Making Progress in the “Decade of Vision”

The number of Americans with vision loss is increasing rapidly as our population increases in age. Costs associated with vision loss are estimated at up to $68 billion annually for healthcare, lost productivity, reduced independence and other factors. In a call to action, Congress declared this the “Decade of Vision” underscoring the unprecedented challenges associated with vision loss and eye disease, and highlighting the need for increased surveillance and nationwide action.

As the leader in vision + health care, Lighthouse Guild is advancing initiatives that promote prevention, early detection, access to treatment and rehabilitation, and vision-related research.

Leveraging leadership

As we stand at the midpoint of the decade, Lighthouse Guild will continue to ensure that advancements in care, treatment and technologies increasingly expand new possibilities for people who are blind or visually impaired. Inside this edition of Vision + Health, we want to share some of our strategic initiatives that are contributing to this “Decade of Vision”. Among the things you’ll learn are:

- The ways we are bringing advancements in vision science to life by providing specialized rehabilitation that enables people to realize the functional, day-to-day benefits of the latest advancements in medical technology.

- Why strengthening the vision research community can bring new energy to our shared purpose, and help lay the foundation for tomorrow’s treatment breakthroughs.

- How the creation of a national support network for college-bound students with vision loss is helping to

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Are you unable to read traditional print books because of vision loss? Lighthouse Guild’s Adaptive Technology Center provides technology solutions and training to address a wide spectrum of needs. Using technology fosters independence, allows people to stay connected to a larger community, helps them continue to do things they love to do, and enables lifelong learning.

**Bookshare** is a great example of putting technology to use. Even if you are no longer able to read standard print, you can still enjoy your favorite books, newspapers, and magazines with Bookshare, the world’s largest collection of accessible ebooks for people with disabilities that affect their ability to read traditional print.

Bookshare has over 385,000 titles covering all subject categories that you can listen to, read in larger print size, read in Braille and more. Materials can be read on a variety of standard computers, smart phones, tablets, MP3 players, and assistive technology devices.

Lighthouse Guild is excited to be working with Bookshare to facilitate enrollment for all the people we serve to help them get started using Bookshare and enjoying books.

To learn more about Bookshare go to: www.bookshare.org.
Revolutionary medical research is continuously producing cures for disease, improving health and increasing longevity. Lighthouse Guild is contributing to breakthroughs in vision loss prevention, treatment and rehabilitation and helping to sustain this strong momentum by gathering renowned vision scientists together each year at our Bressler Vision Science Symposium.

**Energizing advancements in vision science**

“Improving the lives of people who are blind or visually impaired is a core tenet of Lighthouse Guild’s mission. By recognizing, encouraging and engaging some of the greatest minds in the vision research field, we bring new energy to our shared purpose, and help lay the foundation for tomorrow’s breakthroughs,” says Dr. Alan R. Morse, President & CEO of Lighthouse Guild.

“Lighthouse Guild’s Bressler Vision Science Symposium brings together the best and the brightest from all over the world. Only by being exposed to and understanding that level of very important research can we advance our field – and that’s our directive,” says Dr. Roy Chuck, Chairman of the Department of Ophthalmology and Visual Sciences at Montefiore Medical Center and the Albert Einstein College of Medicine, who faithfully attends the annual symposium along with a group of his ophthalmology residents.

**Increasing exposure to ground-breaking research**

Having focused on many pivotal research topics, ranging from epidemiology to genetics and gene therapies, as well as stem cells, service delivery, surgical techniques and neuro-ophthalmology, the symposium has become a leading professional development event for the vision science field.

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With new vision research findings touting the promise of gene therapy treatment, this year’s recipient, Dr. Krzysztof Palczewski, Chair of the Department of Pharmacology at Case Western Reserve University in Cleveland, Ohio, led a timely, in-depth examination of this potentially promising type of treatment.

The breadth of subjects explored has bolstered the symposium’s reputation as one of the nation’s most prestigious vision science gatherings.

“Research has become so specialized that everyone is in their own cubbyhole,” explains Dr. Chuck. “But this annual event pushes us outside of our comfort zones to appreciate what others are finding. This by definition is progress. After all, progress is about exploring what you didn’t know or understand before.”

**Recognizing leaders in vision science**

Dr. Richard Lewis, an ophthalmologist at the Cullen Eye Institute and the Alkek Eye Center, was the recipient in 2003. He believes the symposium is set apart by highlighting professionals who are continuing to make important advancements in the field.

