



# Vision+Health

## Addressing an Under-recognized Public Health Problem

The U.S. Centers for Disease Control has declared vision loss to be a “serious public health problem” that will only get worse in the coming decades – and the communities we serve are deeply affected by this extraordinary and growing need for specialized services. Last year Lighthouse Guild reached more lives than ever before and served more people with vision loss than any other organization in the country.

So how do we effectively address the wide range of needs of people who are blind and visually impaired, often with multiple disabilities or chronic medical conditions? By providing a full spectrum of programs and services that meet the individualized needs of people of all ages – young and old – who face a broad array of challenges.

The strong relationship between vision loss and other medical conditions underscores the importance of comprehensive and integrated health care for people with vision loss. Services targeted toward prevention, diagnosis and treatment of conditions that are the predominate causes of vision loss, such as diabetes, are especially important. Our medical, rehabilitation and vision services address this public health issue and meet the unique health care needs of people who have, or are at risk for vision loss.

We also address other key components that can impact a person’s independence and well-being. Programs such as schools for children with vision loss and other disabilities, academic and vocational skills training, and support and education for parents across the country who have children with vision impairment are all important for people with vision loss.

As you read about our efforts that make it possible for people to achieve and maintain the highest levels of function and independence, we invite you to join us in our mission. Together we can make a difference. ■



## Turning Low Vision into High Quality of Life

For individuals with low vision, a term used to describe vision loss that cannot be corrected with medical care or regular eyeglasses, learning new skills and strategies is essential to remaining safe, independent and active.

Teaching these skills requires a specialized approach. The multidisciplinary vision rehabilitation team in Lighthouse Guild's Low Vision Clinic focuses on helping people learn to make the best use of their remaining vision.

Vision rehabilitation services are central to the full range of clinical services we offer to provide people with vision loss, with primary and specialized medical care in one location. Our physicians and other healthcare professionals work in collaboration to help patients manage the range of chronic conditions that are prevalent among people with vision loss, and restore or maintain their health and independence.

"We see clients of all ages, and for each we develop an individualized treatment plan that leverages the latest tools and technologies. We do this with one goal in mind: to help them become independent in their daily activities and everyday life," explains Inna Babaeva, an Occupational Therapist at Lighthouse Guild.

### Restoring quality of life

**"What you have done for me is remarkable, says Arnold. Now I have a quality of life again, and I can't believe it."**

For 86-year-old Arnold Riback, one of Inna's clients, vision rehabilitation has produced a remarkable change in his life.

Arnold has severe vision loss in his right eye. He then experienced a hemorrhage in his left



*As part of the low vision examination, Dr. Laura Sperazza examines a patient's retina to detect any signs of eye disease.*

eye which left him with very limited vision. He was devastated. This longtime owner of a financial business and a once-avid bridge player suddenly required a full-time health aide in order to live safely at home.

"I was at a point where I could not function," he said. "I could see almost nothing."

With Inna's support and guidance, Arnold began vision rehabilitation in hopes of regaining visual function. With special exercises and high-powered glasses, he was able to develop the skills he needed to return to his independent and active life.

Soon others noticed a change in Arnold's life too. "For a long time I did not see my father smile much at all," said his son, Philip. "But now you've brought back his smile."

### Providing hope and solutions

"Over and over again I see patients with vision loss who go from doctor to doctor looking for a cure and they're told nothing can be done," says Dr. Laura Sperazza, Director of Low Vision Services. "That may be true medically, but it's often not true visually. Once we get them into

our clinic and get them involved with low vision devices and vision rehabilitation, we can really change their life.”

For clients like Arnold, vision rehabilitation provides the tools to live independently with their remaining vision. “The hardest part is to teach the brain how to adapt to low vision. It’s not like when you get glasses and you put them on to see better,” Inna explains. “It takes time and work with a trained professional.”

“What you have done for me is remarkable,” says Arnold. “Now I have a quality of life again, and I can’t believe it.”

