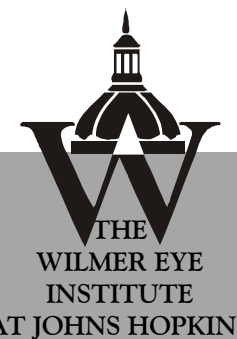


The Wilmer Macular Degeneration Center  
Johns Hopkins Hospital  
Maumenee 706  
600 N. Wolfe Street  
Baltimore, MD 21287-9228

Address service requested

NON PROFIT ORG.  
U.S. POSTAGE PAID  
Baltimore, MD  
PERMIT NO.  
2589



The Newsletter of the Wilmer Macular Degeneration Center

# MACFACTS

Volume 7, Issue 1  
2006

## In This Issue

- 1 - 3  
Family Members Wanted
- 3  
Genetic Study
- 4  
Macugen Approved
- 5 - 6  
Research Updates
- 6 - 7  
Charles Bonnet Syndrome
- 8  
Low Vision and Medicare
- 9 - 11  
Electronic Eye & Ears
- 12 - 13  
Medical Evaluation of AMD
- 14  
Wilmer Nurses Awarded Grant
- 15 - 16  
Driving--Vision Concerns?
- 17  
Did You Know About?  
Recommended Reading
- 18  
Resource Tips
- 19  
Support Group Schedule

## Family Members Wanted

When you love someone, you want good things for them. We want our children to grow up healthy, get a good education, marry a person with a noble character and live happily ever after. What do we want for our parents and for our spouses? We want them to be able to enjoy the fruits of their labors, to retire after a satisfying working career and to reap the benefits of all their years of hard work. We want time for them to pursue their favorite hobbies, to be able to

---

*“Research has shown that when the family has a positive attitude and is involved with the care of their loved one, the better the loved one adjusts to the vision loss.”*

---

travel to Venice, to go on a safari, to be independent and to live the good life. But sometimes that is not what the future holds.

Sometimes your loved one develops macular degeneration and life as he or she knows it, changes. All of a sudden, the “golden years” are filled with anxiety, confusion and fear of loss of independence. Activities that were taken for granted, now need to be relearned. Picking out matching clothes, handling money, and even cooking can be challenges. Suddenly or gradually, your loved one needs more of your time and attention. Or maybe he or she is reluctant to ask for help, hesitant to admit difficulties, or apologetic for these new limitations. Maybe some are depressed, not wanting to adjust, or don't have the energy to see beyond this vision loss.

Most family members want to help, most have good intentions. But many “just can't understand what it is like” as often reported by our patients. There are good reasons to be involved in Mom or Dad or spouse or Grandma or Grandpa's

*Continued on page 2 . . .*

# MACFACTS 2006

Look for our next issue in 2007

The Newsletter of the Wilmer Macular Degeneration Center

# MACFACTS

THE  
WILMER EYE  
INSTITUTE  
AT JOHNS HOPKINS

## Directions to the Wilmer Macular Degeneration Support Group Meetings



Johns Hopkins at Green Spring Station is located at the Baltimore Beltway and the Jones Falls Expressway interchange. Take exit 23 B off the Baltimore Beltway and go north on Falls Road to Green Spring Station at the intersection of Falls and Joppa Roads. From the City, drive north on the Jones Falls Exp. (I-83N) to the Beltway (I-695) until the Jones Falls Exp. becomes Falls Road (25). Go ½ mile on Falls and turn right at the 2nd traffic light (Station Drive). Continue to the 4- way stop sign. The Johns Hopkins Pavilions I & II will be directly in front of you. Parking is free and handicapped parking is on the East side of Pavilion I and the South and East sides of Pavilion II. For those using public transportation, the MTA's M10 bus stops on the campus of Green Spring Station.



**Family members. . . continued from page 1**

care; not excluding the fortunate patients who have very interested and supportive friends. Research has shown when the family has a positive attitude and is involved with the care of their loved one, the better the loved one adjusts to vision loss. Support and concern can make life better for Mom or Dad but what are the critical issues that can make the family response most effective?

◆ **Understand the disease.** Maintain communication with the ophthalmologist, nurse and low vision specialists. Understanding the cause of vision impairment, the extent of vision loss, treatment options and prognosis will enable family members to clarify issues with the patient and assist with medical decision making. Patient's misconceptions can often cause unnecessary anxiety. The family member may be privy to these worries and can help the patient obtain clarification. Bring a list of questions to medical and low vision appointments. This time with the ophthalmologist is critical not only for understanding the medical management of the disease, but also to obtain referrals to resources, support groups, and low vision evaluations.

◆ **Set up a plan for care.** The ability to perform everyday tasks is basic to the health and happiness of your loved one. An open discussion will reveal problem areas as well as strengths. They may be having difficulty with a certain tasks such as dressing,

grooming, cooking, eating, using the phone, taking medicines and doing laundry but be unable or unwilling to ask for help, unless each issue is individually addressed.

◆ **Support independence.** The support given to your loved one is not "doing for" but rather helping him find new ways to perform vital tasks. After years of taking care of many people in the family, the adult with low vision often does not want to be on the receiving end. Ways to keep independence should be considered and emphasized. Occupational therapists often make home visits to evaluate this very issue.

