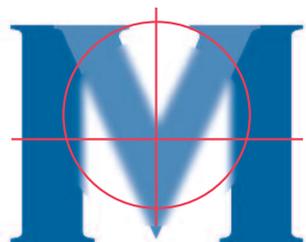


# SupportSightNEWS<sup>SM</sup>



MACULA  
VISION  
RESEARCH  
FOUNDATION

**Funding  
Visionary  
Research**

## WHAT'S NEW AT MVRF?

- **THANK YOU** – we are grateful for your generous gifts in 2013
- **SAVE THE DATE** - Please join us for our Greater Philadelphia SupportSight<sup>SM</sup> seminars this summer
- We recently held our 12th MVRF Scientific Conference in Atlanta
- We are excited to announce our new partnership with Optelec

***100% of every dollar you donate goes directly to research***

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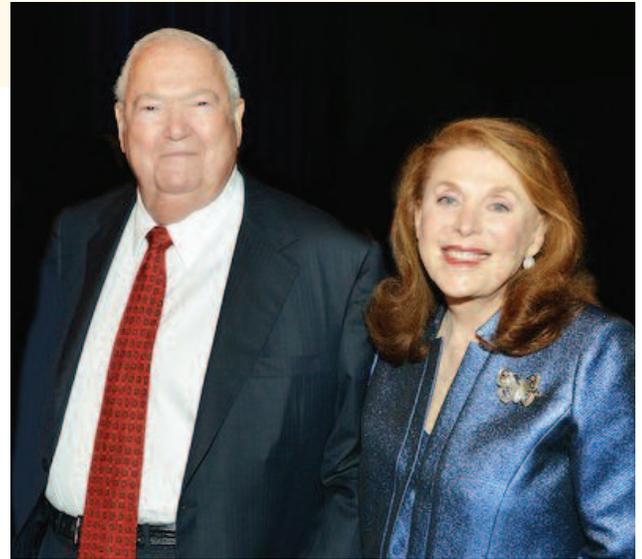
## FROM OUR FOUNDERS

Dear Friends,

After all of the crazy weather this winter on the East Coast and elsewhere, we are certainly happy that spring is finally here!

One theme we have been focusing on at MVRF is **the power of bringing people together.**

Helen Keller once said, *“Alone we can do so little; together we can do so much.”*



Our 12th MVRF Scientific Conference recently took place in Atlanta and brought together top scientists from all over the world to share their important discoveries and learn from one another. The conference provides a unique setting for collaborative conversations about macular degeneration and other retina diseases, sparking new ideas to ultimately find a cure.

Science and research are at the heart of what we do. However, we are also deeply committed to staying connected to the people for whom we are trying to find a cure for. Our SupportSight<sup>SM</sup> seminars bring together those affected by this devastating disease including family members, caregivers and patients with the healthcare professionals who care for them. In the past year, we have touched thousands of people, sharing the latest research findings, low vision techniques, treatment and prevention.

In this issue, we recognize the generosity of our 2013 donors. These individuals and organizations have come together in the spirit of giving because they, like us, care about the impact of macular degeneration on the people in their lives and believe a cure is on the horizon.

We owe our continued success to our generous donors, world-renowned scientists and our loyal MVRF community. **We believe that together we will find a cure and that one day, macular degeneration will be a thing of the past** – because, *believing is seeing.*

Warmest Regards,

*Karen and Herb Lotman*

**Karen and Herb Lotman**

## FROM OUR EXECUTIVE DIRECTOR



Dear MVRF Friends and Supporters,

*We are confident. We are optimistic.* We believe that a cure for AMD and other retinal diseases will soon be found. We will look back at how far we have come and what all of us – MVRF, researchers, scientists, doctors, patients and donors – *were able to accomplish together.*

As I reflect on my first year as Executive Director, I am amazed by how many people's lives are affected by AMD and how valuable our funding is for vision research.

