Spring 2012

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Answers for Sudoku puzzle from page 16

2	3	5	1	4	7	9	8	6
4	1	8	9	6	5	7	2	3
6	9	7	2	8	3	1	4	5
9	8	6	5	7	4	2	3	1
5	7	3	8	1	2	4	6	9
1	4	2	6	3	9	8	5	7
7	5	9	3	2	8	6	1	4
8	6	4	7	5	1	3	9	2
3	2	1	4	9	6	5	7	8

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SupportSightNEWS®

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Funding Visionary Research

WHAT'S NEW AT MVRF?

- Support MVRF while you shop! Shop at hundreds of stores on cafegive.com and you can direct a portion of your purchase to support MVRF
- Three SupportSight® Seminars coming up this Spring in Austin, Cleveland, and Los Angeles... details inside
- Introducing the MVRF *Living Legacy Society*

100% of every dollar donated goes directly to research.

IN THIS ISSUE

LETTER FROM OUR FOUNDERS

We hope the Spring finds you well and we'd like to thank you all for your continuing support of MVRF. The number of donors who supported MVRF in 2011 was nearly double the number from 2010. For that we thank you. We wouldn't be able to fund the innovative, ground-breaking research we do without your support. We look forward to continuing to increase our base of support so that we can increase the research grants we award. The more financial support we have, the faster we can reach our goal:

A cure for all retinal diseases, including macular degeneration and congenital childhood blindness

We are looking forward to MVRF's International Scientific Conference, which will be held this October in Chicago. We are excited to bring together leading researchers in the field to share their research and ideas, and collaboratively move towards better treatments and a cure. Our family foundation pays all costs associated with this conference, ensuring that **100%** of all donations support research.

Donations are what make innovative research possible. Please consider making a donation to MVRF. As always, 100% of all donations go directly to research. Our family foundation pays all expenses (including administrative and fundraising costs), allowing you to give confidently and generously.

Donations = Research = Cure

Our exceptional MVRF team continues to work tirelessly, continuing our commitment to bringing you the latest information on research and treatment options, as well as helpful tips and advice about living with macular degeneration. Through our comprehensive website, social media, and SupportSight® programs, we are available for you when you need us.

Best wishes for a safe and healthy spring,

Karen and Herb Lotman

Karen and Herb Lotman
Founders, Macula Vision Research Foundation

LETTER FROM OUR EXECUTIVE DIRECTOR

When Dame Judi Dench, critically-acclaimed, world-renowned, actress, announced that she has Macular Degeneration in February, she raised public awareness of the diagnosis. However, the media frenzy that followed, declaring that she is "going blind," illustrates just how misinformed the public is about the disease and how little they understand about its impact on those affected.

Judi Dench, whose accolades include two Golden Globes, a Tony Award and an Academy Award, bravely acknowledged that because of Macular Degeneration, she is no longer able to read scripts or see the person sitting across from her. Despite the challenges she faces, she is determined to make the best of her situation. In her case, she has her agent, a friend, or her daughter read a script out loud while she imagines the story in her mind. She also uses glasses, lenses and bright lights to improve her limited vision. To those of you who are finding ways to cope with impaired vision, you know you're not alone.

We continue to raise awareness of retinal diseases and increase funding for research for a cure. Now there's a new way for you to support MVRF that won't cost you a dime! We are partnering with CafeGive. Visit **www.cafegive.com** and designate MVRF as your charity of choice. Then shop on-line at any store on the site, from Target to Nordstrom, Sam's Club to Best Buy, and a percentage of your sale will be directed to MVRF. It's that simple to fund research for a cure.

We're happy to share articles by the world's premier researchers and clinicians, bringing you the best, most timely information available about retinal diseases. We thank these experts for sharing their expertise and experience with out readers.

MVRF's Facebook community has quickly become a source of support and encouragement for our 5,500+ Fans. Please join the community and share your experiences.

Look for us on Guidestar.org to see our top rating for non-profits, nationwide. Please let others know about our work and encourage them to support MVRF by donating today. Working together, we will find a cure!

Many thanks,

Keith A. Lampman

Keith A. Lampman
Executive Director

FACT OR FICTION:

Self-driving cars will revolutionize the lives of the visually impaired

by Philip J. Rosenfeld MD, PhD, Professor of Ophthalmology Bascom Palmer Eye Institute, University of Miami Miller School of Medicine and Member of MVRF International Scientific Advisory Board

According to the Associated Press, Google has successfully road tested a self-driving car. The company has been testing their self-driving system with the Toyota Prius, however the system can be installed on any vehicle. Google received a patent for its driverless car system late last year. Recently, Nevada became the first state to change its laws to permit the large scale testing of self-driving cars on its highways. Florida, California, Oklahoma, and Hawaii are considering similar legislation. According to Wikipedia, "other companies such as General Motors, Volkswagen, Audi, BMW, and Volvo have begun testing driverless car systems. General Motors stated that they will begin testing driverless cars by 2015, and they could be on the road by 2018."

