Aim

Developing Health Networks in Rare and Neglected Diseases is a novel course offering launched by the CRND. The aim is to train undergraduate students to become clinical experts in one rare disease so they can assist in developing natural histories of rare diseases. They also raise awareness for rare diseases. The first disease students researched was Niemann Pick Type C disease. It is a fatal, neurodegenerative genetic disorder. Student research has now been extended to other rare diseases in local communities. It is important to define natural histories to shorten the time to diagnosis. Students also assist as interns with the National Organization of Rare Diseases (NORD).

Moving forward

The class has become a model to recruit students from other pre-med programs to train them in assessing and defining rare disease natural histories from patient records. By collecting and recording natural histories, a rare disease may become non-rare. A patient-oriented, centralized repository of natural histories can overcome the barrier of access to rare information. Families and Physicians may be able to diagnose more quickly, and therapeutics can be evaluated with small patient sizes.

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Sixty-four undergraduate students, expertly trained to assess medical records, published their clinical research in the scientific journal *PLoS One*. The manuscript is titled, “Defining Natural History: Assessment of the Ability of College Students to Aid in Characterizing Clinical Progression of Niemann-Pick Disease, Type C”. [http://www.plosone.org/article/info:doi/10.1371/journal.pone.0023666](http://www.plosone.org/article/info:doi/10.1371/journal.pone.0023666) The work was done in collaboration with National Institute of Child Health and Human Development, National Institutes of Health and Notre Dame. Upper-class pre-med undergraduate and biomedical graduate students first received HIPAA certification and learned the rules governing patient privacy and security.

Then they learned the clinical disease, how to recognize symptoms, diagnosis and emerging therapies. Using de-identified records from NPC patients, they converted clinical notes into quantitative digital information. Student assessment of new records donated by NPC families directly to the study also revealed that the disease progressed more quickly at later stages.

Students have also begun work with the Michiana Health Information Network (MHIN) to examine the assessment of rare diseases in the local community. Students assist patient families in donating medical records directly to Rare Health Exchange (RHE) [http://rarehealthexchange.org/](http://rarehealthexchange.org/) and engage as NORD (National Organization of Rare Diseases) interns to assist with rare disease reports [http://www.rarediseases.org/rare-disease-information/rare-diseases/byID/1097/viewAbstract](http://www.rarediseases.org/rare-disease-information/rare-diseases/byID/1097/viewAbstract)