

Wills Eye Research Team Leads the Way in Analyzing **BIG DATA**

ONE OF JUST FOUR INSTITUTIONS IN AAO'S GROUNDBREAKING IRIS® REGISTRY

With over 700 million electronic records, the American Academy of Ophthalmology's (AAO) Intelligent Research in Sight (IRIS®) is the largest medical specialty registry in the world. And Wills Eye Hospital is one of just four academic institutions in the United States with full access to this vital trove of information.

“The IRIS® Registry is an incredibly powerful resource with amazing potential to help shape patterns of eye care for the future,” said Leslie G. Hyman, PhD, an ocular epidemiologist and Vice Chair of Research and Director of the **Vickie and Jack Farber Vision Research Center at Wills Eye**, who oversees numerous pioneering projects utilizing the expansive data set. The registry contains the records of more than 70 million patients (anonymously to comply with HIPAA) and data from about 17,000 practices (ophthalmologists and allied eye care providers) across the country.

Wills Eye and the other institutions—University of Washington, Stanford University, and Massachusetts Eye and Ear/Harvard Ophthalmology—form the IRIS Registry Analytic Center Consortium in collaboration with AAO. The registry has enabled Dr. Hyman and her research team to collaborate with investigators at Wills Eye and other centers on novel topics across an array of subspecialties.

“The availability of this large database presents a remarkable opportunity to advance knowledge in ophthalmology through studies of rare eye conditions, treatment outcomes using real world clinical data, and investigations of disparities in eye care patterns,” she said.

Leslie G. Hyman, PhD, standing, collaborates with her research team to plan a new IRIS® Registry analysis.

Dr. Hyman joined Wills Eye in 2016 after serving as Head of the Division of Epidemiology and Biostatistics, Department of Family, Population & Preventive Medicine at New York's Stony Brook Medicine, Stony Brook University. She has led groundbreaking studies and published more than 250 papers, abstracts, and book chapters throughout



“The IRIS® Registry is an incredibly powerful resource with amazing potential to help shape patterns of eye care for the future.”

—Leslie G. Hyman, PhD

her career. With expertise in observational epidemiologic research and clinical trials, much of her work has focused on identifying the etiology, risk factors, and treatment of some of the leading causes of visual impairment and blindness.

Dr. Hyman explained that AAO launched the IRIS Registry in 2014 to help clinicians track quality metrics and assist practices with reporting requirements. Tracking was done using MIPS—the Merit Based Incentive Payment System. Clinical quality measures were then submitted to the Centers for Medicare and Medicaid Services (CMS) for reimbursement.



After a few years, as the volume of patient records grew, elaborated Dr. Hyman, AAO realized that IRIS had evolved into an incredibly rich database. So, they expanded its application to include scientific discovery.

Wills was among a select group of specialty institutions to apply for full access to the IRIS Registry. Dr. Hyman led the highly competitive application process at Wills Eye, working closely with Dr. Julia Haller, Dr. Allen Ho, and a team of colleagues. Acceptance into the consortium required specific skills and qualifications. “In addition to clinical expertise, we needed to be proficient at working with large data sets and the many intricacies that entailed,” said Dr. Hyman, who recruited a team of data scientists, biostatisticians, and programmers. Wills Eye was selected and access began in late 2019. Since that time, the team has been intensely focused on multiple studies. Several have been completed, and at least 10 more are under way.

One study, led by Michael Morano, MD, a recent graduate of Sidney Kimmel Medical College, examined the risk factors associated with retinal tears after cataract surgery (one of the most common surgical procedures in the U.S.). This study received a 2022 “Best Poster” Award from AAO for its novel findings.

Other research has included examining the risks and associated factors related to thyroid eye disease (TED), visual outcomes in traumatic eye injuries leading to rupture of the eye globe, prevalence of eyelid cancers and their associated factors, and disparities in the use of eye injections to treat retinal vein occlusion.

“Each study has provided new information that helps inform patient management,” said Dr. Hyman. One example is with TED, often associated with Graves’ disease. Dr.

Hyman described TED as a relatively rare condition that can have a devastating impact on an individual’s appearance and vision. “We wanted to learn more about its epidemiology,” she said, “such as its prevalence in different age, gender, race, and ethnicity groups, as well as the frequency of complications.”

Previous research found two peak ages for TED disease onset. “In our analyses, we found one peak age of prevalence, which varied by race and ethnic group,” said Dr. Hyman, “with the highest prevalence among African Americans.” These findings raised questions about the different patterns and led the Wills team to conduct a small pilot study in collaboration with colleagues at LV Prasad Eye Institute in Hyderabad, India, consisting of 30 patients in the U.S. and 30 in India to compare the two populations.

IRIS® TEAM SETS SIGHTS ON FUTURE

“The IRIS Registry opens up new ways of thinking and piecing together many parts of a puzzle,” explained Dr. Hyman. “Some questions can be answered, but we need to also consider limitations typical of large data based on electronic medical records.

“Having a rich data set can help us understand the patterns of diseases and in the long-term this can translate to more precise diagnoses as well as better patient management, education, and guidance.”

In a world increasingly driven by big data and artificial intelligence, Dr. Hyman is excited about the future of the registry. The IRIS team is working toward the goal of merging eye imaging data with clinical data. “The power of that is huge,” she said. “We are literally at the forefront of innovation in the field of ophthalmology.”

◀ *Research Team (from left): Qiang “Ed” Zhang, PhD, Lead Biostatistician; Danielle Trappanese, PhD, Senior Research Program Administrator; Leslie G. Hyman, PhD, Vice Chair of Research and Director, Vickie and Jack Farber Vision Research Center; Luke Alonoso, Data Scientist; Maurizio Tomaiuolo, PhD, Data Scientist.*



Qiang “Ed” Zhang, PhD, gives a lecture on biostatistics to residents at Wills Eye Hospital.



The Vickie and Jack Farber Vision Research Center at Wills Eye

The transformational philanthropy of Vickie and Jack Farber has propelled the research efforts of Wills Eye to new levels. With combined gifts totaling \$7 million, the Farbers’ generosity has enabled Wills Eye physicians and researchers to continue their pursuit of better treatment and cures in all areas of eye disease.

The Farbers both came from modest upbringings in Philadelphia and have experienced the debilitating impact of loved ones touched by neurodegenerative diseases. With their unwavering commitment to vision research and giving back, in 2018, the research center was named in their honor.

Led by internationally recognized epidemiologist, Leslie G. Hyman, PhD, the Vickie and Jack Farber Vision Research Center at Wills Eye fosters a vibrant, collaborative, intellectually stimulating environment focused on the clinical and translational science of ocular disease. It aims to preserve vision through preventing, treating, and curing eye disease.

To learn more, visit willseye.org/research

Note: As we were going to press, we received the very sad news that Jack Farber had passed away on December 7. Our deepest condolences and prayers go out to Vickie, Ellen, and the entire Farber family.

Read more about Jack’s legacy at willseye.org/jackfarber

