

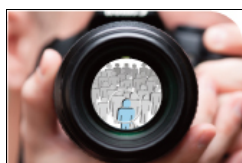
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## The Big Picture: Studying Populations to Understand Parkinson's

By Beate Ritz, M.D., Ph.D.



Despite the significant progress we have made in diagnosing and treating Parkinson's disease (PD), many basic questions remain unanswered. Among them: How many people have Parkinson's disease? What puts people at risk of developing PD? Are there some groups — for example, people who live in certain

geographic locations, or are of particular ethnic backgrounds — who are more likely than others to develop PD? Are people being diagnosed with Parkinson's more frequently than before? Are there toxins in the environment, or aspects of people's lifestyle, that contribute to PD? And the elusive "holy grail," is there anything that could prevent it?

Epidemiologists approach these problems by studying large groups of people over long periods of time. They use these data to formulate a picture of who gets certain health conditions, and to investigate whether chemicals, or foods and health habits, among other things, might cause disease or protect against it. The answers they receive can help us to understand, treat and — in the long run — prevent many health conditions, including Parkinson's disease.

### Getting at PD Risk and Protective Factors

Through epidemiological studies of this kind, we do already have some basic information about how many people live with Parkinson's, and who has a higher risk of developing it.

For example, in the United States, studies have shown that in the population aged 60 years or more, about one percent — or five to 10 adults per thousand — have Parkinson's. That makes PD the second most common neurodegenerative disease after Alzheimer's.

We know some other things about people who are more or less likely to develop Parkinson's disease. These factors include the following:

- Age is the chief risk factor for Parkinson's. As the number of people over age 60 increases, an increasing number of people will be diagnosed with PD.
- PD is more common in men. About 60 percent of people with PD are male and 40 percent are female.
- PD is more common among whites than it is among blacks, or among people of Asian ancestry.
- People who have Parkinson's report that they smoke less and drink less coffee than do other people. But we do not know whether long-term use of caffeine or nicotine may prevent PD or whether people with PD may simply stop drinking coffee or smoking in the early (or preclinical) phase of PD. Or could it be that these behaviors are part of what some doctors hypothesize to be "a Parkinson's personality?"

Research has suggested other factors that may reduce PD risk, although these are not proven. They include taking anti-inflammatory medications and statins; exhibiting high blood levels of uric acid; and eating foods rich in antioxidants, or



*"If I can help the California PD Registry to identify the people with PD living in this area, we are making a difference in understanding the disease."*

James R. Wong, Ph.D.

### PAIRing up for PD Registries

Dr. Ritz initially presented, "The Big Picture" at a training for PDF's **Parkinson's Advocates in Research (PAIR) program**. She has paired up with James Wong, Ph.D., one of the 200 PDF Research Advocates who are part of the PAIR program, to develop the California PD Registry. Dr. Wong put together the following list of registries in the US.

- **California** | Facilitated by The Parkinson's Institute and Clinical Care Center, the University of California Los Angeles and the California Department of Health.
- **Nebraska** | Facilitated by the Department of Health and Human Services.
- **Washington** | Facilitated by the University of Washington and Veterans Administration of Seattle.
- **National** | The National Neurological Diseases Surveillance System Act is under consideration by Congress.

taking supplements. Research also suggests factors that may increase the risk of developing PD, including living in a rural area, working as a farmer, and drinking well water. Stronger evidence points to occupational and general exposure to pesticides, and perhaps exposure to certain metals and to PCBs (organic chemicals), as increasing the risk of PD.

We discovered these associations by looking at behavioral and health data, from thousands of people, that originally had been collected over many decades for another purpose altogether. In one example of this type of research, researchers set about gathering health information regularly on more than 8,000 men of Japanese ancestry who lived in Hawaii in 1964, with the purpose of studying heart disease. But the scientists also followed these men for other aspects of health, including Parkinson's diagnoses. In the 1990s, looking back at almost 30 years of records, researchers compared the 149 men who had developed PD with others in the group. They found that the men who were smokers or who consumed caffeine at the beginning of the study were less likely to have developed PD than were the others. Later studies bolstered these observations.

