



Are You AWARE?

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Special Issue on Macular Degeneration

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A Message From Our President,

Anne Yeadon

An estimated 15 million Americans live with macular degeneration – the most common cause of vision loss in the United States. Since we founded VisionAWARE in 2006, our readers and visitors have continually requested information on age-related macular degeneration, or AMD. For this reason, we are pleased to present this comprehensive *Special Issue* on AMD – its causes, types, symptoms, treatments, as well as vision-related rehabilitation services, publications, and associations.

We are especially honored to have Lylas G. Mogk, MD, as this newsletter's guest author. Dr. Mogk, a renowned expert on AMD, is Director of the [Visual Rehabilitation and Research Centers, Henry Ford Health](#)

[System](#) and co-author of [Macular Degeneration: The Complete Guide to Saving and Maximizing Your Sight.](#)

Dr. Mogk is especially skilled in explaining the complexities of AMD in easy-to-understand language. Whether you're concerned about your own vision loss, or are a family member or professional seeking to understand more about AMD, this special issue newsletter contains information that will be of help to you.

If you have additional questions or concerns, or would like to share your personal experiences with AMD as a patient, caregiver, or family member, our team at Vision AWARE would like to hear from you. You can contact me at anne.yeadon@visionaware.org or Maureen Duffy, AWARE's Editorial Director, at maureen.duffy@visionaware.org.

All good wishes, Anne Yeadon

News From VisionAWARE.org

Resource Links In This Issue

In this special edition of Are You AWARE devoted to AMD, you will find a variety of resource links to help you and your family better understand Age-Related Macular Degeneration. Read the informative articles, and then continue learning by perusing these various resources:

- [definitions of medical and anatomical terms](#)
- [publications, organizations, and support groups](#)
- [where to find low vision services](#)
- [where to find vision rehabilitation services](#)

Watch for the **Are You AWARE** September issue that will focus on **Diabetes and Diabetic Retinopathy**. Sign up for all newsletter editions at the [VisionAWARE web site](#).

What is Age-Related Macular Degeneration (AMD)?

Dr. Mogk explains:

"Age-Related Macular Degeneration (AMD) is a gradual, progressive, painless deterioration of the macula, the small area in the center of the retina that gives us our detailed vision. When we look directly at an object to see it as clearly as possible, we are using our macula. Everything else around the object we are seeing with our peripheral retina. The macula gives us detailed vision, for reading for example, and the peripheral retina gives us a large area of vision that

allows us to move through our environment safely. This is why someone with vision loss from macular degeneration may have trouble reading mail or newspapers but have no trouble spotting an object off to the side or walking around, even in unfamiliar places."

Age-related macular degeneration (AMD) is an incurable and progressive retinal eye disease and the leading cause of low vision, severe vision loss, and legal blindness for people aged 60 and older in the United States. [The Macular Degeneration Partnership](#), an online resource for information about AMD, defines and describes AMD as follows:

"Macular degeneration is a progressive eye condition affecting as many as 15 million Americans and millions more around the world. The disease attacks the macula of the eye, where our

sharpest central vision occurs. Although it rarely results in complete blindness, it robs the individual of all but the outermost, peripheral vision, leaving only dim images or black holes at the center of vision. [AMD can] reduce contrast sensitivity and color perception ... [and] destroy the clear, 'straight ahead' central vision necessary for reading, driving, identifying faces, watching television, doing fine detailed work, safely navigating stairs and performing other daily tasks we take for granted. "

To help family members and friends better understand the visual and functional effects of AMD, Macular Degeneration Support has created an online simulation gallery, entitled [Through Our Eyes: How People with AMD See.](#)

What Causes AMD?

Dr. Mogk:

"AMD is currently understood to be caused by a combination of individual factors and environmental exposures. The four individual factors that predispose us to AMD that we cannot control are age, Caucasian race, a variation on a gene that regulates inflammation, and a family history of AMD. The individual factors that we can control include smoking, dietary habits, unprotected sun exposure, and possibly exercise, blood pressure and cholesterol. The environmental exposures that promote AMD and are not generally under our control include smoke, air pollution, sunlight less modulated because of a thinner ozone layer, and insufficient nutrients in our food.

