

A Brief Overview About the FFB Rare Eye Donor Tissue Inventory:

- FFB supports the collection of whole globes post mortem from donors with retinitis pigmentosa, Usher syndrome, Stargardt disease, and other rare inherited retinal degenerative diseases (RDDs). FFB also collects donations from individuals affected with age-related macular degeneration. FFB does not collect normal eyes.
- To sustain the collection the Foundation supports an RDD Pathophysiology Facility housed at the Cleveland Clinic Foundation Cole Eye Institute under the direction of Joe G. Hollyfield, Ph.D.
- This facility is supported through FFB's Grants & Awards Program and undergoes periodic peer review as do all FFB funded research grants. Investigators who use FFB funded tissue and whose research results are reported in publication(s) should acknowledge the Foundation's rare eye donor program and provide copies of the publication to FFB and the Cole Eye Institute.
- Over 900 pairs of eyes have been collected since the mid-1980s.
- Most of the tissue samples are fixed in a buffered 4% paraformaldehyde-0.5% glutaraldehyde solution or 10% formalin when the FFB fixative is not available. The tissue is transferred to buffered 2% paraformaldehyde when the eye is cut through the ora serrata and anterior and posterior segments are imaged. Detailed information regarding the fixation of individual samples is included in each donation's pathology report. In addition, the fellow eye may be frozen.
- Initial fundus microscopy examination is done by Dr. Hollyfield and his staff and they provide pathology reports for all donations that are then made available to researchers upon request.
- The most useful donor eyes on which detailed follow up analysis is performed are those with full clinical history and the genetic basis of the disease is established. Such donations are extremely rare. To gather such information, the facility includes a genetic counselor who interacts with the eye donor's family to obtain a complete family history and authorization for medical record release. Once these records are received and reviewed by the genetic counselor, she consults with Dr. Elias Traboulsi, an expert in ophthalmic genetics and inherited retinal dystrophies. A determination is then made as to the type of RDD the donor eye is most likely affected by and if genetic testing for molecular diagnostic confirmation is feasible.
- The genetic counselor also interacts with the family of the donor eyes to obtain DNA samples from family members for molecular analysis. Genetic testing is performed on a case by case basis. Through this interaction with and participation from families, the ability to determine the genetic basis of the RDD in donor eyes has greatly improved.
- Tissue samples are available to RDD researchers whose stated research matches the mission of the Foundation's research program. Investigators interested in using tissue from the FFB inventory should complete the "application for obtaining ocular tissue for research" and submit it to Dr. Hollyfield at hollyfj@ccf.org or fax it to his attention at 216-445-3670. Dr. Hollyfield will determine if there is tissue available in the collection to meet the investigator's request and if the project matches FFB's goals for the program.

For more information, please visit http://my.clevelandclinic.org/eye/research/donor_program.aspx, a webpage hosted by the Cole Eye Institute on Dr. Hollyfield's research about the FFB tissue inventory. On the webpage is a place to download an inventory of available tissue and the application to complete if interested in obtaining tissue for research.