◆ **Consider socialization.** Family relationships are very important for healthy functioning, but friends provide a special and unique support system that has been shared over a lifetime. Loss of the ability to drive or relocation to another home and/or town due to the disability may be particularly distressing to the adult with impaired vision. The affected person not only has vision loss but may also feel the loss of friends. These circumstances can add to the emotional vulnerability of the person with AMD. Encourage social relations and plan outings and activities to keep these social ties strong.

◆ **Share finance concerns.** Children are considered grown when they can pay their own bills and be independent from their parents. To go back to having another person oversee bill paying, banking and investing can be difficult. But a second set



# THE WILMER MACULAR DEGENERATION CENTER

## Support Group Meeting Schedule

### Winter - Spring 2006

- January 30, 2006**  
**Monday**  
"Learning New Skills & Habits For Successfully Living with AMD"  
**Katherine Mertens, Occupational Therapist**  
The Lions Low Vision Rehabilitation Center
- February 21, 2006**  
**Tuesday**  
"Nutritional Supplements for AMD; What We Do & Do Not Know"  
**Ed Quinlan, M.D.**  
Assistant Professor of Ophthalmology  
The Johns Hopkins School of Medicine
- March 21, 2006**  
**Tuesday**  
"The Silent Sadness; Suffering With Depression"  
**Marsen McGuire, M.D.**  
Director of Geriatric Services, Sheppard Pratt Hospital  
Associate Professor of Psychiatry  
The Johns Hopkins School of Medicine
- April 18, 2006**  
**Tuesday**  
"New Research Advances for AMD"  
**Quan Nguyen, M.D.**  
Assistant Professor of Ophthalmology  
The Johns Hopkins School of Medicine
- May 16, 2006**  
**Tuesday**  
"Optimizing Your Abilities, Talents & Interests With Low Vision"  
**Panel Discussion, presenters to be announced**

**No meetings in June, July, or August. Meetings will resume in September**

- AGENDA:** 7:00 p.m. – 8:00 p.m. – Guest Speaker  
8:00 p.m. – 9:00 p.m. – Small Group Discussions
- LOCATION:** Johns Hopkins at Green Spring Station  
10753 Falls Road, Pavilion II, Room 125 A  
Enter through the main doors, take the first left through the coffee shop to the conference room. It is wheelchair accessible.
- DIRECTIONS:** I-695 to Exit 23B North, continue on Falls Road to Green Spring Station at the intersection Falls and Joppa Roads. (see map on back cover of this issue). **FREE PARKING**



**Resource Tips**

**Support Groups locators**

Looking for a group in your area? Go the Lighthouse International sponsored website, [www.visionconnection.org](http://www.visionconnection.org) Click on 'Help Near You' and you will come to a search page representing an expansive database covering the majority of the US. Support groups and many other resources may be found in your local or regional area with the touch of a button.

For groups in the Washington, DC area, listings can be found at the Low Vision Information Web Site, [www.lowvisioninfo.org](http://www.lowvisioninfo.org). Click on resources, then low vision support groups. Join one today and share your knowledge!

**Verizon Exemption**

Need help making those calls? Apply for a free service from Verizon for directory assistance and operator assistance calls. Obtain the application from Verizon services that will qualify you as having a disability that prevents you from using a telephone book or touch tone phone. Call the Center for Customers with Disabilities, 1-800-974-6006.

**Computer Screen Magnifiers**

Would you like to try magnifying text and images on your computer screen without the cost of an expensive software program? Go to [www.magnifiers.org](http://www.magnifiers.org) and

browse the download section for screen magnifiers. You may need a bit of help saving and then running the program but that help may be gotten from a willing grandchild. The program called "Dragnifier" is like using a magnifying loop over the screen controlled by your computer mouse.

**NFB-NEWSLINE®**

Does macular degeneration make it too difficult to read your newspaper? There is a service that can give your newspaper back to you. Sign up for Newsline, a free electronic news service created by the National Federation of the Blind. It automatically converts publications like the *Baltimore Sun*, the *New York Times*, the *Washington Post*, the *Los Angeles Times*, *AARP the Magazine*, and more into electronic speech. NFB-NEWSLINE® delivers more than 170 newspapers and three magazines to you, free, over the telephone.

Using NFB-NEWSLINE® is just like reading a newspaper's print edition. You select the publications, sections, and articles that you wish to read and listen to these items using a standard touch-tone telephone. The service is available 24 hours a day, 7 days a week.

If you enjoy reading the daily newspaper or special interest magazines, but find this increasingly difficult due to vision loss, call the National Federation of the Blind at 866-504-7300 to learn more about how you can continue to read the paper for news about current events, sports, and community activities over the telephone.

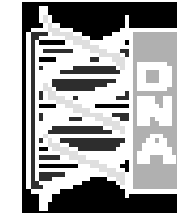


of eyes may be needed for the person with low vision. Often trusted family members may assist with these tasks. When possible, the family member should be careful not to make the financial decisions but follow the wishes of the person with low vision.

◆ **Don't forget safety.** The home should be free of clutter, well lit and organized, making accidents less likely. There are numerous ways to manage the home. Some examples include; marking the edges of steps with contrasting tape, placing a string of Christmas lights along steps to outline them, using dark light switch plates on light walls, keeping like color clothes together. The kitchen and laundry can be approached with the same creative thinking, use contrast and touch wherever possible. Consistent use of space will help the patient find things easier.

