

SupportSightNEWS

FREE MATTER
for
the BLIND or
HANDICAPPED

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A MESSAGE

FROM EXECUTIVE DIRECTOR LEA S. BRAMNICK

To All of You,

I write to you with great pleasure and pride. The Macula Vision Research Foundation has the goal of providing the opportunity to communicate with all of you in a “conversational way.” Our hope is that the Macula Vision Research Foundation SupportSightNEWS will enable us to share with you the “news” – tips and hints, gadgets that make life easier, answers to questions raised at seminars and support groups as well as clear information about research and treatments written by some of the most distinguished retina specialists and researchers.

These pages will also share feelings, inspirations and reflections of remarkable people living very well with macular degeneration – if they can do it, you probably can, too! Please open yourself up to new ideas, new opportunities and the promise of all the good things that are possible.

It is very special for me to be able to present MVRFF SupportSightNEWS to you. Please write by email, lea@mvrff.org, by U.S. mail or by using our toll-free number 1-866-462-2852 to give us your ideas, experiences and questions.

I look forward to sharing the best, which is yet to be, with you!



Lea Bramnick



SupportSightNEWS

A MESSAGE FROM THE MVRF FOUNDERS

Dear Friends,

Welcome to the Macula Vision Research Foundation SupportSightNEWS.

In 1989 when macular degeneration was present in two generations of our family, we became interested in finding out who was working to find the cause, prevention and treatments for this disease. To our dismay, we learned that there was very little coordinated research being focused exclusively on macular degeneration – even though it is the leading cause of severe vision loss in adults over the age of 50. We formed a distinguished Board of Scientific Advisors and moved forward with an aggressive research program. To date, over 13 million dollars in research grants have been awarded.

Next was the creation of MVRF SupportSight, the first national series of educational seminars and support groups for people with macular degeneration. MVRF SupportSight can now truly be seen as having national impact with over 26,000 people attending support groups and educational seminars.

The Foundation has enjoyed great growth programmatically and in support of research since its creation, as you will see below in “By the Numbers.”

The goals of MVRF SupportSight**NEWS** are to keep you informed about:

- the newest information concerning macular degeneration research and treatments
- living interesting, positive, productive and successful lives with macular degeneration
- helpful tips and hints to make life easier

MVRF is truly unique! 100% of each dollar raised goes to research and public education as all administrative costs are underwritten.

We believe in making a positive difference in the vision of the future and making each day better NOW.

Karen and Herb Lotman

Karen and Herbert Lotman

MVRF IS TRULY UNIQUE!

100% OF EACH DOLLAR RAISED

GOES TO RESEARCH AND

PUBLIC EDUCATION.

ALL ADMINISTRATIVE COSTS

ARE UNDERWRITTEN.

MVRF BY THE NUMBERS

The Macula Vision Research Foundation's **MISSION** is 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.

\$13 million to outstanding vision scientists doing cutting edge research in macular degeneration

27 research studies, in progress

11 new grants began in 2009

45 scientists awarded grants

99 grants awarded

34 departments of ophthalmology work with MVRF

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

9 International Research Conferences

86 scientists have attended the MVRF conferences

over **26,000** people have attended MVRF SupportSight educational seminars and support groups

28 cities have MVRF SupportSight programs



Symbolizes the successful ways of living with macular degeneration.

WHY DO I SEE THINGS I KNOW ARE NOT THERE?



What is Charles Bonnet Syndrome?

Charles Bonnet Syndrome (or CBS for short) is a term used to describe the situation when people with sight problems start to see things which they know aren't real. Sometimes called visual hallucinations, the things people see can take all kinds of forms, from simple patterns of straight lines to detailed pictures of people or buildings. These can be enjoyable or sometimes upsetting.

A Swiss philosopher named Charles Bonnet, first described this condition in 1760 when he noticed his grandfather, who was blinded by cataracts, describing seeing birds and buildings which were not there. Although the condition was described very early, it is still largely unknown by many doctors and nurses. This is partly because of a lack of knowledge about the syndrome and partly because people experiencing it don't talk about their problems out of fear of being thought of as mentally ill.