“There is no other event quite like this,” Dr. Lewis observes. “Those selected for the prize or award and asked to serve as the featured presenter each year are the rising stars who hold great promise for the field. It features those individuals who are productive and recognized, but haven’t been fully discovered by the scientific world.”

**Improving the future for people with vision loss**

Research is like a puzzle, with today’s advances building upon yesterday’s discovery. By recognizing the importance of continued research and facilitating future collaborations, Lighthouse Guild is taking a leadership role in strengthening the vision research community. This gives promise to a better future for people who are blind or vision impaired.

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**RECOGNIZING ACHIEVEMENTS**

- The annual Alfred E. Bressler Prize and Vision Science Symposium supports and recognizes the research of an established mid-career vision clinician or researcher whose work has led to important advancements in the understanding of vision loss, treatment of eye disease or rehabilitation of people with vision loss.

- Each year, the recipient of the Bressler Prize is invited to help organize a Vision Science Symposium, selecting peer vision clinicians and researchers to present their related research.

- Lighthouse Guild also awards the Pisart Award each year to an early-career vision clinician or scientist whose scholarly contributions have the potential for substantial influence in the understanding of vision loss, treatment of eye disease or rehabilitation of people with vision loss. The recipient is invited to present a lecture on his/her research.
Bringing Advancements in Vision Science to Life

Across the vision and health care spectrum, research is producing new and exciting treatment options for individuals who are blind or visually impaired. And Lighthouse Guild is at the center of bringing these exciting advancements to daily life.

From miniature telescopes and “bionic eyes” to the futuristic-sounding “brain-port,” today’s advancements in vision technology might sound like science fiction. Increasingly, however, these options are becoming reality and improving the lives, and in some cases restoring some vision for people with vision loss.

“The expertise we’ve gained from serving people who are blind or visually impaired for more than a century is unparalleled,” says Dr. William Seiple, Vice President of Research at Lighthouse Guild. “From innovative companies developing the latest technology, to pharmaceutical researchers, or even government researchers – they come to us for input because of our experience and specialized knowledge.”

Leading the field in rehabilitative treatments

For years, Dr. Seiple has studied how best to help people with macular degeneration – the leading cause of vision loss among older adults – to improve their reading abilities. Because of Lighthouse Guild’s work, these rehabilitation treatment programs have dramatically advanced.

“Magnifiers were once considered the only way for people with macular degeneration to read, but our research has shown that’s not always the case. We shouldn’t be focusing just on magnification, but also on eye movement. So over the last few years, we’ve been working to develop more effective rehabilitative training programs to teach clients with impaired vision how they should be moving their eyes when they read. Our work has shown that this change in approach can increase reading speeds by 20 to 30 percent.”

A team approach to advance new technologies

In addition to new treatment approaches, medical technology is also making a meaningful difference in the lives of many people with vision loss. But, just as a computer is of little use without proper programming and user training, specialized rehabilitation is often essential to maximize results of technological advances that seek to improve or restore vision.

“Our unique model of care and our team approach to treating vision loss allow us to make significant contributions in advancing these new technologies,” says Dr. Andrea Zimmerman, a low vision clinician at Lighthouse Guild. “For people newly fitted with these devices, what is key is

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that we have doctors to evaluate their functional vision, occupational therapists to work with them on how to scan or use their vision more effectively, mobility instructors to help them travel safely, social workers and psychologists to help them deal with the changes they’re experiencing, and more – and all under one roof.”

**Translating technology into everyday life**

Inna Babaeva, an occupational therapist at Lighthouse Guild, works with Dr. Zimmerman and her team to help patients with implanted miniature telescopes learn how to get the most out of their new device. She explains that, while exciting, these new advancements require a great deal of specialized rehabilitation to be effective. “A new implanted telescope is not like putting on a new pair of glasses. Clients have to retrain their brains how to process images in an entirely new way,” explains Inna.

The surgical procedure to implant a miniature telescope into the eye is just the first of many steps. Soon after surgery the recipient and Lighthouse Guild’s team of experts begin a rehabilitative journey to improve functional vision.

When Pat Gajewski became one of the first patients in the New York area to receive an implanted telescope, she turned to Lighthouse Guild to retrain how she used her eyes – one at a time. Pat slowly began to realize the marvels of what modern vision science can achieve, and the impact on her daily life. “Now I can go to the supermarket, write my own greeting cards, do my own banking, tell time and watch TV,” says Pat.

**Advancing state-of-the-art solutions**

Lighthouse Guild’s multi-disciplinary teams of professionals are uniquely positioned to integrate the latest approved treatment advancements into vision care and to provide critical input during the development of new technologies.

