The history of the Lions Clubs' service to the vision-impaired is a long and storied one. It dates to the 1920s, when Helen Keller challenged the Lions to become the "knights of the blind." Since then, the Lions have been irrepressible in their aid, starting numerous innovative and impactful initiatives ranging from leader dog training programs and eye banks to pressing for white cane laws across the nation.

"You don't join the Lions unless you are interested in service, and for the Lions, that service is focused on the blind," says Robert Massof, Ph.D., director of the Lions Vision Research and Rehabilitation Center at the Wilmer Eye Institute at Johns Hopkins.

The Lions Low Vision Center is one of the many programs that Lions in the Maryland, District of Columbia and Delaware region—known to the Lions as Multiple District 22—have supported through tireless service and generous philanthropy. Recently, that relationship took a new and unparalleled turn with a program designed to provide direct service to some 5,000 underserved people in the region with low vision. Known as the Lions Low Vision Rehabilitation Network—and aptly dubbed LOVRNET—the program will address a troubling dearth of options amid growing demand for low vision rehabilitation. Other funders include the Reader's Digest Partners for Sight Foundation.

"Low vision is not any one condition, but rather a broad term describing any vision loss that cannot be reversed by glasses, medication or surgery," says Judith Goldstein, O.D., chief of low vision and rehabilitation at the Lions Vision Center. "It is one of the major areas of research and treatment at Wilmer. LOVRNET will deliver novel solutions at an unprecedented scale to address what has been largely an unmet need for many patients."
LOVRNET calls upon the grassroots reach of local Lions Clubs and leverages funding to train and provide professional consultative support to rehabilitation teams, creates a unified support network for patients, matches patients to medical and service providers, and improves the quality of care through continuous professional education for health care providers. Organizers expect the regional LOVRNET initiative to serve as a model for a nationwide rollout.

“The response by the Lions across the board has been overwhelming. The direct service component of LOVRNET has been enthusiastic to the point where they are in many ways ahead of us in ramping up the program’s efforts. The Lions have just been tremendous,” says James Deremeik, education and rehabilitation program manager at Wilmer and director of LOVRNET.

“It is innovative and far-reaching programs like LOVRNET that get the Lions Clubs excited,” says Ted Ladd, chairman of the Lions Vision Research Foundation, which has raised much of the funding for the pilot program.

The relationship between Wilmer and the Lions Clubs began in the late 1980s through the encouragement of Arnall Patz, M.D. As then-director of the Wilmer Eye Institute and as a practicing physician, his transformative ideas and work saved countless individuals from blindness. His contributions continue to improve the lives of millions.

Together, Patz and the Lions created the Lions Vision Center at Wilmer, a multidisciplinary team of doctors and rehabilitative specialists collaborating to restore and improve day-to-day functions—including reading, driving, shopping and other important activities—lost to visual impairment.

Vision rehabilitation at the Lions Vision Center focuses on the person and his or her individual daily needs, not only on treating the disorder. While low vision services are not a cure, visual ability can be improved, sometimes dramatically, in certain patients.

When Patz died in 2010, many who had known, worked with or been treated by him, including the Lions, rallied to endow the Arnall Patz Distinguished Professorship in Ophthalmology, which will benefit the Lions Vision Center, at the behest of Patz’s widow, Ellen, and their children. In this effort, like so many others at Wilmer, the Lions of Multiple District 22 were once again instrumental. With their help, the Patz Professorship’s total recently surpassed the full funding level of $2.85 million (see sidebar), providing the Lions Vision Center the firm financial footing to better serve patients, educate trainees and conduct research on low vision.

“Helen Keller told Patz years ago: ‘If you want to get anything done, call the Lions,’” recalls Ladd. “Since then, the Lions and Wilmer have been tightly connected. We’re proud of our connection with Dr. Patz’s legacy and the work we and Wilmer have done together for all people with low vision.”

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—JUDITH GOLDFEIN, O.D.
PROGSTAR
A NEW PARADIGM IN THE STUDY OF STARGARDT DISEASE

One of clinical ophthalmology’s leading researchers, Hendrik Scholl, M.D., director of visual neurophysiology and of the Retinal Degeneration Clinic, plays a critical role in designing studies to ensure tomorrow’s breakthroughs are both effective and safe before they come to market.

