



THE MAGNIFIER

Macular Degeneration Foundation
P.O. Box 531313
Henderson, Nevada 89053

FREE MATTER FOR THE BLIND

Macular
Degeneration
Foundation

The Magnifier

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Book on CD

A recorded copy of "Macular Degeneration, 'The Complete Guide to Saving and Maximizing Your Sight', by Lylas G Mogk, M.D. is now available on CD.

Sight Into Sound is making it available upon request.

Call 713-622-2767 or email carol.pierce@sightintosound.org

Free DVD

Hallucinations:
Am I going
Crazy?

AMD and
Charles Bonnet
Syndrome.
DVD available
on request with
detailed informa-
tion! Call:
888-633-3937

Special Edition:

I Was Just Diagnosed With Macular Degeneration ... What Should I Do?

**Joe Fontenot MD, CLVT - Medical Director
Community Services for Vision Rehabilitation**

You have just been told by your eye doctor that you have age-related macular degeneration (AMD).

What should you do?

First, don't panic! Most (85%) of cases of age-related macular degeneration (ARMD) are the so-called "dry" or atrophic variety, and tend to progress slowly. The other 15%, the "wet" or exudative type, has bleeding and growth of new blood ves-

sels inside the eye. This more aggressive form of ARMD can now be treated. For the last 10 years treatment in the form of "anti-VEGF" or anti vascular endothelial growth factor drugs have helped slow down the progression of this previously untreatable condition.

Although not a complete cure, the anti-VEGF drugs do slow the progression of the disease and usually keep vision loss from being very severe.

Clinical Trial Information

Nat'l Eye
Institute
800-411-1222 or
www.nei.nih.gov

Clinical trials have guidelines called "inclusion" and "exclusion" criteria. These criteria (age, gender, type and stage of disease, etc.) keep participants safe and ensure researchers will be able to answer the questions they plan to study.

Single-Injection Gene Therapy

By Katrin Long

A new gene therapy that could revolutionize treatment of a severe type of macular degeneration has been developed by scientists at the Lions Eye Institute and University of Western Australia.

In a medical research first for Australia, scientists using gene therapy have developed a way to replace invasive monthly injections of preventative drugs with a single injection.

The injection contains a modified and harmless version of a virus containing a gene that stops the condition.

After the Perth trial, multi-centre studies will be run in the United States and US Food and Drug Administration approval will be sought.

Resource Consultant

For assistance identifying agencies in a specific area, call

Dan Roberts
Resource Consultant

toll free at:
1-888-866-6148

Resources

NFB Newsline
866-504-7300

Choice Magazine
Listening
888-724-6423

National Library
Service
888-657-7273
(Books on Tape)

Free Low Vision
Catalogs and
Independent
Living Catalog
800-537-2118

Maxi Aids
800-522-6294

Enhanced Vision
888-811-3161

EyeSmart
<http://www.get-eyesmart.org/eyesmart>

Total Blindness is Rare with ARMD

Another reason to not panic is that if your only vision problem is ARMD, it is very unlikely that you will go totally blind. Your vision probably will slowly get worse, and you may have to give up driving and reading normally. However it is rare to have total blindness, not being able to tell night from day and needing a white-tipped cane or guide dog. Peripheral vision is almost always retained, enabling you to find your way around familiar surroundings and, with some help, even in unfamiliar places.

The same is not true of glaucoma, diabetic eye disease and retinitis pigmentosa. In these diseases, total loss may occur. But with ARMD alone, it is rare.

So, What Should I Do?

First, do what your doctor says. If recommended that you see a retina specialist, do so. If recommended that you return every 6 months, do likewise. Even if treatment is not recommended initially, you still might benefit from active treatment later on.

Your doctor may recommend several general health measures to slow down the progression of ARMD. These may include:

Stop smoking. If you have ARMD and smoke, you are much more likely to have rapid progression of vision loss and develop the more aggressive "wet" form.



Control other risk factors such as high blood pressure, high cholesterol and poor diet. These do predispose to ARMD and may increase the rate of progression.

Supplements: The doctor may prescribe certain types of vitamins shown to slow progression of ARMD.

Exclusive Online Videos Featuring World's Leading Eye Researchers



Dr. David Seftel, Director of Research Development for the Macular Degeneration Foundation, is interviewing the world's foremost scientists and medical practitioners who are actively investigating cures and treatments

for Macular Degeneration and related eye diseases.

Visit **MacularNews.org** for the latest news and register to receive an email notice when new videos are first posted.

