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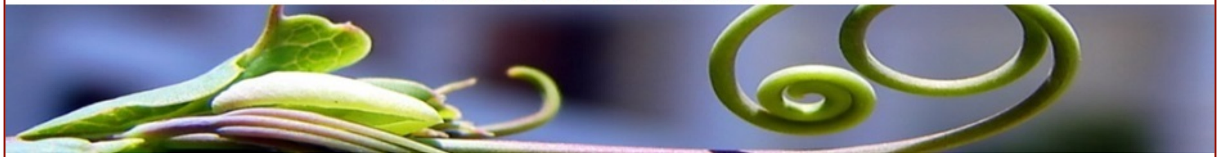
movement consultant for people with

PARKINSON'S DISEASE



Dear Friends,

April is Parkinson's Awareness Month...which can mean a lot of different things...we need to be aware; to make others aware, and yet sometimes we need to be aware that we need relief from our awareness too.

I could write many things based on those three awareness ideas, but instead I've decided to share some thoughts from one of our heroes, Steve DeWitte, who recently had the honor of being received by the White House for his effective work in the PD community. Click here to learn more about Steve and the other White House Champions of Change for Parkinson's.

I know Steve. As his last name suggests, he has a good sense of humor, an endearing charm and he brings conviction and compassion to whatever he takes on.

I asked him for a few words of wisdom. He gave me many, but I think these three thoughts may be the most important:

"I believe there are three things people with Parkinson's must bear on themselves in the battle with this disease

that cannot be adopted by or passed along to care providers, medical professionals, researchers, or other supporting agencies and individuals."

* Education

Patients need to understand the progressive nature of the disease, and stay current with the various treatment options available to them. With this information, they can better communicate their symptoms to their neurologist, and in partnership with the physician, determine the treatment plan best suited for their needs. Sharing their knowledge with others, helps the greater Parkinson community assess what treatments are most effective, as well as encourages others to be involved with efforts designed to make a difference in improving the lives of PWP.

* Advocacy

The largest funding source for Parkinson's research is the United States Government. The National Institute of Health (NIH) oversees distribution of Federal Funds to chosen trials. It receives its funding through the budget approved by Congress. Our congressional leaders seek advice from their constituents on matters important to them, as they prepare to vote on issues affecting the communities where they live and serve. It's important for patients to express their support for research funds and health care initiatives that will lead to learning about what causes this disease and what can be done to limit its impact on the more than one million people afflicted with it.

* Participating in Clinical Trials

It is estimated that it can take upwards of fifteen years and over $1 billion to bring a symptom-relieving drug to market. One of the leading causes of products failing to reach this point has been the inability to recruit a sufficient number of patients in to the various stages of the clinical trials. Some promising studies have been shelved due to a lack of recruitment success.

Thank you Steve!

The fewer trials we participate in, the longer it takes to find a cure. Choose what's right for you and help to move the effort forward. What has made you hesitant about participating in a trial so far? Is it the fear of having to alter your drug regime? (Many trials don't involve changing your meds at all). Is it the discomfort of not knowing if you have a placebo or what they're testing? (How else can we get a good reading on a drug?) Is it a transportation problem? (Ask Steve about that). Figure out what YOUR barrier is, and then try to think creatively about how to address it. We need you!

To find a trial for you, go to Fox Trial Finder, PDF, or ask your doctor for guidance.

Thank you all for listening,
Pam
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