CALIFORNIA PARKINSON’S DISEASE REGISTRY
FACT SHEET

Background:
It is unknown how many people have Parkinson’s disease. No one knows if young onset Parkinson’s disease is increasing or what environmental factors trigger the disease. The California Parkinson’s Disease Registry can help answer these questions. In late 2004, Governor Arnold Schwarzenegger signed the California Parkinson’s Disease Registry Act into law. Physicians and researchers from UCLA and the Parkinson’s Institute worked together to create the Registry through a contract with the California Department of Public Health (CDPH). The Registry Act required the CDPH to establish a statewide confidential database of people who have Parkinson’s disease. The PD Registry was designed to provide key demographic data in tracking the disease (similar to the California Cancer Registry) in order to identify the underlying causes, risk and environmental factors of Parkinson’s disease.

What we need:
When the bill was originally passed, California was experiencing one of its worst economic times; as a result, the Registry was set up without the state funds needed for its implementation. Legislation is now needed to provide the necessary funding (estimated $4 million) to fully implement the Registry.

Why the Registry is Needed:
Parkinson’s disease is a chronic, progressive neurological disease. It is estimated the disease costs patients about $14.4 billion annually in medical costs, which translates to about $1.7 billion per year in California. There is a growing consensus among researchers that the disease is triggered by something in the environment. The Registry gives us the best opportunity to identify these triggers. California is the only state that has tracked the use of pesticides and other toxic chemicals since the 1970’s, and we now have a unique opportunity to geographically map the incidence of Parkinson’s in the state, overlaid by a map of toxic chemical usage.

Pilot Program Shows Pesticide Link: A pilot program, funded privately, that began in 2008 covering four counties (Fresno, Kern, Santa Clara, and Tulare) indicated that geographic areas using the highest level of pesticide use also had the highest rates of Parkinson’s disease. Unfortunately, there was not enough funding to complete the program.

Who We Are:
Parkinson’s patients, caregivers, physicians, public health professionals, scientists, policy advocates, and non-profit organizations throughout California support the funding and implementation of the California Parkinson’s Disease Registry.

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For more information, contact Mark Siegel (marksiegel11@yahoo.com), Neptune Mizrahi, PhD (capd.action@gmail.com), or Aurora Soriano (forevermao@msn.com)