Who is affected by Charles Bonnet Syndrome?

Charles Bonnet Syndrome affects people with serious sight loss and usually only people who have lost their sight later in life but can affect people of any age, usually appearing after a period of worsening sight. The visual hallucinations often stop within a year to eighteen months.

What causes Charles Bonnet Syndrome?

At the moment, little is known about how the brain stores the information it gets from the eyes and how we use this information to help us create the pictures we see. There is some research that shows that all this constant seeing actually stops the brain from creating its own pictures. When people lose their sight, their brains are not receiving as many pictures as they used to. Sometimes, new fantasy pictures or old pictures stored in our brains are released and experienced as though they were seen. These experiences seem to happen when there is not much going on, for example when people are sitting alone, somewhere quiet, which is familiar to them, or when they are in lying in bed at night.

Don't only 'mad' people see things?

It is fairly normal for people who start to see things to worry about there being something wrong with their minds. Seeing things is often a sign of mental illness and the threat of Alzheimer's can often be a worry. People often keep quiet about their hal-

lucinations for fear that people will think they are losing their minds. It is important to realize that failing eyesight and not any mental problems normally causes CBS.

Another difference between the hallucinations, which people with mental health problems and people with CBS have, is that in CBS, people quickly learn that the hallucinations, although interesting are not real. On the other hand, people with a mental illness have trouble telling the difference between their fantasies and reality and will often come up with complicated explanations for the things they are seeing (sometimes called a delusion). If you think you are having Charles Bonnet Syndrome hallucinations then tell your general practitioner about them. You may find it useful to take this article along with you to show to your doctor.

What kind of things do people see?

There seem to be two different kinds of things people see. Both of them can be black and white or in colour, involve movement or stay still, and they can seem real, e.g. cows in a field or unreal e.g. pictures of dragons.

Firstly, there are the hallucinations of patterns and lines, which can become quite complicated like brickwork, mosaic or tiles.

Secondly, there are more complicated pictures of people or places. Often whole scenes will appear such as landscapes or groups of people, which are sometimes life size and other times tiny people and tiny things. These pictures appear out of the blue and can carry on for a few minutes or sometimes several hours. Many people begin to recognize similar things appearing in their visions such as distorted faces or the same tiny people in particular costumes.

Generally the pictures are pleasant although the effects can be scary.

What are the effects of the hallucinations?

Sometimes the complicated pictures can make it difficult to get around. For example, streets and rooms may have their shape changed and this can make it difficult for you to judge exactly where you are. A gentleman described how once, approaching the top of the stairs, he had a vision of being on top of a mountain and had considerable problems getting down the stairs. However, good knowledge of your surroundings can help overcome this particular problem.

WHY DO I SEE THINGS I KNOW ARE NOT THERE?

(Continued from page 2)

The complicated pictures can sometimes be a little scary. Although the visions themselves may not be of anything frightening, it is disturbing to start seeing strangers in your home or in your garden. People often overcome this by getting to know the figures in their visions. One man describes how when he wakes up in the morning he says to the figures he is seeing, "what have you got in store for me today?" This allows him to have some control over the way he feels about seeing things.

Is there a cure for Charles Bonnet Syndrome?

Unfortunately, at the moment, there is no known cure or treatment for CBS. However, just knowing that it is poor vision and not mental illness that causes these problems often helps people come to terms with them. Generally these experiences will disappear after about a year or eighteen months but of course this will not happen for everyone with

this problem.

It is worth trying to change things when the visions occur to see if this will help them disappear. For example, if it happens in the dark then try switching a light on, or if it happens in the light, try switching the light off. If it happens when you are sitting down then try standing up.

Sometimes talking over feelings with a counsellor or psychiatrist can help provide people with ways of coping with the visions. If you are having problems with yours, then talking to your general practitioner may be a good way to find some help.

The Royal National Institute for the Blind

This information is provided by the Royal National Institute for the Blind (RNIB) in the United Kingdom.



HOW DO WE KNOW WHAT TOPICS WILL BE MOST HELPFUL?