Some highlights of my first year include:

- **Magnitude of hopefulness:** Every day we receive phone calls and emails from people who have a story to tell about how devastating this disease is in their lives. So many of the conversations end on a positive note – hopeful that MVRF will lead the way to new discoveries in retinal diseases. *People believe in us.*
- **Impacting thousands of people:** Attending SupportSight<sup>SM</sup> seminars in Cleveland and Phoenix gave me the privilege and opportunity to meet so many wonderful people, like many of you! Hearing your stories and how macular degeneration has impacted your lives and your families inspires me as the Executive Director to take MVRF to the next level.
- **Scientific breakthroughs:** It has been an extraordinary experience working with the MVRF grantees who have dedicated their entire lives to medical research to find a cure for retinal diseases. Their commitment and passion for discovery fuels our mission.

I know for certain that the future holds big, bold things for MVRF and we are happy you are a part of it.

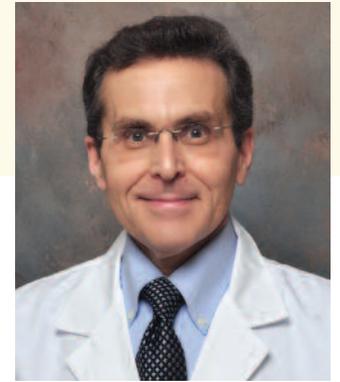
A handwritten signature in black ink that reads "Dawn Prall George". The signature is written in a cursive, flowing style.

Dawn Prall George

## FACT OR FICTION:

### Caution Is Recommended When Considering the Implantable Miniature Telescope (IMT)

**Philip J. Rosenfeld, M.D., Ph.D.**  
**Professor of Ophthalmology**  
**Bascom Palmer Eye Institute**  
**University of Miami Miller School of Medicine**  
**MVRF International Scientific Advisory Board Member**



This is a fact. The Implantable Miniature Telescope (IMT) from VisionCare Ophthalmic Technologies ([www.visioncareinc.net](http://www.visioncareinc.net)) was developed as a low vision aide for patients with advanced age-related macular degeneration (AMD). To help identify those patients who might qualify for the implant, VisionCare has created a program called CentraSight, which can be accessed online ([www.centrasight.com](http://www.centrasight.com)). The implant definitely isn't for everyone with advanced AMD. In fact, I can't say that I have found anyone in my AMD practice who I thought would function better with the implant compared with regular cataract surgery and aggressive low-vision training.

First, let's identify those patients who might benefit from the implant. The website does an excellent job of identifying those patients who should be considered. The most important criteria include advanced AMD (poor central vision), patients who are not undergoing current treatments such as injections, patients who can't drive, and patients who have not had cataract surgery. Previous cataract surgery excludes patients from getting the implant because the implant is placed in the same location in the eye as the regular plastic replacement lens when cataract surgery is performed. So why not just exchange the plastic lens with the IMT? That's not a good idea given the potential

risks associated with removal of the plastic lens. Moreover, there's a good chance the IMT won't have the support it needs within the eye, and this structural support is necessary for good positioning of the IMT and the best possible vision.

Even if the patient qualifies based on these criteria, there are several other issues that need to be considered. The most important issue is the fact that the eye that gets the IMT loses all peripheral vision. For my patients, this is a very big deal. Patients need to appreciate that AMD is a chronic, progressive disease. Even in the setting of advanced disease, in which central vision has been diminished, additional vision loss will continue in AMD and the peripheral vision becomes a precious commodity. Everyone with AMD progresses at different rates and compensates for this vision loss differently. But, for everyone with advanced AMD, central vision loss is unavoidable and stressful, and as central vision is lost, peripheral vision becomes a precious resource that they rely on. Many patients ask if the IMT can be removed if the disease progresses to the point where the magnified central vision is no longer useful. While it's possible to remove the implant, it is not recommended due to the large incision that is necessary, the potential damage to the corneal epithelium, and the inability to insert a normal plastic replacement lens.