This breakthrough technology has been widely reported on the Internet and a search of "driverless cars" or "self-driving cars" yields over 5.7 million sites with information! This isn't a crazy, futuristic idea depicted in science fiction movies. This is real technology. It will also be big business. And, in terms of its social value, it will have a dramatic impact on those who are visually impaired, especially those with age-related macular degeneration (AMD). For my patients in South Florida who have depended on cars all their lives and, with the progression of their AMD have lost their driver's licenses, lost their cars, and lost their independence, it will be profoundly life-changing.

The self-driving car will revolutionize the lives of all who suffer with vision loss from macular disease. Where I practice, public transportation is inadequate and county transportation services, reserved for those with very poor vision, require painfully long wait times. My patients rely on friends and family to keep their appointments, go to the supermarket, and manage their day-to-day activities. For wet AMD patients receiving frequent eye injections to save their vision, the treatments alone place a huge burden on family and friends. These patients need someone to drive them to the appointments, wait for them as they undergo evaluations and injections, and drive them back home. Each visit can last hours, and can be required every month. Patients who can drive under normal circumstances are strongly discouraged from driving immediately after an eye injection, thus rendering them in need of a companion for their treatments.

What if it were possible to get into a self-

FACT OR FICTION (continued)

driving car, tell it where to go, and miraculously arrive at your destination? It is possible! The technology already exists. What lags behind are the laws and infrastructure to support this technology.

We should demand that every state legislature follows Nevada's lead. Of course, there are issues that need to be resolved, such as establishing who is licensed by the state (is it the car or a person) and who is liable if a self-driving car gets into an accident. Nevada has provided a blueprint for these issues by revising their laws and instituting a number of safeguards, starting down the path on which other states can follow.

There is still much work to be done. There must be a concerted effort on the part of politicians, auto manufacturers, and civic leaders to design communities and roads that are receptive to self-driving cars. This technology alone will create an economic boom wherever it is introduced. While it can be installed into existing cars, I'm sure newer self-driving cars will offer even better technology resulting in increased car sales. If a business wants to attract customers who use self-driving cars, they will need the technology to manage these vehicles in their parking lots. Municipalities will need to accommodate these cars by installing wireless control towers at intersections to function stop signs and traffic lights. Finally, updating software and hardware, as well as ongoing maintenance of this technology, will create an entirely new industry of high-tech jobs.

It is clear to me that in the near future, a patient with macular disease will tell his car's guidance computer where to go, much like the voice activated systems already on our smart phones. Using GPS, radar, computer vision, and beacons strategically positioned along the roads, the car will drive its passenger to his destination. When the car arrives, the occupant of the car will be let out of the car at the entrance of the destination and the car would then maneuver into an open parking space, directed by an automated self-parking system. Then, when the passenger is ready to leave, the process would be just as simple. The car would be remotely activated and the passenger picked up at an entrance.

We know this is all possible. We don't yet know the cost and time frame, as these require real-world testing. That is why we must get these driving systems on the open road. Though we can't cure macular degeneration or restore vision at this time, we can build self-driving cars that will improve quality of life for those who have lost their independence, and especially those with vision loss.

RESEARCH UPDATE FROM SCHEIE EYE INSTITUTE

by Joan M. O'Brien, MD
Chair, The Department of Ophthalmology, Scheie Eye Institute, University of Pennsylvania Medical Center

With the support of many generous philanthropic organizations and individuals, as well as the National Institutes of Health and the hard work and expertise of Scheie researchers and clinicians, the Scheie Eye Institute at the University of Pennsylvania has again made great progress in our mission to eliminate blindness. The Department of Ophthalmology at the University of Pennsylvania is particularly grateful for the continued support of the Macula Vision Research Foundation, which has helped fund many of these projects. Without such generosity, we could not have achieved these important results.

Below are some of our most recent research breakthroughs and accomplishments as well as some of our plans for the future.

Jean Bennett, MD, PhD's lab concluded its study on gene augmentation therapy for Leber Congenital Amaurosis (LCA), resulting in significant improvements in vision in all 12 of the subjects. The lab began re-administration studies for this disease and children given the gene replacement in their second eye have tolerated treatment and have visual restoration bilaterally.

In addition to this form of LCA, the Bennett Lab is developing proof-of-concept of gene therapy for a number of other sensorineural inherited diseases, including LCA due to CEP290 or Lebercillin mutations, Usher Syndrome 1C, X-Linked Retinitis Pigmentosa, Choroideremia, and Stargardt macular degeneration.