By helping our clients meet their goals through our vision rehabilitation services, Lighthouse Guild is showing that people can live productively with vision impairment. And for our dedicated professionals, nothing is more rewarding than helping people reclaim their independence. ■

## Moving Forward and Staying Mobile – Safely

The challenges associated with moving around safely can threaten the independence of individuals with vision loss. With the help of Lighthouse Guild’s Orientation and Mobility Services, our clients are learning how to safely navigate their homes and the biggest city in the country.

Our team of specialists provides clients with instruction in their homes and communities so they can develop skills to orient themselves to their environment, and independently map out and navigate a route to another location. Instruction includes using all senses, along with mobility techniques to move safely in an environment, mobility skills to use landmarks and traffic patterns to travel pre-determined routes, and problem-solving skills to know what to do if you’re lost or disoriented.

Our clients, who range in age from teenagers to seniors in their 90s, experience a variety of mobility challenges due to their vision loss. Many are also dealing with other health issues or disabilities. Providing help requires an individualized program approach.

“We talk with each client to find out what their most important needs are in terms of travel and getting out and about,” explains Orientation and Mobility Specialist Patricia Roldan. “Some just want to be able to walk to the corner, or get fresh air on their front stoop. Others need to travel to work or school, which might be in a different borough.”



*An orientation and mobility specialist instructs a client on how to navigate outdoors using a guide cane.*

### Helping people achieve their goals

For 33-year-old Devon Bovian, who has partial vision loss after experiencing a retinal artery occlusion, (sometimes referred to as an eye stroke), being able to safely leave the house without needing to depend on his wife was an important treatment goal. “Before my training,

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## Moving Forward and Staying Mobile *Continued from page 3*

**“Despite my vision loss, I’ve regained my independence and have a positive attitude about life.”**

if I had to travel somewhere I’d have to ask a lot of people for help, and I wouldn’t know where I was heading,” he states.

Devon, who is preparing to attend college next year, needed to make sure he’d be able to travel safely and independently. “With my mobility training, I’ll be

able to take the bus, get off at the right stop, and then walk the two blocks to campus – without needing anyone to travel with me.”

“We start with teaching pre-cane skills – learning how to use your own body to protect yourself at home,” Patricia says. “Then how to travel with a guide by holding onto the other person the proper way to protect yourself without a cane. Finally, we introduce using a cane.”

Though some might view the white cane as a universal symbol for blindness, many of the people you see using them have some vision.

“There’s a whole spectrum of vision loss, and the cane is also an effective tool for those with partial sight,” Patricia adds. “The cane is sort of a backup to their vision. They’re using it in combination to help detect curbs and stairs, cracks in the sidewalk and objects in their path.”

For Devon, learning to navigate with a white cane has given him a renewed sense of excitement. “I’m very happy now. Despite my vision loss, I’ve regained my independence and have a positive attitude about life.”

Helping clients like Devon reach their goals reinforces why orientation and mobility specialists at Lighthouse Guild chose such a uniquely satisfying career path. “It’s very rewarding when I know that I’ve made a difference,” says Patricia. ■

## A Model for Success

For children who are blind, visually impaired or have additional special needs, a high-quality education can go a long way toward preparing them for a successful future. Lighthouse Guild’s schools represent a distinctive educational model that is designed to help our students gain greater independence and to help their families manage the challenges associated with vision loss and other disabilities.

The Harriet and Robert Heilbrunn School provides a full educational curriculum, life skills training, rehabilitation services, communication skills, adaptive technology training and more to our students ages 5-21 who are blind or visually impaired and have other disabilities. The program enables students to more fully participate as contributing members of their families and communities. We also support our older stu-



*Preschool students explore sounds and textures as part of their recreational play.*

dents and their families through the transition process to post-school placement services or supportive employment opportunities. Our Ethel and Samuel J. LeFrak School serves preschool children ages three to five, and enables them to develop academic and social skills in a welcoming learning environment.

