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.

Free DVD

Hallucinations: Am I going Crazy?

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

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

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 vessels 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.
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.

Disclaimers - Articles in the Magnifier are for information only and are not an endorsement by the Macular Degeneration Foundation editorial staff.
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 you 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.
Are You Missing Out on Benefits?

If you are 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

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 “MDSupport” discussed adaptation and events in early macular degeneration.

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.