

Award Number: W81XWH-07-1-0261

TITLE: California's Parkinson's Disease Registry Pilot Project – Coordination Center
and Northern California Ascertainment

PRINCIPAL INVESTIGATOR: Caroline M. Tanner, M.D., Ph.D.

CONTRACTING ORGANIZATION: The Parkinson's Institute
Sunnyvale, California 94085-2934

REPORT DATE: March 2008

TYPE OF REPORT: Annual

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Fort Detrick, Maryland 21702-5012

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13. SUPPLEMENTARY NOTES					
14. ABSTRACT The primary goal of this project is to conduct a pilot study for the legally mandated population-based Parkinson's disease (PD) registry in the state of California. This is a collaborative partnership with The Parkinson's Institute (PI), the California Department of Public Health (CDPH) and the University of California-Los Angeles School of Public Health (UCLA). The PI will conduct ascertainment work in Santa Clara County as well as serve as the coordinating center for the pilot project, overseeing the administrative and developmental aspects of the project. PD cases will be identified from legally mandated sources (pharmacists, health care institutions, physicians and other providers) and a secure prototype database will be established. The Pilot Project will be carried out in two phases, the first of which will focus on disease surveillance and registry establishment, while the second phase will address exploratory research aims. Differences in patterns of PD care will be assessed among groups defined by age, gender, place of residence and, as possible, socioeconomic status and race/ethnicity. The value of the registry to stakeholder groups, and the registry cost, will be assessed.					
15. SUBJECT TERMS Parkinson's disease, disease registry, active case ascertainment, prevalence.					
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a. REPORT	b. ABSTRACT	c. THIS PAGE			USAMRMC
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A. Introduction

This project consists of a pilot study conducted in partnership with the California Department of Public Health (CDPH) and the University of California-Los Angeles School of Public Health (UCLA) to establish a legally mandated statewide population-based Parkinson's disease (PD) registry in California for surveillance and research purposes. Investigators at the Parkinson's Institute will conduct case ascertainment work in Santa Clara County, as well as design, set up and coordinate the field efforts of both groups, including the establishment and maintenance of a secure data enclave for storage of this sensitive medical data; the UCLA group is funded to conduct registry field work in Kern, Tulare and Fresno Counties and to coordinate with the Parkinson's Institute on registry-related surveillance and research activities. PD cases in the four target counties will be identified from legally mandated reporting sources (i.e. pharmacists, health care institutions, physicians and other providers). As part of the initial surveillance effort on the pilot project, a secure prototype database will be established at TPI to store data from both the UCLA and the Parkinson's Institute field work. The Pilot Project will be carried out in two phases, the first of which will focus on disease surveillance and registry establishment, while the second phase will address exploratory research aims.

B. Body**SCOPE OF WORK**

The goals of this research are to conduct a feasibility study for the legally mandated California statewide population-based PD registry and utilize pilot registry data to explore trends in PD prevalence, patterns of care and possible relationship to the distribution of environmental toxicants. This project is linked with a DOD-funded project based at UCLA (Award Number W81XWH-07-1-0005, PI: Beate Ritz), under which case ascertainment in southern California will be performed.

The initial phase of this project involves establishment of a secure, high quality registry database, via completion of the specific tasks listed below; activities under this initial phase represent public health surveillance activity conducted under the authority of CDPH. As the registry methods and database are constituted, project research activities will be initiated. This report describes our progress related to the initial, surveillance phase of the overall project, achieved in close collaboration with project partners UCLA and CDPH.

C. Key Accomplishments

Task 1: Obtain deputization status from the CDPH as designated agents for creation of the registry.

A zero-dollar contract which designates TPI as a state-authorized agent for creation of the PD registry was developed and finalized in the Fall; a copy of the confirmation letter dated October 12, 2007 is attached (Appendix 1). A similar contract was completed for the linked UCLA project.

Task 2: Obtain approval from Institutional Review Boards.

To enable creation of the registry and related public health surveillance activities, a human subjects research waiver for this initial work was obtained from the Army Medical Research and Materiel Command Office of Research Protections Human Research Protection Office, the State of California Committee for the Protection of Human Subjects, the Kaiser Permanente Northern California Institutional Review Board and the UCLA Office for Protection of Research Subjects. Copies of these waivers are attached (Appendices 2-5). IRB approval for project research activities will be sought later this year.

Task 3: Notify case reporting sources and professional organizations of registry implementation, as required by the California Parkinson's Disease Registry Act.

A notification letter was developed in conjunction with CDPH, and mailed in January 2008 to the state Medical Board and the Board of Pharmacy, professional organizations representing potential case reporting sources (pharmacists, physicians and health care facilities) and public health officers in the project target counties. A sample letter is attached (Appendix 6).

Task 4: Initiate outreach to stakeholders.

A free-standing website was created, and launched in March, 2008 (www.capdregistry.org). A public fact sheet and informational brochure were developed. Samples of these materials are attached (Appendices 7, 8, 9). Planning for further outreach to the broad spectrum of project stakeholders is underway.

Task 5: Convene guidance committees.

The Stakeholders Advisory Committee is being convened by its Chairman, Mr. Mark Siegel; this Committee will create a forum and network in which registry stakeholders can be informed of project activities, provide advice to the project and promote greater awareness of the Registry in the stakeholder community. Planning for the functions of and membership in a Scientific Advisory Committee has also been initiated.

Task 6: Define case ascertainment strategies.

Project leaders at CDPH, the Parkinson's Institute and UCLA have identified four California counties as designated reporting zones for the pilot project: Fresno, Tulare, Kern and Santa Clara. (Santa Clara was elected instead of the earlier provisional choice of Alameda County, as it offers population diversity and case-finding opportunities which better complement those of the southern Counties). Initial case-finding efforts will target the practices of local neurologists and then expand to a broader sampling base involving pharmacy chains, health care facilities/organizations and non-neurologist physicians. The feasibility of accessing governmental databases (California Office of Statewide Planning and Development, MediCal and MediCare) is being explored.

Task 7: Create tools for data collection.

A series of draft data collection forms has been elaborated and pilot-tested by staff (both physicians and non-physicians) at the Parkinson's Institute using patient medical charts

as a source for data abstraction. The form includes fields for obtaining information on basic demographics, key clinical parameters and characterization of data collection feasibility; a copy of the current draft is attached (Appendix 10). This document will next be converted to an electronic data collection tool (using Microsoft Access) and pilot-tested in the field. Work on standardized training materials for field abstractors in northern and southern California has also begun.

Task 8: Develop policies and procedures for ensuring data confidentiality, quality and appropriate use.

Prior to initiating data collection, it is necessary to formulate procedures that will ensure data confidentiality and meet the related specifications required by the CDPH contracts. A Data Access and Disclosure Policy has been drafted, based on the existing protocols established for the California Cancer Registry (<http://www.ccrca.org/PDF/CCRfacilityAccessPolicy-100206-v04-3.pdf>). The content of the pilot registry policy will define the criteria, training and practices required to permit access/disclosure of any data for health surveillance or research purposes.