There are a lot of families struggling with the best way to help their loved ones. And there are many ways of helping. These are just a few suggestions which we hope will be useful. Care giving can be a both joy and a hardship, and these conflicting emotions can be very confusing. Don't forget to help yourself, meet with others in similar situations, exchange ideas, problems and concerns. Share ideas on how to help your loved one lead a more satisfying life. The old saying "A problem shared is a problem halved" has foundation in truth. It is rough going alone. And it's not necessary.

--Kitty Sackett, R.N., C.A.N.P.  
Betsy Campochiaro, R.N., M.S.N.



**Genetic Study of Macular Degenerations**

**Do you have macular degeneration?  
Do you have a living brother or sister who also has macular degeneration?**

If your answer is yes to **both** of these questions, we are looking for you! The Wilmer Macular Degeneration Center is conducting a study aimed at increasing our understanding of the causes of macular degeneration. We are searching for mutations (mistakes) in genes that contribute to these conditions. A small blood sample and a photograph of the back of the eye are all that is needed from each participant.

If you would like to learn more about the study, please contact the coordinator of the study:

Betsy Campochiaro, R.N., M.S.N.  
Maumenee 706  
600 N. Wolfe Street  
Baltimore, MD 21287  
Voice: 410-614-6208  
E-mail: [bcampo@jhmi.edu](mailto:bcampo@jhmi.edu)



**Pegaptanib (Macugen) Approved**

Over the past several years, research in animal models has suggested that vascular endothelial growth factor (VEGF) is an important stimulus for the growth of abnormal blood vessels in the eye. Recently, this was proven to be the case in patients with wet AMD. In 2 large clinical trials, it was demonstrated that Pegaptanib (trade name: Macugen), a drug that blocks VEGF, provides benefit for patients with wet AMD. The benefit is not huge, but it is a step in the right direction. Thirty percent of patients with wet AMD who received an intraocular injection of Macugen every 6 weeks for one year experienced moderate or severe vision loss compared to 45 % of patients who did not receive Macugen. It reduced the percentage of patients who became legally blind from 56% to 38%. Substantial improvement in vision (3 lines on the chart) occurred in only 6 % of patients treated with Macugen compared to 2% who did not receive it. So, it is not a magic bullet, but it was beneficial compared with not giving Macugen; therefore, the Federal Drug Administration approved it making it the second approved treatment for wet AMD. The other approved treatment is photodynamic therapy (PDT). Should you develop wet AMD, your doctor will discuss the pros and cons of both Macugen and PDT or other treatments (see article "New Drugs Provide Benefit To Selected Patients With Wet AMD" on page 5 in this same issue) and

together you will decide what is best for you.

The ultimate goal for treatment of wet AMD is to get improvement in vision and since Macugen rarely does that, it is not the final answer. Studies are continuing to try and identify new treatments.

--Peter Campochiaro, M.D.

**MACFACTS**

Volume 7, Issue 1  
2006

Editor: Betsy Campochiaro, R.N., M.S.N.  
Co-editor: Kitty Sackett, R.N., C.A.N.P.  
Layout & design: Anne Meltzer

This newsletter is published once a year and is available on our website:

<http://www.hopkinsmedicine.org/wilmer/news/macfacts/index.html>

Excerpts from this newsletter may be reproduced for educational purposes only.

For a free subscription, send your name and address to:

The Wilmer Macular Degeneration Center  
706 Maumenee, 600 N. Wolfe Street  
Baltimore, MD 21287-9228

Email: [mdc@jhmi.edu](mailto:mdc@jhmi.edu)

General information & referrals:  
410-955-5080  
Appointment line:  
419-955-3518



**Did you Know About . . .**

**The importance of good lighting?** More light provides for better reading ability. As we age, our light demands increase and glare becomes more of a problem. The list below identifies several ways for you to reduce glare and improve lighting.

- ◆ A small goose neck type lamp with an indoor floodlight bulb can be carried around the house, directing the flood of light where it is needed and out of the eyes to reduce the glare. Ask your low vision specialist about the Ott-Lite. This is a light source that is designed to reduce glare of ordinary lights and improve color contrast and detail definition. It comes in a variety of designs to meet the needs of people on the go or for stationary lighting.
- ◆ Change all the incandescent light bulbs in the house to 100 watts.
- ◆ Have a flashlight available for extra light.
- ◆ Use sheers to cover windows and reduce sun glare in the home.
- ◆ Cover all surfaces that are shiny and polished. i.e. floors with rugs, tabletops with cloths.

**Closed Circuit Televisions (CCTV)?** This is a stationary desk type unit that provides magnification and contrast with a screen monitor and a camera. Items placed under the camera are projected to the screen where the color, contrast, and image size may be manipulated for the best viewing for the individual. This device makes it possible for

some low vision individuals to read books, newspapers, mail, write checks and view photos. Because this device is very expensive to purchase; (a black and white unit may start at \$1800), it should not be purchased without the assistance or advice of your low vision specialist and only if it can be used for a trial period and returned if necessary.

**Recommended Reading for Older Adults With Low Vision and Their Families**

**Driving with Confidence: A Practical Guide to Driving with Low Vision** (2002); by Peli, E. and Peli, D., Singapore; London: World Scientific Publishing Company, Pte. Ltd..