At the end of the 2008-2009 MVRF SupportSight support group year, we asked the attendees at 20 locations across the country to tell us what topics they would like addressed at their support group meetings.

An overwhelming 77% wanted to learn more about current research and treatments for macular degeneration. With so much encouraging news recently in the press, it is not surprising that this was the most popular request. The theme is HOPE. As a result, the most up-to-date information on research and treatments will be discussed.

The second highest request was for HELP; therefore demonstrations on aids and devices, magnifiers, reading machines and electronic magnification to make reading easier, as well as the use of proper lighting will be highlighted.

Information regarding the importance of good nutrition, diet and exercise will be presented under the topic of HEALTH. People are very willing and interested in helping themselves by learning the best practices.

The HAPPINESS topic addresses the adjustment to vision loss and continuing to be active – to be connected and making connections – in essence – the theme is staying in the game of life.

Maintaining a household; shopping, cooking, entertaining, learning the best tools for the task while staying safe in your own home is a vital and meaningful topic entitled HOME.



WHAT WORKS FOR YOU?

How are you coping with less vision?

Please send MVRF SupportSightNEWS your creative coping ideas so that we can share them and help others:

- What enabled you to think positively?
- What encouraged your change in attitude?
- What did you discover, so that you can _____?
- What tool or gadget have you found that helps you to do something you want to do?





COMPUTER OPTIONS FOR THE VISUALLY IMPAIRED

The ability to surf the internet, email or play games is still a reality for the vision impaired person! However, many individuals with low vision either give up or do not attempt to use a computer. Among adult computer users in the United States, 1 in 4 has a vision difficulty. Unfortunately, many do not know that there are numerous options for individuals with vision difficulties to modify their computers to make them easier to use, to see better, and to receive information. There are numerous tools that can help to aid in using the computer. Many accessibility features are built into Windows PC's, MAC computers and Microsoft products that are useful to people with vision impairments.

What's available in Assistive Technology for the visually impaired?

- **Screen magnifiers** ~ work like a magnifying glass. They enlarge a portion of the screen as the user moves the focus—increasing legibility for some users. Some screen enlargers allow a user to zoom in and out on a particular area of the screen.
- **Screen readers** ~ are software programs that present graphics and text as speech. A screen reader is used to verbalize, or "speak," everything on the screen including names and descriptions of control buttons, menus, text, and punctuation. A free basic screen reader called Narrator is available in Windows 7 and Windows Vista.
- **Speech recognition** ~ (also called voice recognition), allows data entry by voice commands rather than a mouse or keyboard. Windows 7 and Windows Vista include speech recognition in their operating systems.



- **Speech synthesizers** ~ (often referred to as text-to-speech (TTS) systems) receive information going to the screen in the form of letters, numbers, and punctuation marks, and then "speak" it out loud.
- **Talking word processors** ~ are software programs that use speech synthesizers to provide auditory feedback of what is typed.
- **Large-print word processors** ~ allow the user to view everything in large text without added screen enlargement
- **Large-print keyboards** ~ have larger letters on the keyboard without changing the size of a standard keyboard size. Available in contrasting colors for easier use. **(see photo)**
Computer use can open a whole new world for the vision impaired person.

Recommended sites:

- www.microsoft.com/enable/products/default.aspx
- www.apple.com/accessibility/
- www.aisquared.com/

Deborah M. Kogler, LDO
Magnifiers & More 

In many situations, just **increasing the font size on the computer is enough to help.** Today most computer operating systems and internet browsers allow you to increase the size and text on web pages which can help to make them more visible.

FOR EXAMPLE:

- In browsers such as Microsoft's Internet Explorer, Mozilla's Firefox and Google's Chrome, Netscape Navigators and Apple's Safari, you can enlarge text on your screen by holding down the Control ("Ctrl") key on your keyboard and tapping the "+" key.
 - To return the text to its normal size, tap the "-" key while holding down the Control key.
- or
- Holding down the Control or Command key, and using the wheel on your mouse to increase or decrease the text size on your screen.
- or
- Using the "Text Size" or "Make Text Larger" command within "View" in the drop-down menu bar that appears at the top of your screen, but only when you use popular software programs such as Microsoft Word and Outlook.