D. Reportable Outcomes

Since the Pilot Project has not yet initiated data collection, there are no reportable outcomes at this time.

E. Conclusions

Substantial progress has been made in laying the foundations for this new registry, and we anticipate commencement of field data collection within the next three months. Important next steps for the project include the following:

1. Convene the Scientific and Stakeholder Advisory Committees
2. Finalize the data collection form in electronic format
3. Fully define the sampling approach
4. Complete the contact lists for initial phase data sources
5. Establish a secure database structure and data collection/transmission/storage procedures
6. Establish the means to identify duplicate cases obtained from multiple reporting sources
7. Retain a health economist to identify cost analysis landmarks
8. Finalize data access and confidentiality procedures, and submit for CDPH approval
9. Hire and train research assistants for field medical abstraction
10. Initiate data collection in the field

F. References

None.

G. Appendices

1. CDPH Deputization letter
2. California IRB Waiver
3. DOD IRB Waiver
4. UCLA IRB Waiver
5. Kaiser IRB Waiver
6. Notification Letter of Registry Launch
7. Website (home page)
8. Fact Sheet
9. Brochure
10. Data Collection Form



MARK B HORTON, MD, MSPH
Director

State of California—Health and Human Services Agency
California Department of Public Health



ARNOLD SCHWARZENEGGER
Governor

October 12, 2007

Mr. Ken Toren
Executive Director
The Parkinson's Institute
1170 Morse Avenue
Sunnyvale, CA 94809

Dear Mr. Toren:

This letter confirms that we have finalized a contract with you designating the Parkinson's Institute and the University of California, Los Angeles School of Public Health (UCLA) as our authorized agents to implement the California Parkinson's Disease Registry Act (Assembly Bill [AB] 2248, Frommer, Chapter 945, Statutes of 2004).

As the State of California's agent, the Parkinson's Institute has agreed to collect, share, and analyze pilot project data collected from specific target regions in Northern California. You will work in coordination with UCLA (which has responsibility for Southern California) in areas that the California Department of Public Health (CDPH) has designated as disease reporting regions. You will contact and visit health care providers, health care facilities, and pharmacies to obtain confidential information from their records on Parkinson's patients, for calculating rates of this disease in various demographic groups.

This registry effort will not involve contacting the patients. AB 2248 requires health care providers, health care facilities, and pharmacies to cooperate in providing this information, which is for public health purposes and exempt from Health Insurance Portability Accountability Act (HIPAA) patient consent or authorization requirements. You have agreed to maintain the collected information with the strictest physical and electronic security to guarantee its confidentiality. We urge you to share this letter and a copy of AB 2248 with the parties who must cooperate with you as our authorized agent in carrying out this important work.

Mr. Ken Toren
Page 2
October 12, 2007

Thank you for your cooperation and collaboration with CDPH and UCLA. If you have any questions please contact Dr. Paul English at (510) 620-3684.

Sincerely,



for Mark B Horton, MD, MSPH
Director

STATE OF CALIFORNIA - HEALTH AND HUMAN SERVICES AGENCY

ARNOLD SCHWARZENEGGER, Governor

COMMITTEE FOR THE PROTECTION OF HUMAN SUBJECTS

1600 Ninth Street, Room 432
Sacramento, California 95814
(916) 653-0176 FAX (916) 651-6222



March 26, 2007

Caroline Tanner, MD, PhD
Director, Clinical Research
The Parkinson's Institute
1170 Morse Avenue
Sunnyvale, CA 94089-1605

RE: Project Title: "California Parkinson's Disease Registry Pilot Project"
Project Number: 07-02-08

Dear Dr. Tanner:

The Committee for the Protection of Human Subjects (CPHS), California Health and Human Services Agency, reviewed the above-entitled project at its regular meeting on February 2, 2007, in Sacramento. The CPHS decided that the project you proposed is public health surveillance and not research. For this reason it does not require further review by CPHS at this point. However, any uses of the data to carry out research will require CPHS review.

For future research projects, principal investigators will need to submit a protocol for CPHS for approval. Instructions for protocol submission are available on the CPHS web site at www.oshpd.ca.gov/cphs. Releases of data from the Parkinson's Disease Registry for research may not be made without prior CPHS approval.

Please contact the CPHS office at (916) 653-0176 or e-mail cphs-mail@oshpd.ca.gov if you have any questions.

Sincerely,

A handwritten signature in cursive script that reads 'Joan M. Mock'.

Joan M. Mock
Assistant Administrator

cc: Raymond Neutra

DOD IRB Approval Letter (surveillance portion)

Roucoux, Diana

From: Jewell, Sarah
Sent: Thursday, May 24, 2007 3:20 PM
To: 'ctannermd@aol.com'; Tanner, Caroline
Cc: Roucoux, Diana
Subject: Hooray! CA PD Registry, DOD IRB; FW: A-13985, Determination Memo (Proposal Log Number 06122002, Award Number W81XWH-07-1-0261) (UNCLASSIFIED)

-----Original Message-----

From: Katopol, Kristen R Ms AMDEX [mailto:Kristen.Katopol@us.army.mil]
Sent: Thursday, May 24, 2007 3:14 AM
To: Tanner, Caroline; Jewell, Sarah
Subject: FW: A-13985, Determination Memo (Proposal Log Number 06122002, Award Number W81XWH-07-1-0261) (UNCLASSIFIED)

Classification: UNCLASSIFIED
Caveats: NONE

-----Original Message-----

From: Duchesneau, Caryn L Ms USAMRMC
Sent: Wednesday, April 18, 2007 10:36 PM
To: 'ctanner@theipi.org'
Cc: 'ssnow@parkinsonsinstitute.org'; Herndon, Dana L Ms USAMRAA; Hover, Carl G LTC USAMRMC; Bennett, Jodi H Ms USAMRMC; Brosch, Laura R COL USAMRMC; Burdette, Buffy J Ms GENERAL DYNAMICS; Katopol, Kristen R Ms AMDEX; Duchesneau, Caryn L Ms USAMRMC
Subject: A-13985, Determination Memo (Proposal Log Number 06122002, Award Number W81XWH-07-1-0261) (UNCLASSIFIED)

Classification: UNCLASSIFIED
Caveats: NONE

SUBJECT: Protocol, "California Parkinson's Disease Registry Pilot Project" in support of the proposal; "California Parkinson's Disease Registry Pilot Project" Coordination Center and Northern California Ascertainment," Submitted by Caroline M. Tanner, M.D., The Parkinson's Institute, Sunnyvale, California, Proposal Log Number 06122002, Award Number W81XWH-07-1-0261, HRPO Log Number A-13985

1. The subject protocol has been administratively reviewed by the U. S. Army Medical Research and Materiel Command (USAMRMC) Office of Research Protections (ORP) Human Research Protection Office (HRPO) for applicability of human subjects protection regulations.
2. It was determined that the protocol does not involve research, as defined by 32 CFR 219. The project involves creation of a registry for public health surveillance. The proposal may proceed with no further requirement for review by the HRPO.
3. Any future research projects involving human subjects or human anatomical substances using funding from this Department of Defense award will require submission of a separate protocol for review and approval by the HRPO.
4. Modifications to the scope of work, to include changes in use of human anatomical substance or human subjects, require review by the Contracting Officer at the U.S. Army Medical Research Acquisition Activity and the HRPO prior to implementation.
5. Further information regarding the award can be obtained by calling the assigned contract specialist, Ms. Dana Herndon at 301-619-7140.