Age and the environmental factors together produce an increased number of free radicals in the macula. Free radicals are unstable molecules that must be neutralized to keep them from causing damage and Mother Nature has provided anti-oxidants in food to neutralize the free radicals. However, when we have too many free radicals and not enough anti-oxidants, damage is done. The first sign of damage in the macula is small white spots called drusen, which the ophthalmologist can see usually before the individual is experiencing vision loss. This initial damage triggers inflammation, which causes more damage, exacerbated by more free radicals, resulting in more inflammation and the cycle continues, eventually scarring the macula and causing central vision loss. "

How Does AMD Affect Vision?

Dr. Mogk explains:

"Since the macula is the only part of the retina that gives us crystal clear, detailed vision, when it is damaged, details – such as the words on this page or a facial expression – become obscured.

Your relative or friend with AMD may not be able to see your eyes, but still makes eye contact because they can see at least the outline of your face and knows where your eyes are. Their eyes also look fine, just like they always did, and their peripheral vision is preserved, so they can walk around with little or no difficulty and may even spot a small dark button dropped on a light rug.

This ability to see a lot but not to see the very thing one is looking at is confusing to others, in part because of our habit of thinking of vision as a choice between the

two alternatives of sight and blindness. Individuals with AMD are in between; they may not have full sight, but they are certainly not blind and never will be.

They have [low vision](#), or an even better description is that they are 'hard of seeing,' a term coined by Dr. Lorraine Marchi, director of the [National Association for Visually Handicapped](#). Like the familiar term 'hard of hearing,' it sounds more manageable and it is more accurate.

In addition, about 20% of individuals with vision loss, from any cause, from time to time see life-like images that they know are not really there.

This phenomenon is named [Charles Bonnet Syndrome](#) (CBS) after the Swiss philosopher who first described it in 1789. The phantom images of CBS are common, pleasant, every day things like

flowers or animals or people and the experience is somewhat like looking at a picture or watching a silent movie in color.

The images are life-like, in full color and they may move but there is no sound, smell, or contact. It's important to know that CBS is related to vision loss, not to loss of mental capacity. "

What Is the Difference Between "Wet" and "Dry" AMD?

There are two types of AMD: "wet" (neovascular) and "dry" (atrophic). It's possible to experience the wet type in one eye and the dry type in the other; in addition, the dry type can progress to wet in approximately 10-15% of cases.

The dry/atrophic type affects approximately 85-90% of individuals with AMD. Its cause is unknown, it tends to

progress more slowly than the wet type, and there is not – as of yet – an approved treatment or cure. In dry AMD, small white or yellowish deposits, called drusen, form on the retina, beneath the macula, causing it to deteriorate or degenerate over time.

The wet/neovascular type affects approximately 10-15% of individuals with AMD, but accounts for approximately 90% of all cases of severe vision loss from the disease. In wet AMD, abnormal blood vessels under the retina begin to grow toward the macula.

Because these new blood vessels are abnormal, they tend to break, bleed, and leak fluid, damaging the macula and causing it to lift up and pull away from its base. This can result in a rapid and severe loss of central vision. Although its cause is unknown, [several new treatments](#) are now available for wet AMD.

You can read more about both types of AMD at [Macular Degeneration International](#), [Macular Degeneration Partnership](#), and [Macular Degeneration Support](#), where you can also view a [retinal photograph of dry AMD and drusen](#) and [a retinal photograph of wet AMD](#) (also called exudative).

What Are the Symptoms of AMD and How Is It Diagnosed?

Symptoms of AMD can include the following:

- Blurred or “fuzzy” vision
- A blank, blurred, gray, or “blind” spot in the center of vision
- Straight lines, such as sentences on a page, appearing wavy or distorted

- Difficulty reading or seeing details in low light levels

To effectively diagnose AMD, most macular specialists recommend the following procedures:

- Distance and near vision [acuity tests](#)
- A [dilated eye \(or fundus\) examination](#), which includes the use of an ophthalmoscope. In a dilated eye examination, it is the pupil that is dilated – not the entire eye. This allows the examiner to see through the pupil to the macula at the inside back wall of the eye. Acuity tests alone may not be sufficient to detect AMD in its early stages.
- A [fluorescein angiography](#) test, if wet AMD is suspected.