WHAT DO CLEVELAND, TUCSON, LOS ANGELES, PITTSBURGH, LEXINGTON, AND ATLANTA ALL HAVE IN COMMON?

Let me tell you...

My name is Deb Kogler. I am a licensed optician and low vision specialist. I am also the owner of Magnifiers & More, a company that works with the visually impaired.

During the last several months, I have had the distinct pleasure of traveling to the above mentioned cities for the Macula Vision Research Foundation's SupportSight Seminars and I wanted to share what I learned on my trips with you!

The best part about my travels was meeting all the wonderful VIP's. No, not the movie stars and athletes, but the Visually Impaired People that attended and spoke at the seminars. It is truly amazing the spirit and courage that all these wonderful folks have. They do not let their vision impairment stop them from embracing life!

- Dr. Mary Fox, from **Lexington, KY** was an inspiration as she talked about her life and dealing with macular degeneration. She still continues to pursue one of her favorite hobbies of basket weaving, not only does she continue to make baskets but she also teaches others how to basket weave. Her work is truly amazing and I couldn't help but think; I have perfect vision and I could not weave a basket if my life depended on it.
- Mary Betty Roeder from **Philadelphia** traveled alone despite her severe vision loss, to **Pittsburgh** and **Los Angeles** to speak at the seminars. Mary Betty's approach to her inconvenience in life is simply "to make the best out of what you have." Her comments, stories and humor were enjoyed by all.
- The "wife" who came up to me after the seminar with tears in her eyes and a smile on her face said to me, "you made me cry!" Concerned, I apologized and she said, "Oh, no it's good." When you were talking my husband turned to me and said, "That lady just said exactly what I feel but have not been able to express to you." It was their first seminar and exposure to the MVRF SupportSight program. They were very grateful that they had come. And, I know they will be back.
- Jim, from **Los Angeles**, commented that he couldn't believe how many people at the seminar had Macular Degeneration. He thought he was a rare case and that no one would ever understand his impairment. Now he knew he could connect with others.

- Alice who was so happy to hear and "see" that there was such a large turnout because she thought she was the only one with "bad eyes" and that she was doomed to be blind the rest of her life — and she was only 54. She learned **she would never be blind**. She would always have some peripheral vision.
- Tyler Thompson from **Kentucky** was a treat to meet. He retired after 20 plus years as an "inventor" for IBM and a national sales manager for QS/1 Data Systems and then learned to play golf. He is now a "professional golfer." He does not let his legal blindness stop him from playing a sport he loves. But the best part in talking with him was learning that he didn't learn to play golf until after he started to lose his vision. Once again, I couldn't help but think, I have perfect vision and I can't play golf!

The remarkable part about my travels was that no matter what city, no matter what time zone and no matter what venue, every single person I met was so hungry for information and affirmation.

The affirmation that people wanted and were searching for was that they would be ok; that they would not go blind and that there was help available.

It was an honor, for me, to let all the attendees know that the Macula Vision Research Foundation was the place that they could find the information and affirmation that they so needed.

Many of the attendees commented on how surprised and happy they were to hear that all monies donated to MVRF were used 100% for research and education. All administrative costs are underwritten. The opportunity to share this information was exciting.

So, the answer to what all the cities that I traveled to have in common is simply: You are never alone if you have macular degeneration because you may attend the Foundation's seminars and support group meetings. **Call the Foundation's toll free Help Line 1-866-462-2852 (1-866-4MACULA) or gain information from the Foundation's website, www.mvrf.org. MVRF SUPPORTSIGHT IS ALWAYS THERE FOR YOU.** 

YOU ARE INVITED!

FROM MY MIND'S EYE By Betty Mathews, Dr PH THE RIGHT TOOLS FOR THE TASK

To pound a nail with something other than a hammer or to cut with a knife when the cut only requires a pair of scissors are often costly mistakes and can be very frustrating. I am a firm believer that if a task is worth doing, the right tools are needed to do it well. The task of managing everyday life with visual impairment is no exception.