**Living Well With Macular Degeneration** (2001); by Rosenthal, B., Kelly, K., New York: London; Toronto: New American Library.

**Macular Degeneration: The Latest Scientific Discoveries and Treatments for Preserving Your Sight** (2001); by D'Amato, R., Snyder, J., United States: Walker Publishing.

**Macular Degeneration. The Complete Guide to Saving and Maximizing Your Sight** (2003); by Mogk, L., Mogk, M., New York: Toronto: Ballantine Books.

**Overcoming Macular Degeneration-A Guide to Seeing Beyond the Clouds** (2000); by Solomon, Y., New York: Avon Books, Inc..



***Driving--Vision concerns . . . continued from page 15***

eligible for the MVA's Modified Vision Program (see below), or an improvement in their current level of visual performance to maintain or renew their current license.

Current Maryland law provides for three categories of licenses based upon the individual's visual acuity. In addition to a visual acuity requirement, there is a visual field requirement (this is the measure of peripheral vision while the person is looking straight ahead) ranging from 140 degrees to 110 degrees depending upon the type of license. These categories are as follows:

1. **UNRESTRICTED LICENSE:** The visual acuity requirement for an unrestricted license is **20/40** and better.
2. **RESTRICTED LICENSE:** A restricted license is offered to individuals with acuity between **20/41** and **20/70**. These individuals may have certain restrictions such as driving in daylight only or requiring an extra mirror on the outside passenger side of the vehicle.
3. **MODIFIED VISION PROGRAM LICENSE:** Individuals with vision between **20/71** and **20/100** may have the opportunity to pursue a driver's license at the discretion

of the Maryland MVA Medical Advisory Board. After application to and a positive review by the MVA Medical Advisory Board, applicants will be evaluated by an occupational therapist and a certified driving instructor recognized by MVA who have completed specialized training. This MVA program requires potential drivers to complete clinical and behind the wheel evaluations. These evaluations help to determine if other skills are being used to compensate for the loss of vision. The behind the wheel evaluation determines the baseline driving skills and can establish goals for future driver training. All potential low vision drivers are required to complete a minimum of 20 hours of driver training. These services can be coordinated by the Hopkins Greenspring campus.

It is the intent of the Hopkins Low Vision Driving Program and the Maryland MVA to help individuals safely maintain their license with the proper interventions. Should you have any questions relating to your ability to drive with visual difficulties or that of a family member please contact the Johns Hopkins Lions Low Vision Research and Rehabilitation Center at 410 955-0580.

--Jim Deremeik



**Research Update**

**New Drugs Provide Benefit To Selected Patients With Wet AMD**



Recent studies have demonstrated that vascular endothelial growth factor (VEGF) is a key stimulator of abnormal blood vessel growth and leakage in patients with wet AMD. Pegaptamib (trade name: Macugen) is a drug that blocks VEGF that has been approved by the FDA. Results with a new drug that blocks VEGF, Ranibizumab (trade name: Lucentis), have been released in the summer and fall of 2005. Two large clinical trials have shown that a monthly injection of Lucentis into the eye is helpful in selected patients with wet AMD. This drug may not be helpful for some individuals that have had wet AMD for a long time. Both studies showed that more than 90% of patients treated with Lucentis compared to 60% of patients that did not receive Lucentis, did not experience severe loss of vision. More impressively, this is the first treatment that has resulted in visual improvement in a minority of patients one year after starting treatment. About 1/3 of patients treated with Lucentis had an improvement in vision of 3 or more lines compared to about 5% of patients not receiving Lucentis. These results are much better than results with any previous treatment and approval of Lucentis by the FDA is likely to occur in 2006 (possibly in the summer). The Sailor Trial is starting in

December of 2005, and patients with active leakage and reduced vision from wet AMD who meet other eligibility criteria may enter the Sailor Trial and receive treatment with Lucentis prior to its approval by the FDA.

Another drug, Bevacizumab (trade name: Avastin) has similar actions in the eye as Lucentis, and is being used as an "off label" drug, meaning it has not been approved by the FDA for use in the eye. This drug has been approved by the FDA for use in certain cancers and many ophthalmologists have found it effective for wet AMD. This drug may be recommended until Lucentis becomes approved for use by the FDA, which is expected in the summer of 2006.

In addition, another study is starting in which eligible patients will be randomized to receive photodynamic therapy with or without PTK787, an oral medication that blocks the effect VEGF. This medication is very interesting, because treatment for wet AMD can take time, and it would be advantageous to be able to take a pill rather than receive repeated injections in the eye. This is particularly true if both eyes are affected. So, it is important to find out if this pill that blocks VEGF has similar effects to Lucentis which is given by multiple injections into the eye. Many years of research trying to understand what causes abnormal blood vessels to grow under the retina in patients with AMD is finally beginning to pay off.

--Peter Campochiaro, M.D.



