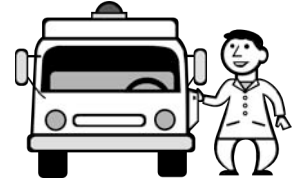


MARCH 2008



Be Prepared for EMERGENCIES



Nina Brown

A recent trip to the emergency room for my husband reminded me, once again, of the importance of being prepared should an emergency arise. As we handed over three pages that included a listing of his doctors, insurance information, emergency contacts, all his medications and a complete medical history, we were thanked over and over again by both nurses and doctors who told us that faster and more accurate medical decisions can be made if more people would plan ahead and have all the information they need readily available.

Parkinson's can complicate your care. What if you were rushed to the emergency room, unconscious or unable to speak clearly? What would you like the medical team to know about you? If they are unfamiliar with Parkinson's, your symptoms could be misinterpreted and you could be labeled an "uncooperative" patient or you might get additional blankets for a chill when you are really shaking from a tremor.

To avoid a bad experience, have a card in your wallet that tells where comprehensive emergency-hospital information can be found. Get a three ring binder and include additional data:

- 📄 Photocopies of your prescriptions along with instructions how to use each medication.
- 📄 A page of business cards that include pertinent numbers (pharmacist, dentist, Parkinson resources, employer, etc.).
- 📄 Copies of latest blood tests.
- 📄 A running log sheet listing the date and reason for any surgeries or hospital visits.
- 📄 A Living Will, if you have one. Consider having a close family member get a limited power of attorney to represent you. If you have a Durable Power of Attorney for Health Care, have copies to give the hospital and doctor.
- 📄 Have sufficient copies of the following information guide and give one to your admitting physician, one to the nurse on each shift and, if you're having surgery, one to the attending surgeon and anesthesiologist.

Save the emergency room for emergencies. It's one thing if your Parkinson's symptoms have suddenly become worse because of an infection or you've fallen and are worried about a broken bone or blood clot. Otherwise, why wait six hours to be seen, get a chest x-ray, blood work and numerous other unnecessary tests when a neurologist may not be at the hospital; the attending doctors and busy nursing staff may not be knowledgeable or have had much experience with people who have Parkinson's. Don't waste your time, body fluids and money. Unless it's a real emergency, call the doctor you consult for Parkinson's who knows you and your history. Next month we will discuss how to handle a visit to the hospital.

PARKINSON'S ACTION NETWORK FORUM - 2008

As state coordinators, my husband, Joe, and I attend the educational/advocacy forum that PAN holds every year. This year, due to Joe's heart problems, we had to cancel at the last minute; but Carol Arnaud, a new advocate whose father has Parkinson's attended and was so enthusiastic when she returned that I asked her to write a report for our HAPS readers. As chairman of HAPS advocacy committee, I invite you to become involved with issues that affect all of us. It's a wonderful way to "feel good by doing good."

Nina P. Brown

This being my first attendance at a PAN forum, I had no idea what to expect. The PAN forum taught me so much about the importance in advocating for what you believe in and need. I left the forum empowered with the knowledge of what we really need to do to find a cure for Parkinson's and how to go about getting it.

The PAN forum also brought me life-long friends. I met so many people with such incredible stories of triumph and hope. The amazing thing is that not only people *with* Parkinson's, and not just people who *know* someone with Parkinson's, are advocating; but everyone at this event is avidly trying to find a cure and genuinely care about the quality of life for people affected from Parkinson's and other neurodegenerative disorders.

One person who really impacted my life was Linda O'Leary. Linda is such an energetic, full of life person that from the moment I sat down she made me feel right at home; but what I didn't know is that Linda also had an incredible story.

Linda has a form of Parkinson's that is genetic, which I did not even know existed--her grandmother, mother, and brother also all had Parkinson's. After hearing her story and seeing her strength, I realized Parkinson's does not have to control who you are.

The forum was the most educational event that I have been to from the cutting edge research that was explained to the understanding of how our local and national governments work. This event has created my base for future advocacy and for being able to explain to my friends, family and anyone else who will listen to what needs to be done to help find the cause of and cure for Parkinson's disease.



Jimmy Guerrero (3rd time PAN attendee, Alamo Area Young Onset PD group) **Bill Salem** (1st time PAN attendee, non-PD, came as friend and supporter of James Schraeder) **Carol Arnaud** (1st time PAN attendee, The Woodlands, **Cayce Kovacs** (State coordinator) **James Schraeder** (State coordinator) **Neil Jarrell** (2nd time PAN attendee, Alamo Area Young Onset PD group) **Charles Drake** (1st time PAN attendee, medical military disability for Parkinson's, Alamo Area Young Onset PD group, DBS clinical trial participant in Houston) **Dianne Johnson, RN** (5th time PAN attendee, Alamo Area Parkinson's Support Group APDA Information & Referral Coordinator) **Mark Davis** (Congressional coordinator - was unable to be in the picture)

Photo taken by **Tammy Drake**

Sincerely,
Carol P. Arnaud
Texas Congressional Coordinator

**"One determined person can make a significant difference;
a group of determined people can change the course of history."**

...Sonia Johnson

HOPE:

Innovative Approaches in Parkinson's Disease

April 26, 2008
8:30 AM - 2:15 PM

United Way
Community Resource Center
50 Waugh Drive
Houston, Texas 77007

An Update on Parkinson's Research
Maintain the Brain
Nina talks about "HOPE"
New and Emerging Treatments in Parkinson's Disease
An Introduction to Neuro-rehab



HAPS Participants

Just Wanna Have Fun!

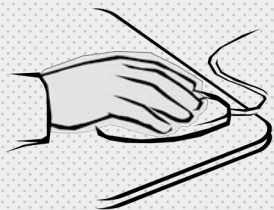
HAPS water
therapy
and
Missouri
City
exercise
group
members
celebrate
Mardis Gras
in grand
style!



