Network of New England PATIENT PAGE

Fall/Winter 2007 • Volume 2 • Issue 3

American Association of Kidney Patients (AAKP) Convention August 30 – September 2, 2007: St. Louis, Missouri

Wesley J Johnson Sr. is a member of the New England Patient Advisory Committee (PAC) – a standing committee of the Board of Directors. Mr. Johnson is a kidney transplant patient, husband, father, and grandfather. He recently traveled to St Louis, MO to attend and represent the ESRD Network of New England at the AAKP 2007 Annual Convention.

I attended the Welcome Reception Thursday evening, August 30, 2007. At this event, AAKP's Annual Chapter Awards were presented. The New England Chapter was recognized as the newest chapter.

On Friday, August 31 the First Time Attendees Luncheon was held. This was an excellent opportunity to meet people and be orientated to the happenings of the convention.

My first educational session was "I'm in it for Life – Managing and Minimizing Long Term Effects of Kidney Disease". The speaker was Dr. Eli Friedman, with the patient panel consisting of Steve Henderson, David Staple and Bridgett Jones. The next session was entitled "Washington Update: Celebrating the 35 Year Anniversary of the Medicare ESRD Program, and the speaker was John Schall. The third session of the morning was "Knowledge is Power: Maintaining Your Medical History, with Stephen Fadem and Kim Buettner being the presenters. This medical history program is available through the AAKP website. The final session of the morning was "Factors to Consider When Managing Fatigue" and the speaker was Dr. Jay Wish.

The first session of the afternoon was "Listening to Your Body and Taking Time for Yourself " and the presenter was Mary Heisick, MSW and had several good ideas to help reduce stress. The next session was called "Lighten Up with Laughter" and the speaker was Alex Rosenblum, BSRN, CNN, CPHQ. The final session of the day was "Kidney Friendly Nutrition: Eating Well". Dr. William Finn and Marianne Hutton, RD, CDE were the speakers and featured Katie Lee Joel, former host of Bravo's Top Chef.

The Welcoming Ceremonies were held Friday night. Following dinner and the program an evening of dancing made for a great evening.

Saturday morning's first session was "Straight Talk about Living Donation". Amy D. Waterman, PhD was the speaker, with a patient panel consisting of Steve Henderson, Bill Henderson, Brenda Dyson, Bobbi Wager and Robert Wager. The second session "Simple Techniques to Add Exercise into Your Routine" led by Kathy Howard, RN, BSN, CCRC, CCTN. The third session was "Maintaining Bone Strength-Preventing Fractures and Deterioration" and the speaker was Dr. Daniel Coyne. "ESRD Health and Safety Survey Reveals Opportunities for Improvement" was the next session. Dr. Susan Higley Bray, FACP, MBE was the presenter. This topic was of particular interest since we had discussed some of the issues at the last PAC meeting. The last session of the day was "The Great Debate: Solicitation of Organs" and the speaker was Thomas Peters, MD, FACS, FASN.

On Sunday, I attended the President's Breakfast where the site of next year's convention will be held. It will be held in Washington, D.C.

Wesley J. Johnson, Sr.

Dialysis Patient Disaster "To Do" List

It is important to be aware that disasters can take on many forms, and can strike at any time. While none of us like to think about something bad happening, taking the time to prepare for emergencies now, will not only save you time and worry later, but also may save your life. Although nothing can prepare us for every possible problem, we should all do our best to be as prepared as we can be. The following list has been developed to help patients prepare themselves for emergency situations that may prevent them from getting their dialysis treatment.

- ❑ Learn which evacuation zone your home is in and create a personal plan
- ❑ Ask your facility whom to contact during disasters
- ❑ Learn your dialysis facility's emergency policies (scheduling / change of location pre and post event)
- ❑ Get a list of dialysis facilities and hospitals in the area
- ❑ Write down toll-free numbers to call for dialysis after the event (if your facility is closed)
- ❑ Ask your facility what to do if phones down
- ❑ Update your emergency contact information at the facility (local and out-of-state)
- ❑ Update your medicine / allergies list
- ❑ Gather emergency supplies, medicines & personal papers and place in a secure container (plan for two weeks)
- ❑ Get a copy of the emergency diet for dialysis patients
- ❑ Ask about care of your vascular access during a disaster
- ❑ Get an emergency supply list from your dialysis unit (if available)
- ❑ Plan for back-up transportation to dialysis
- ❑ Ask your social worker about "special shelters"
- ❑ Listen to local TV and radio for "dialysis updates"
- ❑ PD patients should have enough supplies for 5 - 7 days
- ❑ Transplant patients should have enough medicine for two weeks

State Emergency Agencies

- ❑ Connecticut Department of Emergency Management **http://www.ct.gov/demhs/site/default.asp**
- ❑ Maine Emergency Management Agency **http://www.state.me.us/mema/**
- ❑ Massachusetts Emergency Management Agency **http://www.mass.gov/** (search for MEMA)
- ❑ New Hampshire Department of Safety and Emergency Management **http://www.nhoem.state.nh.us/**
- ❑ Rhode Island Emergency Management Agency **http://www.riema.ri.gov/**
- ❑ Vermont Emergency Management Agency **http://www.dps.state.vt.us/vem/**

Additional Resources

- ❑ *Preparing for Emergencies: A Guide for People on Dialysis* (CMS) – available in English and Spanish **http://www.networkofnewengland.org/Emerg.htm**
- ❑ PD Travel "Tool Box" **www.annanurse.org**
- ❑ Dialysis Facility Compare **www.medicare.gov**
- ❑ Centers for Disease Control and Prevention (hurricane information in Spanish & other languages) **www.bt.cdc.gov/disasters/hurricanes/index.asp**

Patient Page is written, designed, published and distributed by the Network of New England and the Patient Advisory Committee, while under contract with Centers for Medicare and Medicaid Services, Baltimore, Maryland. Contract # HHSM-500-2006-NW001C.