

## OTHER THINGS “PD” COULD MEAN

We know that the first diagnosis of Parkinsons was made by James Parkinsons in 1817, and subsequently became known as “PD.” There are other reasons it might be known as “PD” such as:

Patient’s Despair

Physician’s Dilemma

Physical Discomfort

Progressive Disease

Personal Disaster

Possible Dementia

Potential Disability

Premium Drugs

Pesky Disease

Perplexing Dilemma

Below are some of the reasons I am in this clinical trial program, and I will do my best to convince other patients to participate in the appropriate clinical trials so we can conquer this Painful Distressing disease that threatens the well being of so many individuals.

Possible Discovery

Proposed Divinely

Positive Disposition

Proud Determination

Perfecting Dopamine

Can you think of others??

## THE TRIALS OF/FOR PARKINSON’S DISEASE

Wednesday, April 26, 2006

Where were you today, Mr. Parkinson's? You moved out for the day and your absence was a gift and a joy for me. You are so unpredictable I never know what to expect from you, but at the end of today I realized you left me at peace for the day. Yesterday I couldn’t walk when I got up in the morning – my feet and legs hurt so I could make my way around the house only with great difficulty. My head and body shook so much all day I could hardly eat, let alone do the routine things that most people take for granted, like taking a drink of water or a bite of cereal with milk. I couldn’t use the computer, read, or rest. You were relentless in the pursuit of my discomfort.

But today you were gone. Where did go? Were you temporarily defeated by the clinical trial medicine I am taking? Did you give me a day of rest in answer to the prayers of my family and friends who see me suffer with you daily? Wherever you went, we all hope you find a place to go where you no longer torment those of us who have been diagnosed with your presence.

We know you will someday be defeated and leave our suffering bodies at rest. We are grateful to all in the medical profession who are working to finally make you move out of our bodies and give us peace.

But thank you for moving out for today. It gives me hope for the future and your absence forever.

Thursday, April 27, 2006

You are back stronger than ever, you thief of comfort and independence. Today I could go downstairs only with the utmost discomfort and pain. Did you go away to gather strength to make me more miserable? You are winning this struggle now, but the day or my life is not over, and I will not give in to you!

I will continue with clinical trials and encourage others with PD to do the same.

### Things Parkinson's Patients Can Do

1. Practice smiling, scowling, making odd faces in the mirror in the morning – it will help eliminate the “Parkinson’s Mask” that is so typical of Parkinson’s patients.
2. Keep a bottle of “Ensure” nearby when taking medicine for pain pills that are hard to swallow. PD meds recommended to be taken with carbonated beverages or caffeine
3. Use “Walkie Talkies” with you and your caregiver. It makes it much easier for our caregivers to hear us when our weakened voices don’t carry.
4. Become part of a support group (our swim class is excellent), or a more formal group. Exchange of ideas and information is very important.
5. Admit to yourself and others that you have Parkinson’s disease. We need to educate the general public about our disease if we expect support to defeat this malady, and it also makes it easier to accept ourselves if our friends and family know. We need to create public awareness and help educate the public about PD.
6. Always carry medications and water with you whenever you leave the house. It’s good to have a snack bar, chocolate kiss, or something else handy if medicine gets caught in your throat.
7. Eat your apple first in the morning – washed, cut in small pieces with skin still on. Maybe not your favorite thing, but it gets done for the day.
8. Challenge yourself to accomplish some small task you have been putting off – it’s productive plus it makes you feel good about yourself.
9. Practice reading as loud as possible every day – preferably when alone so we don’t feel so self-conscious.

10. Give away something you treasure to someone you love whenever possible – you have the added benefit of making sure they get it, know its history, and you benefit from seeing them enjoy it.
11. Take advantage of good sources of information like [www.pdf.org](http://www.pdf.org), if you use a computer.
12. Do an unexpected kindness each day – it may be simple or more involved – just do it.
13. Be prepared when going to the doctor – take a current list of all medications you are taking, plus their concentration and number of times per day you take them. Also list medication allergies
14. If in hospital for any procedure, make sure they know you have Parkinson's disease, the medications you take, and that it's very important they be taken on time. Also have complete health history.
15. Exercise daily for flexibility – don't become a couch potato.
16. Keep humor in your life. When things go awry, make a joke of it and move on.
17. Don't forget to thank your caregiver – theirs is a very difficult job.
18. Please let me know if you have other thoughts we can add to this list.

**“THEY” SAY PARKINSON’S DISEASE DOESN’T HURT”**

**WE HAVE HEARD IT SAID BY EXPERTS IN THE SCIENTIFIC FIELD, “NO, THIS CAN’T BE PARKINSON’S DISEASE BECAUSE PD DOESN’T HURT.” WITH ALL DUE RESPECT, HOW CAN “THEY” SAY IT DOESN’T HURT?**

**PERHAPS THEY CANNOT SEE BROKEN BONES OR FEEL THE CONSTANT INTERNAL PAIN AND TREMOR THAT WE FEEL, BUT THAT DOESN’T MEAN WE PD PATIENTS ARE NOT CONSTANTLY FEELING PHYSICAL AS WELL AS MENTAL ANGUISH.**

**AT FIRST IT IS SMALL WRITING THAT IS HARDER TO READ AND TYPING THAT IS LABORIOUS – OR PERHAPS IT’S HARDER KEEPING UP WITH A TODDLER RUNNING AHEAD OF US SAYING, “RUN, GRANDMA, RUN – NOT REALIZING WE ARE TRYING AS HARD AS WE CAN TO CATCH UP, BUT OUR LEGS JUST WON’T GO AS FAST AS THEY DID LAST YEAR – AND IT’S HARDER TO PICK UP THEIR BEAUTIFUL SMALL BODIES – NOT BECAUSE THEY HAVE GROWN BUT WE HAVE GROWN MUCH WEAKER.**

**AND THEN FOR THE FIRST TIME WE CAN'T ORDER SOUP IN A RESTAURANT BECAUSE IT HAS ALL SHAKEN OFF THE SPOON BEFORE IT REACHED OUR MOUTHS.**

**WE ALL KNOW WE CAN'T HAVE PARKINSON'S DISEASE BECAUSE SOMEONE SAID PD DOESN'T HURT. AND THEN WE CAN'T PLAY THE PIANO BECAUSE SHAKING FINGERS DON'T HIT THE RIGHT KEYS.**

**PLEASE, PLEASE, YOU SCHOLARS OF BONE STRUCTURE OR ROUTINE MENTAL TESTS – CAN'T YOU SEE OUR HEARTS AND SPIRITS ARE BROKEN BY THIS HUMILIATING, PROGRESSIVE DISEASE? TAKE OFF YOUR WHITE COATS AND WALK IN OUR TREMBLING SHOES, SHARE PAINFUL, SLEEPLESS NIGHTS WITH US, AND THEN SAY, "PARKINSON'S DISEASE DOESN'T HURT."**

**We must all work together, physicians, patients, and political organizations if we are to overcome this puzzling illness that devastates so many of us.**