Donations

The Macular Degeneration Foundation, Inc. is a tax-exempt, non-profit organization.

Please visit our website at eyesight.org to make a tax deductible donation.

Checks may be mailed to:

Macular Degeneration
Foundation, Inc.,
P.O. Box 531313,
Henderson, NV 89053

Call: 888-633-3937 (USA)
Call: 702-450-2908 (Intl)
Email: liz@eyesight.org

Disclaimer - Articles in the Magnifier are for information only and are not an endorsement by the Macular Degeneration Foundation editorial staff.

Organizations That Can Help

National Eye
Institute
800-411-1222
www.nei.nih.gov

AMD Alliance
amdalliance.org
416-486-2500
x-7505

Association for
Macular Diseases
212-605-3719
macula.org

Foundation
Fighting Blindness
888-394-3937
blindness.org

MD Partnership
888-430-9898
amd.org

Prevent Blindness
America
800-331-2020
preventblindness.org

Macula Research
Foundation
610-668-6705
mvrf.org

MD Support
816-761-7080
Mdsupport.org

EARS
Free Tapes to
live life with confi-
dence and dignity.
800-843-6816

Definitions

Ophthalmologist

a practitioner in the medical science of surgery and care of the eye and its related structures. An M.D. degree is required.

Retina specialist

a medical doctor trained as an ophthalmologist, who has received additional training in diseases and surgery of the retina and vitreous.

Optometrist

a degreed (O.D.), independent, primary health care provider skilled in the co-management of eye health and vision care, including examination, diagnosis, treatment, management of diseases/disorders, prescription of eyeglasses/contact lenses, and provision of low vision aids and therapy.

Optician

a person who designs or manufactures ophthalmic appliances or optical instruments ("ophthalmic optician") or deals in prescriptions ("dispensing optician").

What Can I Do After Obtaining This Information?

Keep up to date. **Consider joining a low vision support group**

Periodically **revisit the recommended online resources** for any new developments

Remember to **keep eye doctor appointments** as recommended or at least once a year

Summary

If told you have ARMD, don't panic. ARMD is a chronic, usually slowly progressive disease that rarely causes total blindness

Treatment is now available for the more severe forms of the disease

Resources, aids, devices and training are available to help maintain function and independence. Use them!

Search and obtain information early to reduce anxiety and make adaptation quick and easy if vision loss occurs or progresses. **BE PREPARED!**

By doing the above, you are much less likely to panic, become depressed and lose valuable time and function if vision loss progresses. Follow the Boy Scout's motto and **BE Prepared!**

Credits

This "Resource" Issue of THE MAGNIFIER was made possible by Dr. Joe Fontenot (**Community Services for Vision Rehabilitation**) and Mr. Dan Roberts (**MD Support**). Each of these directors have our deepest appreciation and respect for what they do on a day-to-day basis and we encourage you to save this and other issues of THE MAGNIFIER for future reference.

Eat green leafy vegetables that contain lutein and zeaxanthine. These may improve visual function and possibly prevent worsening of vision.

Wear sunglasses with ultraviolet (UV) blocking and a hat with a brim when outdoors.



Amsler Grid: The doctor may recommend that you check your vision regularly by looking at an Amsler grid. This is a small chart with a grid pattern with a dot in the center. You check each eye separately by looking at the dot and noticing the grid pattern surrounding the dot. If you have ARMD, some part of the grid pattern will be absent or distorted. If this gets worse or abnormal in new areas, you need to let your doctor know.

How to Prepare for Vision Loss?

Even if your vision changes are mild, and even if you are still reading and driving, you should accept the fact that with ARMD gradual decrease in vision is very common. You want to know what to do if this happens, and not be suddenly shocked to find that you cannot read or use your computer. So, find out what can be done early.

* Ask your doctor for local resources such as low vision clinics or other low vision services and visit them. These may help you be able to continue doing the things you need or want to be able to do without interruption if your vision worsens.

* Seek information from reliable sources on-line, in print or by telephone. There are many reliable sources of information and advice about the many magnifiers, computer adaptations and training that will allow you to continue to function and even work. Unfortunately, there are also some unreliable sources and even some that attempt to take advantage of desperate people and sell them things that will not help.

MD Support and Prevent Blindness America Establish New On-Line Resource

The new resource provides an extensive list of searchable resource directories, a database of 1,500 municipal paratransit services, a library of self-help guides and workbooks, and up-to-the-minute news.