On September 20, 2011, Dr. Bennett received the Pioneer Award from the Director of the NIH. This award is designed to support bold and innovative scientists who propose pioneering approaches to major research challenges. Dr. Bennett will use the award to fund her research on molecular therapy for blinding retina disorders. This work focuses on "optogenetics" and has the potential to treat not only rare inherited diseases, but also millions of patients with blindness due to diabetes, retinal detachment and other common causes. This work will use existing neural networks in the retina and replace photoreceptor loss with a vector containing a light signaling channel protein, to restore vision.

Josh Dunaief, MD, PhD's lab, which focuses on retinal iron regulation, has tested iron binding drugs for their protective activity, and has accumulated evidence that the drugs are indeed retina-protective, in cell culture and in mice. These drugs protect both the retina and the brain when they are iron overloaded, as occurs in humans with aging. Dr. Dunaief is planning a sabbatical to better understand how iron accumulation with age is associated with oxidative stress in the retina and brain. He is proposing a clinical trial using iron chelation therapy. This work could have important application to both age related macular degeneration and Alzheimer's disease.

RESEARCH UPDATE FROM SCHEIE EYE INSTITUTE (continued)

Artur Cideciyan, PhD studies early onset genetic macular degeneration and potential treatment options, which are mechanism-specific. A long-held hypothesis stated that gene mutations that produced no ABCR protein resulted in the most severe forms of Stargardt disease, and those that produced mutant ABCR protein resulted in milder forms. Dr. Cideciyan's research, however, has shown that some of the most severe phenotypes are caused by genotypes that are expected to produce mutant proteins. Greater severity of disease compared to no protein production could occur due to misfolding of the mutant protein. With this new understanding, patients without misfolding types of gene mutations, who would benefit from the addition of the normal protein, may be the first candidates selected for upcoming gene therapy trials.

Juan Grunwald, MD is world renowned for his research on blood flow in the retina. His studies have shown a link between the progression of macular degeneration and decreased blood flow in the choroid. Dr. Grunwald found that one to two years prior to transforming from dry AMD into wet AMD, and prior to the appearance of choroidal neovascularization, there was a significant decrease in blood flow in the choroid. This insight may shape new studies of therapy to improve blood flow in AMD patients.

RESEARCH UPDATE FROM SCHEIE EYE INSTITUTE (continued)

Samuel Jacobson, MD, PhD is investigating the RPE65 form of retinal degenerative disease as part of the Ocular Gene Therapy Clinical Trial of Childhood Blindness project, funded by the NIH. The first cohort, given injections of vector-genes over the past years, has responded so well that the study will continue to enroll patients over the coming years. Dr. Jacobson's work also focuses on Usher's Syndrome, which is a systemic illness that results in Genetic Deaf-Blindness. Dr. Jacobson is also investigating electronic chip artificial retinal implants as a treatment for severe blindness due to retinitis pigmentosa and many other causes.

Albert Maguire, MD has continued his work in surgically delivering novel gene therapies for retinal degeneration and ocular neovascularization into the subretinal space. He performs the surgical component of Jean Bennett's work and collaborates with her extensively. He is also a recipient of the Pioneer Award from the Director of the NIH, given to support scientists of "exceptional creativity who propose pioneering and potentially transforming approaches to major challenges in biomedical research".

Maureen Maguire, PhD directs the Coordinating Center for the NIH-funded Comparison of Age-related Macular Degeneration Treatments Trials, which found that Avastin is just as effective through one year of evaluation as the more expensive drug Lucentis in treating wet macular degeneration. The multicenter, randomized clinical trial involved 1,200 patients with choroidal neovascularization, and was recently published in the *New England Journal of Medicine.*

Dwight Stambolian, MD, PhD recently completed a multi-site study focusing on the discovery of common gene variants in AMD. It included 8 different international laboratories that provided over 8,000 cases and controls for a high throughput genome wide association study. The results of the study confirmed several genes previously identified as risk factors along with 3 new genes influencing the development of AMD.

Dr. Stambolian also recently identified a region on human chromosome 22 that appears to be causing nearsightedness, a form of refractive error. This region contains 3 genes that have not been shown to function in the eye and Dr. Stambolian's team is in the process of functionally assessing the significance of these genes in the eye. If successful, this information will provide insight into the biology of nearsightedness and possibly lead to improved treatments superior to eye glasses or refractive surgery, neither which stop the progression of nearsightedness as one ages.

Finally, Dr. Stambolian has submitted a grant using 10 years of blood samples from his Amish outreach program to study the genetics of eye disease in this cohort.

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DRUG THERAPY FOR WET AMD: WHICH DRUG, AND HOW OFTEN?