**Research Update**

**Gene Therapy Report:  
Phase 1 Study Shows Good  
Safety Profile for Ocular Gene Therapy  
with AdPEDF**



Abnormal blood vessel growth as seen in the wet type of macular degeneration appears to be influenced by factors which inhibit the growth of blood vessels and factors that encourage the growth of blood vessels. In Volume 4, Issue 1 of *MacFacts*, the role of VEGF (vascular endothelial growth factor) and the potential use of PEDF (pigmented epithelium-derived factor) in gene therapy was presented. PEDF is one of the factors that blocks growth of abnormal blood vessels. Laboratory studies in animal models demonstrated that the injection of an adenoviral vector containing the PEDF gene caused the abnormal blood vessels to partially shrink and go away. A Phase 1 clinical trial in patients with advanced AMD has been completed and has shown an excellent safety profile for this type of gene therapy in humans. As a result, a new part of the study has just been started to test patients with less severe wet AMD (vision of 20/40 or worse). Watch for more information in the next issue of *MacFacts*.

--Peter Campochiaro, M.D.

**Formed Visual Hallucinations in  
Patients with Macular Degeneration**

Visual hallucination is a subjective perception of light or image that does not exist. Although “unformed” visual phenomena such as flashes of light are by definition hallucinations, the term hallucination is more commonly reserved for “formed” images such as faces, people, animals and scenery.

Formed visual hallucinations can occur in sane people with poor vision. This was first described by Charles Bonnet, a Swiss naturalist, in 1769. He reported the case of his 89-year-old grandfather who had severe vision loss due to advanced cataracts, and visions of figures, people, and animals. Apart from the eye problems, his grandfather was in good physical and mental health. This syndrome is now known as Charles Bonnet syndrome.

**Prevalence**

The exact prevalence of Charles Bonnet syndrome in the general population is unknown. It is associated with vision loss from a variety of eye disorders, including age-related macular degeneration. Some studies have shown that formed visual hallucinations occurred in up to 12-13% of clinic patients with macular degeneration.

**Risk factors**

Charles Bonnet syndrome tends to occur in elderly people above the age of 65



**Driving – Vision Concerns?  
Evaluation for an Objective  
Recommendation**

Many patients with macular degeneration report driving as a major functional difficulty encountered in their daily routine. Although many of these patients are able to retain current driver’s licenses, the question of their safety on the road is one of debate in the opinion of Jim Demereik, Low Vision Specialist at the Wilmer Eye Institute.

These safety issues are addressed in a new driving evaluation program introduced by the Hopkins Lions Low Vision Service. A professional evaluation of the individual’s driving skills may help the individual and the family, deal more objectively with a potentially emotional and life changing event - the issue of whether to continue driving when vision may be impaired and improvement in vision is unlikely. The evaluators are occupational therapists and/or certified driving instructors that are trained in low vision driving training and evaluation. These professionals focus on factors that can impact driving in many ways, including driving skill, reaction to driving events, i.e. red lights, other cars etc as well as the individual’s ability to think clearly while driving. This evaluation provides objective feedback of an individual’s driving ability.

The low vision driving program includes:

- ◆ Low vision evaluation to

determine if the individual qualifies for the driving program.

- ◆ Clinical evaluation to assess functional vision, perception, thought processes and other skills that must be intact to be able to compensate for low visual acuity.

- ◆ A behind the wheel road evaluation to examine driving skill

- ◆ Assessment of reaction time to sudden events incurred while driving

These evaluations are conducted at Johns Hopkins at Greenspring Station (10755 Falls Road, Lutherville, Maryland 21093) by an occupational therapist and/or certified driving instructor recognized by the Maryland Department of Motor Vehicles. The clinical and driving evaluation is done over two visits. The clinical evaluation occurs on the first visit lasting approximately two hours and costs \$180. During the second visit, the behind the wheel road evaluation is completed lasting 2 hours and costs \$180. This program might be especially helpful for the following groups:

- ◆ **Individuals whose vision is 20/70 or better** experiencing difficulty with driving, or have been told by their eye doctor they should not drive.

- ◆ **Individuals whose vision is 20/71 or worse** would benefit from a low vision evaluation to determine if there were any interventions that would allow them to be

***Continued on page 16 . . .***



### **Wilmer Nurses Awarded Grant for the Support and Education of Patients Living With AMD**

We are delighted to inform our readers about a nursing grant received from The Atlantic Philanthropies (USA) Inc. that may have benefits for persons living with low vision across the country. This initiative may result in the development of as many as 35 support groups for low vision patients in 16 different states. Here is how it started!

A collaboration has been initiated between American Society of Ophthalmic Nurses (ASORN) and American Nurses Association's Nurse Competence in Aging initiative and the Hartford Institute of New York University. This partnership seeks to improve the knowledge and practice of the ophthalmic nurse as he/she cares for the patient diagnosed with age related macular degeneration (AMD). A two-year grant was awarded to nurses at the Wilmer Eye Institute to develop, teach and implement an educational program for ASORN nurses to incorporate support groups into the nurse clinician's practice. The ophthalmologic nurse is in a unique position to strengthen the individual's and family's ability to adjust to AMD. Nurses can effectively initiate and lead support groups that can be the vehicle to acknowledge and address the needs of the patient.

The program consists of several phases over a 2-year time frame. Phase 1

was the development of a portable kit the nurse can use to competently begin a support group in his/her practice setting. Examples of items included in this kit are: low vision resource book, small group dynamics book, audiotapes from the Wilmer AMD support groups, videos of AMD disease information, aging issues of the AMD patient, videos on low vision rehabilitation, advice on support group meeting details such as topic/ speaker suggestions, format, advertisement, forms needed, suggested support personnel. Alternative ways to educate low vision groups are addressed through the use of large print publications, web pages and computer software.

