



**ESRD
NETWORK 13**

KIDNEY CONCERNS

WINTER/JANUARY 2001

ISSUE 35

TRANSPLANT JOURNEY: A

BEGINNING AND END

My name is Rod "Smokey" Gwoompi and I am a proud member of the Kiowa Tribe of Oklahoma. In my youth I was active in sports in school at Carnegie and Anadarko OK. I was active in Indian Pow-wows in and around Oklahoma. I enjoyed life. In 1974 while on vacation in Colorado I first became aware that something was wrong with me. I was witnessing the tell-tale signs of diabetes. I cut my vacation short and returned to the Indian Hospital in Muskogee where I was diagnosed with diabetes. Things seemed to come crashing down on me and my family. I got used to the regime of medications to try and control my diabetes when in March, 1999 my kidneys failed. Dialysis was the course of treatment suggested by the doctors but I was not sure I was ready to handle this. I had made up my mind not to start dialysis. I made plans to visit the Gulf coast. Two days before the trip I went to the hospital because of feeling ill, hoping to get some medication for comfort. At this point I had started sleeping sitting up due to the discomfort. They took some x-rays of my chest and immediately sent me to the hospital in Tulsa by ambulance. I was put on the dialysis machine for four days in a row. I discovered that I could manage dialysis. The Director, Social Worker, Dietician and Staff Nurses at my dialysis facility were and still are priceless in their help. Without them I do not know if I would have made it. I came to learn to work with them and follow their directions so I could get the most benefit from my dialysis treatments. I learned to live life again with dialysis included in it.

(Cont. on page 2, Smokey)

My name is Penney Pilkington and my kidneys failed when I was a child. I had a transplant from my mother. At that time dialysis was in its infancy. As a child in Arkansas peritoneal dialysis (PD) was the only option available. I was on the children's ward with others who received PD. We played and watched TV to pass the time. I remained there until I got the transplant from my mother on September 12, 1966. I returned home and tried to lead as normal life as possible.

Hemodialysis was used only for emergencies due to the need to have a physician attend to the patient throughout their treatment that lasted 24 hours at that time. Dialysis machines were large and cumbersome and required constant monitoring. There were not many dialysis machines available.

My own kidney disease directed my career path. I have been a secretary at a dialysis unit, managed the Harrison House for transplant patients and worked on other ESRD projects. For the past 23 years I have been a RN at Baptist Hospital, 18 years working on the urology and nephrology units. The past five I have worked with the oncology unit.

I have battled with transplant rejection for the past several years. I was informed this past year that my transplant was no longer functioning and I had to return to dialysis. I initially tried peritoneal dialysis as this would provide me with more options with work and cause the least disruption in my lifestyle. I experienced complications on PD and got very ill so a decision was made for me to begin hemodialysis.

(Cont. on page 2, Penney)

(Cont. from page 1, Smokey)

I started to think more about transplant as I learned more about it. In September of 1999 I approached my doctor about getting an evaluation for a kidney transplant. It was a difficult trip with the waiting and wondering if a kidney would become available that would be a match and trying to stay as healthy as possible with dialysis. There were days that the pager seemed to be a weight on my mind and emotions. Checking the batteries to make sure it might go off with the news that a kidney had been found. June 13, 2000 at 5:45AM my weight was lifted with a phone call from my transplant center that a kidney was available if I was still interested. Yes I was interested. I was falling all over myself trying to put together things I would need for the hospital. I stopped long enough to notice that I had put my socks on the same foot. I did make it to the hospital and received the transplant.

I am doing well. I had one set back that required a brief hospital stay due to a mix-up on my part with my medications. My new addition in my life is doing fine and I feel great.

Thank the Creator, my family and my friends for walking beside me. Thank the person I didn't know who came to my room at 3:45 to encourage me to be brave. Thank the family who provided me with a gift I can never repay. Things are going good for you if you take this life to help others to cope and win out.

Written by PAC At-Large Member
Rod "Smokey" Gwoompi

(Cont. from page 1, Penney)

I was very hesitant when I began hemodialysis. My memories of friends who had been on hemodialysis were not very pleasant. I tried to remember that my memories were from the beginning of dialysis and that conditions had drastically improved over the years.

I have now been on hemodialysis six months and have to admit it has been much better experience than I expected. My health is much better and I have no problems with my treatment. I have had to adjust to the routine of going to the center for dialysis, the renal diet and fluid restrictions. These are just different things I have to do than when my transplant was functioning. As a member of the Patient Advisory Committee (PAC) I was involved with issues regarding hemodialysis patients and situations at their center, that I could be empathetic to, but seemed at a distance from my experience as a transplant patient. I now have a better sense of those experiences now that I am on hemodialysis.

Re-education helped me to understand and adjust better. I knew what to expect. Having knowledge about dialysis and your part as a patient can positively affect your outcomes.

My experiences have made me realize that I should not let my fears control matters I have not tried. I am grateful to have the option of hemodialysis and the better health because of it.

Written by PAC Chairperson
Penney Pilkington

AAKP PATIENT PLAN A© AVAILABLE AT NATIONAL OFFICE

AAKP's newest educational program, the AAKP Patient Plan A©, is now available free-of-charge from the National Office. The Plan provides kidney patients with a comprehensive guide to kidney disease and discusses how they can care for themselves as they progress in their treatment.

Released in four phases, each phase of the AAKP Patient Plan A© includes a book and accompanying newsletter. Patients, family members and professionals may obtain the Plan by contacting the AAKP National Office at 800-749-2257 or through e-mail at aakpnat@aol.com. Subsequent phases may be ordered by returning the postage-paid return card included in the back of each book.