## One Preschool for all

The LeFrak School offers a preschool that meets the individual needs of our students, and ensures that visually impaired and/or developmentally disabled students have the same opportunities as their sighted peers. The curriculum and classrooms are modified and adapted to ensure full participation by all students, with or without

special needs. And with a maximum of 12 students in each classroom, the school is able to provide a community atmosphere. "I know every child, and they know me – that means a lot to me," says Principal Joanne Shen.

**"Parents have called our school a 'hidden gem', though I'm not sure we're so hidden anymore."**

For 5-year-old Milagros Linares, a recent graduate who is blind, The LeFrak School enabled her to blossom in ways, her mother, Ana, never imagined were possible. "My daughter learned how to be more independent," she says.

To facilitate child development, our LeFrak

School offers occupational, physical and speech therapy, an extensive early childhood curricula and strong literacy studies – including Braille lessons, physical education, outdoor play, neighborhood field trips and community outings.

"Through our activities, the creative curriculum and specialized art, music and yoga therapies, we are able to offer a really memorable classroom experience," says Joanne.

## Using technology to improve self-expression

With computers equipped with age-appropriate programs in every classroom, many students are finding that new technologies can allow them to express themselves more easily. "With technology getting easier and easier to use, children are becoming more and more interested in learning," says Teacher of the Visually Impaired Nancy Doyle. "Once a child learns how to express themselves, it's like they become another child entirely!"

Strong endorsements from satisfied parents like Ana is one reason The LeFrak School continues to be in high demand. "Parents have called our school a 'hidden gem,' though I'm not sure we're so hidden anymore," says Joanne. ■

## Empowering Parents

Finding information and advocating for the services your child needs can be challenging and stressful for parents of children with visual impairments, many of whom have additional disabilities. Parents often find that there are no other children in their community with the same medical condition, and are faced with the challenge of raising a visually impaired child without a strong and informed support system.

We serve as a centralized resource for parents throughout the United States and beyond, and provide education, support and unique networking opportunities that help parents care and advocate for their children.



*The Rivera family at Lighthouse Guild's National Family Conference.*

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## Empowering Parents *Continued from page 5*

### National tele-support network

One of our programs is the National Tele-Support Network for Parents of Children with Visual Impairment. We host weekly tele-support groups that connect parents of children who are blind or visually impaired, living across the United States or in other countries, with other parents whose children have similar disorders. Groups are each geared toward a specific childhood eye condition.

“Many participants are busy, working parents overwhelmed with the challenges of raising a child with multiple disabilities,” says Tele-Support Network Director Susan LaVenture. “Being able to call in from anywhere – including from home

– is often what makes their participation possible.”

Psychologists or social workers facilitate each support group. Pediatric ophthalmologists and low vision and rehabilitation specialists are guest speakers

**“The opportunity to ask questions about your child’s condition from a leader in the field is invaluable.”**

to share their expertise and answer parents’ questions on topics such as raising a child with vision impairment in the early years, strategies for starting the school year, dealing with negative comments, and participating in sports.

“The opportunity to ask questions about your child’s medical condition from a leader in the field is invaluable to parents,” adds Susan. “They are eager for information about services, accessible technology and learning strategies that can help them raise their child to be independent and productive.”

### Enduring support networks

Tele-support members also become friends with each other and create connections for a lifetime. “We have a special bond because we share the same challenges and have a greater understanding for each other,” explains one parent from Texas.

The following free parent tele-support groups currently meet weekly: Albinism, Autism and Blindness, CHARGE Syndrome, Chediak-Higashi Syndrome, Cortical Visual Impairment, Hermanski-Pudlak Syndrome, Leber Congenital Amaurosis and Retinopathy of Prematurity. ■

## A Community-Based Solution for Healthy Living

For many adults with chronic health conditions, adult day health care programs enable them to stay in their own homes and communities. But for those who are also blind or visually impaired, finding a program to meet their specialized needs can be difficult. Now entering its fourth decade, Lighthouse Guild’s GuildCare Adult Day Health Care program provides adults who are blind or visually impaired with a comprehensive care solution.