But, didn't the clinical studies show that this IMT was beneficial in patients with advanced AMD? The answer is that the Food and Drug Administration (FDA) approved the IMT as a device. When it comes to devices, the FDA does not require the same rigorous study design that is required to show benefit as when a drug gets approved. The studies showed that the implant was safe; however, picking your surgeon is crucial since there was evidence that corneal damage could occur at a higher rate than expected compared with routine cataract surgery. Damage can occur more frequently to the corneal endothelium due to the size of the IMT and the surgical manipulations needed for implantation. This damage could result in a greater likelihood of corneal swelling and clouding, which may require the need for a corneal transplant in the worst-case scenario. At the very least, it's fair to say that recovery of best visual acuity after surgery takes longer following the IMT surgery than after regular cataract surgery. Moreover, compared with the latest and most sophisticated cataract surgical techniques using a femtosecond laser, small incision, and minimal ultrasonic power, which wasn't available when the IMT was studied, the risk of corneal damage with a normal lens implant is minimal. But, most importantly, the studies were not controlled to show that the IMT was truly beneficial compared with patients who received standard cataract surgery and the same prolonged, intensive low vision training. While patients receiving the implant, on average, performed better after the implant, the unanswered question is whether similar patients given the same training with an external telescope or some other low vision device after cataract surgery would have done just as well or better.



So what do I recommend for my patients? I recommend regular cataract surgery when needed, rigorous low vision training both before and after surgery, and I encourage participation in clinical trials to help develop better treatments to stop or slow the disease so that they may potentially benefit and future generations can avoid the devastating vision loss from AMD.

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# SUDOKU

SOLUTION ON BACK COVER

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

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

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[WWW.MVRF.ORG](http://WWW.MVRF.ORG)

## MEET THE NEWEST ADDITION TO THE MVRF TEAM!

### PATRICIA CHAMBERLIN

*Annual Fund & SupportSight<sup>SM</sup> Program Manager*  
[Pat@mvr.org](mailto:Pat@mvr.org)

Patricia recently joined the MVRF Team as the Annual Fund & SupportSight<sup>SM</sup> Program Manager. She will be focusing on grantmaking, enhancing the SupportSight<sup>SM</sup> program and growing MVRF's annual fund. Pat has more than 20 years of experience in fund development and program management and will put her technical and communications skills to work facilitating these areas within our organization. Because of her lifelong passion and training in the visual arts, Pat is uniquely qualified and inspired to advocate for MVRF's mission to find a cure for macular degeneration and help "save sight" for generations to come.



**Dawn Prall George**  
*Executive Director*  
[Dawn@mvr.org](mailto:Dawn@mvr.org)



**Nikki Grossman**  
*Marketing & Communications Coordinator*  
[Nikki@mvr.org](mailto:Nikki@mvr.org)



**Lynn Rinaldi**  
*Outreach & Education Coordinator*  
[Lynn@mvr.org](mailto:Lynn@mvr.org)

**JOIN THE TEAM! Check out our social media:**



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## SUPPORTSIGHT<sup>SM</sup> SEMINARS

*Sharing the latest research, prevention, treatment and low vision techniques for those living with age-related macular degeneration*

### March 2014: Arizona

Thank you to the more than 400 people in sunny Arizona who attended our SupportSight<sup>SM</sup> seminar at the East Valley JCC in Chandler, AZ and our individualized mini-sessions at the following Continuing Care Retirement Communities (CCRC): McDowell Village, Pueblo Norte Senior Living Community, Vi at Silverstone, Vista del Rio and Thunderbird Retirement Resort.

*"The presentation was incredibly informative and engaging... Representatives were patient and thorough and answered everyone's questions plainly. I would recommend this program to any senior community."*

- Cassandra Brooks  
Enrichment Coordinator, Vista del Rio

Presenters included: Arizona Retina and Vitreous Consultants, ViewFinder, Optelec and Tucson Vision Rehab, LLC

If you reside at a CCRC that may be interested in hosting a SupportSight<sup>SM</sup> program, please contact Lynn Rinaldi, Outreach & Education Coordinator at [Lynn@mrvf.org](mailto:Lynn@mrvf.org) or 1.866.4MACULA.



Videos of the presentations are available on our YouTube channel: [www.youtube.com/user/MVRFoundation](http://www.youtube.com/user/MVRFoundation).

