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HAPS HAPPENINGS

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TRAVELING TIPS

Nina Brown



“Summertime and the living is easy”... but is it? If you have Parkinson’s disease and you’re going to do some traveling this summer, it may require a little extra planning. I’m writing this article from a personal perspective as my husband and I fluctuate from delightful anticipation to anxious apprehension when thinking of making travel plans. To ease my anxiety, I decided to take the Boy Scouts motto, “Be Prepared” to heart. I hope the following suggestions will be helpful to you as well.

→ **Plan ahead for easy traveling.** Always leave plenty of time to get to each location. Try to coordinate your medication schedule with your travel time. Wear a whistle around your neck in case you find yourself stranded in a bathroom, hallway, elevator, etc.

- **If you are traveling by air,** save your energy--a few days before your flight request a wheelchair at the gate and at your destination. If you travel with a wheelchair that is stored with the baggage, ask the airline for a wheelchair on board that fits in their small aisle, so you can use the restroom. The law requires that all airlines leaving from America *must* carry a scooter at no additional charge regardless of weight. Request early seating to get a convenient place. Ask for an aisle seat close to the bathroom. Airlines will accommodate a special diet if you order one eight hours ahead of the flight. Keep flight information and identification easily accessible. Consider taking a sedative prior to the flight to alleviate undue stress.
- **If you are traveling by water,** you can eat watch movies, see live shows, gamble, shop and relax as most ships have special rooms designed to handle adults with physical limitations. Just let the cruise line know if you need special assistance.
- **If you’re driving,** remember that some medications can make you drowsy, so share the driving time. You will want to drive medicated to avoid muscle stiffness and allow you to get from the car to a restroom.
- **If you’re traveling by train,** you can relax and see the countryside without a worry. Amtrak has wheelchair lifts and seats that can be removed to accommodate wheelchairs. Most trains have at least one compartment equipped and reserved for the disabled. Food can be ordered and delivered directly to your compartment if getting to the dining car is too difficult.

TRAVELING TIPS Continued

→ **Consider taking out travel and health insurance.** You certainly anticipate taking planned trips, but if you are unable to go for some reason or you're out of the country and you need a doctor or dentist, the cost of the insurance may be worth your peace of mind.

→ **Prearrange your accommodations.** Make sure you have confirmed hotel reservations. You don't want to have to search for a place to stay after traveling for hours. In addition to non-smoking rooms, some hotels may have special rooms for those with limitations. The rooms are often equipped with larger entrance doors, doorbells, telephones and alarms that use flashing lights rather than ringing (for the hearing impaired.) Everything is lowered to wheelchair height from sinks, to peepholes in the doors, to clothes rods in the closets. Most bathrooms also have wheel-in shower stalls or benches so that you can sit while bathing. Hotels and cruise ships are often quite large, so we always request a room close to the elevator. **If you need a wheelchair or scooter...** most hotels can tell you where to rent one. Although I don't normally use a wheelchair, we had one delivered to the hotel in Washington because of the long walks from office to office and we rented one at Disney World. You can also arrange with the hotel to have the local taxi company send a "handicap" taxi which is usually a hi-top ramp equipped van and are available upon request subject to prior commitments.

→ **Pack carefully.** Select mix and match, layered, washable clothing that can be varied with jewelry or scarves and will be suitable to the weather. If you have a handicapped parking permit, take it with you. If you are traveling by air, don't pack your medications or pack double so you don't arrive without your medications. If you have to deal with lost luggage it's easier if you can move. Carry a water flask or bottle so you can take pills wherever you go.

→ **Consider your medications.** Take more medication with you than you think you need. You could lose your pillbox, drop pills on the floor or have a change of plans. You don't want to get caught short. Carry your medications in their original bottles, with the name of the drug, your own name and that of your doctor on the label, particularly if you are traveling abroad. Another consideration when traveling abroad is you may need to adjust your drug scheduling to a different time zone, which may take a day or more to acclimate and get the full benefits. Schedule your activities to allow your body time to adjust. Another hint: if you are traveling for long periods, you may want to obtain a referral to a Parkinson's specialist should an emergency arise.

→ **Take time to rest during or after each day's activities.** Whatever type of trip you take, it helps to take a little mini-vacation to refresh yourself. Allow extra time when making your plans so you won't feel rushed.

→ **Look for the "easiest" way to do things.** For example, Disney World will send purchases to the front gate for pick-up. Mail packages home rather than carry them.

→ **Consider taking an organized tour for people who are disabled.** A good tour company dedicated to this purpose can take many of the hassles out of traveling.

→ **Check out different travel newsletters.**

Don't allow Parkinson's to stop you from traveling; but do invest a little extra time and effort before leaving home in order to make your trip more organized and less stressful. For as we all know, along with less stress come fewer symptoms.

Milton Berle said "laughter is an instant vacation." So if traveling is not in your plans, listen to "Uncle Miltie" ~ enjoy a good laugh and you can vacation without leaving the comfort of your home.

APOKYN – A Rescue Drug

Despite treatment with drugs used to increase or replace dopamine, as Parkinson's disease progresses, people begin to experience immobilizing "off" episodes –the loss of motor control that makes routine tasks such as walking and even speaking extremely difficult. The intensity, duration and frequency of "off" episodes vary for each sufferer.

The Food and Drug Administration (FDA) has recently approved APOKYN™ (an apomorphine hydrochloride injection given under the skin) as an effective rescue treatment to use during an 'off' episode. APOKYN is not used to prevent "off" episodes, nor does it replace other Parkinson's disease medications, but rather treats an existing "off" episode when it occurs.