Want to know when to stop pouring liquids? You can!

Were you surprised when the water you were pouring missed the glass and washed the counter instead? To prevent this, a favorite tool is an inexpensive item named "Say When" available in Low Vision stores. It fits over the edge of the glass or cup and when liquid reaches full status, it sings and you stop pouring. This is useful for all pouring and especially when liquids are hot.



Want to hang a picture? You can!

First assemble the equipment you will need. For each picture select a picture hanging nail, a hammer, a scissors and a roll of masking tape. Cut a small square of tape, and then stand close to the wall exactly where you want the picture to hang. Place the square of masking tape on the wall measuring exactly from the center of your forehead. Hold the nail on the center of the masking tape with your fingers. Begin tapping the nail head with short, light strokes of the hammer. By such tapping you maintain control of the hammer hitting the nail head instead of your fingers. Once the nail is secure, hang the picture. The secret lies in the tapping rather than pounding with the hammer. As with most things these days, it will take longer than

it used to, but you will succeed and that is the most important objective.

Need More Light Over the Chopping Board or Your Dinner Plate?

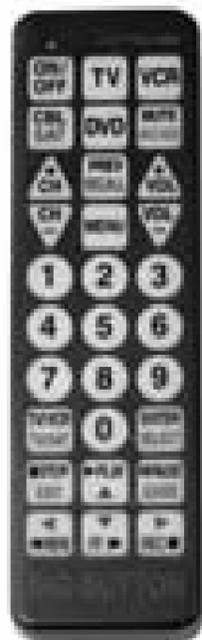
The electric task lamp that is produced by the Ott Lighting Company is the answer to chopping with low vision. It is a special lamp eleven inches high, three inches wide with a cover nine inches long that when raised to horizontal position throws the light rays over the task. This enables those of us with limited vision to cut or chop food rather than fingers. It is also useful to light your dinner plate well so you can see the food that you are eating. I find seeing the food presentation much more satisfying than being told what food is at twelve or six o'clock. I find this lamp useful for any task that requires special lighting in order to accomplish it.

Recently a battery powered task lamp has been produced by the Ott Company for use wherever a convenient electric wall plug does not exist as in restaurants or social gatherings. Both lamps are available at many Low Vision stores. These lamps provide the special lighting usually needed by those of us with macular degeneration.

Telephone Books

Because macular degeneration contributes to making telephone books more and more difficult to see, it is helpful to create your own large print directory with frequently used numbers for friends, services and medical needs. This can be a folder on your computer and also a large print reference for your desk.

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FROM MY MIND'S EYE By Betty Mathews, Dr PH THE RIGHT TOOLS FOR THE TASK (continued from page 6)

Recipe File

A computer file of favorite frequently used recipes is especially helpful as one can enlarge the type, print it and read it in the kitchen. A more expensive way to read recipes from your book or recipe cards is the use of the Clear View Video Camera connected to a small television or desk-top computer monitor. An adapter is required to convert the computer monitor. Both camera and adapter are available in most Low Vision stores.

Finding the Numbers on the Keyboard

Never able to incorporate the keyboard numbers into touch-typing, I learned a neat solution at the V.A. Blind Center. Velcro was on numbers 1, 4, 7 and 0. This tactile identification enables one to easily find any number key by touch.

Still want to use a calculator? You can!

Until the calculator came on the market I calculated in my head, but then I became addicted. Recently, as I was trying to magnify both the enlarged checkbook and the calculator under my only closed circuit television, it was a difficult juggling act and took too much time. I thought if only I could see the calculator without magnifying it, I could balance my checkbook quickly.

When shopping, I noticed the clerk was using a large, manual calculator. I could see the numbers on it from a distance. Making a mental note of this, I continued my errands. In the Desert Low Vision Services display, that same calculator appeared. It is eight inches wide, eleven inches long and a quarter inch deep. The black buttons with white numbers are one inch by three-fourth inches wide. In the summation window, the numbers are displayed in one inch size. With light focused on the calculator, all numbers are clearly visible to me without magnification. Now I can balance the checkbook without the juggling act. There are also calculators that provide a speaker that announces the numbers you punch and states what appears on the window display. For many, speaker calculators may be a solution.