Over the past seven years we have worked with over 50 people who are blind during the development and testing of the “brainport,” a device that allows people who are blind to detect the shape, size and location of an object in their environment. Using the device, some of our patients have actually been able to identify words.

We also recently began working with Guy Panuccio, one of the early recipients of a retinal implant or “bionic eye” which can restore some vision for people who are blind or almost blind.

With rehabilitation training from Lighthouse Guild, Guy’s goal is to regain self-sufficiency in daily activities. “I hope I’ll be able to identify crosswalk lines again so I can cross streets safely,” he says. “And other things like seeing where my plate is on the table and being able to perceive where the doorways are in unfamiliar places.”

With many other exciting new treatment options on the horizon, our core expertise in vision rehabilitation allows us to play a critical role in new treatment options as they emerge.

“The expertise we’ve gained from serving people who are blind or visually impaired for more than a century is unparalleled.”
Vision loss is one of the top ten disabilities experienced by adults, according to the US Centers for Disease Control (CDC). In addition to the direct impact on their daily lives, the CDC reports that people who are blind or visually impaired are also more likely to have other serious medical conditions that can threaten their overall health and even their longevity.

As doctors and healthcare professionals see more patients with vision loss than ever before, they are increasingly turning to Lighthouse Guild for our expertise.

**Shaping best practices**

In response we are continuing to expand our training programs to sensitize healthcare professionals to the specialized care needs of people who are blind or visually impaired. These programs are shaping best practices and are changing the way healthcare staff care for people who are blind or visually impaired.

"With these training programs, we’re not only raising the bar in terms of the quality of care being delivered to treat people with a particular diagnosis. We’re also helping to change how healthcare providers as a whole think about vision loss. When professionals are equipped to care for a patient holistically, it benefits everyone,” explains Yu-Pin Hsu, an occupational therapist at Lighthouse Guild who helps develop professional training programs.

**Comprehensive professional training**

We are training healthcare staff in all settings, such as hospitals, nursing homes, home care agencies and community-based programs to recognize and respond to the special needs of patients who are blind or visually impaired. Our comprehensive programs are tailored toward various health professionals and provide instruction in how to better identify people with vision loss and respond to their needs.

For example, all care providers can benefit from a basic understanding of how vision loss affects how a person functions, how to walk with a patient with vision loss, and how to use verbal descriptions and cues. Professionals providing rehabilitation and clinical care receive more in-depth training to develop skills such as conducting a vision assessment.

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“Lighthouse Guild exceeds our expectations as a partner...”

assessment and addressing the patient’s vision problems as part of care. And perhaps most helpful to a patient’s long-term health, we provide education about when and how to refer a patient to other specialized low vision services.

Strategic partnerships

An integral part of our programs has been strategic partnerships with major institutions, such as the New York Presbyterian Hospital – Columbia University Medical Center, and professional groups, such as the American Occupational Therapy Association (AOTA). “As vision rehabilitation has become more and more central to the practice of occupational therapy, we sought to partner with Lighthouse Guild so that occupational therapists throughout the country would have access to the best ongoing professional education possible,” says Debbie Amini, Director of Professional Development at AOTA. “Lighthouse Guild exceeds our expectations as a partner toward this goal.”

Lighthouse Guild’s programs have already reached thousands of healthcare professionals and will continue to be a key focus, as this improved model of care becomes even more critical to the well-being of an aging population. For patients with vision loss, being treated by a health provider who understands their specialized needs can make the difference between providing good care and great care.
Beginning the Journey from College Freshman to Future Leader

The transition from high school to college can be challenging for any young adult. For university-bound students who are blind or visually impaired, the demands of college life can quickly become overwhelming.

Lighthouse Guild helps students with vision loss prepare to step onto campus for the first time, providing both the emotional and financial support needed to get ahead.

When leaving home for the first time, many students who are blind or visually impaired find themselves separated from a well-developed support network that they rely upon. In addition to coursework, they’ll now need to advocate for themselves and navigate around an often sprawling college campus. The emotional strain of these changes can pose real challenges.

Peer support builds confidence

Heading to college marks the beginning of a new phase of life. Lighthouse Guild’s free national tele-support groups help prepare students for the new academic and social adventures they’re about to experience. For nearly a decade, this program has been helping high school seniors from around the country cultivate a new, peer-based support network designed to make their freshman year more manageable. Soon-to-be high school graduates meet by phone for one to two hours each week to learn ways to overcome and address the challenges they’re likely to experience when they arrive on campus.

