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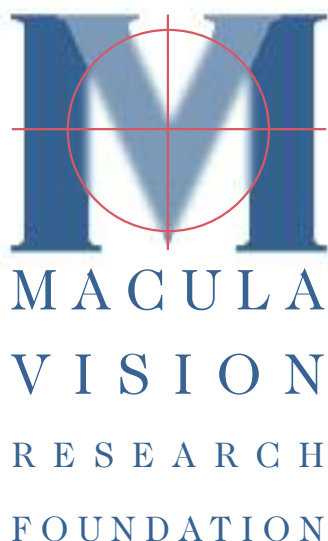
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A Message from Karen and Herbert Lotman

Dear Friends,

Ten years ago, the Macula Vision Research Foundation was an idea, a vision – today, it is a thriving successful reality and truly unique since every dollar raised goes to research and education as we underwrite all administrative expenses.

There are more research studies in progress than ever before, along with the belief that sight-saving treatments and yes — even cures — are within “sight.”

As we look back on a “Decade of Progress and Dedication,” the Foundation’s accomplishments are many and stunning.

In 1998:

- Apple introduced the iMAC
- Microsoft introduced Windows 98
- Google was first established
- There was one treatment for wet macular degeneration – none that stabilized or improved sight – only an attempt to stop the bleeding.
- There was nothing for those with dry macular degeneration.

In 2008:

- There are treatments for wet macular degeneration that slow vision loss and remarkably, in some cases, improve visual acuity.
- Now we know that scientists have found that people at high risk of developing advanced stages of dry macular degeneration lowered their risk by about 25% when treated with a high-dose combination of vitamins and nutrients. They reduced the risk of vision loss in the other eye by about 19%.

People with macular degeneration, are learning new information, understanding that they can do more than they thought they could and are willing to try new things.

We believe that the researchers working today will provide the treatments and ultimately the cure for this disease. In addition, their work is also having a profound effect on the preservation of sight – creating gene therapies, discovering vision-preserving vitamins, employing new technologies and exciting research pathways.

The year 2008 has been dramatic and remarkable! The Foundation has funded gene therapy to restore vision to children born blind.

These early steps are positive signs that future treatment trials for macular degeneration should also be feasible.

As we celebrate today, we also think about the serious challenges that are ahead. It is vital to understand that federal funds for macular degeneration research are continually being cut. That is why it is imperative that we remain committed to supporting the research that has the potential for creating the medical breakthroughs and “cures” we so desperately need.

- Macular degeneration is the leading cause of severe and usually irreversible vision loss in the USA.
- 22 people per hour are diagnosed with macular degeneration in the USA.
- A recent study, published in the “Archives of Ophthalmology” predicts that vision impairment and legal blindness will increase more than 60% in the next 13 years. This percentage will increase as the new kind of “senior,” the baby boomer generation, is maturing and facing vision impairment.

More than 15 million people have been diagnosed with macular degeneration. Each person has about four others (family members, friends, care partners) involved in their care. This effort totals another 60 million people.

MVRF SupportSight Program

Nationally, the MVRF SupportSight Program will soon be in 28 cities – more than 22,000 people have already attended the seminars and support groups.

The MVRF SupportSight program is working to make a difference in the lives of those affected by macular degeneration and the people who care about them. When people are diagnosed with macular degeneration,

they often have never heard of the disease and many do not know others who have it. It is often difficult to find answers to questions, to learn from others who are successfully living well with the disease and how and where to get help. MVRF SupportSight is playing a significant and transformational role in enabling people to lead positive and productive lives.

Seminars and support groups provide speakers of exceptional caliber providing timely and immediately useful information.

MVRF Research Conferences

The MVRF research conferences, every 18 months, bring together the most important vision research scientists, from all disciplines focusing ONLY on macular degeneration. The interactive sharing of ideas has created new and innovative research opportunities and breakthrough collaborations. The ninth conference will be held in Washington, DC, in November, 2009.

MVRF Help Line (1.866.462.2852 or 1.866.4MACULA)

The MVRF Help Line answers questions concerning “how to do things,” where someone can get help, find a Low Vision Specialist, a reading machine, where the support group meets, etc.

MVRF Web Site

The MVRF web site www.mvrf.org is a great resource, providing vital information about macular degeneration, research dedicated to macular degeneration, tips and hints about living well with the disease, a full listing of the Foundation’s programs as well as an on-line contact form to ask questions.

GOAL

We have real concerns about the macular degeneration genetic link to future generations. That is why we have chosen to devote our time, effort and resources to the Macula Vision Research Foundation; making its success a major focus of our lives, with the hope that the members of our family – and yours – will not endure needless suffering from this disease.

Our dream and our mission to find the cause, prevention, treatment and cure for macula vision diseases with our goal of saving sight, providing public education, advocacy and support to those with macular degeneration is clearly moving forward. We are very proud of our decade of accomplishments and challenged by the opportunities that lie ahead.

Please remember that 100% of all funds raised go to research and education, as all administrative costs are covered by the Karen and Herbert Lotman Foundation.

The “Decade of Progress and Dedication” has advanced research and pioneered new ways of treating patients. We believe we are making steady progress toward the day when we will not have to fear this debilitating disease. In fact, there has never been a more exciting time to be part of the Macula Vision Research Foundation.

We mark this important decade milestone by reaffirming our dedication to continue the essential research programs, support groups and educational seminars for the growing number of people diagnosed and in need.

Our hope is that one day soon, each member of your family will no longer need to fear macular degeneration. **Thank you for being part of the very special group improving the vision of the future TODAY.** Sincerely,

Karen and Herb Lotman

Karen and Herbert Lotman

P.S. We believe that a window of opportunity exists, at this moment, to make a significant step forward in research and to make a profound difference in the lives of people with macular degeneration.

