

INTERNATIONAL CHOROIDEREMIA RESEARCH NETWORK LAUNCHES WITH A GLOBAL GOAL TO CURE THIS RARE INHERITED EYE DISEASE

Choroideremia Research Foundation spearheaded ICRN's formation with 90 researchers from 25 countries and growing

SPRINGFIELD, MA, UNITED STATES, October 18, 2021 /EINPresswire.com/ -- The Choroideremia Research Foundation is pleased to announce the establishment of the International Choroideremia Research Network (ICRN), a global alliance that currently has 90 researchers from 25 countries who are working in concert to accelerate scientific knowledge about choroideremia (CHM). The ICRN convened its first meeting in August 2021.

The network is composed of multi-disciplinary vision professionals with varied experiences, backgrounds and interests, who share a passion to improve outcomes for patients with CHM, a rare inherited retinal disease that causes progressive vision loss which may lead to blindness for which there is currently no treatment or cure.

The ICRN established five initial working groups as a core strategy to achieve the network's goal of accelerating scientific knowledge of CHM. The working groups include:

Industry Collaboration

Members will hear presentations from industry companies that are interested in validating their preclinical agents for CHM with animal or cell models, including CHM patients in upcoming trials, receiving feedback on trial design and enrollment protocols, and identifying PI's or trial site partners.

Pathophysiology/Mechanism of Disease

Members will discuss the root causes of CHM such as mutations, biomarkers, protein expression, phenotyping, phagocytosis, genetics, as well as imaging results, and how identified abnormalities may affect outcomes for CHM patients. Collaborating with other working groups, the intent is to conduct research, publish papers and launch clinical trials.

Therapeutics/Clinical Trials

Members will discuss gene therapy, stem cell therapy, pharmacological therapy, complementary

therapy, and optogenetics trials designed to slow or stop progression, or regenerate lost vision in CHM patients. Establishment of endpoints related to trial outcomes will also be discussed. Collaborating with other working groups, the intent is to conduct research, publish papers and launch clinical trials.

International Data Collection

Gathering global natural history and incidence data is critical to gaining a better understanding of CHM, and this group will work to collect data and standardize the information to allow for improved statistical analysis. Review of a proposed CHM Staging document will be included.

Female Carriers

Little is known about females who carry the CHM gene; group participants will discuss imaging results, conduct surveys, and study progression and pathology of women diagnosed with CHM.

Membership in the ICRN is free and open to all interested clinicians and academic researchers that have an interest in CHM. For more information about ICRN or CRF, or to become a network member, please visit curechm.org/icrn/

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