“For many, they are not just the only blind student in their high school, but in their whole towns,” says Daria Zawadski, the group’s facilitator, a clinical social worker who is visually impaired herself. “From an academic perspective, we discuss how to get around their new school, how to connect with the college’s disability office, and how they should approach their professors. We also address a full range of social issues,” Daria explains.

A network that lasts beyond college

Most important, these students build a strong network that can continue to provide support long after the tele-support sessions conclude. “Many students keep in touch during college and some even visit each other in person. Last year’s support group still meets informally every few months, and former support group members now in college will often attend a meeting to answer questions and give advice,” says Daria.

Facilitating academic achievement

In addition to helping college-bound students build a support network, we also foster future success with scholarships that help students overcome challenges to their academic achievement. Based on academic merit, our scholarships can be used to meet the needs of the recipient. Because each student is unique and each campus is unique, this flexibility ensures that individual barriers to achievement can be addressed.

Our college-bound scholars come from all across the country

Numbers indicate the number of scholarship recipients per state.
Our unrestricted scholarships have supported students across the country in many meaningful ways, ranging from offsetting tuition and room and board costs, to ensuring access to specialized technology, to academic tutors, to orientation and mobility assistance and to travel costs. Because they may need more time to complete their coursework, students who are visually impaired often have little free time to take on a part-time job.

Making an impact nationally

In the past ten years alone, Lighthouse Guild scholarships totaling over $2.2 million have been awarded to nearly 200 outstanding legally blind students across the nation. Hailing from small towns, like Blair, Nebraska, and big cities such as Los Angeles, these scholars – selected after a rigorous application process – are demonstrating that vision loss is not a barrier to success, in or out of the classroom.

“I remember receiving my acceptance to Stanford and thinking it wouldn’t be financially possible to attend,” says scholarship recipient Elizabeth Haro of San Antonio, Texas. “The Lighthouse Guild scholarship helped give me the opportunity to attend a top tier university.”

For Emily Michael of Jacksonville, Florida, the value of the scholarship was far greater than the dollar
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amount. “The whole idea that you believed in me was so important. It was an investment in me, and I look back on it as a catalyst for my success.”

Creating future leaders and mentors

While the primary objective of the Lighthouse Guild scholarship program is to help alleviate the barriers to success that each individual is facing, many of these future leaders are also inspired to encourage others to pursue their academic dreams, too. “As Lighthouse Guild scholars, we feel a responsibility to ‘pass it on’ by helping others,” explains Emily. “We feel truly fortunate at Lighthouse Guild to be able to work with so many amazing students from across the country, and it’s going to be exciting to see what the future holds for them,” Daria concludes.

Staff Notes


Laura Sperazza, OD, Director of Low Vision Services presented “Low Vision Grand Rounds” at the Inter-American Course in Clinical Ophthalmology, Bascom Palmer Eye Institute, Miami, FL.

Jeannette Christie, NYC-NAPVI Parent Coordinator, presented to the NYS Association for Education and Rehabilitation of the Blind and Visually Impaired, on the goals of NAPVI and how to include parents and professionals in the field of visual impairments and blindness working together for the growth of children with visual impairments.

NAPVI Executive Director Susan LaVenture addressed 44 Superintendents of Schools for the Blind in the US about the NAPVI Program and Lighthouse Guild services for parents, students and families at the annual meeting of the Council of Schools for the Blind in Louisville, KY. She also presented parent seminars in Oklahoma City and Tulsa, invited by NewView Oklahoma, on the subject of the federal special education law, Individuals with Disabilities Education Act (IDEA), emphasizing sections that pertain to students with visual impairments and parent rights.

TOGETHER WE CAN MAKE A DIFFERENCE

Lighthouse Guild’s programs and services make it possible for people of all ages who are blind, visually impaired and multi-disabled to lead productive, dignified and fulfilling lives. We invite you to join our mission by leaving a legacy of support.

To learn more about the ways you can make a difference through your estate plan, visit lighthouseguild.org/donate or call Annette Dorsky, Director, Gift Planning at 646-874-8443.

Together we can make a difference.
GuildNet members had the opportunity to experience a wide range of Lighthouse Guild services firsthand at a two-day health fair in November. Lighthouse Guild health and vision professionals provided services, screening and information, including flu shots, vision screenings, foot checks, diabetes risk assessments and prevention education, nutritional advice and much more. Those attending also had the opportunity to learn about low vision and assistive devices, and speak one-on-one to social work counselors and vision rehabilitation staff.