WHY A REGISTRY?

We don't know how many people have Parkinson's disease (PD). We don't know why Parkinson's disease is becoming more common, or why it is affecting younger individuals. We don't know what causes Parkinson's disease and how to prevent or cure the disease.

What we do know:
- There is currently no accurate way to track Parkinson's disease.
- Identifying factors that cause PD is the first step toward prevention.

The Registry will:
- Make a major contribution toward finding the causes of PD and is the most accurate approach in determining the number of people affected by the disease.
- Determine which genetic and environmental factors will influence the likelihood of getting the disease.
- Identify whether the number of persons with PD or with Young Onset PD is increasing.
- Provide a systematic way to link PD to chemical toxins.

California's Cancer and Birth Defects registries are making a significant contribution in understanding those afflictions. A Parkinson's registry will be an important tool for understanding neurodegenerative diseases.

WHY PARKINSON’S?

- It is estimated that over 1.5 million people in the U.S. suffer from PD, with 70,000 newly diagnosed per year.
- PD is the second most common neurodegenerative disease, surpassed only by Alzheimer’s disease.
- PD is the 14th leading cause of death in the U.S., according to the Centers for Disease Control and Prevention's 2010 analysis of mortality data. [www.cdc.gov/nchs/data/nvsr/nvsr60/nvsr60_04.pdf]
- Parkinson's is affecting both young and older individuals.
- As our population ages, the number of elderly in the United States is rapidly growing. As a result, the social and economic impacts of neurodegenerative disorders will significantly increase.
- Current research studies indicate PD is caused by both genetic and environmental factors and that we are closer to a better understanding the causes of PD, an important step toward prevention and finding a cure.
- Understanding Parkinson’s disease will aid us in further clarification of steps involved in related disorders such as Alzheimer’s and motor neuron disease.
- Certain prescribed medication can be used as a specific indicator for selective identification of cases of PD for the Registry.

WHY CALIFORNIA?

- California has a strong scientific community, dedicated to understanding and eradicating Parkinson’s disease, including several Parkinson’s research centers supported by federal (NIH) and private funding.
- California has mandated reporting of pesticide and toxicant use for decades, and chemical exposure is one likely cause of Parkinson’s disease.
- California is the national forerunner of environmental surveillance of pollutants and has a strong track record for environmental research.
- California’s rich diversity and resources provide an ideal climate to investigate risk factors for PD.
- California has long standing experience in disease registration, with its statewide cancer and birth defects registries.
- California has experience with the creation of and strict adherence to confidentiality guidelines through its existing registries.

We must give our scientists and researchers the tools they need to find a cure for Parkinson’s disease.
THE CALIFORNIA PARKINSON’S DISEASE REGISTRY ACT

- Mandates the State Department of Health Services Director to create a database of persons with Parkinson’s disease for research purposes only.
- Requires that all personal information, including the name and address of registered patients, be kept strictly confidential.
- Requests that physicians and pharmacists report new cases of Parkinson’s disease.
- Provides for a staged process implementation to assure maximum efficiency at the lowest possible expense.
- Allows private contributions to fund the Registry.

WHY YOU SHOULD SUPPORT FULL FUNDING FOR THE REGISTRY

A mandatory registry gathering basic information on all patients diagnosed with Parkinson’s disease in California will provide researchers crucial tools for uncovering the causes of Parkinson’s and can lead to prevention and a cure.

That is why individuals affected by Parkinson’s disease must join with scientists, physicians, and concerned organizations to support full funding for the California Parkinson’s Disease Registry.

The economic burden of Parkinson’s disease is at least $14.4 billion a year in the U.S., and the prevalence of Parkinson’s will more than double by the year 2040.


Want to get involved? Contact the
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FIND THE CAUSE
FIND THE CURE