- The newer technique of [optical coherence tomography](#) (OCT) may be used to gain a clearer picture of the macula and its supporting layers.
- In addition, an [Amsler Grid](#) test can be used to monitor changes in AMD. The macula is particularly sensitive to horizontal and vertical lines; therefore, waviness, distortion, or missing lines on the grid may be noticed before a change in visual acuity.

Online Amsler Grid tests are available from the [Macular Degeneration Foundation, Inc.](#) and [Macular Degeneration Support](#). Wavy, distorted, missing, or broken lines, or holes or black spots in the grid, as shown here, can indicate the presence of AMD.

Individuals who are over 50 should have a dilated eye examination from an ophthalmologist or optometrist at least

every two years. [The National Eye Institute](#) and [Macular Degeneration Support](#) list and explain additional risk factors, health considerations, and lifestyle recommendations related to AMD.

What Is the Age-Related Eye Disease Study (AREDS)?

[The Age-Related Eye Disease Study \(AREDS\)](#) is a major clinical trial sponsored by the National Eye Institute to:

- Learn more about the history of, and risk factors for, AMD and cataract;
- Evaluate the effect of high doses of antioxidants and zinc on the progression of AMD and cataract.

[Results from the AREDS trial](#) indicated that five years of supplementation with high doses of antioxidant vitamins, copper, and zinc reduced the risk of developing

advanced AMD in 30% of individuals in the study who took the supplements and had already-existing moderate to advanced dry or wet AMD. Macular Degeneration Support provides a [follow-up information sheet about the AREDS results](#) and future AREDS clinical trials.

Dr. Mogk:

"The AREDS formula includes 25 IU of beta carotene (not for smokers), 500 mg of Vitamin C, 400 mg of Vitamin E, 80 mg of Zinc (and 2 mg of Copper to avoid copper deficiency with high zinc intake).

The role of beta-carotene and the high dose of zinc are now being questioned, however, and are currently being re-evaluated in a second AREDS trial that will include lutein, its cousin zeaxanthin, and omega-3 fatty acids.

The inclusion of these three new ingredients in the second AREDS trial is based on research showing that those who eat five or more servings of dark green leafy vegetables, rich in lutein and to a lesser degree zeaxanthin, have significantly less AMD. "

How Can I Learn More About Clinical Trials?

In order to receive approval from the U.S. Food and Drug Administration (FDA), a new drug or treatment must be proven to be both safe and effective by undergoing a rigorous series of controlled unbiased studies.

To prevent bias, neither the patient nor the examiners can know which patients received the actual treatment and which were the untreated (or "control") subjects. These are called "double blind" or "double

masked” studies and usually yield the most reliable results.

The medication is coded and patients are placed at random into either the treatment or control group. When the study is concluded, the code is revealed and it is then possible to determine who received the actual drug and who received the inactive substance, or placebo.

As defined by the U.S. National Institutes of Health, most clinical trials are designated as Phase I, II, or III, based on the questions the study is seeking to answer:

- In **Phase I** clinical trials, researchers test a new drug or treatment in a small group of people (20-80) for the first time to evaluate its safety, determine a safe and effective dosage range, and identify possible side effects.

- In **Phase II** clinical trials, the study drug or treatment is given to a larger group of people (100-300) to determine if it is effective and to further evaluate its safety.
- In **Phase III** studies, the study drug or treatment is given to even larger groups of people (1,000-3,000) to confirm its effectiveness, monitor side effects, compare it to commonly used treatments, and collect information that will allow the drug or treatment to be used safely.
- In **Phase IV** studies, after the Food and Drug Administration has approved the drug, continuing studies will determine additional information, such as the drug's risks, side effects, benefits, and optimal use.