6. Further information regarding this review can be obtained by contacting Ms. Kristen Katopol, MS, CIM, Human Subjects Protection Scientist, at 301-619-1119.

CARYN L. DUCHESNEAU, CIP
Chief, Human Subjects Protection Review
Human Research Protection Office
Office of Research Protections
U.S. Army Medical Research and Materiel Command

NOTE: The official signed copy of this approval is housed with the protocol file at the Office of Research Protections, 504 Scott Street, Fort Detrick, MD 21702. Signed copies will be provided upon request.

NOTE: Do not construe this correspondence as approval for any contract funding. Only the Contracting Officer or Grants Officer can authorize expenditure of funds. It is recommended that you contact the appropriate contract specialist or contracting officer regarding the expenditure of funds for your project.

Classification: UNCLASSIFIED

Caveats: NONE

Classification: UNCLASSIFIED

Caveats: NONE



APPROVAL NOTICE

OFFICE FOR PROTECTION OF RESEARCH SUBJECTS
1401 Ueberroth Building
169407
www.oprs.ucla.edu

DATE: February 9, 2007

TO: Beate Ritz, M.D., Ph.D.
Principal Investigator

FROM: Alison A. Moore, M.D., M.P.H.
Chair, South General Institutional Review Board

RE: UCLA IRB #G07-01-067-01
Approved by Expedited Review
(Approval Period from 02/09/2007 through 02/08/2008)
California Central Valley Parkinson's Disease Registry Pilot Project

Please be notified that the UCLA Institutional Review Board (UCLA IRB) has approved the above referenced research project involving human subjects in research. The UCLA's Federalwide Assurance (FWA) with the Department of Health and Human Services, Office for Human Research Protections is FWA00004642.

PLEASE COMPLY WITH THE FOLLOWING CODICIL(S) IMPOSED BY THE IRB:

1. The investigator is required to submit the finalized protocol for the Parkinson's Registry prior to the initiation of research procedures.

Approval Signature of the UCLA IRB Chair

PRINCIPLES TO BE FOLLOWED BY PRINCIPAL INVESTIGATORS:

As the Principal Investigator, you have ultimate responsibility for the conduct of the study, the ethical performance of the project, the protection of the rights and welfare of human subjects, and strict adherence to any stipulations imposed by the UCLA IRB. You must abide by the following principles when conducting your research:

APPROVAL NOTICE
IRB #G07-01-067-01

1. Perform the project by qualified personnel according to the approved protocol.
2. Do not implement changes in the approved protocol or consent form without prior UCLA IRB approval (except in a life-threatening emergency, if necessary to safeguard the well-being of human subjects.)
3. If written consent is required, obtain the legally effective written informed consent from human subjects or their legally responsible representative using only the currently approved UCLA-IRB stamped consent form.
4. Promptly report all undesirable and unintended, although not necessarily unexpected adverse reactions or events, that are the result of therapy or other intervention, within ten working days of occurrence. All fatal or life-threatening events must be reported to the UCLA IRB in writing within 2 working days after discovery.
5. In clinical medical research, any physician(s) caring for your research subjects must be fully aware of the protocol in which the subject is participating.
6. No subjects may be identified, contacted, recruited, or enrolled until the contract with the sponsor is finalized by the University.
7. Ensure that all individuals who will interact with subjects and/or have access to identifiable research data have completed the UCLA Protection of Human Research Subjects Certification.
8. Ensure that all individuals who will access subjects' medical records have completed the UCLA HIPAA Research Training Certification.
9. If non-UCLA sites or personnel are involved, follow all study-specific requirements and consent processes approved by the UCLA IRB.

FUNDING SOURCE(S):

According to the information provided in your application, the funding source(s) for this research project may include the following: extramural.

PI of Contract/Grant: Beate Ritz

Funding Source: Department of Defense

Contract/Grant No: not yet determined

Contract/Grant Title: California Parkinson's Disease Registry Pilot Project - Southern California Ascertainment

Jewell, Sarah

From: Stephen.VanDenEeden@kp.org
Sent: Tuesday, April 10, 2007 10:26 AM
To: Tanner, C.; Jewell, Sarah
Cc: Amethyst.D.Leimpeter@kp.org; Roucoux, Diana
Subject: Fw: IRB Notification - Not Research - California Parkinson ?s Disease Registry

Our IRB followed the state lead. Below is our official notification.
Stephen

Stephen K. Van Den Eeden, PhD
Senior Investigator
Division of Research
Kaiser Permanente
2000 Broadway
Oakland, CA 94612
Office: 510 891-3718 (internal tieline 8-481-3718)
Fax: 510 891-3761 (internal tieline 8-481-3761)
Email: skv@dor.kaiser.org or Stephen.Vandeneeden@kp.org
<http://www.dor.kaiser.org>

----- Forwarded by Stephen VanDenEeden/CA/KAIPERM on 04/10/2007 10:23 AM -----

Steve M Thompson/PO/KAIPERM

To Stephen VanDenEeden/CA/KAIPERM@KAIPERM

cc Sonia J Whittle/CA/KAIPERM@KAIPERM

04/10/2007 10:13 AM

Subject IRB Notification - Not Research - California Parkinson's Disease Registry



April 10, 2007

Stephen Van Den Eeden PhD
Principal Investigator
Division of Research

Re: California Parkinson's Disease Registry

Dear Dr. Van Den Eeden:

A designated reviewer on the Kaiser Permanente Northern California (KPNC) Institutional Review Board (IRB) reviewed your submission and determined that the design and development activities of the registry as detailed in the submission do not meet the federal regulatory definition of research as defined by 45 CFR 46.102(d). Therefore, IRB review of this project is not necessary. Federal regulations define research as a systematic investigation, including research development, testing, and evaluation, designed to develop or contribute to generalizable

6/5/2007

knowledge.

Please keep in mind that any use of the registry for research purposes would require prior IRB approval of the research plan.

Please feel free to contact me if you have any questions regarding this notification.