Stephen Schwartz, MD


Harry Flynn, Jr., MD

By Stephen G. Schwartz, MD, MBA and Harry W. Flynn, Jr., MD, Bascom Palmer Eye Institute, University of Miami Miller School of Medicine

Over the last 8 years, the treatment of wet age-related macular degeneration (AMD) has evolved from a surgical therapy using various lasers to a medical therapy using various drugs. In order to be effective, the currently available drugs must be injected into the eye, usually on some sort of time schedule. Two important questions have emerged: which drug, and how often? At this time, there is no conclusive answer for either question, but we can review the fundamental principles.

Which Drug?

The drugs all block the action of a naturally occurring substance called vascular endothelial growth factor, or VEGF. This is pronounced "veg-f" ("veg" as in "vegetable"). Interfering with VEGF generally reduces leakage and bleeding under the macula and can improve vision in many patients with wet AMD and some other retinal diseases as well.

Following a large multicenter clinical trial, the first anti-VEGF drug to be approved by the US Food and Drug Administration (FDA) for the treatment of wet AMD was **Macugen** (generic name pegaptanib). Macugen blocks only some forms of VEGF (called VEGF-165) and was recommended to be used every 6 weeks. Macugen is perceived to be generally less effective than the other anti-VEGF drugs and is used infrequently at present.

Used in an "off-label" manner, the second drug to be introduced was **Avastin** (generic name bevacizumab). Avastin is a chemotherapy drug designed to be used intravenously to treat colon and some other cancers. Avastin blocks all forms of VEGF and, when injected into the eye, can be very effective against wet AMD and some other retinal diseases. The FDA approved Avastin to be used as an intravenous cancer chemotherapy drug, and not to be used in the eye, so this use is considered "off-label". Avastin is generally used monthly, although there was no formal clinical trial to establish this fact. Avastin is considerably less costly than the other anti-VEGF drugs and is used much more frequently in the US and around the world.

Again following a large multicenter clinical trial, the third drug to be introduced was **Lucentis** (generic name ranibizumab). Lucentis and Avastin are manufactured by the same company and are very similar at a chemical level. Lucentis was specifically designed to be injected in the eye and there are various technical features which

DRUG THERAPY FOR WET AMD (continued)

would suggest, at least theoretically, that it might be a more powerful drug than Avastin. Lucentis is FDA-aproved to be used monthly to treat wet AMD as well as macular swelling due to retinal vein occlusion. It is significantly more costly than Avastin.

In November 2011, following a large multicenter clinical trial, the fourth drug to be introduced was **Eylea** (generic name aflibercept, also known as the "VEGF trap"). Eylea blocks VEGF as well as another substance, placental growth factor (PlGF). Eylea is FDA-approved to treat wet AMD and is recommended to be used monthly for the first 3 months, then every other month. In the clinical trial reviewed by the FDA, the use of Eylea in this manner was statistically equivalent to the use of monthly Lucentis. The cost of Eylea is very similar to the cost of Lucentis.

How Often?

Following the recommendations from clinical trials, Macugen is used every 6 weeks, Lucentis is used every 4 weeks, and Eylea is used every 4 weeks for 3 cycles, and used every 8 weeks. However, many physicians (and patients) prefer to inject less frequently, and do not always follow the product label. Avastin is not FDA-approved to treat wet AMD and is used in an "off-label" capacity.

There are two main strategies currently used by physicians to reduce the number of injections. One is referred to as "PRN" (Latin for "pro re nata", or "as needed"), or "PRONTO" (the name of a clinical trial that first used this technique), or "as needed". The original PRONTO clinical trial required patients to be examined every month, and treatment with Lucentis was performed if there were any signs of visual loss, macular bleeding, or changes on a test called optical coherence tomography (OCT).

A second strategy is called "treat and extend." The idea is to treat monthly until the macula becomes "dry" and then to gradually extend the interval between treatments. For example, once the macula becomes "dry" using an injection monthly, the physician would perform another injection and ask the patient to return for follow-up at some longer time interval, perhaps six weeks. Six weeks later, if the macula is still "dry," the physician would perform another injection and further extend the interval, perhaps eight weeks.

There are two major differences between the "as needed" and "treat and extend"

DRUG THERAPY FOR WET AMD (continued)

strategies. In “as needed,” the patient is examined every month, but only injected when there is evidence of disease progression. In “treat and extend,” the patient does not have to be examined every month, but is typically injected every time.

What is the Best Treatment?

