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Parkinson's Disease Data and Organizing Center

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The Parkinson's Disease Data and Organizing Center (PDDOC) was established at the University of Rochester in 2004 under a cooperative agreement with the sponsor the National Institute of Neurological Disorders and Stroke (NINDS). It is being developed to serve as a national resource to advance translational and clinical research in Parkinson's disease (PD). The PD-DOC plans to maintain an emphasis on flexibility and malleability, not only because it is in its early phases of development, but also in response to the changing scientific landscape of PD research. In order to be most responsive to the needs of PD researchers, we encourage input from the research community on how to optimize its impact in advancing research progress.

Resources of the PD-DOC

The stated missions of the PDDOC are to facilitate and promote interinstitutional clinical and translational research in PD by providing, maintaining, and expanding specific shared resources.

PD-DOC database

The PD-DOC is creating a centralized and standardized database of clinical, epidemiological/environmental risk, postmortem neuropathological and biological data from subjects with PD and other parkinsonian conditions. In some instances, data from healthy controls will be collected. One of the goals of the PD-DOC is to maintain high quality and reliability of the database, and so data can be submitted only by users who are approved based on their training and experience and documented proficiency with the database rating instruments. Initial users of the PD-DOC will be investigators in the NIH-funded Morris K. Udall Centers of Excellence in PD Research and some members of the Parkinson Study Group (PSG) but it is expected that users will expand to the wide community of researchers in PD. PD-DOC policies on subject confidentiality, data sharing, conflicts of interest, intellectual property rights, publication, and informed consent are located in the PD-DOC website (www.PD-DOC.org). Investigator-Review-Board-approved wording for obtaining subject consent to transfer data to the PD-DOC that can be incorporated into local research informed consent documents can be found at the PD-DOC website.

For each subject enrolled in the PD-DOC database, it is expected that the full Core Data Set will be completed. The components of the Core Data Set were selected by working groups of investigators from the Udall Centers and other consultants and are provided in the PD-DOC website. Descriptions, instructions, and case report forms for each part of the Core Data Set are also available on the website and are contained in the PD-DOC Operations Manual that is

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sent to each approved user. The frequency with which the Core Data Set is repeated may vary from subject to subject, but for those followed longitudinally it is expected that the maximum time between ratings is 3 years.

For each subject whose data is submitted to the PD-DOC database, the investigator should seek consent from that subject to have a blood sample sent to the NINDS Human Genetics Resource Center at Coriell, where lymphoblastoid cell lines will be established as a permanent source of DNA. Information about how to submit samples can be found at the center's web site (<http://ccr.coriell.org/ninds/comm/submit/submit.html>). The opportunity to link standardized clinical information in the PD-DOC database to DNA specimens should prove to be a valuable resource for advancing research in areas such as genotype–phenotype relationships, gene–environment interactions, and biomarker discovery. Each subject whose data are submitted to the database should also be asked to consider brain donation at the time of death and provided with information on how to do this. Linking standardized postmortem neuropathological examination findings to the clinical data should help advance research progress in studies of clinicopathological correlations.

In order to minimize variability in research data gathered across centers and studies that might be merged and shared, our working groups are developing recommendations for “Beyond Core” assessment instruments. It is clear that the Core Data Set may not provide sufficient information for a variety of research purposes and that additional evaluation procedures are needed. The Beyond Core Data Set will provide recommendations for specific measures that have been selected by our experts from various alternatives. A recommended standardized protocol for magnetic resonance imaging has been prepared and can be found at the PD-DOC website.

Catalog of research materials

The PD-DOC is creating a standardized catalog of postmortem brain samples and other research materials available at user sites for investigative collaborations. The initial information will come from the Udall Centers. There will also be electronic links to catalogs of biological specimens available through the NINDS Human Genetics Resource Center and the National Institute on Aging National Alzheimer's Coordinating Center (NACC).

Interconnections to other PD databases

The PD-DOC is creating electronic links to other existing PD research databases that can be used for data analyses and mining. Included will be NINDS-funded clinical trials of the PSG and the NET-PD program. These databases are being modified to standardize information and enhance ease of use.

Efforts are underway to secure funding to support the use of large subject cohorts that have completed PSG neuroprotective therapy trials as sources of information for the PD-DOC database. Following completion of the trials, participating subjects will be invited to undergo longitudinal follow-up with the core data set and to contribute blood samples to the NINDS genetics repository. This should provide a valuable opportunity to link prospective data on disease course, information on response to therapy and genetic make-up, and possibly other biologic sample analyses to advance pharmacogenomic and biomarker studies.

Electronic links will also be provided to the databases of the NINDS Human Genetics Resource Center and the NACC, both of which already contain information on many cases of PD, relevant conditions such as dementia with Lewy bodies, and healthy controls.

Services of the PD-DOC

Consultation and assistance

PD-DOC investigators and consultants are available to provide consultation and assistance regarding the design, conduct, and analysis of research studies utilizing the PD-DOC and interconnected databases. Specialized consultation can be made available in virtually any relevant field, such as bioinformatics, epidemiology and environmental risks, and outcomes analyses. For approved users, consultation and assistance can be sought via the PD-DOC website.

Training

Direct, paper and electronic means of training will be conducted by PD-DOC investigators for users who submit data to the PD-DOC database to ensure quality and reliability of the captured information. Training in the proper completion of all components of the PD-DOC Core Data Set and in the accurate submission (paper and electronic) of data will take place.

Public access for scientific papers

In order to facilitate the NIH directive in expediting public access to scientific information, the PD-DOC website is available as a central location to post via electronic links scientific manuscripts related to clinical and translational research in PD and related disorders that have been generated by NINDS research support.

Data sharing

In order to help investigators comply with NIH requirements to share research data, the PD-DOC website is also available as a central location to provide electronic links to databases resulting from NINDS-supported clinical and translational research studies in PD and related conditions.

Information center

The PD-DOC website will act as a centralized location to provide investigators with electronic access to other websites that might help advance clinical and translational research in PD, such as those of the NINDS describing animal model, genetic and antibody resources, the Udall Centers, the PSG, the National Institute of Environmental Health and Safety's Cooperative Centers for PD Environmental Research (CCPDER) and PD advocacy groups.

Interactions with the PD research community

The PD-DOC is envisioned to function as a centralized hub that can organize and integrate existing and future PD clinical and translational research resources and activities to advance collaborative work and to maximize the yield of all funding dollars. We hope that the aforementioned information allows PD researchers to understand the goals, resources, and services of the PD-DOC and to see its potential to promote, facilitate, and accelerate research progress. The ultimate success of the PD-DOC will rest with the investigators who will utilize it. In this light, we invite open communications between the PD research community and the PD-DOC to optimize its efforts. Investigators with large clinical research databases in any area of PD clinical or translational research are requested to contact us about establishing electronic linkages through the PD-DOC. Any suggestions on how the PD-DOC can best fulfill its missions are welcome. Information on contacting members of the PD-DOC is located at its website. We look forward with enthusiasm to work with researchers nationwide to alleviate the many critical problems facing patients with PD today.

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