An Appreciation

Colin J. Barnstable, D. Phil.

All private foundations hope to make a difference in their chosen area, few do it as successfully as the Macula Vision Research Foundation. During the 10 years of its existence, the MVRF has had tremendous impact in the areas of scientific research and communication through its grants program as well as service for those suffering from this blinding disease through its SupportSight program. When you look at the major advances in our understanding of macular degeneration that have taken place during the past ten years, almost every one of them has been facilitated by support from the MVRF.

The conferences sponsored by the MVRF have achieved a level of intensity and vigorous discussion that is rare in scientific meetings these days. These meetings have sparked new ideas and new collaborations and have helped establish a community of scientists with the common goal of defeating macular degeneration.

I am proud to have been associated with the MVRF since its inception. The past ten years have been a time of excitement and rapid advances. If the success of the MVRF continues at the same pace during the next decade, we may well be in a position to offer relief to the millions suffering from this disease.

MVRF Awards Research Grants in Central Serous Retinopathy

The Macula Vision Research Foundation has awarded two research grants of \$240,000 each to determine the causes of central serous retinopathy (CSR). Dr. Rando Allikmets at Columbia University will use the MVRF grant to identify genetic variants responsible for CSR and Dr. Steven Fisher at the University of California at Santa Barbara will investigate molecular and cellular mechanisms underlying retinal detachment in a recently discovered animal model that exhibits characteristic features of CSR.

Central serous retinopathy (CSR), also known as central serous chorioretinopathy (CSCR), is a relatively common visual disorder that most often affects middle-aged individuals. It is characterized by leakage of fluid in the central macula resulting in neural retina detachment. Affected individuals typically experience blurred or distorted vision. Currently, there is no effective treatment for CSR. The MVRF research grants will greatly enhance our understanding of CSR and provide the basis for improving the diagnosis of the disease and developing treatments that will improve vision in affected individuals.

Research Update

Robert Molday, Ph.D. Chairman, MVRF Board of Scientific Advisors

In 1997, Herb and Karen Lotman brought together leading vision research scientists to discuss and evaluate current research in macular degeneration. It was clear from this initial meeting that significant progress was being made in understanding the genetic and molecular basis for such inherited retinal diseases such as retinitis pigmentosa, but research in macular degeneration and in particular age-related macular degeneration (AMD) was largely limited to clinical diagnosis and analysis of environmental risk factors associated with AMD. This prompted Herb and Karen to establish the MVRF a year later to encourage basic and clinical scientists to focus their research on understanding the genetic, molecular and cellular basis for macular degeneration.

The progress during the past 10 years has been extraordinary. We have gained a deep understanding of the mechanisms underlying many inherited forms of macular degenerations including Stargardt macular degeneration, Best disease, Doyme honeycomb dystrophy and others. The breakthroughs in AMD research have been even more impressive. Geneticists have identified variants in a large number of genes that increase one's risk of developing AMD. Many of these genes encode complement proteins that regulate the innate immune system.

These discoveries serve as a basis for ongoing research directed toward understanding the molecular and cellular mechanisms responsible for AMD and developing novel therapeutic strategies to prevent or at least slow vision loss in affected patients. Indeed, we have recently witnessed the development of a number of therapeutic agents that

slow and in some cases reverse vision loss in wet forms of AMD.

The development and application of therapeutic agents that may limit vision loss in dry forms of AMD are currently under investigation. Significant advancements have also been made in the application of gene therapy as a treatment for retinal degenerative diseases including some forms of macular degeneration. Vision in a number of animal models for retinal degenerative diseases has been restored through the viral mediated gene replacement in retinal pigment epithelial and photoreceptor cells. These successful studies have led to the first human Phase I clinical trials for Lebers congenital amaurosis or LCA, a severe inherited retinal degenerative disease. Initial reports indicate that such viral mediated gene therapy is not only safe, but also effective in improving vision in a number of patients enrolled in these trials.

The MVRF has played a major role in this remarkable progress. It has provided more than eleven million dollars in research grants to scientists who have made these ground-breaking discoveries. The MVRF has also sponsored numerous research conferences during the past 10 years that have enabled scientists from all over the world to exchange information and develop productive collaborations to solve complex problems in macular degeneration. In addition to its support of research, the MVRF has played an important role in increasing the public awareness of AMD and providing information and support to affected individuals.

Thanks, Support Group

Joan, West Chester, PA — MVRF SupportSight Group at Fern Hill

When I was first diagnosed with macular degeneration, I, like many others, was very bewildered. What is this? Am I going to go blind? Where can I get advice and knowledge to deal with it? These are the questions one would ask of any new diagnosis. I tried one "support group" locally, but the programs were too technical for so many of the people attending that the audience soon dwindled to two and was soon disbanded. Then a bright light came on the horizon — a notice in the mail from the MVRF! What a great relief! This is a group that really addresses the need for information that is understandable to everyone, so helpful, in fact, that I hardly notice my limitations any more. Fortunately, my case is the dry type of the disease and there has been very little change in three years. I am sooo lucky. The support from this group has given me the confidence to go back to my beloved hobby of counted cross stitch, which was the biggest loss I had. I just use a brighter light and a stronger magnification, and of course a larger stitch count for my fabric. I still drive, only locally and never at night, but am able to do most everything with little limitation. Thanks for starting this group at Chester County. I am sure there are others who can also attest to the benefits of group support. **I am so thankful to have found this group.**

MVRF by the Numbers

\$11 million to outstanding vision scientists doing cutting edge research in macular degeneration

23 research studies, in progress

11 new grants to begin 2009

41 scientists awarded grants

79 grants awarded

31 departments of ophthalmology work with MVRF

213 articles cited MVRF for support of research in leading scientific peer-reviewed journals

8 International Research Conferences, #9 to be in November 2009

75 scientists have attended the MVRF conferences

22,000 people have attended MVRF SupportSight educational seminars and support groups

28 cities have MVRF SupportSight programs

An Appreciation

William W. Hauswirth, Ph.D.