With all this information, what is the best treatment? Again, no one really knows. A major clinical trial, called CATT (Comparative AMD Treatment Trials), was performed to attempt to answer this question. In CATT, patients with wet AMD were randomly placed into one of the following groups:

1. Lucentis monthly
2. Avastin monthly
3. Lucentis as needed
4. Avastin as needed

Macugen and Eylea were not used in CATT. In addition, the “treat and extend” strategy was not used in CATT. The study was primarily interested in the visual results after one year of treatment. The major findings were:

1. Lucentis monthly was statistically equivalent to Avastin monthly
2. Lucentis monthly was statistically equivalent to Lucentis as needed
3. The comparison between Avastin monthly and Avastin as needed was inconclusive (no definite answer could be determined)

How should we interpret these results? There are several points to keep in mind. Groups of patients may have statistically equivalent results, but any one patient may or may not experience similar results. This phenomenon is poorly understood but there may be many explanations. CATT, like other clinical trials, only allowed very specific types of patients to enter the study, and the results therefore may not apply to the types of patients not allowed to enter the study. In addition, many physicians and scientists believe that there is an interaction between a person’s genes (DNA) and medications, and that this interaction may affect how the drugs work. This science is called pharmacogenetics, and there is currently much research into this topic in wet AMD drugs.

The good news is that, compared to 10 years ago, we now have many excellent drugs for wet AMD that will preserve or improve vision in many patients. The bad news is that, sometimes, too many choices can be confusing. In general, we believe that treatment should be personalized for each patient. This may require one or more conversations between the patient, the physician, and possibly the family members. It is difficult to always know ahead of time which drug, and how often, will be the best for any individual patient. By following the guidelines discussed here, excellent results may be obtained for many, or even most, patients.

SupportSight® SEMINARS

MVRF hosts SupportSight® seminars in cities across the nation so we can share the latest research findings and low vision techniques. At our seminars, you can expect to hear from both retinal and low vision experts and see demonstrations of low vision techniques. For more information please contact our SupportSight® Coordinator, **Julie Sokoloff, at 1-866-4MACULA (1-866-462-2852).**

SupportSight® Seminars are open to the public. There is no charge to attend these seminars, which are paid in full by Genentech, a member of the Roche Group.

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10:00 am-noon
University of Texas at Austin
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Big Tex Auditorium
10100 Burnet Road
Austin, TX 78758

CLEVELAND, OH:
Saturday, May 12, 2012
9:00 am-noon
Crowne Plaza Cleveland South
5300 Rockside Road
Independence, OH 44131

LOS ANGELES, CA:
Saturday, June 30, 2012
10:00 am-noon
Skirball Cultural Center
2701 North Sepulveda Boulevard
Los Angeles, CA 90049

PHILADELPHIA, PA:
Saturday, November 17, 2012
10:00 am-noon
Rosemont College,
McShain Auditorium
1400 Montgomery Ave
Bryn Mawr, PA 19010

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THE IMPORTANCE OF CONTRAST

By Nicole Patterson OD, FAAO
Chief, Low Vision and Geriatric Services,
Nova Southeastern University College of Optometry

Contrast has many definitions. The first is to note opposite nature. Black and white are opposites, and have high contrast. Acuity, or how well we see, is measured using a bright white card with dark black letters. In reality, the world we live in is full of color and has much less contrast than an eye chart. The newspaper is not truly black and white, but dark grey print on a light grey background. A person may be able to read a line the size of newspaper print when looking at it on a reading card, but be unable to read an actual newspaper.

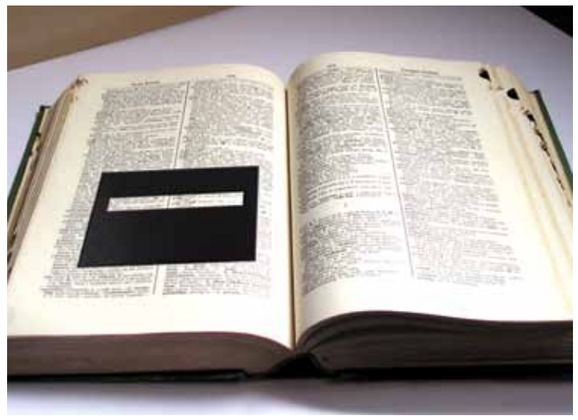
Contrast is important for more than just reading the paper. It is a factor in our day-to-day activities, which is one way in which macular degenerations presents challenges. Macular degeneration impairs our ability to detect contrast. Colorful labels can be difficult to read because of their decreased contrast. It may be unclear if a break in the sidewalk is a crack or a curb because they are the same color and provide poor contrast. While injections for wet macular degeneration can restore high contrast acuity, low contrast acuity does not improve.

There are, however, things we can do to improve the contrast we perceive in our environment.

Improving our **lighting** is probably the easiest and most important change we can make. Many people find it beneficial to change the light bulbs in our home to daylight bulbs.