### NEXT UP: June 2014 Greater Philadelphia Region

If you or someone you know has macular degeneration, we hope you will make the time to attend one of these FREE SupportSight<sup>SM</sup> seminars:

- **Tuesday, June 24, 2014**  
Chemical Heritage Foundation  
Old City, Philadelphia, PA  
10 AM - 12 Noon
- **Wednesday, June 25, 2014**  
Virtua  
Barry Brown Education Center  
Voorhees, NJ  
1:30 - 3:30 PM

**To register** by June 20th, please contact Pat, Annual Fund & SupportSight<sup>SM</sup> Program Manager, at 1-866-462-2852, [pat@mrvf.org](mailto:pat@mrvf.org) or visit [www.mrvf.org](http://www.mrvf.org).



The SupportSight<sup>SM</sup> program is provided through the generosity of our sponsors:  
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## INTRODUCING A NEW MVRF PARTNER IN SERVING THE LOW VISION COMMUNITY



Optelec is delighted to announce our national partnership with the Macula Vision Research Foundation (MVRF) to further our mission in reaching the low vision community impacted by macular degeneration. With our U.S. headquarters in Vista, California and distribution in more than 75 different countries, Optelec is a world leader in innovative and life-changing assistive technology and adaptive aids for the blind and visually impaired. This unique collaboration centered around MVRF's SupportSight<sup>SM</sup> program, allows us to spread awareness so that optical, daily living aids, electronic video magnification, and speech solutions are readily available for those coping with any stage of vision loss.

We often encounter people who feel defeated by their diagnosis and have been told by their doctor that nothing more can be done. We want you to know that you are not alone! This partnership allows us to connect directly with you, your communities and organizations to discuss the latest in AMD research, provide local support and share types of low vision solutions that can help maximize your remaining vision to its fullest. Many people face the same diagnosis and still enjoy their independence.



The Optelec Team

Simple lifestyle changes like improved lighting in your home, using a video magnifier to enlarge small print, changing the color contrast, or even scanning materials to read aloud, are just a few examples of how our products make everyday activities easier for you.

Most optical aids or services may vary based on your daily needs and intended use, whether it's reading the newspaper, watching TV or looking at family photos. Our trained and knowledgeable Authorized Dealer Network can even come to your home, support group or on-site facility and offer a hands-on demonstration.

We are thrilled to be working with MVRF to provide education and outreach and we look forward to the upcoming SupportSight<sup>SM</sup> seminars in Philadelphia and New Jersey.

### Friends of MVRF

Visit [www.Optelec.com](http://www.Optelec.com), email [info@optelec.com](mailto:info@optelec.com) or call 800.826.4200 to learn more about our life-changing products.

**Make sure you mention MVRF to receive a FREE Low Vision Kit!**

## LEADERSHIP GIFTS

*Cumulative Gifts of \$10,000 and Above*

With pride and gratitude, we acknowledge our leadership donors who have made gifts of \$10,000 or more to the Macula Vision Research Foundation.

Their generosity supports our commitment to funding scientific research and enhances the impact of our important work in fighting blindness and saving sight. This list includes both current annual donors and cumulative major gifts since 1998. *This listing is updated quarterly.*

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Karen and Herb Lotman Foundation  
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If we have misspelled or omitted your name, please accept our sincere apologies and let us know so we may correct our records. We make every effort to list your name according to your personal preference. Due to space considerations, we recognize donors who give \$100 or more. However, we are truly grateful for every donation and we thank all of our MVRF supporters for helping in every way.



## *In Memoriam ~ Marvin Micklin*

Marvin Micklin may have had age-related macular degeneration (AMD), but that did not define him. He was a husband, a father, a friend and a volunteer. Or, as his wife Ann would say, he was just “a super guy.”

Marvin was also a devoted donor to the Macula Vision Research Foundation (MVRF). Every week for six years, Marvin sent \$10 to MVRF. Even as his health diminished, his loyalty was unwavering. From his first gift to his last, he gave more than \$3,000, helping us fund research to cure the disease that had become a part of his life.