The central achievement of the MVRF has been to invest in researchers developing novel technologies for treating a wide variety of degenerative retinal diseases. Foremost among these technologies has been the Foundation's continuous support of investigators utilizing the non-pathogenic human virus AAV to deliver therapeutic genes to cells of the retina. This has led to therapeutic validation of this approach in animal models for autosomal dominant and recessive forms of RP, an X-linked form of RP (XLR5), cone dystrophy (achromatopsia), nonhuman primate retinal disease (red color blindness), and attenuation of retinal and choroidal neovascularization in mouse models of Diabetic Retinopathy and AMD. Most importantly for the field, MVRF partially supported the first FDA-approved GMP compliant safety study for retinal gene therapy, and with that data a gene therapy clinical trial for a childhood form of blindness (LCA2) was successfully taken through University, FDA, RAC and NEI review to the point of initiation. The first three LCA2 patients have been treated with all three benefiting by substantial improvement in their ability to see light falling on the retina within the treatment area. Without MVRF support this key advance would not have been possible, and its clinical success portends many more trials in the near future.

Quality of Life for a Visually Impaired Person

In 1997, the National Eye Institute conducted qualitative research among individuals with low vision to learn how low vision affects quality of life. People with low vision were interviewed in focus groups, one on one and through telephone interviews.

Respondents' quality of life was impacted by loss of ability to perform daily activities. Losing the ability to drive caused a great change in quality of life because it limits independence. Reading, was mentioned by all, threading a needle and sewing was mentioned very often by women.

Most people coped by accepting their physical conditions and deciding that they had to make up their minds that low vision is something with which they can live. They were not always aware of the many devices that could make their lives easier, although many mentioned "magnifiers."

Most were not aware of services and/or did not think they would be eligible because they could "still see."

Many were interested in finding a support group, "finding other people who knew what it was like."

What should you do if you are diagnosed with Macular Degeneration?

Scott A. Edmonds, O.D., F.A.A.O. Co-director, Wills Eye Institute Low Vision and Contact Lens Service

Many people are diagnosed with this disorder every day. With a little research, people can learn that this disorder is one of the leading causes of legal blindness! So what do you do if you find that you have this eye condition? Fortunately, although there is no cure for macular degeneration, much can be done to manage the problem. Below are the logical steps to maintain the best visual function in spite of this diagnosis.

Step One: Develop a relationship with a retina specialist. The macula is a specialized component of the retina. Retina specialists are ophthalmologists that have completed a fellowship in the medical and surgical management of retina problems. These doctors follow the latest research and concepts in managing macular problems. New drugs are available to treat the "wet" or active form of the disease. Several research studies are underway to look at ways to prevent or retard the progression of the "dry" form of macular degeneration.

Step Two: Low vision refractive evaluation. Low vision refractions are provided by low vision specialists. Low vision specialists are optometrists who have completed specialized training beyond optometry school. Most have completed a residency, fellowship or have attended special training programs. Low Vision refractions are different than the traditional refraction or auto refraction that are provided by a general optometrist or ophthalmologist. The low vision refraction is often done at a closer distance than the standard eye examination and often done with loose lenses in a trial frame or with the assistance of prisms. Sometimes filters or telescopic lenses are employed. Refractions are often overlooked in patients with macular degeneration but are actually critical to optimal function. The difficult aspect is obtaining the best focus to the part of the retina with the best function. Glare and other problems that affect image quality can be managed with filters that are often prescribed as tints or coatings to be added to the final eyeglasses.

Step Three: Magnification. When the best corrected vision is below the level for reading or the performance of other detailed tasks, magnification is then added to the optical system. The most common way to add magnifica-

tion is to increase the power of the bifocal or reading glasses. Although this shortens the focal distance, often very good results can be obtained when just a small increase is added to the reading power and this is combined with the optimal refractive result. When this is not practical for the required task, a series of handle-held magnifiers, stand magnifiers, telescopic lenses or video magnification are employed.

Step Four: Rehabilitation. When the best corrected vision drops below a certain level, patients with macular problems cannot easily position their eyes to use the part of the retina that is not damaged. When attempting to use their eyes for any detailed task such as reading or television, they execute the normal eye movements, which are designed for central fixation. When doing this, the object of regard drops completely into the "blind spot" and literally disappears. This only adds to the frustration of the patient and often leads to the common complaint that their vision is worsening each day and that they are "heading for total blindness." **These patients can be taught how to avoid the "blind spot" and use their peripheral vision for reading and discerning details though a course of rehabilitation.** The process includes the shrinking of the "blind spot" with optical lenses that allow for a very close working distance. The patient then executes a series of simple and repetitive reading tasks that re-pattern the coordination between the eye and the brain. The system slowly increases the difficulty of the reading task until the patient is able to read normal text. Once this is achieved, the patient then learns to use this pattern of eye movements to watch TV, cook, eat, and perform the other skills of daily living. Depending on the final level of function, various magnification options are then re-introduced to meet the needs for specific vision tasks.

Long-term follow-up for patients with this disease are best coordinated with both the retina specialist and the low vision specialist. Both the disease and the patient's visual needs will change over time and when these doctors work together, the patient has the best opportunity for life long visual function.

Just in....new genetic findings

Kang Zhang, MD, Ph.D.