A **magnifier** with a built in light can be extremely helpful in places with poor lighting, such as in restaurants, churches, temples, and synagogues. Key chains with mini flashlights are convenient tools to ensure a readily available light source.

A **typoscope**, which is a piece of cardboard with a slit, serves two purposes. First it can help to isolate a line in a book or magazine, preventing us from losing our place while reading. Secondly, it works to increase the contrast by putting a black background around what we are trying to read.



Typoscope

THE IMPORTANCE OF CONTRAST (continued)

Portable handheld electronic magnifier

The newer **portable handheld electronic magnifiers** also allow us to increase contrast. With these magnifiers, we have the ability to convert a colorful label it to black and white, providing the necessary contrast. These magnifiers also permit polarity inversion, taking black print on a white background and changing it to white print on a black background. The change in polarity is helpful to many people.

Reading handwriting written with pencil or ballpoint pen is often challenging. Many patients tell me they make grocery lists before going to the store, but cannot read their writing once they get there. A **20/20 pen**, also called a fine tipped marker, provides good contrast to make reading grocery lists much easier. Black gel pens also improve contrast.

The use of **filters** is another method to increase contrast. Yellow and orange lenses may increase contrast while reading. Filters also work to provide improved contrast at distance. Sunglasses are filters that protect our eyes from harmful UV rays while providing us with higher contrast. All sunglasses, however, are not created equally in this regard. Dark grey sunglasses further reduce contrast, while brown or amber lenses protect from the damaging rays without reducing the contrast.

There are other adjustments we can make in our everyday life to improve our perception of contrast. We can play cards on a dark tablecloth. We can use white coffee cups when pouring coffee. We can affix tape of a contrasting color to the edge of a step, making it easier to see and reducing our risk of a fall. Macular degeneration may impair our ability to detect contrast, but with some thought and preparation, we can make adjustments that improve our ability to perceive contrast, and make our lives safer and more enjoyable.

SUDOKU

Fill in the blank squares so that each row, each column and each 3-by-3 block contain all of the digits 1 thru 9. If you use logic you can solve the puzzle without guesswork.

2		5			7			6
4			9	6			2	
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	6			5	1			2
3			4			5		8

SOLUTION ON BACK COVER

INTRODUCING THE MVRF *Living Legacy Society*

We are excited to announce the founding of the MVRF *Living Legacy Society*. While outright gifts of cash and checks are common donation types, planned gifts are popular options that will enable you to make a positive impact while ensuring your ability to meet your family's current financial needs. There are a variety of planned giving options available.

Your planned gift can be as simple as including MVRF in your Will. Your gift can also be irrevocable, allowing the benefit of an immediate income tax deduction. This is an attractive option because though you make the decision to fund visionary research now, the actual gift is deferred until a later time. You may maintain the use of the asset until a time you designate for the transfer, often not until after your lifetime or that of your surviving beneficiary.

The key factor of any planned gift is that it provides important financial benefits to you, the donor, while providing significant financial benefits to MVRF. If you have already included MVRF in your Will or estate plans, please let us know as we would like to include you in our publications as a member of the MVRF *Living Legacy Society*. Your participation may encourage the participation of others. As always, 100% of your donation goes directly to research.

Beginning in our July issue, we will include in each SupportSightNEWS® a current list of our *Living Legacy Society* members (unless anonymity is requested). If you have included MVRF in your estate plans, please let us know so we can acknowledge your generosity. We simply need a copy of the legal document that includes MVRF in your plans. If you have any questions or would like additional information, please contact our Executive Director, Keith A. Lampman, at keith@mvrf.org or call him at 610-234-0091. Thank you for your continuing support of MVRF and research for a cure.

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Joe and Mary Fenkel
Melva and Mel Herrin
Robert B. Kern
Paul Kramer & Selma and Raymond Kramer Foundation
Joanne and Edward E. Miller, Sr.
Karyn and Charles Murray
John W. Rich, Sr.
Roxanna and E. Lorraine Schlimm
Jan and Paul Schrage
Sickles Charitable Fund
The Sidewater Family Foundation
Charles and Nancy Valluzzo

RETINA GIVING SOCIETY
$25,000 +

Anonymous
Irma and Robert E. Blumenthal
Donna Calvert
Ellen and Win Churchill
Coca-Cola Company
Judi and Bruce Goodman
Francine and Steve Katz
The Laurel Foundation
The Liebowitz Foundation
Nicholas V. Martell
Mellon Financial Corporation
Peter G. Peterson Foundation
Philadelphia Fountain Society
Marcia and Ron Rubin
Harriet and Larry Weiss

MVRF GIVING SOCIETIES (continued)

