

Data Sharing Plan for the Parkinson's Disease Biomarkers Program (PDBP)

- Clinical data will be entered by PDBP sites in real time via the PDBP DMR
- All clinical data, including imaging data used for clinical evaluation (i.e., DAT scanning, anatomic imaging) should be made immediately available to all PDBP consortium investigators.
- Embargo period: During the first year of the PDBP, data cannot be viewed by those outside the consortium.
- As of November 2013, an up to twelve month embargo period for PDBP has been established. Generally, during this timeframe only PDPB investigators can publish on findings from analysis of PDBP data. However, it may be possible during this embargo period that some approved researchers with a valid institutional affiliation (academic and industry) outside of the PDBP consortium, and with a research request that addresses the goals of the PDBP, can request and receive access to both the clinical data and the biospecimens for analysis, as long as they agree to respect any specified embargo period.
- Following the embargo period which begins in November 2013, all clinical data will be available to the general research community (via a controlled and tracked approval process, i.e. Data Access Committee Approval). Data updates will be made on a regular basis to the controlled access PDBP database.
- Aggregate (non-individual level) data will be released immediately and publicly available (on website, no application or approval process required).
- Analyzed data including laboratory and hypothesis testing imaging data will be made available per the individual project milestones.