Recently, a group of investigators led by Kang Zhang, MD, Ph.D., associate professor, Department of Ophthalmology and Visual Science, John Moran Eye Center, University of Utah, reported an association of the toll-like receptor 3 gene (TLR3) and age-related macular degeneration. **In a study funded in part by the MVRF** and recently published in "The New England Journal of Medicine," Zhang and his collaborators showed that a Phe412 genetic variant of the TLR3 gene protects individuals from developing geographic atrophy, an advanced form of dry AMD, by suppressing retinal pigment epithelial cell death.

Andrew Lotery, MD FRCOphth

A team of clinicians and scientists at the University of Southampton, England, have identified a major new gene association with age related macular degeneration. Age related macular degeneration is the most common cause of blindness in the Western World. This team included Professor Andrew Lotery and his research group in the Clinical Neurosciences Division and Dr. Sarah Ennis and Professor Collins from the Genetic Epidemiology & Bioinformatics Group in the Human Genetics Division. This work was published October 7th in "The Lancet." This exciting discovery now implicates a novel pathway in the disease. Therefore, this discovery both better helps predict who is at risk for the disease and ultimately should lead to better treatments. Andrew Lotery who is Professor of Ophthalmology at the University says "I am delighted that researchers at the University of Southampton have made such an important contribution to understanding this devastating disease. **Funding from the MVRF was crucial to the success of this project.**"

MVRF GENE IDENTIFICATION

The MVRF has supported most of the research scientists who have identified genes associated with age-related and early onset macular degeneration.

An Appreciation

Roderick R. McInnes, M.D., Ph.D.

“The MVRF has played a key and international role during the past 10 years in supporting research on age-related macular degeneration (AMD). Ten years ago, when Herb and Karen Lotman started the MVRF and organized the first meeting of researchers, almost nothing was known about the causes of AMD (except that smoking is a great risk factor). This ignorance was surprising, because AMD is such a common disorder, an important one that can cause several vision problems and blindness in up to 8% of individuals over the age of 75 years.

When we researchers got together at meetings in the years before 2005, we were frustrated. The field wasn't making much progress. Then, suddenly, the most exciting period in the history of AMD research began. In a remarkable series of discoveries in 2005, several groups of geneticists in the United States found some of the most important genes associated with AMD. The proteins made by many of these genes are called “complement factors,” and we know that they regulate inflammation. These findings have pointed the way forward. It now seems likely that AMD is due primarily to uncontrolled inflammatory processes in the retina, processes associated with aging. All of us in the research community are confident that these seminal genetic discoveries are the key to AMD, the key that will eventually lead to preventions and treatments of this debilitating disease. At last, there is real hope.

The MVRF has been a critical contributor to this wonderful success, by supporting more than 77 AMD research grants. The grants were awarded to virtually all of those who discovered the link to the complement factor genes. But the MVRF has done much more, by bringing AMD researchers together, in its research meetings, and in providing support and education to families and individuals affected with AMD.



Remarks by Patrick McGowan

Atlanta SupportSight Seminar, May 31, 2008

Good Morning Everyone. My being here today was the outcome of a serendipitous occurrence in the office of my eye doctor, Robert Stoltz, M.D., Ph.D, who on learning I was an artist asked me if I would mind telling my story on having macular degeneration. I am an artist... a sculptor to be exact. Sculpture has been my life, my passion from the time I left the crib. My career as a sculptor has had its ups and downs, but the experience of touching people through my works with sadness, gladness and laughter has brought its own rewards. At 79, my fervor for sculpting continues to swell; it is for me a way of life. Getting the word that I had macular degeneration and would be losing my eyesight – well, it was my own 9-11.

Several years ago, I walked into my living room to watch evening television and noticed my vision was suddenly blurred and the center of what I was viewing looked as though it was smeared like what is done on TV to hide a person's face and/or undesirable area. Several days later, I was diagnosed with wet macular degeneration in my left eye. I had little knowledge of macular degeneration and its consequences. When the retinologist described the condition and its devastating potential gone untreated, I was painfully stricken. As an artist whose life was through my eyes, it was crippling news on a spiritual, emotional and physical level. I was temporarily down, but not out.

All too often, we blame God directly for the misfortunes that befall us. My way of looking at my having macular degeneration, cancer and other maladies is in the belief that God created all things with an end. He also created all things with their own unique nature or modus operandi. Spiritually, I had no problem in that I didn't strike out at my maker. What had happened to me was the result of my body acting out its nature and how I used or misused its assets over the years. I have never believed God singles out any mortal with the intent of doing them harm or in punishment. Everything has an established nature from its creation and it is in acting out that nature in conjunction with or in opposition to other natures that we have juxtapositions or collisions, so to speak.

My emotional recovery though was a matter of accepting the situation, which came without too much difficulty. My philosophy is that survivors of life look at disasters as a challenge and find ways to beat them. You push yourself back up, dust off your knees and take the first step. Good can be found in every bad event and that good always renders us stronger than before. My right eye was unaffected and I found the peripheral vision in the left eye was still useable. So, I had a way through this. Many years ago, midway in my career, I asked myself what I would do were I to lose my sight. To answer that question, I began practicing my sculpting blind folded. With a highly developed sense of touch, I found I could do a masterful portrait by feeling the contours of the subject and comparing them to the clay model. It would not be as exacting nor would it have the detail as would be with normal vision, but the portrait I modeled took on a character that was unique, unlike any I had ever done before. It was more sensitive. I have since seen works done by those who are blind and have found in those works the same uniqueness, the same sensitivity to the subject being rendered. So, I was encouraged knowing I had this option to work with as well.