As the incidence of AMD increases, due primarily to the aging of the US population, a number of in-depth studies, clinical trials, and remedial interventions are presently underway. ClinicalTrials.gov is a web site that provides [a searchable list of all current clinical trials related to AMD.](#)

The Macular Degeneration Partnership provides information on clinical trials and links to current clinical trials related to AMD:

[Anti-angiogenic Drug Therapy](#)

[Genetics](#)

[Implantable Miniature Telescope](#)

[Laser for Drusen](#)

[Microstimulation Therapy](#)

[Photodynamic Dye Therapy](#)

[Radiation Therapy](#)

[Rheophoresis](#) (from Macular Degeneration Support)

[Submacular Surgery Trial](#)

[Transpupillary Thermotherapy](#)

What Treatments Are Available for AMD?

Dry AMD

Although there is not – as of yet – an approved treatment or cure for dry AMD, several [clinical trials](#) are in progress, including a new study by [OccuLogix](#) to assess [Rheopheresis](#) as a potential therapy for dry AMD. In addition, the National Eye Institute, the Macular Degeneration Foundation, Inc., [The Macular Degeneration Partnership](#) and [Macular Degeneration Support](#) provide the following recommendations for slowing down, or

preventing the progression of, **both dry and wet AMD:**

- **Diet and weight control:** Studies suggest that eating antioxidant-rich foods such as fresh fruits, dark green leafy vegetables (a good source of lutein) and at least one serving of fish per week may delay the onset or reduce the severity of dry AMD; in addition, obesity may increase the risk for progression to advanced AMD.

- **Nutritional supplements:**

[The National Eye Institute's AREDS trial](#) indicated that supplements containing high doses of antioxidant vitamins, copper, and zinc may reduce the risk of developing advanced AMD by approximately 30%.

Be sure to talk with your doctor before adding any nutritional or vitamin supplements to your diet.

- **Blue Light:** Avoid ultraviolet and blue light (particular light waves that make the sky, or any object, appear blue) as much as possible and wear sunglasses that block blue light. In commercial sunglasses, this is usually in the yellow-orange-amber tints. Macular Degeneration Support provides two online articles about this topic: [Blue Light and Macular Degeneration](#) by Dr. Mogk and [Artificial Lighting and the Blue Light Hazard](#) by Dan Roberts.
- **Control blood pressure:** In the AREDS trial, individuals with hypertension were 1.5 times more likely to have wet AMD than persons without hypertension.

- **Avoid smoking:** If you do smoke, stop – and avoid secondhand smoke as well.

More from Dr. Mogk:

Nutrition: "You may want to eat wolfberries as well, which are the richest source of zeaxanthin. They are available dried in health food stores and on the Internet. Eat a lot of fish and fish oil, or flaxseed oil, rich in omega-3 fatty acids.

Minimize your intake of packaged and processed foods, all of which contain much omega-6 fatty acid. Avoid artificial fats. If you want to eat a cookie, eat a real one rather than a low fat one; just don't eat the whole box. The trans fats that are put into foods to substitute for real fat are not good for you or for your eyes. "

Supplements: "If you have AMD, take supplements. If you don't have AMD and wish to take nutritional supplements, take

a good multiple vitamin/mineral combination with additional lutein and omega-3 fatty acids. The AREDS formula is not recommended for those who don't have macular degeneration because of the high dose of zinc. "

Research: "A number of other studies have shown that intake of fruit, rich in anti-oxidants, and fish and fish oil, rich in omega-3 fatty acids, are associated with lower rates of AMD.

While none of these smaller studies have demonstrated cause and effect, their findings make sense in terms of the current understanding of the process of AMD as involving excess free radicals, insufficient antioxidants, and chronic inflammation.

The environmental factors of smoke, including second hand smoke, air pollution, and sunlight, increase free

radicals and our modern system of food production and packaging is likely to decrease the antioxidant content in our food, and even to increase chronic inflammation. "

Wet AMD

In wet AMD, the choroid (a part of the eye containing blood vessels that nourish the retina) begins to sprout abnormal blood vessels that develop into a cluster under the macula. This process is known as choroidal neovascularization, or CNV.

Because these new blood vessels are abnormal, they tend to break, bleed, and leak fluid under the macula, causing it to lift up and pull away from its base, damaging the fragile photoreceptor cells, which sense and receive light.