Scholl was recruited to the Wilmer Eye Institute from Germany to lead several groundbreaking studies. Most recently, he set his sights on Stargardt disease, a debilitating and degenerative disease that begins in childhood, by leading a $4.8 million study known as ProgStar. The project is a collaboration between Wilmer and the Foundation Fighting Blindness.

“Stargardt is a fascinating disease for study, first because it starts in childhood, but also from a medical standpoint, “ says Scholl, the Dr. Frieda Derdeyn Bambas Professor of Ophthalmology. “Stargardt’s molecular biology is extremely well understood, and we have gene, medical and stem cell therapies in early clinical trials now. I’m not aware of another disease where you have those approaches in clinical stages of development.”

The challenge from the clinical researcher’s standpoint is that Stargardt is a very slow-progressing disease with complex effects that cause the rate of progression to vary from patient to patient. Symptoms of Stargardt usually begin early on with difficulty reading and spots (visual field defects) in the center of vision. Telltale yellowish flecks in the macula—the heart of the retina where fine details are registered—confirm diagnosis. The yellow flecks are lipofuscin, a normal byproduct of cell function that usually accumulates only slightly. But due to a genetic defect in Stargardt, there is increased accumulation over time. The prognosis is a slow progression to permanent blindness.

Stargardt is so slow-growing, however, that it can take 20 years or more to conduct a single clinical trial to ascertain the efficacy of an intervention using standard methods.

“PROGSTAR IS ALTERING THESE TIME FRAMES. IT’S A VERY IMPORTANT EFFORT TO SHOW INDUSTRY THAT IF WE TAKE A MEASURED APPROACH TO A CLINICAL TRIAL, WE CAN SHOW RESULTS IN JUST ONE TO TWO YEARS, NOT ONE TO TWO DECADES.”
HENDRIK SCHOLL, M.D.
Few pharmaceutical companies have that sort of patience, but ProgStar is altering these time frames,” Scholl says. “It’s a very important effort to show industry that if we take a measured approach to a clinical trial, we can show results in just one to two years, not one to two decades. The patient variability in Stargardt complicates the selection of patients for study and has fostered a debate as to how best to measure the success of clinical trials.

ProgStar, therefore, is actually two studies in one. The first half is a retrospective study of up to 250 patients that looks back at clinical exam results and retinal images collected between 2008 and 2014 to evaluate how Stargardt progresses. The second aspect is a prospective study that will track up to 250 other patients every six months for a two-year period. The patients in the studies, both children and adults, will be recruited from nine clinical centers across the U.S. and Europe. ProgStar is not a clinical trial of a single new therapy. Instead, it will employ advances in retinal imaging and in tools for measuring visual fields and acuity to accelerate evaluation of how existing therapies are performing. Among its many goals, ProgStar will explore and accelerate the study of new drugs informed by advances in genetic science.

In 1907, Karl Stargardt, a German ophthalmologist, first identified the juvenile macular degenerative disease that bears his name. Stargardt is a genetic abnormality that affects the production of a protein that helps remove lipofuscin, a waste chemical, from the retina. As the yellowish lipofuscin builds over time, eyesight degenerates.

Though occurring in just one in 10,000 children, Stargardt nonetheless affects some 30,000 Americans, and many thousands more worldwide. Symptoms usually begin between the ages of 6 and 20.

Though it progresses slowly at first, the degeneration eventually accelerates. In some cases, a person can go from a relatively moderate case to virtual blindness in a matter of months. There is no cure or treatment for Stargardt.

In Stargardt research, there’s nothing quite like ProgStar,” Scholl says. “No one in the world has built the patient cohort we have, and the Wilmer Eye Institute has amassed an unprecedented database of information on the disease that this study will surely enhance. ProgStar will lead to better studies of treatments and increase our chances of success against the disease.”

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“I hope that day won’t come,” she says. “I have four children, and I hope to watch them grow, see their weddings and their children.”

Morris lives in Cincinnati and travels to Baltimore twice a year to visit Wilmer’s Hendrick Scholl, one of the world’s leading experts in the disease. She’s also enrolled in ProgStar, the first-of-its-kind study Scholl is leading to bring a small measure of hope to those suffering from Stargardt.

“I just can’t say enough how lucky I feel to be in Dr. Scholl’s care,” Morris says. “And, being in ProgStar, I know that I’m providing others with Stargardt the same hope I have. Studies like this really do matter.”