In relating the physical aspects of my situation, I need to explain some basic theories about what I see and how I see as an artist. Without light... there is no dimension. Sight is the embodiment of light into shapes and forms.



It is digitized, so to speak, and sent on to the brain for interpretation. Following that interpretation, we get a print out of a recognizable image. We get a picture. Everything we see is an aggregate of shapes and forms defined by light or the lack thereof. In the true sense of the term, we don't see detail, we see impressions. This is a fact brought to the fore by early painters who used dots, lines and posterizing in composing their paintings of everything from landscapes to portraits. This theory was primary in my coping with macular degeneration. I found methods to contrast one shape or contour against another. I increased studio lighting and donned a head mounted magnifying apparatus to further enhance my impaired vision. One such piece done under these circumstances is the sculpture, “Surf's Up” (see above) which was at the height of my eye problem.

Having worked out all that had befallen me and settled once again in my work, I was told my right eye turned from dry to wet. Both eyes were in trouble. Now that news was a little more difficult to swallow. I felt suspended over a bottomless pit. The condition was in its early stages and had not yet affected the macula, it just laid off to the side in a threatening manner. If I closed my left eye and looked at a white wall, I could see the black spots in the lower portion of my view. Dealing with this new development was primarily a reenactment of my past ordeal with the left eye. However, this time, the prospects were a bit more threatening and it took a little longer to recover.

As if this were not enough, about a month ago, the retina in my left eye became detached. This same eye also has a cataract. Through surgery, the retina was repaired and I can still see color and large shapes relatively well.

The medical field has done miraculous things in changing the course of our body's nature. Public awareness of this disease has been brought to the fore and the research for solutions has been aggressive. Then, there's Dr. Stoltz of Georgia Retina who has shown me meticulous care and compassion using the latest in technology. Nature besets us with trials that are the consequence of other natures interacting with our own. We have no control over these events leaving us with little choice but to accept them. We do have the choice though to innovate, to change, to reconstruct and make a new way. Modeling a sculpture takes longer, but changing my style of modeling makes it easier. Increased lighting and magnification have also helped me surmount my malady.

Giving up is not a solution, it only makes the matter worse. Oh, I feel pangs of despair at times, but they are only temporary as I reason that there is excitement in the challenge to overcome my enemy. I have this need to win and win, I will.

**Sculpture. . . it adds another dimension to art.
Creativity is the embodiment of a vision, emotion, or thought.**

An Appreciation

Dean Bok, Ph.D.

Karen and Herb Lotman founded the Macula Vision Research Foundation (MVRF) in 1998. This year, we have the pleasure of celebrating the 10th Anniversary of this wonderful Foundation and to reflect on its accomplishments.

The first and most obvious amongst these has been the provision of over \$11 million dollars to distinguished and dedicated scientists with the goal of treatments and cures for macular diseases. However, for those who have witnessed the operation of the MVRF at closer range, its value transcends the critical endeavor of philanthropy and fund raising. Under the gentle, generous and insightful guidance of Karen and Herb Lotman, the MVRF functions with minimal bureaucracy and unparalleled efficiency.

One hundred percent of the money donated to the MVRF is used for research, with all of the administrative costs covered separately by Karen and Herb. Moreover, the SupportSight program makes a significant difference in the lives of patients by organizing support group meetings and seminars that serve thousands of individuals.

Finally, the MVRF Research Conferences, held every 18 months at various venues across the USA, provide a first class exchange of scientific ideas within the field of macular disease research and across medical research fields through the inclusion of experts in related fields such as Alzheimer's and Parkinson's disease.

One cannot overstate the manifest success of the MVRF. We look to even greater strides during the next decade.

Silent Cars

Silent vehicle technology is posing a new problem for visually impaired people. When one's ability to see is lessened by not being able to locate and evaluate traffic, often the other senses become more acute. People listen to discover speed and direction – "listening for the car to come around the corner" to determine its position is a common phrase used by those who have diminished vision. The new quiet cars are making a big difference.

The new vehicles, that use hybrid or electric engine technology, can be very dangerous in situations where cars and pedestrians are in close proximity.

The visually impaired, like all people, must now learn to be much more vigilant, more careful and more aware of the silence of traffic.

Lifestyle and Dietary Modification for Patients with Age-related Macular Degeneration

Michael A. Novak, M.D., Retina Associates of Cleveland

Various studies have demonstrated that modifying one's lifestyle and/or diet may be beneficial in preventing loss of vision and preventing progression of age-related macular degeneration. Since there is no cure for age-related macular degeneration, the hope is that by performing some or all of these modifications, you may prevent your vision from becoming worse.

A number of studies have demonstrated that smoking can make macular degeneration worse. In particular, smoking does appear to be linked more closely with the development of the wet form of macular degeneration. Therefore, **it is recommended that anyone with macular degeneration should completely stop smoking.** This obviously is quite difficult for those individuals who have smoked for a number of years. In such cases, their medical doctor or internist may make recommendations for the use of medications that can help in the cessation of smoking. For those patients who absolutely cannot stop smoking completely, then reducing smoking may be beneficial also, although this has not been studied. For nonsmokers, exposure to smoking (second-hand smoke) increases the risk for macular degeneration. Reducing exposure to second-hand smoke may reduce the risk for macular degeneration.

Other studies have demonstrated that prolonged exposure to sunlight, especially when people are in their 20s and 30s, may contribute to the development of age-related macular degeneration later in life. In particular, the ultraviolet and blue wavelengths of light may be harmful to the retina. Therefore, the general recommendation is that **all patients with macular degeneration wear sunglasses that block out at least ultraviolet light.** Blocking out some blue light may also be beneficial, but this is uncertain. Blocking out all blue light would prevent the individual from seeing blue light. Anything that is blue would then be black. This color misperception may be difficult for some patients to accept. Therefore, it is recommended that all patients with macular degeneration wear sunglasses that block out ultraviolet light and do so whenever they are outdoors, except at night.