This can result in a rapid and severe loss of central vision. Unlike dry AMD, however, a number of treatments are now available for wet AMD. We will discuss several of these treatments for wet AMD next, including the use of anti-angiogenic drugs, photodynamic therapy, macular translocation surgery, and thermal laser photocoagulation.

Anti-Angiogenic Drugs

The study of anti-angiogenic drugs has received considerable attention in ophthalmology and cancer research and is an exciting and promising development in the treatment of wet AMD.

According to [The Macular Degeneration Partnership](#), [angiogenesis](#) is a term used to describe the growth of new blood vessels and plays a crucial role in the normal development of body organs and tissue.

Sometimes, however, excessive and abnormal blood vessel development can occur in diseases such as cancer (tumor growth) and AMD (retinal and macular bleeding). Substances that stop the growth of these excessive blood vessels are called **anti-angiogenic** (anti=against; angio=vessel; genic=development), and **anti-neovascular** (anti=against; neo=new; vascular=blood vessels).

The focus of current anti-angiogenic drug treatments for wet AMD is to reduce the level of a particular protein ([vascular endothelial growth factor](#), or VEGF) that stimulates abnormal blood vessel growth in the retina and macula; thus, these drugs are classified as [anti-VEGF](#) treatments.

At present, these drugs are administered by injection directly into the eye after the surface has been numbed. The needle is very small and is inserted near the corner of

the eye – not the center. During the injection procedure, the doctor will ask the patient to look in the opposite direction to expose the injection site, which also allows the patient to avoid seeing the needle.

The following anti-angiogenic/anti-VEGF drugs are currently in use to treat wet AMD:

Macugen

Macugen was approved for AMD treatment by the U.S. Food and Drug Administration (FDA) in December 2004 and is administered once every six weeks. You can learn more about this drug on the Macugen web site: [“About” Macugen](#).

Lucentis

Lucentis was approved for AMD treatment by the FDA in June 2006 and is administered once every four weeks. Additional clinical trials are underway to

determine the optimal dosing schedule. You can learn more about this drug on the Lucentis web site: [“What Is Lucentis?”](#)

Avastin

Avastin is an anti-VEGF drug that is FDA-approved for intravenous use in colorectal cancer. It is currently used on an “off-label” basis (i.e., via eye injection) to treat wet AMD. At the National Eye Institute, a [clinical trial investigating Avastin and comparing it to Lucentis](#) is underway. You can learn more about this drug at the [Avastin](#) web site.

The Macular Degeneration Partnership provides a [listing of additional drugs](#) with anti-angiogenic properties that are in development as potential treatments for AMD. Most are either in the early laboratory stage or Phase I [clinical trials](#).

AMD Alliance International provides a [summary](#) of all current and proposed treatments for wet and dry AMD.

Photodynamic Therapy:

[Photodynamic therapy \(PDT\)](#) has been approved for AMD treatment by the FDA since April 2000. PDT works as follows: A 10-minute intravenous administration of [Visudyne](#) (a photosensitive drug) is followed by the application of a low-dose, non-thermal (light only) laser to the affected area of the retina.

The drug circulates throughout the body's blood vessels, and is particularly attracted to new blood vessels, including the abnormal vessels under the macula. The laser activates the drug, which selectively seals off the leaking blood vessels without damaging the surrounding healthy retinal

tissue. This feature allows PDT to be used directly beneath the center of the macula, unlike thermal (heat) laser photocoagulation, which can burn and destroy normal retinal tissue.

Macular Translocation Surgery:

Dr. Mogk:

[“Macular translocation](#) is a surgery that involves detaching the retina from its base, rotating it slightly, and replacing it in a different position, so that the macula sits on a new, healthy base.

While macular translocation surgery is unlikely to become standard treatment for everyone with wet AMD, it has proven effective for some when done promptly. It does not work for dry AMD because, for reasons not yet understood, the degeneration recurs in the new position. "

Thermal Laser Photocoagulation:

[Thermal laser photocoagulation](#) is a technique used by retinal surgeons to treat a number of eye conditions, one of which is wet AMD. A thermal (heat) laser is directed into the eye at abnormal blood vessels growing beneath the retina. The heat from the laser closes off the unwanted blood vessels, preventing further leakage and vision loss.

