

THE MACULA VISION RESEARCH FOUNDATION'S RACE TOWARDS THE CURE

Finding answers when your life presents you with difficult questions should be easy, like getting an umbrella to protect you when the rain starts to fall.

But when they researched macular degeneration, Herbert and Karen Lotman realized there was no “umbrella” for those suffering from the disease. Karen contracted macular degeneration in 1989, so she and her husband had a vested interest in learning what was being done in terms of research or testing. What they learned was indeed eye-opening – there was little being done in that area, nor was there much in the way of a support system for those living with macular degeneration.

“Macular degeneration is the leading cause of blindness in adults,” says Lotman. “It was amazing that so little was being done in a field that affected so many.”

So the Lotmans decided to open an “umbrella” of their own. Ten years ago, the couple founded the Macula Vision Research Foundation.

“The mission of the foundation is to research the cause, prevention, treatment and ultimately find the cure for macular degeneration with the goal of saving sight and providing public education, advocacy and support to those with macular degeneration” says Lotman.

Macular degeneration is the name given to a group of visual disorders that destroy cells located in the macula. The macula is the small, highly sensitive central portion of the retina that is responsible for detailed vision. The damage to these cells dramatically impacts vision and can even cause complete blindness in the central vision field, leaving one with only peripheral vision. If you cover your eyes with the palms of your hands, what you can see is all that a person with advanced macular degeneration can see.

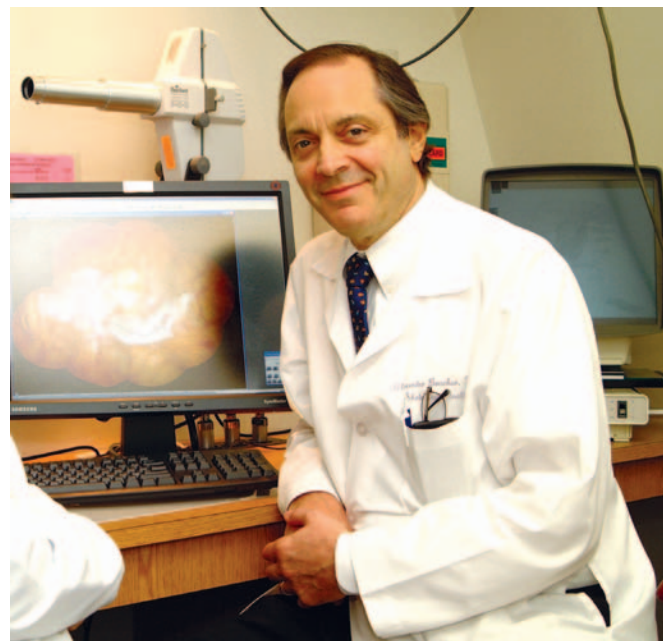
The degeneration – which is often hereditary – may first be noticed when straight lines appear blurry and the central vision field becomes distorted or dark.

Macular degeneration often accompanies aging – but the age of onset is on a downward swing. “The numbers are interesting,” says Lotman. “Most believe the age for vision loss is 65, but that is descending downward. About 10,000 people turn fifty each day. Many of them will be affected at that age or even younger.”

Recent studies indicate that by the year 2025, the population of people over the age of 65 in the United States will be six times higher than it was in 1990. Add to that number more than 10 million. That’s the number of Americans who are currently living with macular degeneration. Considering the amount of people affected, it is shocking to realize how many are not even aware of this disease. It’s a staggering figure, and, taken with the study projections, this indicates how important and far reaching is the work funded by the Macula Vision Research Foundation.



HERB AND KAREN LOTMAN



DR. ALEXANDER J. BRUCKER, CO-CREATOR OF SUPPORTSIGHT



DR. SAMUEL JACOBSON (CENTER) WITH COLLEAGUES, DR. TOMAS ALEMAN AND DR. ARTUR CIDECIYAN SHOWING DEVICE TO MEASURE VISUAL RESPONSES IN CHILDREN WITH BLINDNESS.



LEA S. BRAMNICK, EXECUTIVE DIRECTOR.

Lotman describes the foundation as a three-legged stool, with each leg necessary to support the Foundation's goals. "First and foremost, we make a difference by funding cutting-edge research," he explains. "The Foundation works to raise funds for basic bench research, which could provide the answers necessary to solve the riddle of macular degeneration."

"As a Foundation, we're unique because one hundred percent of every donation goes directly to research. Not a penny of it is spent on administrative costs," Lotman says. The Karen and Herbert Lotman Foundation underwrites all the Foundation's operating expenses. By the end of the 2005 calendar year, MVRF will have awarded over \$9 million to the vision scientists doing the most promising work.

The second leg involves conferences held throughout the country every eighteen months which include top surgeons, clinicians and vision researchers in the field," says Lotman. "It's the only time this combination of expertise is gathered in one room. It's an amazing interchange between parties. I listen at these conferences and was told by some of our researchers that within a couple of years, we will make a real difference."

Making a difference in the daily lives of those with the disease is the third leg of the stool. Lea Bramnick, the Foundation's executive director, affirms the need for such an organization to liaison between the medical community and its patients.

"When someone is diagnosed, doctors don't always have the time to explain sufficiently," says Bramnick. "Many people cannot find information, and they need the support of people meeting together to discuss issues and ways of coping with the effects of the disease and the lost sense of independence. They also need adaptable information concerning nutrition, travel, and what they can and can't do."

RECENT FOUNDATION DISCOVERIES:

- Two new genes
 - One to help understand how age-related macular degeneration develops
 - One to allow scientists to develop tests for the disease before symptoms begin to appear
- Insight into the molecular and cellular basis for the disease
- Application of gene therapy for retinal degenerations
- Agents to slow the development of new blood vessels
- Preventing further loss of vision or restoring vision after it is lost

FOR MORE INFORMATION CONTACT
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OR 866.462.2852, OR VISIT www.MVRF.com

Alexander J. Brucker, M.D. of the Scheie Eye Institute of the University of Pennsylvania realized that more information about the disease was necessary for his patients. He wanted to put a group together for better patient understanding.

Dr. Brucker, with the help of Ms. Bramnick, helped create the support system leg of the Foundation, which centers on a series of free seminars specifically designed for people living with macular degeneration. This series, named SupportSight, provides information about research, treatment and living with macular degeneration. Seminars include a variety of subjects such as information about clinical trials, nutrition, genetics, dealing with depression, a low vision fair to raise awareness about products and information, and a seminar for caregivers explaining their role and relationship with patients.

The first seminar was held in Cleveland in December, 2001. Since that time, SupportSight has become a national support organization, currently operating in 18 cities, reaching out with practical advice through seminars (including those at eight locations in the Philadelphia area), a hotline (866-462-2852) and the website www.mvrf.org.

At the seminars, Bramnick invites those with questions to meet her under her red umbrella. The umbrella - red for visibility - becomes a gathering place for those who need answers to questions, from the simplest (like "How do I find my keys in my purse?") to the most haunting ("When will they find a cure?")

The answer to the last question may still be unknown, but with the support of grants from the Macula Vision Research Foundation, an answer may soon be within our sights.

By Mary Dixon Lebeau