NIH adds first images to major research database

November 23 2010

The National Institutes of Health has expanded a genetic and clinical research database to give researchers access to the first digital study images. The National Eye Institute (NEI), in collaboration with the National Center for Biotechnology Information (NCBI), has made available more than 72,000 lens photographs and fundus photographs of the back of the eye, collected from the participants of the Age-Related Eye Disease Study (AREDS).

These images are now accessible to scientists through NCBI's online database of Genotypes and Phenotypes, known as dbGaP, which archives data from studies that explore the relationship between genetic variations (genotype) and observable traits (phenotype). Though study descriptions and protocols are publicly accessible, researchers must apply for controlled access to de-identified information about study subjects, including the new images.

"The availability of AREDS images through dbGaP may transform the way we conduct vision research," said NEI director Paul A. Sieving, M.D., Ph.D. "Scientists can increase their understanding of the impact of genetics and gene-environment interactions on blinding eye disease progression, which could aid in diagnosis and in developing effective treatments."

The NEI-supported AREDS was one of two studies included in the December 2006 launch of dbGaP. The first version of controlled-access AREDS information was made available in 2007, including data

gathered from genome-wide scans of DNA samples from 600 study participants. The database was updated in November 2008 to include clinical trial and natural history information from the 4,757 total AREDS participants over 10 years. The latest addition to the AREDS dataset includes more than 72,000 lens and fundus photographs from 595 study participants with genome-wide scan data available.

"The National Center for Biotechnology Information is very pleased to be involved in this effort to provide researchers with access to the images from AREDS," said NCBI director David Lipman, M.D. "Linking individual study subjects' eye photographs with their phenotype and genotype data provides a valuable new dimension of information for researchers to explore in attempting to understand age-related eye disease."

AREDS began in 1992 as a multi-center, prospective study designed to evaluate the progression of age-related macular degeneration and age-related cataract. Participants, who were age 55 to 80 when the study started, also enrolled in a clinical trial of high-dose vitamin and mineral supplements. They were followed for a median of 6.5 years during the trial and five years after the study ended. Beginning in 1998, DNA was also isolated from blood samples obtained from more than 3,700 AREDS participants.

"AREDS has been the main focus of the translational research program at NEI for a number of years," said NEI clinical director Frederick L. Ferris III, M.D. "This new group of lens and fundus images from well-described study participants provides a new opportunity for vision research, and is a valuable resource for clinical teaching and training as well."

More information: Open-access AREDS data and a link to apply for controlled access to individual-level data, including the new images, can

be found on the NEI-AREDS study page at www.ncbi.nlm.nih.gov/gap

Provided by NIH/National Eye Institute