Want to Read Books Again? You Can!

Some tools to enable you to read anything have various names such as Book Reader, Human Ware and others. Basically, each is a closed circuit television or CCTV. It is a camera focused on a revolving desk top that projects the images onto a TV screen that can be magnified. In addition to reading books, it is useful for check writing, bill paying and many other needs. One should look at different models and prices to find the type that best fits your needs.

Maran Graphics Series includes User Friendly books on Computer Simplified, Word 2003 and 2007 Simplified, Windows 95 through Windows Vista, and the Internet among others. These books are available in most book stores and are published by: IDG Books Worldwide, Inc., An International Data Group, Forest City, CA 

HEALTH WEB SITES MUST BE CHOSEN CAREFULLY

The web has become an increasingly important tool for information. However, one must choose very carefully when searching for material about a condition, a disease, a treatment. Look for health information from a distinguished university, a major medical center or the **National Institutes of Health/National Eye Institute** or recognized health organizations such as the **Academy of Ophthalmology**, which are linked to the MVRF web site.



HOW MACULAR DEGENERATION CHANGED MY LIFE FOR THE BETTER

BY BARBARA SARRETT

I knew when it finally happened. I was waiting for it to keep its date with my eyes. Macular degeneration! One morning I woke up and there it was, not just a whisper of itself, but full blown shouting at me I'm here, are you ready for me?

I was waiting and I was ready. You see, both my parents have macular degeneration. And I knew, one day, even though I did everything possible to prevent it...I stopped smoking, I watched my weight, I took my special vitamins, I even started eating salads and I learned to love brussel sprouts. Even doing all the right stuff, I lost all central vision in my left eye...overnight...

There it was, I woke up one morning...no central vision!

How did I figure it out...

I accidentally put my hand over my right eye and the TV disappeared! Gone, nada, invisible, just like magic except there was no magician in the room...just me. I could see up, down, left, right, but not straight ahead.

I was not surprised. I expected that, one day, in the distant future it may happen. But now at age 63, I'm too young. My parents were in their late seventies when "you" attacked their eyes. They were retired. I am an advertising executive. I need my eyes to do my job successfully. I need to see color clearly; I need to tell the printer the color is wrong. I need to drive to night meetings.

Then there's reality...

Now I need to find another way. And I did. I still had my brain and my creative juices didn't stop flowing just because I didn't see color. I was lucky. I was able to restructure my job and I continued working.

One day a client handed me a business card and I could not read the phone number. Yesterday I was able to read regular size print. What could have happened? Instantly, I knew that macular degeneration had reared its ugly head once again. Only this time, in my one good eye.

I immediately started all the therapies that were available at the time, laser, cold laser, Macugen in-

jections...I cancelled all my newspaper and magazine subscriptions, **went to the library and took out large print books, ordered large print Reader's Digest and the New York Times** and prepared for life as a macular degeneration person.

I started to think about **organizing my closet with different size circles, squares, etc. on my hangers so that I could identify my clothing by color.** All blue tops would be

with circles, red with squares, white with triangles, etc. I was even thinking of producing these things so that others could have the benefit of my idea. After all, I didn't want to leave the house in a striped top and plaid pants...although in today's fashionable places, that would be very much in vogue.

Guess what? There was a bright side. The best part of starting to lose my sight... I stopped working. Now I could retire.

Fortunately my husband is self employed, so it was not a money issue.

Finding something meaningful to do with my time was the issue...and I did. My next job would have a new title – VOLUNTEER!

I had always volunteered in my younger days, I was a Girl Scout leader before I had children. I worked with the mentally challenged as a teenager. I was a youth group leader when my kids were teens, etc.

Along with my new title, macular degeneration made a new job description possible. My resume is really very exciting.

So what do I do, you may be wondering? I go into the high schools and teach a course on teen dating abuse – the warning signs and prevention.