Like most people suffering from AMD, Marvin was diagnosed later in life. To help slow the disease’s progression, Marvin received ocular shots regularly. During this time, he also attended MVRF SupportSight<sup>SM</sup> meetings to help him adjust to the loss of vision he was experiencing. Though Marvin was affected by AMD, he never stopped doing the activities he loved, such as volunteering.

Marvin started volunteering at the suggestion of a friend. After his first day, he quickly became a dedicated member of the Franklin Institute family. He even began recruiting friends, some of whom continue to volunteer to this day. Thanks to his involvement, his wife said he was always coming home with interesting stories and was constantly meeting new people. He was kind, generous and loved by everyone fortunate enough to meet him.

For years Marvin donated his time at the Franklin Institute in Philadelphia, Pennsylvania and the Ronald McDonald House. At the Franklin Institute, he was always eager and willing to take on any job that needed to be done. For Marvin, he wasn’t concerned about the difficulty of the task; he cared more about making people happy.

MVRF would like to extend our deepest gratitude to the Micklin family and our sincere promise that we will continue to search for a cure with the same devotion and enthusiasm that Marvin had.

### **In Honor or Memory of a Loved One**

MVRF is proud to acknowledge those in whose memory or honor we have received donations of \$1,000 or more. This is a meaningful way to memorialize the passing of a loved one or celebrate the birthday or anniversary of someone close to you while having a lasting impact. Our MVRF supporters are special to us and we are honored to recognize them. If you have any questions or want to recognize a loved one, please contact Pat Chamberlin at [pat@mvr.org](mailto:pat@mvr.org) or 1-866-462-2852.

## MAKING A DIFFERENCE

**Anand Swaroop, Ph.D.**  
**Senior Investigator and Chief**  
**Neurobiology-Neurodegeneration & Repair Laboratory**  
**National Eye Institute**  
**2001 MVRF Grant Recipient**



I remember my first MVRF meeting in November 2000. I was one of the first MVRF grantees that was involved in research on “the genetics of AMD.” After more than a decade, MVRF still has the same passion for supporting excellence with great vision and foresight.

A chance encounter with Dr. Marvin Sears at the 1998 ARVO got me an invitation to submit a proposal for MVRF research awards. I was at the University of Michigan Kellogg Eye Center then and had just initiated plans for genetic studies of AMD with support from my Chair Dr. Paul Lichter and my colleague and collaborator Dr. Paul Sieving. Only a few researchers at that time were thinking of genetics being important in AMD pathogenesis. We had some ideas, but it would have been hard to apply to NIH as I was new to the field and had no preliminary data. Thankfully, I received a three-year award from MVRF starting in March 1999, and this was renewed for three additional years. MVRF support was crucial in launching our AMD genetic studies and providing legitimacy to our ideas and efforts. In collaboration with my clinical colleagues, we collected blood samples from individuals with (and without) AMD, permitting us to perform genetic analysis at the whole genome level. Over the years, we reported genetic linkage and association results, including the discovery of complement factor H variants. MVRF grants were critical for our early AMD genetic studies that eventually formed the basis of

broader investigations and support from the National Eye Institute. Now in the intramural program at NEI, we have expanded collaborations with Dr. Emily Chew and collaborators worldwide, leading to the identification of 20 different genes that are associated with AMD risk. More recent studies, involving almost 50,000 individuals from researchers worldwide, are expected to identify numerous additional genes and risk variants in the near future. New insights from genetics have begun to provide clues about the biological pathways that are critical for developing AMD phenotypes. The translation of genetics to the clinic is already emerging with possibilities for better diagnosis and design of treatment paradigms.

I personally owe a ton of gratitude to MVRF and its Founders. They have made a huge difference in AMD research. Also making a difference are thousands of patients, family members and others with their precious contributions. Every day I remember my father who was diagnosed with wet AMD in one eye and dry in the other. Though some treatments helped with the wet form, he was more concerned about the vision loss than his heart disease in the last years of life. We have come a long way, but more remains to be done. I know we all can contribute and make a difference by advocating for biomedical research for debilitating eye diseases. I remind myself of the promise and the hope that one day (*in the near future*) our research will make a difference!