It is important to remember that these risk factors, generally do not necessarily cause Parkinson's disease. But they can help us understand how it develops. Knowing the agents that may be harmful to dopamine neurons may help us find ways to reduce our exposure to them. It can help us to better understand how toxins may increase the risk of developing PD, and thereby help us to identify new targets for treatments.

### **The Importance of Disease Registries**

So far, epidemiologists interested in PD have had to rely mainly on large long-term studies that were designed to study other illnesses. Why are there so few studies and databases designed for Parkinson's?

One reason is that in the United States, there is no centralized place for recording cases of Parkinson's as there are for many other diseases. A second reason is that gathering information about cases of PD is more difficult than for many other diseases. For example, if you want to find out the ages at which people die from strokes, you can look at death certificates. If you want to see who has cancer, the diagnoses will be confirmed by pathologists' reports. But PD often is not listed on death certificates and PD diagnoses are not always accurate. Unless a person with PD has been diagnosed by an experienced movement disorder specialist, there's a strong chance of PD being confused with diseases such as Multiple system atrophy (MSA), Progressive supranuclear palsy (PSP), or Essential Tremor.

In countries with national health care, it is theoretically easier to assess the prevalence of PD. But even here there are problems — for example, numbers cannot be easily compared country-to-country because different methods have been used to identify PD. Even in a small country like Norway, which has universal health care, centralized record-keeping and well-trained physicians, a recent study showed that tremor disorders were often misdiagnosed as PD by non-specialists.

To truly understand PD, we need a focused approach — ideally, a disease registry that includes confidential information on health and other characteristics (for example, employment and residence) for everyone with PD who lives in a large county, state or country.

### **California Parkinson's Disease Registry**

In 2004, in an effort to begin gathering data on PD in a well-defined US population, I worked with a group of collaborators — including Greg and Ann Wasson, Mark Siegel, and Drs. Caroline Tanner and J. William Langston — to pass a law establishing the California Parkinson's Disease Registry. The law mandates the Department of Health to register cases of PD in a confidential database, and it requires health care providers to report cases to the registry. But it too has faced challenges — a key one being that the law forbids the expenditure of state funds to run the registry itself!

In 2007, with many colleagues, I began a pilot project to develop this registry. We focused on three counties in California's Central Valley, which is the nation's most productive agricultural region. We chose this area in part because we wanted to investigate a suspected association between pesticide exposure and PD. It took months of legwork to contact health care facilities and physicians treating people with PD; to encourage their participation; and then to recruit people in the registry to participate in our research.

Following up on mounting evidence that pesticide exposure increases PD risk, one of our first projects with the registry was to look at people who live close to fields that had been sprayed with the fungicide maneb and the herbicide

paraquat. We found that these people had an increased risk of developing PD. In a later study, we found that people whose workplaces were near fields sprayed with these pesticides, as well as the fungicide ziram, had an increased PD risk. People who both lived and worked near fields sprayed with pesticides had the highest PD risk. People who were diagnosed with PD at younger ages had higher exposures to pesticides — both at workplaces and at home.

In another project, we followed 233 people recently diagnosed with PD for five years, to investigate why it is that some people with Parkinson's live for many years without much change in their movement symptoms, whereas others decline rapidly. This long-term study allowed us to compare the genes of "fast progressors" and "slow progressors." One important result of the study was the identification of genetic variations that may help predict the course of a person's PD and suggest a way in which we can identify people with PD who will benefit the most from early treatment.

In a fairly short time, with a PD registry representing only part of our state, we have already accumulated strong scientific evidence both to support changes in environmental regulations and to suggest pathways to developing neuroprotective agents (that is, agents that can protect neurons from dying in PD). These results underscore the need for more comprehensive PD registries in California and elsewhere.

**What You Can Do**

If you are a person with PD, you can make a contribution to research by contacting a PD registry, if there is one near you (see box at right). If you live in the majority of states that don't have registries, you can volunteer for studies and encourage people without PD to do the same. The biggest impediment to observational studies is recruiting volunteers who don't have PD. We need to include their survey responses and DNA samples, so that we can compare their histories to those of people with PD and find the differences.

Studying populations makes it possible to get at some of the most fundamental questions of research — the who, when and why of Parkinson's — and you can be a part of this process. We cannot do it without you!

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