Another study has demonstrated that a certain type of body habitus may be associated with progression of age-related macular degeneration. In particular, the study has recommended that patients with macular degeneration exercise three times a week, an hour at a time, in order to reduce the chance that macular degeneration may advance. This exercise can be as simple as walking.

Lutein is a supplement that may be beneficial for patients with macular degeneration. Lutein can be taken separately or can be taken as part of a multivitamin such as Centrum Silver with lutein. The exact dosage of lutein that should be taken, however, is unclear. Further studies are under way to determine the efficacy and the dosage of lutein.

Several studies have demonstrated that dark, leafy, green vegetables may be beneficial for patients with macular degeneration. These vegetables include spinach, kale, mustard greens, collard greens, and turnip greens. It is recommended that people with macular degeneration eat ½ cup servings of these dark, leafy, green vegetables four or five times a week if possible.

Finally, other studies have demonstrated that **eating fish that are high in omega-3 fatty acids may reduce the risk of developing the wet form of macular degeneration.** Fish that are high in omega-3

fatty acids include salmon, tuna, mackerel, anchovy, and sardines. These studies recommended that patients with macular degeneration eat such fish two or more times a week. For those patients who cannot eat fish, taking fish oil capsules or omega-3 fatty acid capsules may substitute for the fish itself.

Finally, a landmark study called the Age-Related Eye Disease Study (AREDS) has demonstrated that higher than normal dosages of certain vitamins can reduce the risk of loss of vision and progression of macular degeneration in up to 25 to 30% of patients with mild to moderate age-related macular degeneration. The vitamins include Vitamin E 400 IU daily, Vitamin C 500 mg daily, beta carotene 15 mg daily, zinc as zinc oxide 80 mg daily, and copper as cupric oxide 2 mg daily. Rather than taking these vitamins separately, there are a number of pharmaceutical companies that manufacture such vitamins in this combination. Bausch and Lomb's Ocuvite PreserVision Soft Gel Formula is one such vitamin. It requires the patient to take one pill twice a day to achieve these dosage levels of vitamins. Those patients who smoke or who recently quit smoking should avoid high dosages of beta carotene because several studies have demonstrated that beta carotene may increase a smoker's risk of lung cancer. Therefore, patients who are smokers or who recently quit should take only Vitamin C, Vitamin E and zinc. These may be taken individually or as a combination, "Smoker's Formula." **Please check with your family doctor before taking any new vitamins.**

A recent study that evaluated the dietary history of patients to determine what foods may contribute to progression of macular degeneration found that processed foods may be harmful to the eyes of patients with macular degeneration. By processed foods, the study means cookies, cakes, pies, muffins, french fries, and potato chips. Typically, processed foods are foods in which the manufacturer adds vegetable or animal oils or fats, especially trans-fats, to the natural food source. Therefore, it is recommended that patients with macular degeneration avoid such processed foods. Instead, **patients should eat more natural foods in which nothing is added to the food. This would include fruits, vegetables, and nuts.** The study found that eating fruit three times a day was much more beneficial than eating fruit just once a day. Any type of nut may be beneficial in this regard. It is also felt that nuts may be protective to the eyes of patients with macular degeneration. Although peanut butter has nuts, the regular peanut butter that most people purchase and eat is a processed food because hydrogenated vegetable oils are added to this. Therefore, for patients who prefer to eat peanut butter, but without the oils, they should purchase natural or organic peanut butter in which no oils are added. Smucker's manufactures such peanut butter without the oils added.

It is impossible to predict whether following any of the above recommendations will prevent loss of vision in your particular case. However, at this point, we have nothing else that we can offer patients with macular degeneration to prevent visual loss. Therefore, anything that you can do as recommended above may be helpful in preserving your vision.

For family members of patients with macular degeneration, it is recommended that they follow the dietary recommendations, exercise, avoid smoking and wear sunglasses. However, it is not recommended that they take the AREDS vitamins.

2008 Macula Vision Research Foundation Conference Coconut Grove, Florida

Robert Molday, Ph.D. Chairman, MVRF Board of Scientific Advisors

Tremendous progress! Those were the words of the world's top vision scientists attending the 2008 Macula Vision Research Foundation Conference at the beautiful Grove Isle Hotel and Spa in Coconut Grove, Florida. Presentations and round table discussions highlighted recent research on macular degeneration and related retinal degenerative diseases that are major causes of blindness in the world population.

Sessions focused on the identification and characterization of genetic variants that increase one's susceptibility for developing age-related macular degeneration (AMD), characterization of cell and animal models essential for unraveling molecular and cellular mechanisms responsible for photoreceptor cell death and a loss in vision, clinical features and molecular mechanisms associated with specific types of macular degeneration and other retinal degenerative diseases, and advancements in the development and application of treatments to prevent or slow vision loss.

An additional session was devoted to recent research on the genetics, molecular mechanisms, and therapeutic approaches for Parkinson's disease, a complex degenerative disorder of the central nervous system, which like AMD involves neuronal cell death.

AMD is a complex multifactorial disease associated with both environmental and genetic risk factors. It is now well established that smoking, high fat diets rich in cholesterol, lifestyle, and family history in addition to age contribute to AMD. Significant progress has been made during the past several years in identifying genetic factors that increase one's risk for developing AMD. Major contributors are variants in genes that encode immunoregulatory proteins including complement factor H (CFH). To further evaluate the role of CFH in the pathology of AMD, mice deficient in the CFH gene have been generated and characterized using a variety of physiological and morphological techniques. Results of these studies indicate that CFH-deficient mice exhibit many age-related pathological features found in individuals with AMD including diminished visual response and altered retinal structure.