**12th MVRF Scientific Conference  
Atlanta, GA – Intercontinental Hotel  
March 20-23, 2014**

## **A Snapshot**



The words ***powerful***, ***intense*** and ***inspiring*** summarize the 12th MVRF Scientific Conference. It was a very special weekend where science and discovery meets collaboration and camaraderie. By invitation only, MVRF brought together 23 top vision and medical researchers from around the world to dialogue and share ideas in a safe, private, yet free-flowing, setting. Because of this format, the meeting represents a unique opportunity within the vision research community to advance the basic science and biology of AMD and other retina-related diseases.

Throughout the conference the scientists presented their latest research findings relative to AMD and other retina diseases. They discussed numerous approaches such as gene therapy, stem cell approaches, cell transplants, ocular imaging and drug therapy. Also discussed were a wide range of new scientific discoveries, knowledge, data acquisition, technological advancements and current and emerging treatments to prevent or slow vision loss.

All participants acknowledged the leadership role that MVRF has played and continues to play in advancing the knowledge of the retina, macular degeneration and related retinal degenerative diseases by funding cutting-edge research projects.

Below, is a brief summary of topics that were discussed by the experts in the field:

- **Progress in macular degeneration**
- **Research on retinal degenerative diseases**
- **The role of mitochondria in disease**
- **Emerging concepts, techniques and treatments in AMD**

The next MVRF Scientific Conference will be in the fall of 2015.

**IF ONLY EYE COULD...**

by Deborah M. Kogler, L.D.O.  
Magnifiers & More  
[www.magnifiersandmore.net](http://www.magnifiersandmore.net)

How many times have you said: "If only I could \_\_\_\_\_ again"? I am confident that you have said this more than once and have a number of words to use in that blank. If only I had a dime for every time I heard a visually impaired person say those words, I could fund MVRF for a year! Maybe you cannot do everything like you used to, but there is an abundant selection of "gadgets" to help you with the vision you have left. The number one gadget to consider is proper lighting. Using the proper lighting stimulates the retina and helps to increase vision. Fluorescent lighting typically causes a considerable amount of glare and reflection, a chief complaint for the visually impaired. LED and full daylight spectrum lighting are the best lighting sources for a visually impaired person. There are also numerous adaptive living aids that are available to help ease the stress and strain of dealing with diminished vision.

***If Only I Could******Answer*****Read my Mail/Newspaper****Desktop Electronic Magnifier****See to Dial the Phone****Large Button Phone****See my Address Book****Large Print Address Book****Watch TV****Telescopic Glasses****See/Find the Remote****Large Print Remote****Read Price Tags/Labels****Portable Electronic Magnifier****Read What I Wrote****20/20 Pen**

Remember, not just one device is going to serve all your needs. Just like shoes; you need more than just one pair to meet the needs of your activities!

***Next Issue:*** Learn more about the Reading Machine!

## WORKING TOGETHER TO HELP MY MOTHER LIVE (SUCCESSFULLY) WITH MACULAR DEGENERATION

by Joan Biddle

My mother is 95 and has lived with age-related macular degeneration (AMD) for 15 years. Five years ago, she came to live with me and my family. Since then, we have worked together to develop many solutions and ways to make living with low vision easier.

Most of the early difficulties were straight forward. She needed big button, cordless phones and a large magnifying reader machine. Most importantly, she decided early on that she needed to give up driving and developed a team of drivers with compensation, even for close friends.

### Entertainment and Leisure

Television (especially baseball games) is important to my mother. With the use of a bigger TV screen, special TV viewing glasses and a large format remote control (most cable providers provide these free on request or they can be found inexpensively in retail stores) she is able to view the games that she loves so much. We find that taping off access to unnecessary buttons on the remote, using plastic “bumpers” (from hardware stores) to mark key controls and securing battery compartments with tape all help to avoid errors.