The first three phases of The AAKP Patient Plan A© are now available in PDF format at AAKP's web site (www.aakp.org). This format will let readers view the Plan in color, exactly as it appears in the books. Also, a printable version of Phase 1 may be found at www.Nephron.com/aakp_plan/index.html.

FACTS ABOUT TICKET TO WORK PROGRAM

Ticket to Work and Work Incentives Improvement Act of 1999

The President signed the Ticket to Work and Work Incentives Improvement Act of 1999 on December 17.

This new law:

- increases beneficiary choice in obtaining rehabilitation and vocational services;
- removes barriers that require people with disabilities to choose between health care coverage and work; and
- assures that more Americans with disabilities have the opportunity to participate in the workforce and lessen their dependence on public benefits.

Establishment of the Ticket to Work and Self-Sufficiency Program

The program will be phased in nationally over a three-year period beginning January 1, 2001, with the first Tickets issued early in 2001.

Social Security and Supplemental Security Income (SSI) disability beneficiaries will receive a "Ticket" they may use to obtain vocational rehabilitation (VR), employment or other support services from an approved provider of their choice.

The Ticket program is voluntary.

Expanded Availability of Health Care Services

The law includes several enhancements to Medicaid and Medicare that are effective October 1, 2000.

States will have the option to provide Medicaid coverage to more people ages 16-64 with disabilities who work.

States will have the option to permit working individuals with incomes above 250 percent of the federal poverty level to buy in to Medicaid

The law creates a new Medicaid buy-in demonstration project to provide medical assistance to workers with impairments who are not yet too disabled to work.

The law also extends Medicare coverage for people with disabilities who return to work. It extends Part A premium-free coverage for 4 1/2 years beyond the current limit for Social Security disability beneficiaries who return to work.

SSA will issue tickets to beneficiaries in phases, beginning in 2001. This will allow SSA to evaluate the Ticket to Work program and make any necessary improvements before the Program is fully implemented nationwide by 2004.

During the first phase of the Program, SSA will be distributing tickets in the following States:

Arizona	New York	Massachusetts	Florida	Vermont
Colorado	OKLAHOMA	Iowa	South Carolina	Illinois
Delaware	Oregon	Wisconsin		

For more information of the Ticket to Work Program go to website:

http://www.ssa.gov/work/ticket_states_announcement.html

and follow the links to specifics of the program you are interested in.

ARKANSAS and **LOUISIANA** will go into the program within the next two years.

Medicare General Enrollment Period Begins

If you are eligible for Medicare Medical Insurance (Part B), but haven't signed up, you can do so now during Medicare's annual enrollment period from today until March 31. As long as you sign up by this date, your coverage will begin on July 1, 2001. Medicare Part B helps pay for doctor's visits, outpatient hospital treatment, and other medical services and supplies not covered by Medicare Part A. The cost for the Part B premium is \$50 a month for 2001. Beneficiaries with Medicare Part A who originally decided not to sign up for Part B when they first became eligible for Medicare can now take advantage of this opportunity (there is an additional 10 percent added to the premium for each year of prior eligibility). Also, anyone who had Medicare Part B at one time, but dropped out, can now re-enroll.

If you are interested in enrolling in Medicare, call Social Security at 1-800-772-1213, or contact your local Social Security office.

The National Kidney Foundation of Arkansas Presents: People Like Us, Live!

It's educational and it's free. We will serve a kidney friendly lunch on Saturday to all in attendance. Anyone interested in more information or a registration form can call me at the NKFA office at (501) 664-4343 or toll free 1-877-2KIDNEY. Registration deadline is March 1st 2001. The thing I really like about the program is that you not only hear from the professionals, we have patients to come in and share their own experience and answer questions. It is 6 sessions including: introduction to kidney disease, hemodialysis, peritoneal dialysis, transplantation, diet, and coping issues. It is open to new or experienced kidney patients, family members, support people, etc..

Heather Powell, Program Director, NKFA

WHEN:

Saturday, March 24th:
9:00 a.m. - 3:00 p.m.
Sunday, March 25th
1:00 p.m. - 4:00 p.m.

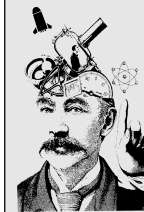
WHERE:

Park Hill Presbyterian Church
3520 John F. Kennedy Blvd.
North Little Rock, AR 72116
(corner of JFK & "F" Streets)

HCFA Notification to Patients

The Health Care Financing Administration (HCFA), the Federal Agency that administers the Medicare Program, has a contract with Abt Associates to conduct a telephone survey among Medicare beneficiaries to ask about their use of two covered preventive services, influenza immunizations ("flu shots") and pneumococcal vaccinations ("pneumonia shots"). The survey results will help HCFA target resources to increase the use of these two very effective medical preventive services.

Beginning in February and continuing through May 2001, randomly selected Medicare beneficiaries will receive a letter from Abt describing the project. The main purpose of the letter is to alert these beneficiaries that they will receive a phone call from Abt, and more importantly to confirm that this telephone survey is an authorized Medicare project. It emphasizes that participation in the survey will in no way affect an individual's Medicare benefits. It also states that any information collected in the survey will remain confidential. The survey responses will only be reported as a group, and they will not identify any individual Medicare beneficiary. A return postcard will be enclosed with the letter. The Medicare beneficiary can complete and return the postcard to show the best times for the survey interviewer to call and to indicate whether the beneficiary prefers to receive a call from a Spanish-speaking interviewer. The phone survey is very brief. It only takes 5-8 minutes to complete.



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

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