Thermal laser photocoagulation does not restore lost vision; therefore, it is critical that treatment be initiated as early as possible in the course of the disease. Unlike PDT, however, thermal laser can also destroy surrounding healthy retinal tissue as it seals the leakage from abnormal blood vessel growth; therefore, it is not used on vessels directly under the center of the macula.

How Does a Person Cope with Vision Loss from AMD?

Dr. Mogk:

"Individuals with new vision loss are at high risk for depression. It is important to recognize, however, that the depression with vision loss does not correlate to how much vision is lost. Instead, it correlates to how many daily activities are affected.

This means that as soon as you are having trouble doing any of your daily activities, it's essential not to give them up but rather to find out about the strategies, adaptations, devices and resources of vision rehabilitation that will empower you to doing your activities.

Learning what you need to know to stay active is your best defense against depression and depression is the real enemy. You can learn to live fully with vision loss but you cannot live fully with

depression.

Staying active with vision loss means learning new skills and it also means taking a few social risks and cultivating your sense of humor.

My father, who had advanced wet AMD, occasionally asked a mannequin in the department store for directions, took the wrong bus, walked past a friend without recognizing him, or hugged a stranger, but that didn't cost him his dignity or his friends.

A woman in his support group who was great cook told about serving a cherry pie to dinner guests which turned out to be made out of kidney beans because she had mixed up the cans. 'We all had a good laugh about that,' she said, and her friends didn't love her any less for it.

Remember that you are not your eyes, that you are much more than your eyes. Your family and friends don't love you because of your eyesight and your value to them, to your community, and to yourself does not fade with fading sight.

You're worth the effort it takes to learn about the skills and resources of vision rehabilitation that will allow you to continue to live fully in spite of vision loss and the sponsors of this wonderful web site are here to help you do that. "

General Information and Resources

Are There Other Vision-Related Rehabilitation Services for Adults with AMD?

Although there is not – as of yet – a cure for AMD, vision-related rehabilitation services and assistive devices can help individuals with AMD to use their remaining vision safely and effectively.

Visit the following links from [VisionAWARE](#) to learn more about eye conditions, vision-related rehabilitation services and professionals, employment issues and concerns, low vision and low vision eye examinations, optical and non-optical low vision devices, eccentric viewing training, and payment options for vision-related rehabilitation:

- [An overview of eye conditions and vision-related rehabilitation services and professionals](#)
- [Resources for vision-related rehabilitation products and services](#)
- [Employment and workplace adaptations for adults who are blind or have low vision](#)

Medical and Anatomical Definitions and Illustrations

To help family members and friends better understand the visual and functional effects of AMD, Macular Degeneration Support has created an online simulation gallery, entitled [Through Our Eyes: How People with AMD See.](#)

Read more about the topic of [low vision, blindness, and visual acuity.](#) For a definition of medical and anatomical terms, see VisionAWARE's [Glossary](#) or go to the MedTerms web site and read these articles:

- [atrophy](#)
- [central vision](#)
- [choroid](#)
- [contrast sensitivity and color perception](#)

- drusen
- exudative
- lutein
- macula of the eye
- neovascular
- omega-3 fatty acids
- ophthalmoscope
- peripheral vision
- phase of clinical trial
- photoreceptor cells
- photosensitive

- [placebo](#)
- [pupil](#)
- [retina](#)
- [zeaxanthin](#)

Eye Care and Low Vision Services

- [Finding the type of eye care professional who is right for you](#)
- [The difference between a vision screening and an eye examination](#)
- [What is a low vision examination?](#)
- [How does AMD affect everyday activities?](#)
- [What are low vision optical devices?](#)

- [What are low vision non-optical devices?](#)

What is [eccentric viewing training](#)? (from Vision World Wide, Inc. and Macular Degeneration Support)

- [What is a closed-circuit television \(CCTV\)?](#)
- [Does Medicare provide funding for vision-related rehabilitation?](#)

Vision-Related Rehabilitation Services and Resources

- [An explanation of vision-related rehabilitation and services](#)
- [The types of professionals who provide vision-related rehabilitation services](#)

- [How do I pay for vision-related rehabilitation services?](#)
- [Reading and writing products and services for adults who are blind or have low vision](#)
- [Self-help and support groups for adults who are blind or have low vision](#)

Also, be sure to visit [VisionAWARE's](#) Question & Answer links for more information on [Personal Self-Care](#), [Home Management](#), and [Home Modifications](#).