I knew nothing about the subject, however, the NCJW organization in my area was looking for volunteers to take a course to learn the subject. I contacted them, told them I had macular degener-

(continued from page 8)

HOW MACULAR DEGENERATION CHANGED MY LIFE FOR THE BETTER

BY BARBARA SARRETT



ation and **needed large print materials**. They were anxious for volunteers and provided me with the printed material in a large print size. I also took three days of classes and memorized the script using 5" x 7" large index cards that I made myself for an outline. Teen dating abuse affects one out of three teens before they graduate from high school...and if they do not break the cycle, it can progress to domestic violence. Teaching this course is extremely rewarding.

I also was appointed to the public relations commission, became a member of the human relations commission of my town and I am the elected Democratic committee woman for my district. My name appears on the ballot every 2 years.

We all know that timing is everything...three years ago along came new drugs, Avastin and Lucentis. I am one of the lucky ones. Avastin restored the sight in my right eye so that I am able to read regular print again. I reordered magazine subscriptions and enjoy the daily newspaper. That's not to say I no longer have vision problems, life doesn't work that way.

Things are often darker than they would be normally, so I carry a flashlight...night walking is sometimes scary, so I hold my husband's hand (feel like a teenager again too). But there are many solutions when problems arise...just reach out and you will find them.

Today, I feel more complete as a human being than when I was working. Now I feel like I am really making a difference. And it's all because macular degeneration tapped me on the shoulder and said, "hello, I'm here!"

Let me say that living with macular degeneration is not easy. It does not get better. But it does get easier.

In the beginning, I stopped enjoying going shopping. Not grocery shopping, I never enjoyed that, but clothes shopping. I couldn't see colors the same way. I used to be able to hit a store and focus on the word "sale" and head right for that rack. Things do change because of macular degenera-

tion, but you are the one that makes the changes happen...you simply find new ways to do the same things.

And they say you can't teach an old dog new tricks, those of us with macular degeneration are living proof that you can.

Macular degeneration also allows you to make a difference in the lives of your friends and family. How? Never be afraid to ask for help...because asking a friend for help says you value that person, that you trust them. And guess what, you make that person feel good!

You know how you feel good when someone asks you to help them ---well spread the goodness around! Give someone the opportunity to feel needed and appreciated, I cannot drive at night...I never hesitate to ask my committee people to pick me up...and do you know what happens...more than one always volunteers. People need and want to do a favor for you and you have the obligation to satisfy their needs.

This time of your life is certainly not the end of something. It is a new beginning. Someone once said that loss of sight does not mean loss of vision. My vision remains 20/20. 

EASY TO READ LARGE PRINT SEARCH ENGINES

www.big.com

www.good50.com

labs.google.com/accessible/

EYE OPENING FACTS

YOU CAN STILL DO IT!

By Mary Betty Roeder

“Well, maybe I can’t do this or that the way I used to, but there must be a way. Now, what is the way?” That has been my motto ever since macular degeneration destroyed my central vision.

And I have figured out new and different ways to do practically everything including cooking and entertaining, travelling by myself and putting my make-up on and fixing my hair when I can no longer see myself in the mirror.

But how to play bridge when I couldn’t see the cards – that seemed like an insurmountable obstacle. I have been a bridge player ever since I was a teenager - both social bridge and duplicate tournament bridge. I was discouraged. Don, my bridge partner at the time, was more optimistic. Don felt that all I needed to do was figure out a way to see the cards in my hand. He would tell me the cards in the dummy and of course, people would have to tell me the cards they played and all I had to do was just remember it all. I doubted that my memory was that good. Don insisted that we try.

I invited Don and another couple to my house for a friendly game one night just to see if I could do this. I wear glasses, hang a magnifier around my neck and hold the cards very close to my eyes, and much to my great surprise, I found I could remember those cards. Now of course, when one goes to play in a duplicate tournament, there is a director and we had to get permission from the director for Don to read the dummy to me. There has



never been a problem as American Contract Bridge League rules say handicapped players must be catered to whenever possible.

