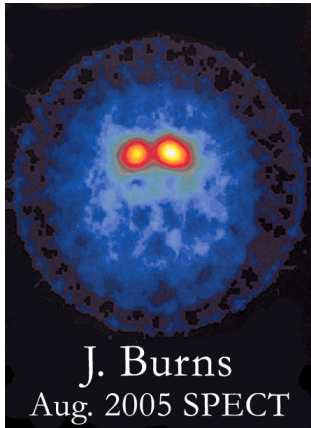


Finding the right clinical trial



If you want to participate in a clinical trial ask your doctor to recommend one or visit websites (e.g. db.pipeline.org, clinicaltrials.gov, and pdtrials.org) listing clinical trials for people with PD. If you prefer researchers with approved studies seek you out, self register on the federal government’s Research-Match.org. You are under no obligation to participate.

When you find a clinical trial that interests you, follow up with a call to the study coordinator. Go to www.pdtrials.org/pdf/checklist.pdf for a list of questions you may want to ask. You may be surprised to learn that clinical trials are not intended to benefit participants (although they

“People who participate in clinical trials tend to do better than those who do not.”

Maryland Parkinson Disease and Movement Disorders Center

often do), but rather to help doctors find the best treatment for future patients.

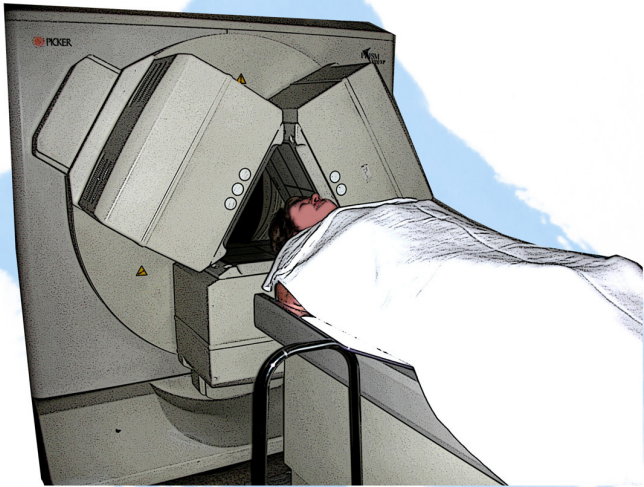
Clinical trials vary greatly from one to another. Testing new drugs is only one of many kinds of trials you can join. Other studies require informational interviews, neurological exams, mini-mental tests, exercise, blood draws, “sniff” tests, PET and SPECT scans, MRIs, EEGs, and vision evaluation. Some trials require one short visit to the study site, others require multiple visits over time, and still others require hospital stays.

Check with your own doctor before committing to participate in a clinical trial.

Even failed trials advance knowledge

Shortly after my diagnosis, I joined a clinical trial for a new drug that looked neuroprotective in tests on primates, and was deemed safe in initial human trials. Two years into my trial it was abruptly halted. Researchers found that participants given the study drug were declining slightly faster than those given a placebo or sugar pill containing no medicine!

These disappointing results underscore the fact that clinical trials offer participants no guarantees. This is not to say that failed trials are a waste of time and money. Every clinical trial, regardless of the outcome, advances researchers’ scientific knowledge of PD and brings us that much closer to finding a cure.



Some 575 of the initial 800 participants, including me, are being followed for life, or until funding runs out. Scientists view us as a large PD control group since we all entered the trial not having started traditional PD meds. As a control group, our data gives scientists a baseline for the progression of PD to which other groups can be compared.

Jean

Benefits of participation

- An opportunity to become actively involved in your own health care.
- Access to the latest treatments before they are available to the general public.
- Investigational treatments may be safer or more effective than the standard one.
- Another option when standard therapy has failed or stopped working.
- Free medical care from a research team at a leading health care facility.
- An opportunity to help others by advancing scientific knowledge and the understanding and treatment of PD.

Risks of participation

Clinical trials are experiments, and as such involve risks, including the possibility that:

- The investigational treatment may not be effective for you.
- New drugs under study are not always better -- and could be worse -- than the standard care to which they are being compared.
- New treatments may have unexpected serious, or even life-threatening side effects.
- You may be required to make more doctor visits and undergo more procedures than if you were not in the clinical trial.

It’s all in the family

Clinical trials not only need to recruit more people with Parkinson’s, but also their friends and family members. Genetic studies depend heavily on the participation of blood relatives. Neurologically healthy friends and family are needed for control groups, the standard by which experimental observations are evaluated.

When asked to join the PROBE trial, my husband didn’t hesitate. After listening to my tales of what goes on in clinical trials, he wanted to see it for himself.



The PROBE trial is focused on identifying biomarkers (alpha-synuclein, olfactory function, and genetic factors) that may predict the future onset of PD, as high cholesterol does for heart disease. Currently, there are no identified biomarkers for PD.

Researchers will follow participants with PD over a 3-year period, comparing them to the control group to evaluate the prognosis for motor complications, postural instability, and cognitive decline.

Jean