

Nephrotic Syndrome Study Network (NEPTUNE)

 consortiapedia.fastercures.org/consortia/neptune/

Research Areas



Tool Development

At a Glance

- Status: **Active Consortium**
- Year Launched: **2010**
- Initiating Organization: **NIH Rare Disease Clinical Research Network**
- Initiator Type: **Government**
- **Rare** disease
- Location: **International**

Abstract

The Nephrotic Syndrome Study Network (NEPTUNE) is an integrated group of academic medical centers, patient support organizations (the NephCure Foundation and the Halpin Foundation), and clinical research resources dedicated to advancing the understanding and treatment of minimal change disease, focal and segmental glomerulosclerosis, and membranous nephropathy.

Mission

NEPTUNE brings together physician scientists at 22 research consortia in the United States and Canada, along with the patient advocacy groups, NephCure Kidney International and the Halpin Foundation, to advance research on the diseases that define nephrotic syndrome (NS). Already, NEPTUNE has collected biological material and detailed clinical data from more than 450 NS research participants and has supported pilot and ancillary studies utilizing the NEPTUNE data resources.

Structure & Governance

This consortium is part of the Rare Diseases Clinical Research Network (RDCRN), an initiative of the Office of Rare Diseases Research, National Center for Advancing Translational Sciences (NCATS). The RDCRN is designed to advance medical research on rare diseases by providing support for clinical studies and facilitating collaboration, study enrollment, and data sharing. Through the RDCRN consortia, physician scientists and their multidisciplinary teams work together with patient advocacy groups to study more than 200 rare diseases at sites across the nation.

Funding and scientific oversight for the RDCRN are provided by NCATS and 10 NIH components: Eunice Kennedy Shriver National Institute of Child Health and Human Development; National Cancer Institute; the National Heart, Lung and Blood Institute; National Institute of Allergy and Infectious Diseases; National Institute of Arthritis and Musculoskeletal and Skin Diseases; National Institute of Dental and Craniofacial Research; National Institute of Diabetes and Digestive and Kidney Diseases; National Institute of Mental Health; National Institute of Neurological Disorders and Stroke; and Office of the Director. In addition, patient advocacy groups provide funds for many of the projects.

Financing

Now in the second five-year funding cycle, NEPTUNE continues to recruit more research participants as well as to support training and research programs for scientists and clinicians.

Patent Engagement

The RDCRN NEPTUNE Contact Registry is a way for patients with NS and their family members to learn about NEPTUNE research studies that they may be able to join. Participation is completely voluntary, and participants can withdraw at any time. There is no cost to join the Contact Registry.

Impact/Accomplishment

NEPTUNE Studies:

6801: [The Nephrotic Syndrome Study Network \(NEPTUNE\) Longitudinal Cohort](#)

Idiopathic Membranous Nephropathy:

6804: [Membranous Nephropathy Trial of Rituximab \(MENTOR\)](#)

Other Nephrotic Research:

[Randomized, Double-Blind, Safety and Efficacy Study of RE-021 \(Sparsentan\) in Focal Segmental Glomerulosclerosis \(DUET\)](#)

[Study of Losmapimod to Reduce Proteinuria in Idiopathic FSGS](#)

Links/Social Media Feed

Homepage

<http://www.rarediseasesnetwork.org/cms/neptune>

Points of Contact

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