The most common side effects of APOKYN are low blood pressure, yawning, dyskinesias, nausea and/or vomiting, sleepiness, dizziness, runny nose, hallucinations, fluid retention, chest pain, increased sweating, flushing, and an unusually pale complexion.

Vaccine for Parkinson's

Scientists at the University of Nebraska Medical Center (UNMC) in Omaha and Columbia University Medical Center in New York have discovered a new vaccine approach that successfully prevents the death of brain cells in a mouse model of Parkinson's disease. The mice developed an immune response from a brain protein that turned off inflammation that damages dopamine nerve cells. If they can get it to work in humans, it may be a way to use the body's own defense to work towards its own repair and prevent the progression of the disease.

Therapeutic Cloning Cures Parkinson's in Mice

New research shows, for the first time, that cloned cells can cure Parkinson's disease in animals. Therapeutic cloning went one step further towards becoming a reality with a report from researchers at the Memorial Sloan-Kettering Cancer Center. They showed that they can turn stem cells from a lab mouse's tail into functioning neurons that produce dopamine.

When they transplanted these cells into lab rat models of Parkinson's disease, they were able to cure the condition. This is notable for being the first time that cloned cells have cured disease in an animal model. The stem cells have been subjected to a technique that eliminates variability that, in previous work, meant that the experiment did not work for each animal. The study produced neurons of many different types and showed how the cloning process closely mimics normal brain development.

Dopamine producing cells are lost in Parkinson's disease and this is what produces the movement abnormalities typical of the condition. With this new study, the possibility of using brain repair to help such patients, by transplanting cloned cells, comes a bit closer to reality.

Reported by Susan Aldridge, PhD, medical journalist
Source: Nature Biotechnology
October 2003

HAPS CAN HELP YOU!



Basic exercise for people with Parkinson's often takes a back seat as treatments focus on drug therapies or pioneering procedures such as deep-brain stimulation, even though it has been shown that those who maintain a simple routine including walking, strength training and stretching have the least motor fluctuations and take the least amount of medications.

So, **why doesn't everyone with Parkinson's exercise?** Some people may be in denial, others are still working and the sessions may conflict with working hours. Some may be physically incapable, while others have trouble getting transportation from their homes to the exercise center.

Or, perhaps your neurologist may not have emphasized the importance of structured exercise or may have just ordered short-term speech or physical therapy to give only immediate help for the twisted and stiff muscles that cause people with Parkinson's to shuffle or not speak clearly. Insurance coverage for such therapy usually runs out quickly .

But HAPS is here to help you! You have the opportunity to attend exercise and speech therapy programs that are free of charge!

Don't let denial keep you down! If you meet transportation guidelines, HAPS has a program to get you there! If you are physically incapable of exercising, ask about our home-respite program.

YOU CAN HELP HAPS!

We spend major amounts of money on medications to make our lives more livable. We want a cure - or at least a reduction of the symptoms, so dollars may go to funding research. And, although many consider exercise to be the key to a long life for people with Parkinson's, precious little funding is left for physical therapy. This is why it is so important to educate the public about the services that HAPS offers! And, here is your opportunity...

“POLO FOR PARKINSON'S”

will feature the United States Polo Association's Western Challenge Polo Match, Sunday afternoon, October 3rd at the Houston Polo Club. At that time HAPS will present the first annual “Quality of Life” awards which will be given to an individual who has helped improve the quality of life for others and to a Parkinsonian whose positive attitude and outlook on life has enhanced not only their quality of life and that of others.

More details will follow, but the committee is working to get sponsors for the event. If you think the company you work for might be interested in becoming a sponsor or know of anyone who might have merchandise to donate for the event or silent auction, please contact co-chairs, Nina and Joe Brown (713-218-8888) or Liz Lary (832-681-7114) for more information. Individual tickets will be \$100. If you would like to receive an invitation or are interested in volunteering to help, please call the office (713-313-1652.)

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YOUR DONATION IS MUCH APPRECIATED. YOUR THOUGHTFULNESS HELPS HAPS CONTINUE TO PROVIDE MUCH NEEDED SERVICES TO PEOPLE WITH PARKINSON'S AND THEIR FAMILIES.

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Everything is always okay in the end, if it's not, then it's not the end.



Experience is a wonderful thing. It enables you to recognize a mistake when you make it again

BROWN'S WIN NATIONAL AWARD



Nina and Joe Brown were honored as recipients of the "Milly Kondracke Award for Outstanding Advocacy" presented by Mort Kondracke at the Parkinson Action Network (PAN) Morris K. Udall awards dinner in Washington May 19th.

When Nina was diagnosed with Parkinson's in 1985, she and her husband, Joe, realized that while circumstances may have determined their lives, they could shape their lives by what they made of their circumstances. Fighting for a cure and helping others living with the myriad of symptoms that accompany this debilitating disease become both their passion and their therapy.

The award was given for their work as full time volunteers. Nina and Joe work at the local, state and national level for the Parkinson community. As board members for the Houston Area Parkinson Society, they chair the Advocacy Committee. Nina is Vice-President of Marketing and Development and also writes HAPS monthly newsletter. Joe is HAPS webmaster.

Their advocacy efforts led them to Austin to testify against a bill that would have criminalized Regenerative Medicine in Texas. After a successful grassroots effort stopped the bill, they became founding board members of Texans for the Advancement of Medical Research (TAMR).

As PAN co-coordinators for Texas, the Browns do not limit their efforts to Texas, but travel to Washington to advocate for Parkinson's at the national level.

***"You must be the change you wish to see in the world."
Mahatma Gandhi***

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