Sincerely,

Steve M. Thompson

Steve M. Thompson
KPNC IRB Specialist

CN-07SVanD-02-H

(Not Research)

~~~~~  
Steve M. Thompson  
IRB Specialist  
Kaiser Permanente Northern California  
Institutional Review Board  
1800 Harrison Street - 16th Floor  
Oakland CA 94612  
tel 510.625.2121 / fax 510.625.2330 / tie line 428  
steve.m.thompson@kp.org

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6/5/2007



MARK B HORTON, MD, MSPH  
Director

State of California—Health and Human Services Agency  
**California Department of Public Health**



ARNOLD SCHWARZENEGGER  
Governor

January 15, 2008

Martin Fensterscheib, Director  
Santa Clara County Public Health Department  
976 Lenzen Avenue  
San Jose, CA 95126

Dear Dr. Fensterscheib:

We are writing to inform you and the members of your organization about an exciting new project that is being launched: the **California Parkinson's Disease Registry**.

As described on the enclosed Fact Sheet, the creation of the Registry is mandated by recent state legislation which makes Parkinson's disease a reportable condition in California (*California Health and Safety Code Sections 103860-103865*). The Registry will be initiated as a pilot project. For this purpose, the California Department of Public Health has established collaborations with two designated institutions, the Parkinson's Institute (Sunnyvale) and the UCLA School of Public Health. Our initial efforts will focus on the registration of Parkinson's disease cases in four California counties (Santa Clara, Fresno, Kern and Tulare).

The California Parkinson's Disease Registry Act requires physicians, pharmacists and other health care practitioners as well as health care facilities and other agencies treating PD patients to report their cases and allow access to their records by authorized Registry staff. For the initial four-county Pilot Project, we will be contacting a variety of health care providers, pharmacies and facilities to collect information, in order to determine the best and most cost-effective methods of maintaining a future high-quality statewide Registry envisioned by the legislation. All data collection, storage and use procedures will be secure and fully compliant with HIPAA and other applicable state and federal privacy laws. This Pilot Project is being funded by the Michael J. Fox Foundation for Parkinson's Research, the National Institute of Environmental Health Sciences and the U.S. Army Neurotoxin Exposure Treatment Research Program.

In coming years, Registry data will provide urgently needed information about the patterns of Parkinson's disease in our population statewide, and allow research into its causes. Our state's experience with public health tracking, together with the size and diversity of our population, make California an ideal place to launch this initiative. We hope you share our enthusiasm, and thank you in advance for your support of this important first step to establish a **California Parkinson's Disease Registry**.

Please share this information with the members of your organization. Questions about the Pilot Project can be sent to [CAPDRegistry@theipi.org](mailto:CAPDRegistry@theipi.org).

Sincerely,



Paul English, PhD MPH  
Branch Science Advisor  
Environmental Health Investigations Branch  
California Department of Public Health



Beate Ritz, MD PhD  
Professor, Department of Epidemiology  
UCLA School of Public Health

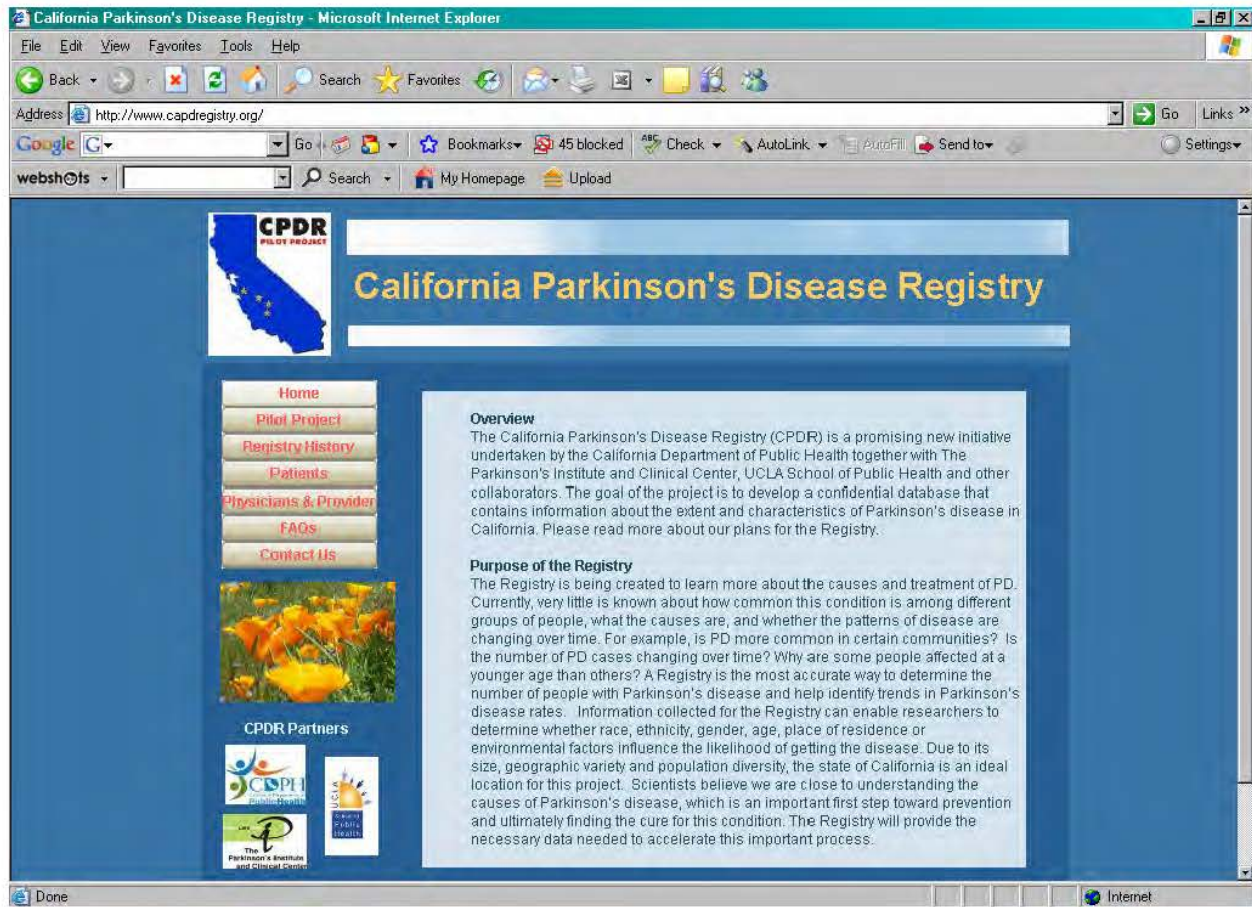


Caroline M. Tanner, MD PhD  
Director, Clinic Research  
The Parkinson's Institute

cc: Mark Horton, MD MSPH  
State Health Officer

Attachment: Fact Sheet

## California Parkinson's Disease Registry Home Page (www.capdregistry.org)





## **The California Parkinson's Disease Registry Public Fact Sheet**

Thanks to strong grassroots support from both Parkinson's disease (PD) advocates and researchers, the California Parkinson's Disease Registry Act was created and became law in late 2004. The Registry is now underway, in the form of a Pilot Project which will establish the best ways to create an ongoing, statewide program to track PD. This Fact Sheet describes the background and current status of this important work.

### **What is the California Parkinson's Disease Registry?**

In late 2004, Governor Arnold Schwarzenegger signed the California Parkinson's Disease Registry Act into law. This act requires the California Department of Public Health (CDPH) to establish a confidential database listing people who have Parkinson's disease. The Registry is this protected list. The new PD Registry will join other state databases (such as the California Cancer Registry) designed to track important diseases and public health hazards.

### **What is the purpose of the Registry?**

The Registry Act was passed to learn more about the causes and treatment of PD. Little is known about how common this condition is among different groups of people, what the causes are, and whether the patterns of disease are changing over time. For example, is PD more common in certain communities? Is the number of PD cases changing over time? Collecting this information in a large and diverse state like California will provide important clues about the causes of the disease, as well as help to make sure that adequate health care resources are available for all patients. Learning more about the causes of PD is key to preventing this disease, and may open new doors toward finding a cure.

### **When will the Registry begin?**

Due to the expense and complexity of this project, the Registry will be developed in several stages over time. The first phase of the project (which is currently being launched) is a pilot program. The Pilot Project will establish a PD Registry in four California counties (Santa Clara, Fresno, Kern and Tulare) chosen by the CDPH. By developing the Registry in stages, we will be able to ensure that the needed data can be collected and secured, and that the burden on participating doctors, pharmacists and

hospitals is minimized. This groundwork will show the best approaches to maintaining an active, high quality Registry over time as it expands to include other areas of California.

### **Who will be in charge of the Registry Pilot Project?**

The Pilot Project will be carried out by the CDPH, along with two partners, The Parkinson's Institute (a not-for-profit clinical and research organization in Sunnyvale) and the UCLA School of Public Health. These partners were selected for the project based on their extensive experience in PD-related research.

### **Who is paying for the Registry Pilot Project?**

Funding for the Pilot Project is being provided by the Michael J. Fox Foundation for Parkinson's Research, the National Institute of Environmental Health Sciences, and the US Army Neurotoxin Exposure Treatment Research Program. Additional support is being sought from other sources. No state funds will be used to support the Pilot Project.

### **What kind of information will be collected?**

For the Pilot Project, Registry staff will be collecting demographic information (such as name, birthdate, address) about people with PD, their health care providers (such as physician specialty), as well as basic clinical information (such as date of diagnosis, medications, disease features).