It is important to keep chair-side resources readily available (food, drinks, phone, tissues, etc.). At first this was challenging, but then we learned to place large trays

on her side tables to keep things from falling off. We use bottles of water with bold labels (instead of easily tipped glasses of water). My mother also enjoys books on tape provided free by the National Library Service for the Blind. Magnifiers of all kinds and sizes are useful to have throughout the house and wrapping the handles with bright tape makes them easier to find.

In social situations with friends and family, it has been important for me and my mom to remind others that she can't see their faces clearly when they approach. Most have learned to immediately identify themselves and even great grandchildren have adapted to that practice!

### Personal Care and Grooming

Plain bedspreads keep belongings from getting lost in the bedroom as do standup storage holders for eye glasses. Flashlights with easy to access buttons, night lights and touch light lamps all make it safer to move around at night. Night lights and touch light lamps are essential and small, lightweight LED varieties are easy to store and find under pillows. Toothpaste tubes with flip up caps, colored toothpaste and bright colored cups make grooming easier. Clear plastic shower curtains allow more light in and orange tape on steps into showers or tubs and sturdy grab bars are also important.

### **Medical Care Management**

There are numerous types of pill boxes and medication distribution systems available. We have found that using these systems, with my assistance, is much easier and safer than taking pills from a variety of bottles. My mother taught me early on the importance of labeling every pill bottle with a unique bold letter, both on the top and side.

### **Electronic and Talking Devices**

Talking watches and clocks of every shape and size have been critical to my mother's daily life. We always have many "time-talkers" around so that when they stop working (or worse, give the wrong time) there are always others to use!

### **Eating and Cooking**

Adding peas, parsley, chopped vegetables, etc. to rice, mashed potatoes and other white food makes them more identifiable. I also make sure that meat, poultry and seafood has some sauce or browning on it. Before eating, I always tell my mom what is on her plate by pointing to each item.

Coordinating a knife and fork is a visual challenge so I cut food that may be difficult into more manageable pieces. Using clear drinking glasses still remains a challenge but adding lime slices to the water or using colored straws helps. When we plan to go out to eat, I get the menu from the restaurant's website to read to my mother before leaving home as reading menus out loud in restaurants is often difficult.

While living with AMD or any disability is challenging, my mother and I have found there are many ways to minimize obstacles when we work together.

My family supports the Macula Vision Research Foundation, not only because of the important research they fund, but also because their publications and staff have been so useful to our family as we have faced the challenges of living happily and successfully with AMD.

***"Your eyes will always be closer to your soul than to any other part of your body except the heart."***

– Sorin Cerin, Wisdom Collection: The Book of Wisdom

Have you considered naming the Macula Vision Research Foundation in your estate planning?

Contact Dawn Prall George, Executive Director, at 1-866-4MACULA or dawn@mrvf.org if you would like to learn more.

## MY JOURNEY WITH STARGARDT DISEASE

by **Michell (Missy) Moody Richmond**

My journey to a diagnosis of Stargardt disease is not a typical one. Most people are diagnosed around age 6-19. It was 2008 and I was 35 with 20/20 corrected vision. Today, I land in the 20/300-20/400 range.

Stargardt disease is a form of juvenile macular degeneration that affects approximately 1 in 10,000 individuals. Most people diagnosed with Stargardt's keep their peripheral vision, however, I've already lost most of mine. I'll never forget the day I looked in the mirror and realized I couldn't see my own face anymore.

I like to describe my vision like looking into a circus fun house mirror. Lines are never straight. I experience lots of floaters in the form of dots, rings or lines and I frequently experience flashes and streaks of light. I have migraines because my eyes are constantly changing, so my brain strains to keep my vision as "normal" as possible.

My entire life has been affected. I was a registered dental hygienist for more than 15 years when I was diagnosed and I had to retire my license. I also had to give up my driver's license which was the hardest thing to this day. I have to rely on my busy sister to take me anywhere I go.