Another major contributor to one's susceptibility for AMD has been mapped to a genetic region known as the LOC387715/HTRA1 locus. This region consists of two closely spaced genes referred to as ARMS2 and HTRA1. Different research groups have reported an association between AMD and genetic variants in each of these genes. Ongoing studies should determine if variants in the ARMS2 gene, the HTRA1 gene, or perhaps both, contribute to one's risk of developing AMD.

A number of presentations at the meeting focused on recent progress in unraveling the complexities of other inherited retinal degenerative diseases that are leading causes of blindness in the world population. In-depth discussions focused on the clinical and genetic characteristics of Usher syndromes, a family of diseases associated with the loss of both vision and hearing. New results on the molecular

and cellular mechanisms responsible for Stargardt macular degeneration, a leading cause of early onset macular degeneration, and Best macular dystrophy, a disorder associated with fluid accumulation in RPE cells, were also presented and evaluated. Finally, the pathogenesis of central serous retinopathy (CSR), a disorder associated with retinal detachment was presented. Although there are numerous reports describing the clinical features and disease progression of CSR, to date little is known about the genetics, cellular or molecular basis for this disease. Round table discussions pointed to the need to increase basic research on CSR with the goal of identifying possible genetics factors that contribute to this disorder and developing animal models to further evaluate the molecular and cellular basis for this disease.

Significant progress has been made in the development of therapeutic strategies to prevent or slow photoreceptor cell death. The efficacy and safety of gene therapy using adeno-associated viral (AAV) vectors to deliver genes to retinal pigment epithelial and photoreceptor cells is now well established in animal models. AAV mediated gene delivery has been successfully used to limit photoreceptor cell loss and in some cases restore visual function in animal models for Lebers congenital amaurosis (LCA), cone dystrophies, X-linked retinoschisis, and selected forms of retinitis pigmentosa. Successful gene replacement studies on animal models for LCA has led to Phase I clinical trials for this disease. Preliminary reports from three independent research groups (two at the University of Pennsylvania and one at the University College, London) indicate that AAV-mediated gene delivery of the RPE65 gene to retinal pigment epithelial cells is not only safe, but also results in significant improvement in vision in a number of LCA patients enrolled in these trials. Continued success in these clinical trials should open the door to the application of gene therapy as a treatment for other retinal degenerative diseases.

In another approach, scientists have reported that delivery of ciliary neurotrophic factor (CNTF), a neuroprotective agent, to the retina can slow the loss of photoreceptors in a number of animal models for retinal degenerative diseases. Clinical trials are currently underway to test the safety and efficacy of delivering CNTF to the retina of human patients using encapsulated cell technology. Finally, the application of stem cell technology as a potential treatment for retinal degenerative diseases was presented at the conference. It was reported that subpopulations of retinal progenitor cells can integrate into the retina and generate synaptic interactions with existing retinal neurons.

At the end of the 2008 MVRF conference, the participants expressed a strong feeling of excitement and optimism that the information derived from recent research will lead to the development of new interventions and treatments for AMD and other retinal disorders. The MVRF has played a major role in advancing our knowledge of macular degeneration through its generous funding for research and support of conferences.

Macular Degeneration and Changing the Way You Think

Betty Mathews, DrPh

I have had macular degeneration for six years. I learned that when macular degeneration is the diagnosis, the shock and disbelief are overwhelming. The mind overflows with questions such as Why Me? or What If? But don't go there. Or your thoughts may be drawn to the past when life seemed easier, colors brighter and sounds more musical, but don't go there either. The past has gone and the future never comes. It is only the present in which life is lived. An enriched present can be yours. It is merely waiting for you to take charge and to make it as easy and as colorful as it used to be. You can still have a beautiful life, but you will need to prepare yourself with the right tools, develop the skills you will require and above all you will need to change the way you think about everyday living tasks and the way you think about yourself.

The first step is to begin the difficult task of changing your focus from the ways you did things in the past to the goals you wish to achieve. That is, the focus is not on seeing, but on reading, or getting the picture on the wall where you want it. The focus is not on cooking but on eating, not on driving but on getting where you need to be. So you take the bus, taxi or have a friend drive you. The focus is always on the goal, not the way things used to be or the way you have used before your vision changed.

When thinking is centered on goals, then it is the time to explore new or different ways to reach each goal given the reality of low vision. It often requires giving up many of the old familiar, often cherished ways of living. For example, assume that the family has annually come to your house for Thanksgiving din-

ner and they are coming this year. You have always made a cranberry relish that has become your specialty. The goal is still to have cranberries at dinner. The question is with the reality of limited vision what is the best way to achieve the goal? No matter what the answer it will not be the cranberry dish you have preferred for years. Given that fact, you might as well buy cranberries in a can from the store. That may seem a distasteful idea to you, but if you concentrate on the goal as more important than the means and the goal is to have cranberries at the dinner, then you accept the fact that you can no longer see well enough to shred cranberries. However, you can still have cranberries for that Thanksgiving dinner. **The goal with the highest priority is to have that holiday dinner with family and friends together.**

Discarding the familiar, the tried and true, and cherished ways you have lived, is extremely difficult. You really do not want to change those things about your life or about yourself. However, the life that awaits you is the life you build by your commitment to being open to all that is there for you.

Changing the way you think means having the same goals you ever had, but reaching them in different ways. As you learn new and successful ways to achieve your goals, you will discover that you are thinking not negatively about yourself but positively, because you are successfully solving the difficult task of living well with Macular Degeneration and experiencing satisfactions in your life that possibly you had not expected.