This kit was presented to ophthalmic nurses at the annual meeting of ASORN in the fall of 2004 & 2005. As a result of these presentations, there are 35 nurses and individuals located throughout the country that have begun work in this important area. These nurses are in various stages of support group development in their own communities. The remaining phases of the program will be to gather feedback and improve this program based on the nurse's feedback. It is hoped that this will result in a network of nurses committed to raising the level of support and education of the low vision patient and family members.

--Betsy Campochiaro, R.N., M.S.N.



years. It is more common in women than men. Those affected may have poor vision in one or both eyes, but the risk of developing formed visual hallucination is greater if both eyes are affected. Other risk factors that have been associated with the syndrome include living alone and a history of stroke.

### **Characteristics**

People with Charles Bonnet syndrome report seeing formed images such as faces, people, animals, flowers, and landscape. The hallucinations coexist with normal visual perceptions and the individual can differentiate one from the other. The content of the visual hallucinations is well organized and defined, as opposed to the normally blurry perception of real objects in people with poor vision. The hallucinations occur while the individual is clearly conscious, and are not accompanied by any other disorders of sensory perception, such as hearing voices. The hallucinations appear suddenly and unexpectedly, and tend to disappear on closing the eyes. They are not accompanied by any particular emotional reaction, and they do not bother most people.

### **Diagnosis**

The diagnosis of Charles Bonnet syndrome is made clinically. There is no specific laboratory or imaging test for this condition. The syndrome is often overlooked or misdiagnosed. In addition, it

is probably under-diagnosed because some people with the condition may be reluctant to recount a history of hallucinations, even on persistent questioning, lest they be considered to have a psychiatric disorder.

### **Treatment**

It is possible to "cure" some patients with Charles Bonnet syndrome by restoring or improving their vision if their eye condition is treatable, such as cataract surgery for advanced cataracts. In others with untreatable eye conditions, some doctors have used medications such as anti-convulsants and neuroleptics, but there are no proven trials to confirm their efficacy. For the vast majority of people with Charles Bonnet syndrome, management will consist of reassurance and education of the patient and his or her family. It is important to stress that people with Charles Bonnet syndrome are not insane.

### **Prognosis**

The prognosis of Charles Bonnet syndrome varies with the nature of the visual dysfunction. In one study, 60% of patients with Charles Bonnet syndrome secondary to age-related macular degeneration experienced cessation of the visual hallucinations within an average of 18 months. Forty percent reported persistence of the hallucinations after three years, but most were not bothered by them.

--Kah-Guan Au Eong, MMed(Ophth), F.R.C.S.  
Gildo Y. Fujii, M.D.  
Dante J. Pieramici, M.D.



**Low Vision Rehabilitation and Medicare Coverage**

Recent changes and rulings by Medicare have impacted the delivery of low vision rehabilitation service at the Johns Hopkins Low Vision Research and Rehabilitation Center. Effective July 25, 2005, Medicare will cover rehabilitation training only if it is provided by an occupational therapist, physical therapist, or speech and language pathologist.

This anticipated ruling has resulted in several significant changes in the center:

- ◆ The clinic hired a full time, fully trained occupational therapist (OT) who provides low vision rehabilitation evaluation, instruction and follow up in the clinic, work and home setting.
- ◆ A continuing education program in the area of low vision rehabilitation was established for training occupational therapists.

The occupational therapist is a valuable new addition to the low vision team, with special emphasis placed on instruction and evaluation in:

1. Visual skills training; such as learning to look around blind spots
2. Use of optical and non optical devices
3. Environmental modifications
4. Referrals to community resources for the patient and family members.

The occupational therapist can meet with the patient in the low vision clinic and in the home setting. The home visit is a new service which not only addresses environmental safety

issues and independent functioning, but also provides an opportunity to reinforce the practical skills learned in the clinic and apply these skills in the home setting. This service is available to those patients that live within one hour driving distance of the clinic and is now covered by Medicare.

The clinical low vision evaluation performed by a doctor with expertise in low vision rehabilitation continues to be covered by Medicare. This evaluation process reviews the patient's overall health status as it relates to the individual's visual impairment. Optical devices may be introduced if appropriate as well as an assessment to determine if the lens in the patient's current glasses need adjusting or changing. Other vision issues related to driving, medical treatments and therapeutic interventions will be evaluated. If it is determined that the occupational therapist could help in the visual rehabilitation process, the low vision doctor will refer the patient to the OT for rehabilitation training.

While there has been progress in low vision services covered by Medicare, low vision devices such as magnifiers, telescopes, video magnifiers are still not covered by Medicare.

These changes have resulted in a more comprehensive service to the patient with low vision at the Johns Hopkins Low Vision Research and Rehabilitation Center. Should you wish to learn more about this service and schedule an appointment contact the service at 410 955-0580.

--Jim Deremeik



your health care and work in partnership with your retina doctor. A few questions to ask your doctor may include:

1. Do I have AMD?
2. Do I have something else?
3. Is my AMD "wet" or "dry"?
4. What treatments are available?
5. What are the treatment risks and side effects?
6. Will I benefit from taking eye vitamins?
7. What can I expect to happen, on average?
8. When do I need to follow-up?
9. When should I call if things change?
10. Would I benefit from low vision services?
11. Can you suggest other resources I may benefit from?