I'm an independent person and I've made it a priority to look at things as challenges instead of obstacles. I began connecting online with other people who have Stargardt's, using Facebook groups and Twitter and

I work to spread awareness for blinding diseases. These groups have become a support system for me.

They're the people that know how I really feel because they are feeling it too. Through these groups, I met a wonderful friend who sent me a YouTube video she used to teach herself how to use a cane. From that one video and talking among my groups, I was able to teach myself how to use a cane in no time. I received my first cane free from the National Foundation for the Blind. They allow a free cane for anyone who needs it.

I always say, "There is ABILITY in disABILITY." I've always wanted to be a writer and I plan on learning Braille. I hope to someday implement improvements to the Disability Laws for Blindness and work to change the prejudices in the disabled community. I depend on my other senses a lot more now. Music has become a big passion of mine and I can hear notes now that I never heard before. I can smell a thunderstorm from miles away. I have to say that I do grieve the loss of the "normal" life I led, but this new blind life is a journey. Stargardt disease took my life from me, however, it also gave me a new one.



Feel free to email me at [mlrichmond@hotmail.com](mailto:mlrichmond@hotmail.com)  
or follow me on Twitter @StargardtEyes for more information about Facebook support groups or the YouTube video that taught me how to use a cane.

## RECIPE FOR GOOD EYE HEALTH

### Cheese & Spinach Stuffed Portobello

Makes 4 servings

Contains calcium, vitamin E, beta carotene, potassium, lutein and zeaxanthin for good eye health.

#### Ingredients:

- 4 large portobello mushroom caps
- 1/4 teaspoon salt
- 1/4 teaspoon freshly ground pepper, divided
- 1 cup part-skim ricotta cheese
- 1 cup finely chopped fresh spinach
- 1/2 cup finely shredded Parmesan cheese, divided
- 2 tablespoons finely chopped kalamata olives
- 1/2 teaspoon Italian seasoning
- 3/4 cup prepared marinara sauce



#### Directions:

1. Preheat oven to 450°F. Coat a rimmed baking sheet with cooking spray.
2. Place mushroom caps, gill-side up, on the prepared pan. Sprinkle with salt and 1/8 teaspoon pepper. Roast until tender, 20 to 25 minutes.
3. Meanwhile, mash ricotta, spinach, 1/4 cup Parmesan, olives, Italian seasoning and the remaining 1/8 teaspoon pepper in a medium bowl. Place marinara sauce in a small bowl, cover and microwave on high until hot, 30 seconds to 1 1/2 minutes.
4. When the mushrooms are tender, carefully pour out any liquid accumulated in the caps. Return the caps to the pan gill-side up. Spread 1 tablespoon marinara into each cap; cover the remaining sauce to keep warm. Mound a generous 1/3 cup ricotta filling into each cap and sprinkle with the remaining 1/4 cup Parmesan. Bake until hot, about 10 minutes. Serve with the remaining marinara sauce.

Enjoy! Thanks to [www.eatingwell.com](http://www.eatingwell.com) for this great eye healthy recipe.

**The Macula Vision Research Foundation (MVRF) is not a healthcare provider, and nothing in this newsletter is intended as a substitute for professional medical advice, diagnosis, or treatment. Seek the advice of your physician or other qualified health provider regarding any questions about your medical condition, medical devices, or treatment options.**

# SupportSightNEWS<sup>SM</sup>

## Macula Vision

### Research Foundation

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***100% of every dollar  
you donate goes  
directly to research***

Answers for Sudoku puzzle from p. 6

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

## NO ONE DOES WHAT THE MACULA VISION RESEARCH FOUNDATION DOES

We applaud anyone who is helping to fund and find a possible cure for AMD. But we don't want any confusion between their work and ours. To be clear, MVRF is the only foundation raising money to fund world-class research on AMD exclusively, ***and the only foundation devoting 100% of donated dollars to that end... nearly \$20 million to date.*** We've made incredible progress. And we're confident that we're close to a cure. As you support AMD research, maximize your donation and support the Macula Vision Research Foundation. Thank you for choosing us!

SupportSight<sup>SM</sup> program funded by

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Life is worth enjoying