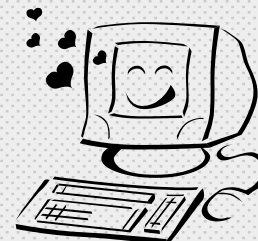
Nina Brown Receives Award

The National Council of Jewish Women presented the prestigious Hannah G. Solomon Award to Nina Brown on February 10th in recognition of her work for social change on the local, national and international level. She is pictured here with State Representative Ellen Cohen.





HAPS Thanks our "Online" Donors



HAPS is extremely grateful for the credit card donations that were made online over the past year through the HAPS web site (www.hapsonline.org). Your support enables HAPS to continue to provide free therapy, support, information and referral, transportation, emergency medical funds and subsidized home care to thousands of people who are affected by Parkinson's disease in the greater Houston area.

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Lee Wunsch	Dr. Steven Croft		

The following donations have been made to HAPS in honor or in memory of individuals through the 2008 Chevron Houston Marathon-Run for a Reason. \$25,763 has been raised through this year's event, which contributes to the support of HAPS ongoing programs and operations.

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		Helen & Dallas Wolf	Fred Stephens

CONTRIBUTIONS

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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In memory of Vernon Delpesce

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In memory of Eleanor Stern

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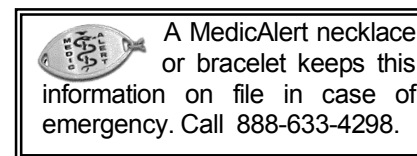
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HAPS HAPPENINGS is published monthly by Houston Area Parkinson Society Editor: Nina P. Brown

INFORMATION FOR MEDICAL CARE AND ASSESSMENT

My full name is _____
Address: _____
Phone: _____
Insurance Info: _____ Phone: _____
Social Security No. _____ Date of Birth: _____



DOCTORS

I was diagnosed with Parkinson's disease in _____. (year)
It is important to have a neurologist/doctor familiar with my condition.

Family doctor: _____ Phone: _____
Neurologist: _____ Phone: _____
Other: _____ Phone: _____

EMERGENCY INFORMATION

Allergies: _____

Please contact:

Name: _____
Address: _____
Phone: _____

Name: _____
Address: _____
Phone: _____

MEDICATIONS

I must be given my medication promptly at the times specified. If this is not possible, consult my admitting physician for authorization to administer my own medication or alternatively, have it administered by my caregiver. The timing of my medication is very important to help my "off" times. *Following are all prescription and over-the-counter drugs I currently take.*

Medication	Strength	Time Taken				

Possible Side Effects: nausea, dizziness, mental changes, confusion, hallucinations, involuntary movements, loss of appetite, dryness of mouth, lowered blood pressure.



If I am on Eldepryl, I MUST NOT BE GIVEN DEMEROL.

Eldepryl with Demerol can be deadly! To be safe, Eldepryl should not be taken for a period prior to taking Demerol. It is imperative that my attending physicians verify and stipulate this interval. **A number of other drugs may be contraindicated with some I take, please check it carefully.**

Name: _____ Room _____

WHAT IS PARKINSON'S DISEASE?

Parkinson's disease is a slowly progressive disorder due to the accelerated loss of the brain chemical dopamine (a neuro-transmitter) that activates the message system controlling movement. Its symptoms are tremors, rigidity, slowed gait and balance impairment (which may resemble intoxication, but is not.) These worsen and lessen several times a day in "on-off" cycles.

It is important that those who care for me outside of my home have a basic understanding of the disease so that observations and impressions can be accurately treated as characteristics of Parkinson's and not as personal behavior traits.

Please note that stress, anxiety, lack of exercise and/or the need for rest may worsen my condition. Therefore, **I HAVE IDENTIFIED PERTINENT INFORMATION AND MY SPECIFIC SYMPTOMS.**

MEDICATION

- ☞ Administer Parkinson medication EXACTLY on schedule
- ☞ Without medicine I may become rigid and disoriented
- ☞ Response to medication may affect physical therapy timing

AMBULATION

- ☞ Have difficulty with balance, stooped posture, swollen feet
- ☞ Difficulty walking (a decrease in natural arm swing, short shuffling steps, difficulty turning)
- ☞ May freeze and fall – may require help getting started and walking
- ☞ Dizziness
- ☞ "On-off" symptoms (able to perform one minute, but not the next—which may be related to timing of medications)

ELIMINATION

- ☞ Urinary problems (hesitancy, frequency, inability to wait, or incontinence)
- ☞ Suffer from constipation (impaction is a significant danger) need special diet or other treatment

COORDINATION

- ☞ Tremor, rigidity (cannot open food or other containers easily)
- ☞ Cannot always repeat a former action
- ☞ May not have strength to push call button
- ☞ Have slow responses...may have trouble turning in bed
- ☞ Dyskinesias (involuntary, unwanted, writhing movements) caused by sensitivity and over-medication--not to get attention

COMMUNICATION

- ☞ Speech problems: low voice volume, slurred indistinct words
- ☞ Face shows little or no emotion (Parkinson's "mask")
- ☞ Depression and dementia from the disease

EATING & SWALLOWING

- ☞ Difficulty swallowing –may choke on food - very slow eater
- ☞ Need special diet due to the effect protein has on my medication.
- ☞ Drooling

SLEEPING

- ☞ Trouble getting to sleep...sleep fitfully
- ☞ Have anxiety sweats

POSSIBLE PROBLEMS TO LOOK FOR:

- ☞ Dehydration from fasting before procedure
- ☞ Hypotension from Parkinson's might be extreme