### **How will the information be collected?**

The Registry Act requires physicians, pharmacists, and other health care providers to report cases of PD and allow access to their records by authorized Registry staff. In addition, people with PD may also voluntarily self-register. For the Pilot Project, trained staff will be contacting health care providers (but not patients) to collect available Registry information.

### **Will the information remain confidential?**

Yes, the information will remain confidential as required by law. All information will be collected and stored using state-of-the-art procedures and technology designed to protect confidentiality. These procedures have been developed and used by other health department registries over several decades without security problems.

### **How can I self-register?**

People with PD who live in one of the four Pilot Project counties are welcome to voluntarily register themselves.

**Where can I get more information?**

Updated information about the Registry is available at [www.CAPDRegistry.org](http://www.CAPDRegistry.org). Also, you may email questions to: [CAPDRegistry@theipi.org](mailto:CAPDRegistry@theipi.org).

## Why You Should Support CPDR & How You Can Help

No one knows exactly how many people have Parkinson's disease. No one knows whether Parkinson's disease is becoming more common, or if it is affecting younger victims. No one knows what causes Parkinson's disease. No one can prevent or cure the disease.

We do know that Parkinson's disease is a progressively debilitating condition for which there is no cure. A mandatory registry gathering basic information on all patients diagnosed with Parkinson's disease in California will give researchers and scientists a crucial tool for the epidemiological studies that may lead to both prevention and a cure.

That is why individuals with Parkinson's disease have joined with scientists, physicians, and concerned organizations to support the registry project.

### How You Can Help

We value your input! If you have a question or would like to offer a suggestion about how to help, please email us at

**CAPDRegistry@theipi.org**

## We Thank the Following Individuals and Organizations for their Continued Support of the CPDR

Parkinson's Action Network (PAN)  
American Parkinson Disease Association (APDA)  
Young Onset Parkinson's Association (YOPA)  
National Parkinson Foundation (NPF)  
Team Parkinson  
Parkinson's Resource Organization (PRO)  
Neurologists

Individuals with Parkinson's disease and their loved ones throughout the state and nation.

For more information about the registry, please visit  
**[www.capdregistry.org](http://www.capdregistry.org)**



# California Parkinson's Disease Registry

*A new database that will provide information about the trends and causes of Parkinson's disease*



## The California Parkinson's Disease Registry

The California Parkinson's Disease Registry (CPDR) Act (AB 2248) was passed on September 29, 2004. The CPDR Act calls for:

- The Director of the California Department of Public Health (CDPH) to create a database of persons with Parkinson's disease.
- Physicians, health care facilities and pharmacists to report new cases of Parkinson's disease.
- All personal information, including the name and address of registered patients to be kept strictly confidential.

### The CPDR Pilot Project

The first phase of registry development will be a pilot project, in which CDPH has contracted with The Parkinson's Institute to allow researchers at the Institute, the UCLA School of Public Health and Kaiser Permanente Northern California to develop a prototype for the registry, and to collect and analyze data from selected target regions in California.

The Pilot Project will explore what methods could be used to create a sustainable model for developing the full-scale registry. The Pilot Project will be led by Principal Investigator Caroline Tanner, M.D., Ph.D. of The Parkinson's Institute and Dr. Beate Ritz of UCLA. Initial funding has been obtained from the National Institute of Environmental Health Sciences, the Michael J. Fox Foundation and the Department of Defense Neurotoxin Exposure Treatment Research Program.

## Why a Registry and Why in California?

- A registry is the most accurate way to determine the number of people with Parkinson's disease and to identify trends in Parkinson's disease rates in the population.
- A registry can determine whether the number of persons with Parkinson's disease, or with young onset Parkinson's disease, is increasing.
- A registry will determine whether factors such as race, ethnicity, gender, age or place of residence influence the likelihood of developing the disease.
- Hospitalization records are inadequate for tracking Parkinson's disease since most care is provided in outpatient settings.
- A registry will provide a systematic way to investigate if Parkinson's disease is caused by exposure to chemical toxins, by linking with environmental health databases in the state.
- Identification of factors causing Parkinson's disease is the first step toward preventing this condition.
- The 35-million population of California means that the new registry could enroll several thousand patients each year, and the state's diversity means it will span a range of socio-economic groups and ethnicities, as well as rural and urban areas.
- A registry will make a dramatic contribution to efforts to find the causes of Parkinson's disease.

## Why Parkinson's Disease?

- Parkinson's disease is the second most common neurodegenerative disease in the elderly, surpassed only by Alzheimer's disease.
- As our population ages, the number and percentage of elderly in the US population is growing rapidly, with a consequent increase in the social and personal burden imposed by these age-related neurodegenerative disorders.
- It is estimated that over 1.5 million people in the United States suffer from Parkinson's disease, with 70,000 newly diagnosed cases per year.
- More people have Parkinson's disease than Muscular Dystrophy, Multiple Sclerosis and Lou Gehrig's Disease combined
- Scientists believe we are close to understanding the causes of Parkinson's disease, a critical step toward preventing the disease and finding effective treatments for it.
- It is likely that understanding Parkinson's disease will open the door to understanding related disorders, such as Alzheimer's disease and motor neuron disease.
- Parkinson's disease drug therapies are used almost exclusively to treat Parkinson's disease, making pharmacy records a convenient and rapid approach to identifying cases.

# California Parkinson's Disease Registry Medical Record Abstraction Form

## Medical Abstractor

Name \_\_\_\_\_ Number \_\_\_\_\_  
Date \_\_\_\_/\_\_\_\_/\_\_\_\_ |\_\_\_\_|:\_\_\_\_|:\_\_\_\_|  
start time

## Patient Information

*\* Primary information required, only complete shaded areas if information is readily available*

**\*Name** \_\_\_\_\_, \_\_\_\_\_  
Last First Middle (MI)

**\*Date of Birth:** \_\_\_\_/\_\_\_\_/\_\_\_\_ ☐ not available

**\*Gender:** ☐ Male ☐ Female ☐ not available

**\*Social Security Number:** |\_\_\_\_|\_\_\_\_|\_\_\_\_|\_\_\_\_|\_\_\_\_|\_\_\_\_| ☐ not available

**\*Medical Record Number:** \_\_\_\_\_ ☐ not available

**\*Home Address (Current):** \_\_\_\_\_ ☐ not available

**\*City, state, zip code:** \_\_\_\_\_ ☐ not available

**Home Phone:** (\_\_\_\_) \_\_\_\_\_ - \_\_\_\_\_ ☐ not available

**Work Phone:** (\_\_\_\_) \_\_\_\_\_ - \_\_\_\_\_ ☐ not available

**Cell Phone:** (\_\_\_\_) \_\_\_\_\_ - \_\_\_\_\_ ☐ not available

**Email:** \_\_\_\_\_ ☐ not available

## Demographic Characteristics (if available)

**\*Ethnicity** ☐ Non-Hispanic/Non-Latino ☐ Hispanic/Latino (*specify*): ☐ not available

☐ Mexican  