This marks the first time in Internet history that two major organizations have joined in such a dramatic way to bring both education and support to the entire global low vision community.

See lowvision.preventblindness.org or mdsupport.org

Are You Missing Out on Benefits?

April Issue of AARP by Joan Rattner Hellman

If you're struggling to pay for health care, food, or utilities, help may be closer than you realize.

Older Americans miss out on more than \$20 billion worth of benefits every year. A nationwide campaign launched by the National Council on Aging and the National Association of Area Agencies on Aging aims to help older adults learn about two easily accessed resources that can connect them to needed support.

BenefitsCheckUp (benefitscheckup.org)

Eldercare Locator (1-800-677-1116 or eldercare.gov)

What Are Some Reliable Sources of information?

A local low vision rehabilitation clinic if recommended by your eye doctor or one of the resources below

The Macular Degeneration Foundation.
Phone (888) 633-3937 and web site www.eyesight.org

MD Support at www.MDSupport.org or (888) 866-6148 or director@mdsupport.org

The American Academy of Ophthalmology "Eye Smart" at www.geteyesmart.org

The American Foundation for the Blind at www.afb.org or (212) 502-7615 or communications@afb.net

The American Council of the Blind at Phone: (202) 467-5081 or (800) 424-8666 or info@acb.org

The National Federation of the Blind at www.nfb.org

Lighthouse International: "Help Near You" at www.visionconnection.org or 1-800-829-0500

Books About Macular Degeneration

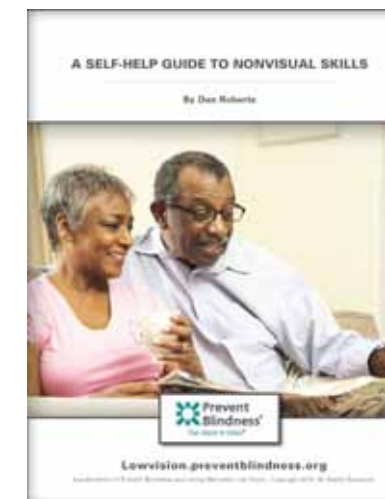
"Macular Degeneration: The Complete Guide to Saving and Maximizing Your Sight" by Lylas Mogk MD is available in hard copy, paperback or as an E-book from Amazon. This is an excellent comprehensive book on all aspects of macular degeneration and vision rehabilitation.

"The First Year-Age Related Macular Degeneration" by Dan Roberts, who hosts the web site "MDSupprt" discussed adaptation and events in early macular degeneration.

Caring for the Visually Impaired



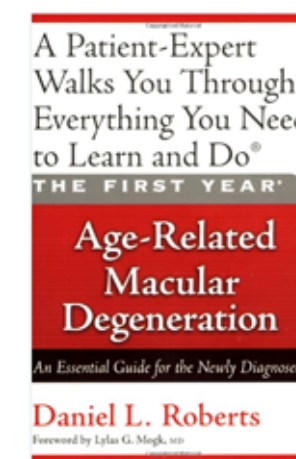
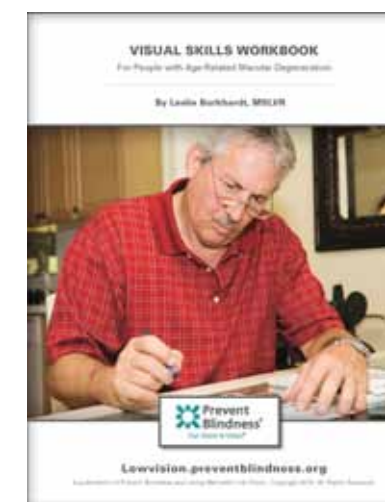
Self-Help Guide to Nonvisual Skills



Reflections, Poetry & Humor



Visual Skills Workbook



The books shown above are available for Free in various forms at **LowVision.PreventBlindness.org** or by calling 1-800-331-2020 x-6018

The 352 page book "The First Year: Age-Related Macular Degeneration" is available for purchase from **Amazon.com** and free on audio tape from **www.loc.gov/nls** to qualified persons

TALKING BOOKS

The National Library Service provides qualifying individuals a bimonthly large print catalog of recorded books and magazine at no charge.

Patrons may order talking books by contacting their local cooperating library. Contact information is online at www.loc.gov/nls/find.html

You may also call our Resource Service Consultant, Dan Roberts, at 1-888-866-6148 to locate the library contact phone number for your state.

AUDIO NEWSLETTER

You may also listen to this newsletter online at **MacularNews.org**