### An interdisciplinary approach

To best address each individual’s unique needs and medical condition, GuildCare enlists a team of professionals, including registered nurses,

occupational and physical therapists, social workers, vision rehabilitation specialists, registered dietitians and activity staff.

“All of our services and programming are focused on and adapted for people who not only have physical and cognitive issues, but also vision impairment,” says GuildCare Network Director Patty Granados. “For example, we provide services ranging from health monitoring and medication management to wellness and nutritional programs and vision rehabilitation services. In addition, we also provide occupational, physical and speech therapy, as well as a variety of activities designed to stimulate memory and improve coordination.”



Sixty-seven-year-old Pearl Bashir, who is blind and suffers from diabetes, has been a GuildCare client for nearly ten years – first in our Albany program then transferring to our Manhattan program when moving there in 2008. Access to ongoing health care and wellness classes has helped Pearl maintain her sense of independence and remain safely in her Brooklyn home.

“I’ve learned how to move around without falling, manage my medications, control my diabetes and live healthier,” says Pearl. “GuildCare has taught me how to stay independent.”

### Creating a community of care

“We also strive to create a sense of community,” adds Patty. “For individuals who have vision loss as well as other medical conditions, they can become quite isolated – and that can lead to depression.”

For 69-year-old Queens resident Barrat Dwarka, who is legally blind and at risk for health challenges associated with diabetes, GuildCare provides a comfortable place for him to interact with others.

“Without this program, I’d likely eat, sleep and watch TV all day- and that’s no way to live,” says Barrat. “I’d rather spend the day at Lighthouse Guild than stay at home alone.”

“Our activities are both recreational and therapeutic,” explains Patty. “We like to focus on further developing the senses other than vision, like tactile stimulation, or activities designed to

help with memory, like word games. And to keep our clients physically active, we even provide a Tai Chi program! We offer a wide variety of sessions that are both enjoyable and therapeutic.”

**“I’ve learned how to move around without falling, manage my medications, control my diabetes and live healthier.”**



*GuildCare clients stay active with the program’s Tai Chi classes.*

For Pearl, it’s the helpful staff and friendly environment that keeps her coming each week. “At GuildCare, I’m around friends, a nice staff, and I continue to learn. I am a part of the community here, and that’s a good feeling!” ■

### Guildcare Celebrates 30 Years of Service!

This summer, our GuildCare Adult Day Health Care program entered its fourth decade of service to visually impaired, chronically ill and frail adults. The milestone was marked with a celebration held at GuildCare Yonkers which was attended by GuildCare clients, staff, community partners and local officials. ■



*NYS Senator Andrea Stewart-Cousins (right) with GuildCare registrants Innoncent (left) and Ceceila Ononaji (center) at the GuildCare 30th Anniversary celebration.*

## Discovering Emotional Understanding and Moving Forward



*Licensed Social Worker Faith Feder speaking with a client.*

Onset of vision loss can be sudden or gradual, and is almost always unpredictable. The change and uncertainty associated with losing your vision can be overwhelming and can impact every facet of your life – physically, socially and emotionally. Vision loss is associated with poorer health status and higher prevalence of depression and isolation.

Lighthouse Guild's Behavioral Health program, with the only clinic of its kind in the country, offers a comprehensive array of therapeutic services in clinical and day treatment settings. Our services are designed and adapted for people with depression, anxiety and fear associated with vision loss. They include individual and

**“When clients hear us acknowledge that, yes, vision loss is affecting everything in your life – there’s just a huge sense of relief.”**

group psychotherapy, psychopharmacology and medication management, and psychological and psychiatric evaluation. We ensure that our clients and their families are not alone in dealing with the personal impact of vision loss.

### Experienced insight and understanding

“It’s hard for our clients because most of the people in their lives, usually the people closest to them, don’t always understand how all-encompassing and profound vision loss is,” says Faith Feder, a clinical social worker who has been helping visually impaired clients at Lighthouse Guild for more than 25 years.