☐ Puerto Rican  
☐ Cuban  
☐ Other Hispanic/Latino: \_\_\_\_\_

**\*Race** ☐ not available

☐ White ☐ Asian (*specify*): ☐ Native Hawaiian & Pacific Islander (*specify*)

☐ Black/African American ☐ Asian Indian ☐ Native Hawaiian

☐ American Indian ☐ Chinese ☐ Somoan

☐ Alaska Native ☐ Filipino ☐ Guamanian or Chamorro

☐ Other: \_\_\_\_\_ ☐ Japanese ☐ Other Pacific Islander: \_\_\_\_\_

☐ Korean  
☐ Vietnamese  
☐ Other Asian: \_\_\_\_\_

## Marital Status

☐ Never Married ☐ Married ☐ Separated ☐ Divorced ☐ Widowed ☐ Living w/partner ☐ not available

## Education

☐ <High school ☐ High school ☐ Trade school ☐ College ☐ Graduate school/professional ☐ not available

## Occupation (if available)

Occupation (longest held) \_\_\_\_\_ ☐ Unknown/not available

Occupation (other) \_\_\_\_\_ ☐ Unknown/not available

**Data Source****Medical record type** (*check all that apply*):☐ Electronic☐ Paper, printed☐ Paper, handwritten**Date range of record:** \_\_/\_\_/\_\_ - \_\_/\_\_/\_\_ (*includes all records within chart*)**Physician Information** (*from primary/current data source*)**Physician code:** |\_|\_|\_|\_|\_|\_|\_|\_| (\*If physician is not in code book, complete information below)**\*Name** \_\_\_\_\_ **City** \_\_\_\_\_ **Zip code** \_\_\_\_\_☐ Neurology ☐ Neurosurgeon ☐ Internal Medicine ☐ Geriatrician ☐ Other: \_\_\_\_\_**Other physician** (*from secondary records within chart*)**Physician code:** |\_|\_|\_|\_|\_|\_|\_|\_| (\*If physician is not in code book, complete information below)**\* Name** \_\_\_\_\_ **City** \_\_\_\_\_ **Zip code** \_\_\_\_\_☐ Neurology ☐ Neurosurgeon ☐ Internal Medicine ☐ Geriatrician ☐ Other: \_\_\_\_\_**Other physician** (*from secondary records within chart*)**Physician code:** |\_|\_|\_|\_|\_|\_|\_|\_| (\*If physician is not in code book, complete information below)**\* Name** \_\_\_\_\_ **City** \_\_\_\_\_ **Zip code** \_\_\_\_\_☐ Neurology ☐ Neurosurgeon ☐ Internal Medicine ☐ Geriatrician ☐ Other: \_\_\_\_\_**Other physician** (*from secondary records within chart*)**Physician code:** |\_|\_|\_|\_|\_|\_|\_|\_| (\*If physician is not in code book, complete information below)**\* Name** \_\_\_\_\_ **City** \_\_\_\_\_ **Zip code** \_\_\_\_\_☐ Neurology ☐ Neurosurgeon ☐ Internal Medicine ☐ Geriatrician ☐ Other: \_\_\_\_\_If case was not reported from a physician's practice, please indicate other source of record below. ☐ N/A

|                                                                                                                                                                                                                                                                             |                                                                                                                                                                                                                                                                          |                                                                                                                                                                                                                                                                                                                                    |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <input type="checkbox"/> <b>Pharmacy</b><br><br><b>Pharmacy code:</b>  _ _ _ _ _ <br><input type="checkbox"/> Chain<br><input type="checkbox"/> Private<br><input type="checkbox"/> Hospital<br><input type="checkbox"/> Mail order<br><input type="checkbox"/> Other _____ | <input type="checkbox"/> <b>Hospital/Medical Facility</b><br><br><input type="checkbox"/> Inpatient<br><input type="checkbox"/> Outpatient<br><input type="checkbox"/> Emergency room<br><input type="checkbox"/> Long term care<br><input type="checkbox"/> Other _____ | <input type="checkbox"/> <b>Other Source</b><br><br><input type="checkbox"/> Physical/Occupational Therapist<br><input type="checkbox"/> Clinical lab<br><input type="checkbox"/> Home health<br><input type="checkbox"/> Social service<br><input type="checkbox"/> Correctional facility<br><input type="checkbox"/> Other _____ |
| <b>Name</b> _____<br><b>Address, city, zip code</b> _____<br>_____<br><b>Phone</b> (____) ____ - _____                                                                                                                                                                      |                                                                                                                                                                                                                                                                          |                                                                                                                                                                                                                                                                                                                                    |

**Primary Diagnosis (required):**

| Diagnostic Term                                                           | Month and Year of Diagnosis |
|---------------------------------------------------------------------------|-----------------------------|
| Parkinson's disease/Parkinsonism (332.0)                                  | ___/___                     |
| Other degenerative disorders of the basal ganglia (MSA, PSP etc.) (333.0) | ___/___                     |
| Secondary parkinsonism (332.1)                                            | ___/___                     |
| Lewy body disease (331.82)                                                | ___/___                     |
| Comment:                                                                  |                             |

**Secondary Diagnoses**

| Comorbid conditions | ICD-9 Code(s) | Month and Year of Diagnosis |
|---------------------|---------------|-----------------------------|
| Dementia (any type) |               | ___/___                     |
| Essential Tremor    |               | ___/___                     |
| Dystonia            |               | ___/___                     |

| Surgical Treatments for PD                                                                                                                                                                  | Month and Year of Procedure |
|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------|
| <input type="checkbox"/> Deep Brain Stimulation                                                                                                                                             | ___/___                     |
| <input type="checkbox"/> Neuroablative procedures:<br><input type="checkbox"/> ventrolateral thalamotomy<br><input type="checkbox"/> pallidotomy<br><input type="checkbox"/> subthalamotomy | ___/___                     |