If you don't understand your retina doctor's responses, ask questions until you do understand. Take notes or get a friend or family member to take notes for you. Ask your doctor to write down his or her instructions to you. You can always ask for a copy of your clinic note to be sent to you although this will be written in medical jargon for communication to your other doctors.

When should you get a second opinion? Second opinions are especially useful when your doctor suggests it, when you would like to explore other options not offered by your doctor, and when you want to be sure that another expert agrees with your doctor's diagnosis and treatment plan. Your doctor will gladly forward clinic notes and test results to another specialist and will arrange for the consultation if you

would like. Some patients are concerned that their first doctor will feel awkward or dislike them for questioning his or her opinion, but this is not the case at all. If there is a viable alternative, it is important to investigate that alternative as quickly as possible to maintain your trust and confidence.

In general, your retina doctor will tell you if you qualify for enrollment into any experimental drug studies or clinical trials, but it never hurts to ask about them if you are interested. Before enrolling in a clinical trial, however, it is important to understand that the treatment is experimental. If we knew for sure that this new drug worked, we would not have to do a clinical trial. A complete explanation of any study including benefits and risks of participation is required before you enroll. This discussion can clarify any issues related to the study and help you decide if an experimental study is right for you.

Keeping a journal or log of your medical visits can help you remember the details of your medical condition. This is also a good place to keep any questions for the doctor you may have. Your doctor will write letters to your other health care provided if requested.

We hope that as new treatment options for AMD become available, your quality of life will improve. Being an active part of this process will maximize these benefits and hopefully lead to a better understanding and adjustment to having macular degeneration.

--Howard Ying, M.D., Ph.D.



**Medical Evaluation of Patients with AMD**

Age-related macular degeneration (AMD) is a progressive, degenerative disease of the central retina. Frequent visits to your ophthalmologist may be necessary to evaluate signs of disease progression or signs of advanced disease so that treatment can be given before a significant amount of vision is lost. Understanding your eye exam can help you better prepare for your next visit to your retina specialist.

Retina problems can be complex and time consuming to diagnosis and treat. This type of examination can require several hours. Plan ahead for a five hour initial visit and two or more hours for follow up visits depending on what tests may be needed.

First, a technician or assistant will check your vision for each eye individually using a projected or illuminated eye chart. This result will be compared to your previous visual acuity. Then, he or she will check your pupils and apply eye drops to dilate your pupils for the rest of the exam. The assistant may check your eye using the slit lamp and indirect binocular ophthalmoscope (head lamp).

Your retina doctor may begin by asking questions to determine if you have had any change in your vision, such as distortions, curvy lines, blurry vision or blind spots. This is a good time to report to your doctor any vision problems you may have experienced. He or she will then perform a comprehensive eye examination. The doctor will look for any changes specific to AMD including:

- ◆ Drusen which are deposits under the retina noting the size and number of drusen
- ◆ Any changes in the color of the tissue under the retina
- ◆ Any evidence of fluid, blood, or fat under the retina

Many times photos of the retina are taken and sometimes a fluorescein angiogram (FA) or an ocular coherence tomogram (OCT) is necessary to complete your examination.

The FA is a procedure done by the ophthalmic photographers. First a dye is injected into a vein in your arm and then a series of flash photographs are taken over the course of several minutes. This test shows the retinal blood circulation and can help identify the presence of abnormal blood vessels, the type of blood vessels and their location on the retina.

The OCT is another way to image the retina that provides a cross-sectional image of the retina. It is useful to confirm the precise location and amount of fluid inside or under the retina.

Once the results of these tests are received by the doctor, he or she will review all of your clinical findings with you and discuss possible treatment, follow-up plans and answer any further questions.

Good communication between your doctor, you and any family members is critical not only to address questions and relieve anxiety but also information is necessary for compliance to the plan of treatment. Staying informed of your condition will help you take an active role in



**Electronic Eyes & Ears: Yours are Ready**

For those of us who cannot see very well, we should be pleased to know that technology offers all of us new ways to see and hear. When we lose our ability to drive a car, move about freely, and otherwise see what we have grown accustomed to, we enter a period of psychological shock. It's a special form of shock where we add to our fears the fear of becoming disconnected from the world of information. We fear that we will no longer be able to keep up with the kinds of information that are most appealing to us, which have special value in our lives.

However, through the eyes of a computer, it is now possible to read a newspaper or a book, surf the internet and conduct research online, send e-mail to friends, write a book, manage our money and plan for the future. New developments in software and computer hardware make this all possible. But, before we can take advantage of these new breakthroughs, we often need to overcome a few obstacles.

There is a certain anxiety in moving into a new environment such as computing. The anxiety can be particularly strong if you have never used a computer before. Even long-time users of computers, if they have recently lost most of their vision, are hesitant and may not feel like trying to deal with yet another problem in their lives. But, this is far from a problem--it is an opportunity to get back in the game and perhaps play better than ever. It takes energy, attitude and action, but it is worth it. I can prove it.

Steve Jobs, founder of Apple Computer Inc., employed a wide array of talent when he was developing the new Macintosh Computers. He used his very capable technical staff as well as 5-year-old children and 70-year-old senior citizens to help with the design. Neither the children nor the senior citizens had ever touched a computer before. Within a few months, they were all using computers and impacting the design of a new generation of computers.

