Angel in Heaven today
My best friend has gone away
My life is so sad and the pain is always bad
Late at night when you're all alone
You find yourself sitting by the phone
The tears start to flow and you can't make them stop
How can you tell others you're o.k. when you're not
He touched so many lives in the short time he was here
God blessed us all, he was so special and very dear
He always had a smile and a wave of the hand
He liked all he met- every child, woman, and man
He liked to pick a friendly fight and fuss with his Dad
His feelings were easily hurt and he often got mad
He didn't want anyone to ever see him cry
His memories and my love for him will never die
His spirit was so free, he would look to the sky and say,
" I wish I was an eagle so I could fly, fly away"
So if you get to Heaven before I do
Would you find my best friend and tell him:
"Someday son your Mom will see you too."

"In loving memory of my son"
James Marvin Crabtree

Paul Stone, a hemodialysis patient from Luling, LA submitted this poem.

OH! PRECIOUS WATER

Oh! Precious water from down in the earth
For years I've swallowed you not caring for girth.

Wet and wild you feel going down
Sloshing and gurgling around and around

Quench my thirst and quench some more
Soothing and cooling my body from chore.

Years aplenty liquid abound
It fills swimming pools kids splash around.

Little ducks swim and big fish jump
A turtle will bask like some fourlegged hump.

Water is for everyone enjoy it all still
But for a renal patient too much will kill!

Two poems by Annie T. Harmon
Lake Charles Dialysis Center

A SAFE HARBOR

There's a Safe Harbor in knowing that
through all our illness, there's
still those that care: like nurses
and techs that stay there, even though
sometimes work becomes a dare

I'm sure at times they would like to
give up too: Just like some of us in
dialysis. But, in spite of it all,
they hang on in there for they also
find a Safe Harbor in what they do.
and they know that when we are
suffering that's the time that they must
stand tall and be there when we call

There's a Safe Harbor in lending a hand,
especially when you know that the person you're
helping can't, but you can. You see our
suffering and at times, you feel our pain,
but most of all you care even if you
see, for you, there's nothing to gain.

When you go home, you're all tired
and worn: but I think then that you
know, perhaps, this is the purpose
for which you were born.

DON'T BE NO COWARD SOLDIER

Don't be no coward soldier,
For Christ calls out to the bolder.
The ones that can stand the test
of time and get older.
God don't need no coward soldier;
For His army needs only those
who can go an extra mile
and still keep the faith,
Those who can cry and still not hate,
Those who can fall and still not lose it all,
Those who get weak, but still remain meek,
Those who know about His grace,
and continue to stay in the race.
God don't want no coward soldier in His band,
but He does need a strong and courageous
soldier to give Him a hand!!!

HOLIDAY RECIPIES

Holiday Eggnog- serves 6 (1/3 Cup Per Serving)

Ingredients:
1 ½ c. liquid non-dairy coffee creamer
½ cup frozen eggs or ½ cup liquid low-cholesterol egg substitute
2 tablespoons sugar
1 ½ teaspoon vanilla; nutmeg

Directions:
Combine the first four ingredients in a blender or beat with an electric mixer until well blended. Chill thoroughly. Serve with a sprinkle of nutmeg.

Renal and Renal Diabetic Exchanges- 1 milk, 1 fat.
Calories 134, Carbohydrates 13, Protein 3, Fat 8, Sodium 88, Potassium 159, Phosphorus 53

Baked Custard- serves 1 (1/2 cup per serving)

Ingredients:
½ cup lowfat (2%) milk
1 egg
1/8 teaspoon nutmeg
1/8 teaspoon vanilla

Directions:
Scald milk, then cool slightly. Break egg into small bowl and beat slightly with nutmeg. Add scalded milk, vanilla and sweetener to taste. Mix well. Set bowl in a baking pan with water ½ inch deep. Bake at 325°F for 30 minutes.

Renal and Renal Diabetic Exchanges- 1 milk, 1 meat.
Calories 142, Carbohydrates 7, Protein 10, Fat 8, Sodium 135, Potassium 256, Phosphorus 207

RENAL RELATED WEBSITES:

* American Association of Kidney Patients (AAKP) http://www.aakp.org
* American Kidney Fund (AKF) http://www.akfinc.org
* Life Options Rehabilitation Program http://www.lifeoptions.org
* National Kidney Foundation (NKF) http://www.kidney.org
* National Renal Administrators Association (NRAA) http://www.nraa.org
* Nephron Information Center http://www.nephron.com
* Nephroworld http://nephroworld.com
* Forum of ESRD Networks http://www.esrdnetworks.org

ATTENTION PATIENTS

The Patient Advisory Committee (PAC) is looking for patients interested in serving as members. The PAC is the VOICE of the patients for Network 13. They are involved in patient education through Kidney Koncerns and the Speakers Bureau, they provide feedback from a patient perspective on Network 13 Quality Improvement Projects and special projects. This opportunity provides you with the ability to assist the direction of Network 13 in addressing patient concerns and the state of dialysis and transplantation. Make Your Voice Heard. If interested contact Patrick Murphy, Patient Services Coordinator, at Network 13. The phone number is 1-800-472-8664 extension 3011.

Patient Recognitions:

Maxine Honeycutt, a patient at North Little Rock Nephrology Associates, wanted to recognize several co-patients that have recently passed away from her unit. They are Mr. Baker, Mr. Taylor, Mr. Oversee, Ms. Johnson and Ms. Hudson. Ms. Honeycutt raised funds for flowers and memorials. She would like to thank all whom contributed.

A letter from Robert Edwards reads:

Hi my name is Robert Edwards. I've been on dialysis now for almost three years. I'm 27 years old. And I'd like to pay good tribute and thanks for their help at Central Arkansas Dialysis Center in Searcy, Arkansas. Thanks you all, keep up the great work.

KIDNEY KONCERNS NEEDS YOU!

Kidney Koncerns is published quarterly by the Patient Advisory Committee of ESRD Network 13. The next edition is scheduled for SPRING/APRIL. To make this newsletter a success, we need your assistance. If you are interested in contributing to this newsletter, please send any articles, materials and/or ideas to:

Kidney Koncerns
% ESRD Network 13
6600 N. Meridian Suite 155
Oklahoma City, OK 73116-1411
1-800-472-8664

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