MACULA GIVING SOCIETY
$10,000 +

Anonymous[5]
Andrew and Lillian A. Posey Foundation
Lucille and Harry Bahm
Irene Bondy
Cagle's Inc.
Cantalupo Family
Ronald Caplan, Philadelphia Management
Janice Coats
Susan and George Cohon
The Cooper Family Foundation
David A. Coquillard
Rena Rowan Damone and Vic Damone
Eleanor and Howard Morgan Family Foundation
Estate of Erna Beyer
Estate of Sophia Levin
Eyetech Pharmaceuticals, Inc.
GFPT Public Company Limited
Willis Gillett
Lindsay Goldberg
Mr. and Mrs. Brent R. Granger
Thomas J. Gravina
Eileen Leary
Nancy and Rudy Lee
Leon L. Levy & Associates
Marilyn and Charles S. Mechem, Jr. Fund of the Greater Cincinnati Foundation
Joel A. Montgomery
Nancy A. and Jerome L. Myers, MD
NSM Insurance Group
Michael A. Peterson Foundation
Mr. and Mrs. Carl E. Ring, Jr.
Robert and Teresa Lindsay Family Foundation
Roberta and Ernest Scheller, Jr. Family Foundation
Rocky Mountain Express Corporation
Charles and Mildred Schnurmacher Foundation, Inc.
Dr. Arlyne Taub Shockman
Space Tech and Research Foundation
The Honorable Marilyn Ware
Marlene Weinberg

Donations = Research = Cure

Karen and Herb Lotman, members of the International Scientific Advisory Board, and the staff of MVRF thank all MVRF Giving Society members for their continuing support and generosity in funding visionary research.

A STORY OF TRANSITION, ACCEPTANCE, AND MOVING ON

By Stewart Hughes, SupportSight® Reader and Contributor

In 1991, when I was 47 years old and living in Northern California, I experienced a sudden and major vision loss. During the course of two weeks, I was diagnosed with an ocular disease called Leber's Hereditary Optic Neuropathy, confirmed by DNA testing. I have the condition in both eyes and am legally blind. I have no central vision and only a bit of peripheral vision. This affords me light perception and allows me to see shadows and forms up to approximately four feet. What I do see is blurry. I describe it as looking through a heavy fog. I am quite light sensitive and wear the darkest available sunglasses when outdoors and sometimes, if necessary, indoors as well. There is currently no cure for this condition.

Due to the lack of rehabilitative information and resources in the area, I relocated to the Philadelphia area to live with my family. I left behind my job at a high-tech manufacturing company, the hills on which I had ridden my mountain bike, and the landscapes I often photographed. I made it my mission to create a new life for myself.

Once settled, I sought new skills and training. Upon completing a six-month Blind Rehabilitation Program for Veterans in West Haven, CT, I returned to Philadelphia and took advantage of the services offered by the Bureau of Blindness and Visual Services. I qualified for and completed a Computer Training Program and learned computer skills for the first time despite having no reading vision.

I learned WordPerfect, spread sheet programs, and a screen reading program called Vocal Eyes. After Windows was introduced, I took classes offered by the Veterans Administration. I now use JAWS, a screen-reading program that reads aloud what appears on the computer screen. I use MS Word, Excel, the internet, and email.

All of my training led to an Internship, which in turn led to part-time employment with The Montgomery County Association for the Blind. While there, I created and maintained a variety of databases and conceived and implemented a Computer Access Training Program for County residents. Seven years later I took on a new position with Virtual Vision Technologies where I headed up its Computer Access Training Program.

My last and most satisfying job was at the Children's Hospital of Philadelphia (CHOP) where I was a Family Resource Coordinator. In a room equipped with tools and computers, I was able to help others avoid my unfortunate experience when faced with vision loss. I worked with patients, families, staff and the general community to make them aware of the variety of resources available in the Philadelphia

A STORY OF TRANSITION, ACCEPTANCE, AND MOVING ON (continued)

area. I also demonstrated and discussed some of the technology used by the visually impaired to support their independence.

I live in a condo in the immediate suburbs of Philadelphia. I trek to the local supermarket, lug my laundry down a floor, and keep my wood floors clean with the help of my man Murphy, a Maine Coon cat. I am an independent traveler, using public transportation to navigate my way around to volunteer or socialize. The regional bus and rail company is in my contact list on my talking cell phone. I may not see all detours, but I know where they are so I can re-route myself in an instant!

Since my diagnosis, my vision has remained the same. Not worse, but no improvement. Because of the rarity of the condition, little research is being done and few treatment options are available. Despite this, I make sure I do the things I enjoy: I use exercise machines to stay healthy, listen to digital recordings on a small machine to enjoy great mystery novels, manage my day-to-day needs, and dine at many of Philadelphia's great restaurants. With hard work and a resilient spirit, I have found ways to make my life fulfilling and enjoyable. But ask me if I'd like to see Philly's historic architecture in focus and in detail – well, you know I would!