“When clients hear us acknowledge that, yes, vision loss is affecting everything in your life, that we understand and can help – there’s just a huge sense of relief,” explains Faith.

Sixty-five-year-old Moishe Rosenfeld, who is experiencing progressive vision loss, appreciates how Faith has helped him cope. “This has really made a tremendous difference because I’m working with someone who understands the range of emotions I’m going through,” he says. “The therapy gives me perspective. No matter what’s going on, we always find a path to move forward when we meet. That’s a really big gift for me.”

### Strategies for coping

For psychiatrists, psychologists, and clinical social workers at Lighthouse Guild, the ability to give clients with vision loss the tools to handle the accompanying challenges and help them realize how much more fulfilling their lives can be when they get the right treatment is gratifying.



“A lot of times, people don’t want to admit that things are changing and they do need help,” says Faith. “There is a notion that to stay independent as a visually impaired person you have to accept help from other people. But if you do accept help, you’re less independent. That’s a paradox that we’re trying to change because of course you can be independent and accept help.”

For individuals with vision loss, the experienced professionals at Lighthouse Guild are united in a common mission: to help our clients cope with the challenges they are faced with so they can lead the most productive and fulfilling lives possible. ■

## Easing the Burdens of Long Term Care

People with Medicare and Medicaid who have long term healthcare needs often find that accessing the services they need, keeping track of all their medical appointments, prescriptions and the associated paperwork is confusing and time consuming. GuildNet’s managed long term care health plans are designed to ease these burdens for people by ensuring that all of their healthcare needs are met.

“My patients have a wide range of diagnoses and concerns,” says GuildNet Nurse Care Manager Cynthia Weis. “In addition to vision loss, many are also receiving treatment for multiple conditions such as diabetes, kidney problems or cancer.”

For many members, if it weren’t for a health plan like GuildNet, their care needs made more complex by their vision loss could require admission to a nursing home. “We deliver coordinated care and that helps people stay in the community and continue living safely at home,” explains Cynthia. “Through ongoing health assessment and regular nursing visits, we’re able to ensure delivery of medical and home care services to meet the changing needs of our patients.”

### Partnering with families

Effective long term health care is a team effort. An interdisciplinary team including a nurse care manager, a primary care physician, a social worker and a mental health liaison develops and modifies an individualized plan of care for each GuildNet member. To foster a strong support network, the team incorporates input from the member,



*GuildNet members receive assistance with all their healthcare needs including medication management.*

other providers involved in their care, and family members.

“Helping members stay safely in their homes often means working closely with their loved ones, as well as any other care providers, to make sure needs are met and to proactively address any problems that may arise,” adds Cynthia.

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**Easing the Burdens of Long Term Care** *Continued from page 9*

**Delivering comprehensive care**

Sixty-eight-year-old Nereida Urraca has diabetes, is legally blind and has a history of falls. She lives with her daughter and granddaughter in Brooklyn, and has been able to navigate the health care system with GuildNet’s help.

**“Our services help people stay in the community and continue to live safely at home.”**

“Cynthia is very helpful. She helps me with everything and is always available,” explains daughter Yajaira. “If there is a problem with any medicine or with Medicaid, she’s able to help. If I need anything for Mom, GuildNet finds it.”

In the ten years Nereida has been a member, GuildNet has delivered and coordinated her health care, including transportation to medical appointments. We’ve provided diabetes care, medication management and self-management education to help her control her diabetes and prevent further vision loss. In addition, vision rehabilitation services, special optical devices and adaptive equipment help her stay independent in daily activities.

We’ve also made Nereida’s home a safer place. “They installed two shower safety grab bars so I won’t fall down in the bath tub. These bars have helped a great deal,” states Nereida.

This year marks the 15th year of service for our GuildNet managed long term care plans. Established in 1997, GuildNet provides comprehensive care to people who have Medicaid and Medicare, and who are eligible for nursing home level of care but are able to live safely in the community with support from our GuildNet team. ■



Attention to detail leads many members to recommend GuildNet to others. “I have recommended GuildNet to others who could benefit,” says Nereida. “I tell them to take the number down and call them.”