If you have never touched a computer before, you're still a good candidate for using computers to connect to a new world of information. The new generation of computers was designed, in part, for those who have never used them before. With a little training, you will be making use of the computer within a few hours. After a few months of using the computer, you will be as smart as anyone.

When I lost most of my vision, now 20/200, I really felt lost since I was a big reader. I am currently the Chief Information Officer of a global company. I was reading about two technical or scientific books each week, for my own enjoyment, and would often read a novel or two each month. Just to keep up with my business, I was reading articles from five to ten different technical journals plus *The New York Times* and the *Wall Street Journal* weekly.

I went from a super speed-reader to zero reading. That lasted about two months. During that time, my wife would read to me from my technical journals and newspapers. It occurred to us, after a while, that she could

**Continued on page 10. . .**

**Electronic Eyes. . .continued from page 9**

make audiotapes of the information I needed for work. That way, I could use my Sony portable tape recorder to listen to the tapes while I was traveling or at the office. I also have a very small Lanier tape recorder I use to dictate things, basically an electronic note taker. I purchased a special Sony recorder with large buttons, from the Columbia Lighthouse for the Blind, which I use to listen to audio books or the tapes my wife makes for me. I can listen through headphones or through an external speaker.

These are all useful tools, but are not enough for me. I have also discovered the existence of software for my computer called ZoomText, which allows me to make everything up to 12 times bigger on my screen/monitor. I bought a very large computer screen, and with the ZoomText software, I can blow up the letters and see enough to navigate my way around the computer. In addition to the larger letters and icons on the screen, my software allows me to read whatever is on the screen. I can create a letter and the computer talks to me as I type. It tells me every letter I type and it can read back to me allowing me to listen to my letter and make sure it is correct.

I signed up for Internet service and can now find the online, interactive version of the *Washington Post*, *The New York Times* and *The Wall Street Journal*, along with NBC, CBS, CNN and all the other news channels. With my software, the computer reads the newspaper to me. I do not have to ask someone to read it; I can do it myself. I can

create email or have email read to me by my computer. By the way, I call my computer Chuck; Chuck will read anything I ask him to read. In fact, Chuck can read in several different voices.

One of the latest improvements in ZoomText is the ability to scan books and documents into the computer. So, I can now feed my articles or even pages from my favorite book into a device, which places them into my computer files. I then ask Chuck to help me find the files and read them to me. My computer can help me dial a phone, write a letter, read almost anything, send and receive email, use my electronic checking and money management software, and otherwise do the things I used to use my eyes for. This keeps me in the game; using my brain, staying on top of things and keeping up to date.

I think that using the eyes of a computer is a good way to create a new life, perhaps a better life. I am more productive than ever before. I have learned how to find the most important information first and to be very efficient in the process. The combination of a smart computer, audiotapes, and a magnification reading machine has put me back in charge of my life.

How do you get started? Start with the audio system. Get a catalogue from the Columbia Lighthouse for the Blind\* and find the Sony recorder for the blind. After you listen to a few good audio books, you will find that listening is one of our most underdeveloped human skills. When you cannot see, you learn to listen to everything. I get more out of audio books than the ones I used to read myself. It is



certainly not as convenient, but it appears to be more effective.

Listening to audio books will make you want to hear more and be more connected to the world of information and knowledge. You may benefit from a counselor who will help you develop the determination and the discipline to rebuild this part of your life. I think most people already have the determination. Most of us, when we lose our vision, get angry enough to fight back. This is a way of fighting back and winning in a big way.

Now that you are ready to move forward, keep your tape recorder with you at all times. I keep mine in a shoulder bag along with my large writing markers, large notepad, audiotapes, white cane, lifesavers, and other junk! For about \$100 per month you can lease a large screen computer, which comes fully loaded with more software than you will ever need, including internet connection software. You can use the magnification software included with Windows XP or you can purchase ZoomText software for about \$150 and create your own Chuck the talking computer; or Betty, or Bill or whatever name you like.

With a little training, you will be connected to the basics and can get access to newspapers and an almost infinite source of reading and listening materials from the Internet and other sources. There you will find educational courses, books, reviews, research, MedScape Medical Information Sites, etc. You will soon find that the fear you may have had of computing has been replaced with a desire to stay connected. In fact, you will have to discipline yourself not to

spend all of your time on the computer or listening to the recorders. Today, you can even connect to your bank and conduct most of your business over the computer. You can trade stock, send email to your favorite doctor at Johns Hopkins and pay bills.

It takes another investment, in the range of \$200, to purchase a scanner that allows you to scan books and articles into your computer. With a scanner, you will have gone about as far as technology takes us today.

However, the future is just around the corner. IBM and others are trying to perfect speech recognition software that will allow you to stay away from the keyboard and just dictate to your computer and it will do the typing. You can command it to set up a letter, then you can dictate the letter, edit it, and send it by email without touching the keyboard.

These electronic eyes and ears are reshaping the way we interact with the world of information and each other. Using these devices is, for our generation, like the car was in the 30's and 40's; you just would not even think about being without automobile technology. As we move through the new century, we will all use computing for more and more purposes. Some of us will use them to see further than we ever thought possible.

\*Lighthouse For The Blind –1-800-829-0500

--Larry Elliot

*Reproduced from a previous MacFacts. Mr. Elliot has formerly served on the Wilmer Advisory Board.*