| Disease Onset                                                                                                                                                                                                                                                                        | Month/Year |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------|
| Onset Date (indicate symptoms noted):                                                                                                                                                                                                                                                | ___/___    |
| <input type="checkbox"/> Resting Tremor ( <input type="checkbox"/> Right <input type="checkbox"/> Left <input type="checkbox"/> Unspecified)<br><input type="checkbox"/> Bradykinesia<br><input type="checkbox"/> Cogwheel Rigidity<br><input type="checkbox"/> Postural Instability |            |

**Case Definition/Diagnostic Criteria**

| Cardinal Signs/Symptoms of PD                                                                                                                                                                                                                                                                                                                          |                                                                                                                                                                                                                                                                                         |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <input type="checkbox"/> <b>Resting Tremor</b> (or one of the following):<br><input type="checkbox"/> Tremor<br><input type="checkbox"/> Shaking<br><input type="checkbox"/> Jerking movements<br><input type="checkbox"/> Trembling                                                                                                                   | <input type="checkbox"/> Noted Present<br><input type="checkbox"/> Noted Absent<br><input type="checkbox"/> Noted Uncertain<br><input type="checkbox"/> Not available<br>Comment:                                                                                                       |
| <input type="checkbox"/> <b>Bradykinesia</b> (or one of the following):<br><input type="checkbox"/> Slowness<br><input type="checkbox"/> Slow movements                                                                                                                                                                                                | <input type="checkbox"/> Noted Present<br><input type="checkbox"/> Noted Absent<br><input type="checkbox"/> Noted Uncertain<br><input type="checkbox"/> Not available<br>Comment:                                                                                                       |
| <input type="checkbox"/> <b>Cogwheel rigidity</b> (or one of the following):<br><input type="checkbox"/> Rigidity<br><input type="checkbox"/> Stiffness<br><input type="checkbox"/> Tightness                                                                                                                                                          | <input type="checkbox"/> Noted Present<br><input type="checkbox"/> Noted Absent<br><input type="checkbox"/> Noted Uncertain<br><input type="checkbox"/> Not available<br>Comment:                                                                                                       |
| <input type="checkbox"/> <b>Postural Instability</b> (or one of the following):<br><input type="checkbox"/> Falling<br><input type="checkbox"/> Loss of balance<br><input type="checkbox"/> Difficulty in maintaining balance<br><input type="checkbox"/> Unstable gait<br><input type="checkbox"/> Stumbling<br><input type="checkbox"/> Unsteadiness | <input type="checkbox"/> Noted Present<br><input type="checkbox"/> Noted Absent<br><input type="checkbox"/> Noted Uncertain<br><input type="checkbox"/> Not available<br>Comment:                                                                                                       |
| <input type="checkbox"/> <b>Asymmetry, at onset</b> (or one of the following):<br><input type="checkbox"/> Any dysfunction (tremor, bradykinesia or rigidity) more pronounced on one side of body than the other<br><input type="checkbox"/> More difficulty moving one side of body than the other                                                    | <input type="checkbox"/> Noted Present: ( <input type="checkbox"/> Right <input type="checkbox"/> Left <input type="checkbox"/> Unspecified)<br><input type="checkbox"/> Noted Absent<br><input type="checkbox"/> Noted Uncertain<br><input type="checkbox"/> Not available<br>Comment: |
| <input type="checkbox"/> <b>Asymmetry, ever*</b> (or one of the following):<br><input type="checkbox"/> Any dysfunction (tremor, bradykinesia or rigidity) more pronounced on one side of body than the other<br><br>*only record if Asymmetry at onset is <u>not</u> available                                                                        | <input type="checkbox"/> Noted Present: ( <input type="checkbox"/> Right <input type="checkbox"/> Left <input type="checkbox"/> Unspecified)<br><input type="checkbox"/> Noted Absent<br><input type="checkbox"/> Noted Uncertain<br><input type="checkbox"/> Not available<br>Comment: |
| <input type="checkbox"/> <b>L-dopa/DA benefit</b> (or one of the following):<br><input type="checkbox"/> ≥ 1 year of continuous therapy                                                                                                                                                                                                                | <input type="checkbox"/> Noted Present<br><input type="checkbox"/> Noted Absent<br><input type="checkbox"/> Noted Uncertain<br><input type="checkbox"/> Not available<br>Comment:                                                                                                       |
| <input type="checkbox"/> <b>Progressive Disorder</b>                                                                                                                                                                                                                                                                                                   |                                                                                                                                                                                                                                                                                         |

|                                                                                                                |                                                                                                                                                                                   |
|----------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <input type="checkbox"/> <b>Early dementia</b> (preceding motor symptoms or in the first year after diagnosis) | <input type="checkbox"/> Noted Present<br><input type="checkbox"/> Noted Absent<br><input type="checkbox"/> Noted Uncertain<br><input type="checkbox"/> Not available<br>Comment: |
|----------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|

