Inherited Neuropathies Consortium (INC)

Research Areas

Tool Development
Resource

Product Development

At a Glance

- Status: Active Consortium
- Year Launched: 2009
- Initiating Organization: NIH Rare Disease Clinical Research Network
- Initiator Type: Government
- Rare disease
- Location: International

Abstract

The Inherited Neuropathies Consortium (INC) is an integrated group of academic medical centers, patient support organizations, and clinical research resources dedicated to conducting clinical research in different forms of Charcot-Marie-Tooth (CMT) disease and improving the care of patients. Funded by the National Institutes of Health (NIH), the INC is part of the Rare Diseases Clinical Research Network.

Mission

The mission of the INC is to conduct clinical research to learn more about CMT with the goal of developing new and better treatments to improve the care of patients with inherited neuropathies. It also seeks to provide up-to-date information for patients to help them manage their diseases and to assist in connecting patients with support groups, expert doctors, and clinical research opportunities.

Goals of the INC are as follows:
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; National Heart, Lung and Blood Institute; the 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; the National Institute of Neurological Disorders and Stroke; and Office of the Director. In addition, patient advocacy groups provide funds for many of the projects.

Patent Engagement

The INC Contact Registry is a way for patients with inherited neuropathies and their family members to learn about INC research studies 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.

Links/Social Media Feed

Homepage http://www.rarediseasesnetwork.org/INC/index.htm

Points of Contact

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Sponsors & Partners

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University of Pennsylvania
University of Rochester
Wayne State University

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