Publications, Organizations, and Support Services for Adults with AMD

Since increasing numbers of adults and older adults experience various forms of AMD, there are many consumer groups, online forums, and publications that provide

ongoing information, resources, and support:

Books

[Macular Degeneration: The Complete Guide to Saving and Maximizing Your Sight](#)

Lylas G. Mogk, M.D. and Marja Mogk, Ph.D.

[The First Year: Age-Related Macular Degeneration: An Essential Guide for the Newly Diagnosed](#)

Daniel L. Roberts

[Living Well with Macular Degeneration: Practical Tips and Essential Information](#)

Bruce P. Rosenthal, O.D. and Kate Kelly

Major associations by and for people with macular degeneration

[AMD Alliance International](#)

Provides a [summary](#) of all current and proposed treatments for wet and dry AMD, in addition to information on early detection, timely treatment, comprehensive rehabilitation and support services, and prevention strategies.

[The American Macular Degeneration Foundation](#)

Works for the prevention, treatment, and cure of macular degeneration through raising funds, educating the public, and supporting scientific research. Publishes “[In the Spotlight](#),” a quarterly newsletter that is provided for a \$25.00 donation to the Foundation.

[American Society of Retina Specialists](#)

Provides the [Find A Retina Specialist](#) online search tool

[The Association for Macular Diseases](#)

Home of The Association for Macular Diseases and The Macula Foundation, Inc. The Association publishes "[Eyes Only](#)," a quarterly newsletter with updates on medical advances and research in macular diseases. The Macula Foundation, Inc. supports basic and clinical research in vitreous, retinal and macular diseases.

[MacDegen.com](#)

Provides the latest scientific information regarding the prevention and treatment of

macular degeneration through [MacDegenTM Science](#), a monthly electronic newsletter.

Macular Degeneration Foundation, Inc.

A non-profit organization, founded by an AMD patient to inform consumers and support research. Publishes “[The Magnifier](#),” a free newsletter distributed via email and regular mail that highlights breaking news, clinical trials, and Internet resources.

Macular Degeneration International

Provides [a quarterly report](#) with research updates and information about clinical trials and seminars throughout the country.

Macular Degeneration Partnership

Publishes a [monthly online newsletter and e-mail subscription service](#). Provides information and resources on experimental treatments, clinical trials, and macular degeneration resources, as well a [free AMD Toolkit](#), which contains a large print information packet on AMD, low vision rehabilitation, nutrition, and a magnetic Amsler Grid.

Macular Degeneration Support

Provides information and publications on AMD and medical advances, an Internet support group, a [transportation database and search function](#), extensive online resources, and a public awareness program to reach individuals who are without Internet access.

AMD News From Around the Web

Drug That Treats AMD May Increase Stroke Risk

Use of [Genentech's](#) new eye drug, [Lucentis](#), might increase the [risk of stroke](#), according to a letter the company has begun sending to doctors. In the letter, Genentech stated that interim data from a clinical trial indicated that 1.2 % of patients treated with the recommended higher dosage of Lucentis had suffered strokes – compared with 0.3 % of patients treated with a lower dosage of the drug.

The difference is considered statistically significant. Approved to treat AMD, Lucentis is the first drug shown in clinical trials to improve eyesight for a significant number of patients, as opposed to merely slowing the rate of vision loss. You can read more

about the Lucentis study in [The New York Times](#).