For Cynthia, it is success stories like Nereida’s that make her work so gratifying. “It’s been really rewarding to be able to help keep so many members in their homes, and to feel that I’ve had a part in that success.” ■

**NOTICE OF NONDISCRIMINATION**

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## EVENTS – SAVE THE DATE!

### Lighthouse Guild Announces Honorees

Lighthouse Guild will hold its annual LightYears Gala on November 23, 2015, at The Plaza Hotel. This year's honorees are Gary Barnett, President and Founder of Extell Development Company, Louise Hirschfeld Cullman, President Emeritus, Al Hirschfeld Foundation, and Lewis B. Cullman, Philanthropist.

LightYears is an annual gala that pays tribute to individuals who demonstrate great vision, philanthropy and civic responsibility. Past honorees have included Mayor Michael R. Bloomberg, Bausch+Lomb, Arlene Dahl, James M. Dubin, Mica Ertegun, Michael Feinstein, Marvin Hamlisch, Stephen Marriott, Robert Osborne, Donald and Barbara Tober and Barbara Walters. ■

### The Young Visionaries' Annual Fundraiser

Join Lighthouse Guild's Young Visionaries as they host their annual cocktail party and fundraising benefit, on Thursday, October 15, 2015, 7-10 pm. This year's event will be held at Avenue New York, 116 10th Avenue at 17th Street.

The event's Co-Chairs are Jesse Berland, Elizabeth Pugatch, David Sandler, Rachel Wolf and Scott Zuckerman. ■

For more information, about these events please call **646-874-8227** or email [events@lighthouseguild.org](mailto:events@lighthouseguild.org)

Proceeds from these events support vital Lighthouse Guild programs and services that help people who are blind or visually impaired, including those with multiple disabilities or chronic medical conditions lead productive, dignified and fulfilling lives.

## STAFF NOTES

President and CEO **Alan R. Morse, JD, PhD**, authored an editorial for *Ophthalmology*, the journal of the American Academy of Ophthalmology. "Improving Medication Adherence to Reduce Vision Loss in Patients with Glaucoma: Low Hanging Fruit?" July 2015, 122(7): 1280-1282.

**Lynn Rothstein, PhD**, joins Lighthouse Guild as Senior Vice President, Chief Development Officer. Her responsibilities include the design and execution of a coordinated, comprehensive and integrated development strategy, generating substantial revenue growth and long term financial stability in the areas of individual, major and planned gifts, corporate sponsorships and foundations.

Prior to joining Lighthouse Guild, Dr. Rothstein has been in executive leadership roles in the nonprofit world for more than 25 years. Most

recently she has led fundraising departments and been in senior fundraising roles at Save the Children, The Central Park Conservancy, New York-Presbyterian Hospital, Mount Sinai Hospital, and UJA-Federation of New York.



Lynn Rothstein

Dr. Rothstein received her AB from Barnard College, Columbia University, where she majored in Anthropology and Psychology. She received her PhD from Cornell University, where her studies in Developmental Psychology focused on the socio-emotional and cognitive development of young children. ■



## Lighthouse Guild

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### Meeting a Wide Range of Student Needs

Enriching quality of life for students who are visually impaired and have other disabilities is part of the unique programming at The Harriet and Robert Heilbrunn School. In addition to a general education curriculum, students ages 5-21 participate in activities that are designed to develop their functional and social skills, and enable them to more fully participate and contribute to their families and communities.

For example, some of our older students participate in work internships at local businesses to develop job skills, interpersonal skills and most importantly a sense of pride in their work. During the school's summer session, a number of students participated in water safety instruction classes at a local park. Another recent activity was a student-run lemonade stand which required students to create advertising posters, make lemonade, interact with customers and collect money. ■



*Students from The Heilbrunn School encouraging customers to purchase a cold beverage from the school's student-run lemonade stand.*