A few weeks after we resumed playing, Don went to see his retina specialist for a check up for he had had a macular hole repaired the previous year. While he was there, he mentioned to his doctor that I was his bridge partner, knowing I was also a patient of his. The doctor was amazed. He told Don “Mary Betty Roeder is a patient of mine and I know she can’t see well enough to play duplicate bridge.” To which Don replied “please don’t tell her that because she hasn’t found it out yet! And we have been winning our share of games.”

I continue to play duplicate bridge. As I said in the beginning, there is always a new and different way to do almost anything. 👁

RESEARCH AREAS SUPPORTED BY THE MACULA VISION RESEARCH FOUNDATION

In each issue, a specific research topic will be discussed. The Macula Vision Research Foundation (MVRF) supports a wide-range of basic and clinical research on age-related macular degeneration (AMD), the leading cause of vision loss in the U.S. and other countries world-wide. The overall goals of MVRF-supported research are to understand the genetic, molecular and cellular basis of AMD and use this information to develop improved diagnostic tools, preventative measures, and therapeutic treatments which will slow or eliminate vision loss in affected individuals. One of the current research areas currently being funded by MVRF is:

Identification of genes which increases one’s risk of developing age-related macular degeneration (AMD). MVRF-funded scientists have identified a number of genetic variants in the population that increase one’s risk of developing AMD. Six genes have now been identified that account for up to 75% of the cases of AMD. Research is being carried out to identify additional genes.

STAYING ACTIVE AFTER THE DIAGNOSIS OF MACULAR DEGENERATION

By Lea S. Bramnick

Life changes and the changes that accompany the diagnosis of macular degeneration are striking. Although it is the leading cause of severe vision loss in people over age 50, surprisingly it is not yet a word in every day language. When most people are diagnosed, they are hearing the words for the first time and do not know people who have the disease. People are living longer.

- **Entertain** – You can't bake the pie – buy the pie; can't roast the turkey, buy it roasted; or send out for pizza; but have all the people you love in one room at special times.
 - **Do things with your grandchildren** – large Scrabble, large playing cards, large chess and checkers. Use "bird-watching binoculars" from a Low Vision specialist to find that kid you love on the baseball diamond, on a stage in the school play, soccer field, etc.
 - **Keep in touch with family and friends** – It costs about \$6,000 to \$8,000 per year to run your car! Once you cannot drive, it is devastating, but please consider what you are not spending and use some of that money for a cab if you cannot get a ride to the event at church or a family get-together. If someone picks you up with great regularity, take that person to lunch, or fill up a family member's gas tank every once in a while.
 - **Volunteer at your church or synagogue** – Answer the phone, welcome people at an event, separate clothes at the clothing drive – you can see the difference between a pair of pants and a dress. According to The Health Benefits of Volunteering: A Review of Recent Research, "volunteers 'help' themselves to better health while helping others. There was a significant connection between volunteering and good health."
 - **Buy a small tape recorder** and record stories from your childhood for your family members.
- **Sing in the choir, play with your chamber music group** by taking the music to Staples, Office Depot, etc. and blowing it up on their large photocopy machine – you can make it darker on those machines, as well.

- **Take courses** – Continuing education, non-credit courses or classes taken after "formal education" are available at a wide variety of settings: universities, community colleges, non-profit agencies, Elderhostel, etc. Course descriptions are available in large-print and books or materials for courses are often available in large-print editions.
- **Join a gym** – Research has consistently shown that physical activity can help prevent cardiovascular disease, keep weight, blood pressure, cholesterol in check and maintain strength. Exercise is also good for your "eye-health." The social interaction at a gym is very healthy.
- **Stay a member of your book club** – You may not be able to read the book, but you can listen to it on tape and remain a participating member of the group.
- **Do puzzles** – There are large-print word-search and cross-word puzzle books. Sudoku is published in large print, too.

This time of your life is not an ending; instead, it is a new beginning. Recognize the transition period as a time of exploration. Loss of sight does not prevent "loss of vision" in exploring and learning about what's out there. Give yourself the opportunity to develop confidence and feel excited about the possibilities ahead.