Sensory Arts & Science Receives U.S. Patent 7,166,079 for MacScope, an Early Detection Method for AMD

[Sensory Arts & Science](#) recently announced that the United States Patent and Trademark Office issued a patent for its MacScope method and technology. The MacScope is a computer-based screening method for identifying the presence of irregularities in the macula. The patent, entitled “Methods and Apparatus for Observing and Recording Irregularities of the Macula and Nearby Retinal Field,” was issued on January 23, 2007.

The MacScope is currently being tested in a multi-center clinical trial in the Philadelphia area in order to determine its effectiveness

in detecting early stage AMD. Further study will determine if additional eye pathologies can be detected with the MacScope, such as diabetic retinopathy. You can read more about this new AMD technology [here](#).

Update on Stem Cell Transplants for AMD

AMD targets a protective lining inside the eye, called the [retinal pigment epithelium](#) (RPE), which provides nutrients to the [photoreceptor cells](#) and is vital for their survival. A transplant of fresh RPE tissue could rescue dying photoreceptors, but this approach is neither practical nor feasible for the millions of Americans who show signs of early AMD; thus, scientists at the biotechnology firm [Advanced Cell Technology](#) have attempted to generate a more abundant and reliable source of RPE cells.

In 2004, they devised a way to transform embryonic stem cells into transplantable RPE tissue and, in a follow-up experiment, injected the transformed cells/new tissue into the eyes of rats with a genetic defect in their RPE cells. As reported in the [September 2006 issue of Cloning and Stem Cells](#), the rats receiving the treatment were able to track stripes on a rotating cylinder twice as well as those that did not. You can read more about this embryonic stem cell research in [Scientific American](#).

Educational Video About AMD and Low Vision Increases Knowledge but Not Behavior

An educational and motivational video, designed to increase subjective emotional well being and the use of adaptive devices

by patients with AMD, did increase knowledge but did not change behavior or emotions, said [Schepens Eye Research Institute scientists](#) in a study reported in the March issue of [Optometry & Vision Science](#).

“While our video succeeded in increasing patients’ knowledge of macular degeneration and the availability of adaptive devices and techniques, it did not change their emotional response to their disease or motivate them to make changes that could improve their quality of life,” said Dr. Eli Peli, senior scientist at Schepens and senior author of the study. You can read more about the video and study at [Newswise](#).

“Vision Loss,” Not “Blindness”

Until last fall, according to Dan Roberts, director of Macular Degeneration Support and author of [The First Year: Age-Related Macular Degeneration](#), a major portion of media releases about AMD included statements such as “AMD is the leading cause of blindness among senior citizens.”

After researching the issue and initiating a publicity campaign, Roberts now reports that a majority of press releases and media broadcasts are now using the term “vision loss.” Roberts, who has AMD, spent five months tracking public articles and news broadcasts about AMD on the Internet. In November 2006, he discovered that 58% used the word “blind” to describe AMD. As of March 2007, he reported that usage of “blind” had dropped to 42%, with the trend continuing downward. His poll is described

in the online presentation [How Blind Is Blind?](#). You can read more about his research [here](#).

Rheopheresis Treatment for Dry AMD – an Update

[OccuLogix](#) has announced a new clinical trial to assess Rheopheresis as a potential therapy for dry AMD. The new study, called RHEO-AMD, is designed to evaluate the safety and efficacy of the RHEO™ procedure in patients with intermediate-to-late stage dry AMD. If successful, OccuLogix is expected to apply to the FDA for approval to market its RHEO™ system in the US.

Although the procedure is available in Canada and Germany, it is not approved for AMD treatment in the US. The trial will take place at up to 25 sites; researchers will

also evaluate patients' responses to a questionnaire that evaluates the impact of AMD upon daily living tasks. You can read more about the RHEO™ procedure at the [Rheo web site](#) and at [Macular Degeneration Support](#).

Fact Of The Day

“AMD signs are present in about 14% of people aged 55 – 64, 20% of those aged 65 – 75, and up to 37% of people over age 75. It is more common in women and in people with blue eyes.”

(Source: Macular Degeneration Partnership)

Thought For The Day

“One doesn’t discover new lands without consenting to lose sight of the shore for a very long time.”

~ [André Gide](#)

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