

Nephrotic Syndrome Study Network (NEPTUNE) Data Archive

Pro non-inflammatory glomerular diseases, including minimal change disease (MCD), focal and segmental glomerulosclerosis (FSGS) and membranous nephropathy (MN), account for approximately 15% of prevalent end-stage renal disease (ESRD) cases in the United States. Development of successful therapeutic interventions is hindered by a limited knowledge of underlying glomerular disease mechanisms. In response to the need for research concerning these conditions, the Nephrotic Syndrome Study Network (NEPTUNE) was established to investigate the underlying disease mechanisms, elucidate pathogenesis, and identify therapeutic targets for clinical trials.

The NEPTUNE cohort study is a prospective, observational study that enrolls children and adults with FSGS, MCD, and MN. Participants have a proteinuria ≥ 500 mg/day, estimated from a 24-hour or protein to creatinine ratio urine collection. Participants with sub-nephrotic proteinuria are also included to capture the broad spectrum of clinical presentation.

Archive files are organized into the following directories:

- Data
- Documents
- Dataset Integrity Check (DSIC)

Data

The NEPTUNE Data directory contains the following datasets:

- LONGITUDINAL_DS.CSV
- longitudinal_ds.sas7bdat
- PATIENT_DS.CSV
- patient_ds.sas7bdat

Data/Contents

- LONGITUDINAL_DD.xlsx
- Patient_DD.xlsx

Data/Formats

- longitudinal_formatscts.sas7bdat
- patient_formatscts.sas7bdat

Documents

The NEPTUNE Documents directory contains the following documents (Note: The data collection forms are located in the Manual of Procedures documents):

- NEPTUNE1 Manual of Procedures.pdf

- NEPTUNE2 Manual of Procedures.pdf
- NEPTUNE6801 Protocol Version 18Mar19_FINAL.pdf

DSIC

The NEPTUNE Dataset Integrity Check (DSIC) directory contains the following:

- NEPTUNE_DSIC.pdf