**Medication for Parkinson's Disease** *\*If taking L-Dopa/Decarboxylase inhibitors or DA then no need to collect information on other medications (shaded boxes)*

| Medication (ever used)<br>*primary medication of interest                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              | Currently on any therapy?                                                                                                                   | Earliest Mo/Yr of initial therapy? (if available) |
|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------|
| <input type="checkbox"/> <b>*L-Dopa/Decarboxylase inhibitors (specify):</b><br><input type="checkbox"/> Levodopa-carbidopa (Parcopa, Sinemet, Sinemet CR, Carbilev)<br><input type="checkbox"/> Carbidopa-levodopa-entacapone (Stalevo)<br><input type="checkbox"/> Carbidopa (Lodosyn)<br><input type="checkbox"/> Levodopa (Bendopa, Dopar, Larodopa)                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                | <input type="checkbox"/> Yes<br><input type="checkbox"/> No<br><input type="checkbox"/> Uncertain<br><input type="checkbox"/> Not available | ____ / ____                                       |
| <input type="checkbox"/> <b>*Dopamine receptor agonists (specify):</b><br><input type="checkbox"/> Pramipexole dihydrochloride (Mirapex)<br><input type="checkbox"/> Ropinirole hydrochloride (Requip)<br><input type="checkbox"/> Pergolide (Permax)<br><input type="checkbox"/> Bromocriptine (Parlodel)<br><input type="checkbox"/> Rotigotine (Neupro)<br><input type="checkbox"/> Cabergoline (Dostinex)<br><input type="checkbox"/> Apomorphine hydrochloride (Apokyn)                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           | <input type="checkbox"/> Yes<br><input type="checkbox"/> No<br><input type="checkbox"/> Uncertain<br><input type="checkbox"/> Not available | ____ / ____                                       |
| <input type="checkbox"/> <b>Dopamine antagonists</b><br><input type="checkbox"/> Neuroleptic, conventional<br><input type="checkbox"/> Chlorpromazine (Thorazine)<br><input type="checkbox"/> Fluphenazine (Prolixin)<br><input type="checkbox"/> Haloperidol (Haldol)<br><input type="checkbox"/> Mesoridazine (Serentil)<br><input type="checkbox"/> Molindone (Moban)<br><input type="checkbox"/> Perphenazine (Trilafon)<br><input type="checkbox"/> Pimozide (Orap)<br><input type="checkbox"/> Prochlorperazine (Compazine)<br><input type="checkbox"/> Thioridazine (Mellaril)<br><input type="checkbox"/> Thiothixene (Navane)<br><input type="checkbox"/> Trifluoperazine (Stelazine)<br><input type="checkbox"/> Neuroleptic, atypical<br><input type="checkbox"/> Aripiprazole (Abilify)<br><input type="checkbox"/> Clozapine (Clozaril)<br><input type="checkbox"/> Olanzapine (Zyprexa)<br><input type="checkbox"/> Paliperidone (Invega)<br><input type="checkbox"/> Quetiapine (Seroquel)<br><input type="checkbox"/> Risperidone (Risperdal)<br><input type="checkbox"/> Ziprasidone (Geodon)<br><input type="checkbox"/> Antiemetic<br><input type="checkbox"/> Metoclopramide (Reglan, Maxolon, Clopra)<br><input type="checkbox"/> Prochlorperazine (Compazine)<br><input type="checkbox"/> Trimethobenzamide (Tigan)<br><input type="checkbox"/> Certain tricyclics?<br><input type="checkbox"/> Amoxapine (Asendin, Asendis, Defanyl, Demolox, Moxadil)<br><input type="checkbox"/> Loxapine (Loxapac, Loxitane) | <input type="checkbox"/> Yes<br><input type="checkbox"/> No<br><input type="checkbox"/> Uncertain<br><input type="checkbox"/> Not available | ____ / ____                                       |

|                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |                                                                                                                                             |  |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------|--|
| <input type="checkbox"/> <b>Anticholinergics (specify):</b><br><input type="checkbox"/> Benztropine Mesylate (Cogentin)<br><input type="checkbox"/> Biperiden hydrochloride (Akineton)<br><input type="checkbox"/> Procyclidine (Kemadrin)<br><input type="checkbox"/> Trihexylphenidyl (Artane)                                                                                                                                                                                                                                                                       | <input type="checkbox"/> Yes<br><input type="checkbox"/> No<br><input type="checkbox"/> Uncertain<br><input type="checkbox"/> Not available |  |
| <input type="checkbox"/> <b>Amantadine hydrochloride</b> (Symmetrel, Symadine)                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         | <input type="checkbox"/> Yes<br><input type="checkbox"/> No<br><input type="checkbox"/> Uncertain<br><input type="checkbox"/> Not available |  |
| <input type="checkbox"/> <b>Monoamine oxidase inhibitors:</b><br><input type="checkbox"/> Selegiline hydrochloride (Eldepryl, Emsam, Zelapar)<br><input type="checkbox"/> Rasagiline (Azilect)                                                                                                                                                                                                                                                                                                                                                                         | <input type="checkbox"/> Yes<br><input type="checkbox"/> No<br><input type="checkbox"/> Uncertain<br><input type="checkbox"/> Not available |  |
| <input type="checkbox"/> <b>COMT inhibitors (specify):</b><br><input type="checkbox"/> Entacapone (Comtan)<br><input type="checkbox"/> Tolcapone (Tasmar)                                                                                                                                                                                                                                                                                                                                                                                                              | <input type="checkbox"/> Yes<br><input type="checkbox"/> No<br><input type="checkbox"/> Uncertain<br><input type="checkbox"/> Not available |  |
| <input type="checkbox"/> <b>Other (specify):</b><br><input type="checkbox"/> Coenzyme Q-10<br><input type="checkbox"/> Other _____<br><b>Foreign name brand PD drugs:</b><br><input type="checkbox"/> Levodopa-beserazide (Prolopa)<br><input type="checkbox"/> Levodopa-carbidopa (Atamet, Madopar HBS)<br><input type="checkbox"/> Apomorphine hydrochloride (Apo-go)<br><input type="checkbox"/> Pergolide (Celance)<br><input type="checkbox"/> Pramipexole dihydrochloride (Mirapexin)<br><input type="checkbox"/> Monoamine oxidase inhibitor: (Atapryl, Carbox) | <input type="checkbox"/> Yes<br><input type="checkbox"/> No<br><input type="checkbox"/> Uncertain<br><input type="checkbox"/> Not available |  |

:

Stop time

Data Collection Efficiency

Please evaluate the efficiency of data collection on the following scale  
(1=very poor, 2=poor, 3=fair, 4=good, 5=excellent)

1. Access to Records:

1

2

3

4

5

Can’t judge

Comments

2. Legibility of Records:

1

2

3

4

5

Can’t judge

Comments

3. Organization of Records:

1

2

3

4

5

Can’t judge

Comments

4. Completeness of Record:

1

2

3

4

5

Can’t judge

Comments

Notes