MVRF welcomes your submissions to SupportSightNEWS®. If you have an article, personal experience, or tip that you think would benefit our readers, we invite you to send it to Robin Davison, Director of Communications, at Robin@mvrf.org. If your submission is selected, it will be included in our SupportSightNEWS® publication with a circulation of more than 20,000. We look forward to hearing from you.

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COOKING FOR EYE-HEALTH WITH MARLON

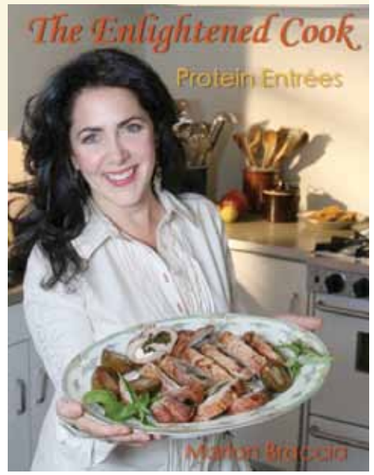

Photo and recipe by Marlon Braccia

Oily fish is a supreme source of Omega 3 fatty acids, so it's become common advice to consume salmon a few times a week to enjoy its benefits. Even though salmon is the most commonly consumed fish in America today, Americans, who all too often claim they "don't like fish," often ignore the good advice. That opinion is probably formed from eating fish that is poorly prepared or not fresh enough, but suggesting alternative Omega 3 sources such as halibut or sardines, isn't likely to gain many converts. Instead, finding more palatable sources of Omega 3s seems a practical solution.

What if there were a delicious fruit that contained Omega 3s plus the other nutrients touted as essential for macular health, lutein and zeaxanthin? Avocados are that miraculous fruit, even if used as a vegetable. Not as rich in Omega 3s as fish, but they also boast both the lutein and zeaxanthin needed for eye health.

Guacamole is among the favorite ways to enjoy avocados, so here's an easy recipe to get those mega-nutrients. As a natural paring with chips and salsa, guacamole is a great party food, but with a little imagination you'll find this true health food is versatile. Terrific on eggs or burgers, great as a mayo alternative on sandwiches or with some olive oil and limejuice, it makes a fantastic salad dressing. You might even try it mixed with pink grapefruit slices for a citrusy salsa the next time you have salmon!

GREEN GODDESS GUACAMOLE

INGREDIENTS

4 Haas avocados
3 T fresh lemon juice
2 T plain yogurt or mayo or sour cream
1 t minced chives (optional)
2 t minced cilantro
½ t sea salt
½ t chili powder
½ t cumin
fresh ground black pepper to taste

COOKING FOR EYE-HEALTH (continued)

Split avocados in half lengthwise and remove the pit and score the avocado's flesh in a grid pattern with a paring knife. Squeeze the skins and drop the avocado cubes into a glass or ceramic bowl. Add all the remaining ingredients and mash with a potato masher or fork to a lumpy consistency.

Refrigerating for several hours allows the spices to infuse more of their flavor, but the guacamole can also be eaten right away. To prevent discoloring from oxygenation, cover the guacamole with plastic wrap so that it makes full contact with the bowl and the guacamole, with no air space in between. Placing guacamole in the freezer for a few hours is a great idea for parties. It's so rich in fat that it won't become too hard to serve, but will remain chilled throughout the event.

Before serving, stir again. Serve with "baked not fried" tortilla chips to conserve calories.

Avocado by Choice

Rich in "good cholesterol," ripe avocado slices are a nutritious substitute for mayonnaise in sandwiches or salads. Most flavorful are Haas or Bacon avocados, which have bumpy blackish skins, not smooth green ones.

Store-bought avocados usually need about a week in room temperature to ripen to supply their luxurious flavor and texture, so buy well ahead of time. A perfectly ripe avocado feels as firm as a banana that has some brown spotting.

Emergency tip: if you need to make guacamole now and the avocados are still hard, add a bit more salt and an extra tablespoon or two of mayonnaise, sour cream or plain yogurt for smoother consistency.

Get Really Real!

A friend, who regularly enjoys citrus juice in his cocktail, was surprised to discover the bottled lemon-lime juice he was using was full of sulfites! It was this preservative, not the gin, that was giving him a headache and allergic skin reaction!

Vitamin C almost immediately vanishes when exposed to air, so give yourself the full benefit by squeezing actual lemons, limes, oranges and grapefruits yourself. You can use an old-fashioned wooden pummel or an electric citrus juicer. The taste and nutrition is far superior with fresh citrus juice.

For more recipes,
visit www.enlightenedcook.com