Low Vision Rehabilitation – Covered Directly by Medicare In Six Designated Areas...More to Come?

Specialized work with people who are blind or partially sighted has evolved over the last century. The core practitioners — certified vision rehabilitation therapists and certified orientation and mobility specialists — honed their skills at nonprofit vision rehabilitation agencies and Veterans Administration Hospitals, in response, in part, to the growing numbers of blinded veterans returning from the two World Wars.

Today, there is a third core practitioner — certified low vision therapists. All combined, these three professions have a singular specialty — vision rehabilitation. Like other health care professionals, these three specialists practice in hospitals and clinics, schools and community based agencies, with funding from local state and federal governments (with the exception of Medicare), and philanthropic dollars. Without Medicare funding, their services in hospitals, outpatient clinics, HMOs and in private practice have been severely limited.

To off-set this severe limitation, in 2003, Congress directed the Center for Medicare and Medicaid Services (CMS) to carry out a Low Vision Rehabilitation Demonstration (LVRD) Project as part of the Medicare Prescription Drug, Improvement and Modernization Act of 2003. The LVRD Project began April 1, 2006, and continues until March 31, 2011, with two important goals: **to ensure national coverage for vision rehabilitation and to allow vision rehabilitation professionals to provide services within a patient's home environment, where these services are most effectively delivered.**

The LVRD Project adds to the Medicare system, for the first time, reimbursement for certified (non-licensed) allied healthcare personnel for providing vision rehabilitation services under the general supervision of a qualified physician. **It does not**

include reimbursement for Low Vision Aids. The ground-breaking inclusion of these professionals is currently allowable only in the six selected demonstration project areas: the states of Kansas, New Hampshire, North Carolina, and Washington; all five boroughs of New York City; and 522 specific zip codes in Metropolitan Atlanta, Georgia.

These therapists, certified by the Academy for Certification of Vision Rehabilitation and Education Professionals, are titled Certified Low Vision Therapists, Certified Orientation and Mobility Specialists, and Certified Vision Rehabilitation Therapists. Vision rehabilitation services provided by Licensed Occupational Therapists, also billable outside the demonstration project, can be reimbursed under Demonstration Project procedure codes.

While the Demonstration Project does not cover physician E&M codes, it does not alter the ability of physicians to submit E&M codes for office visits for low vision patients who are Medicare beneficiaries. Submission of vision rehabilitation therapy claims to Medicare is currently allowable only in the geographic regions covered by the Medicare National Low Vision Demonstration Project. Accepted Demonstration Project claims are currently paid within the standard Medicare 14-day reimbursement timeliness guidelines. The availability of Medicare Demonstration funds continues to assist the Center for the Visually Impaired in Atlanta to offer our low vision services to more patients. In addition, it enables us to develop mutually beneficial linkages with local eyecare practices and to speak the same language regarding reimbursement.

A wealth of evidence has been presented in recent years supporting vision rehabilitation services as an important benefit to keep seniors safer and independent longer. The U.S. Centers for Disease Control and

Prevention (CDC) has testified that falls among older people cost the government more than \$20.2 billion, specifically citing vision problems as one of the leading causes of falls. Hip fractures are among the most costly fall-related injuries common to older adults and provide a compelling example of the value of vision rehabilitation. If only one in five of the hip fractures due to vision impairment were prevented each year, the annual cost savings would be more than \$440 million.

In addition, vision impairment has been identified by the Alliance for Aging Research as one of the four leading causes of lost independence among older people, with additional medical and long term care costs estimated at \$26 billion greater than if these individuals had remained independent.

If you are interested in more information about the LVRD Project or would like to participate in one of the six demonstration sites, contact Roxann Mayros at rmayros@agenciesfortheblind.org or 314-961-8235.

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Purpose of Foundation: macula vision research and public education

Mission: to find the cause, prevention, treatment, and cure for macula vision diseases with the goal of saving sight; and providing public education, advocacy and support to those with macular degeneration.

If you have questions, please call Lea Bramnick at 610-668-6705 or email Lea@mvr.org.

If you know someone... who could benefit from the information published in "focus," the newsletter of the Macula Vision Research Foundation, please complete the following information

Name _____
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We will add the new name to our database so that he/she can receive future issues. **Thank you.**

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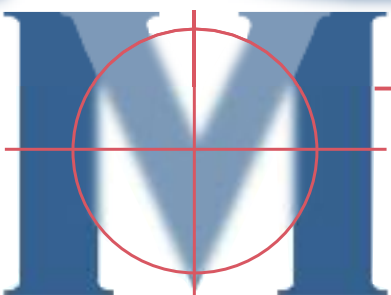
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MVRF Grant Award Winners

From March 16, 1998, the Macula Vision Research Foundation has awarded more than \$11 million in research grants with the support of the Ronald McDonald House Charities and the Karen and Herbert Lotman Foundation.

The Macula Vision Research Foundation Logo

The logo for the Foundation was carefully designed to pinpoint the powerful symbolism of the fuzzy, fading central parts of the letter M indicating the loss of central vision. The red circle reminds us that vision is the center of our lives, allowing us to focus on the people and activities that mean the most to us. The red + defines our mission of focusing our attention, efforts, and resources to finding the cause, prevention, treatment, and cure for macula disease. **M**

DISCLAIMER

The information presented in the MVRF newsletter is not intended as a substitute for the advice of a physician. If you have a medical problem, you should consult your physician about any suggestions made in this publication. All information is intended for your general knowledge only and is not a substitute for medical advice or treatment for specific medical conditions. Please discuss any medical questions or concerns with your doctor.

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