MACULAR DEGENERATION CENTER

INSIGHT

WINTER 2002

CASEY EYE INSTITUTE

Casey photographer Chris Howell uses Optical Coherence Tomography, a new way to visualize the retina.

A Reason For Hope

Thanks to recent breakthroughs and aggressive research, better cures for macular degeneration are in sight

Just three years ago, patients diagnosed with age-related macular degeneration (AMD) had little or no options for treatment. Most patients with this debilitating disease were not even candidates for the only clinically proven therapy at the time, laser photocoagulation.

Since then, the door has opened wider to better diagnosis, prevention and treatment. Not only have significant breakthroughs recently emerged, but medical science is perched on the threshold of other promising discoveries. For the millions of people worldwide who struggle with AMD, hope is on the horizon. At the Casey Eye Institute, researchers from a wide range of disciplines, including retina specialists, geneticists, ocular pathologists and cell biologists, are tackling the disease on every possible front.

Here is a look at recent advances in AMD diagnosis, research and treatment:

Diagnostic Tools

Indocyanine green angiography (ICG): This photographic method of evaluating the retina gives Casey ophthalmologists added information to the widely used fluorescein angiography (FA). In both procedures, a colored dye is injected in a vein in the patient's arm, eventually reaching vessels in the eye. A series of photographs is then taken of the back of the eyes to highlight abnormal blood vessels or leakage in wet AMD. The special properties of the dye in ICG enable an

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INSIDE

OHSU

infrared light to see into the deeper choroid layer, which is photographed by a special digital camera.

Optical Coherence Tomography (OCT): The OCT combines the principles of ultrasound and x-ray to produce a cross-sectional view of the retina. This tool helps guide treatment for many macular diseases, including wet AMD.

Prevention And Treatment

Drug Therapy: The use of anti-angiogenic drugs to treat wet age-related macular degeneration holds a great deal of promise. The Casey Eye Institute and other eye centers around the country are actively studying these medications, which are designed to halt the growth of abnormal blood vessels in the eye.

Macugen, an anti-angiogenic drug being tested at Casey, is programmed to block the destruction caused by a certain type of protein called vascular endothelial growth factor, or VEGF (pronounced vej-ef). Growth factors like VEGF encourage abnormal blood vessels to proliferate, explains Dr. Michael Klein, principal investigator of the study. These drugs block VEGF, so that cells no longer receive the message to make new blood vessels. Dr. Klein is also conducting a study of the steroid Anecortave Acetate, which is injected under the lining of the eye.

Anti-angiogenesis studies for wet AMD are not new. However, in the last decade, most of the drugs studied were administered systemically. Because drugs like the anti-VEGF aptimer Macugen are delivered locally in and around the eye, patients can get a more concentrated dose with fewer side effects than if the drug is administered systemically.

Photodynamic Therapy: When the Food and Drug Administration approved this new laser treatment in spring 2000, it was hailed as a major medical breakthrough for wet AMD and the first approved treatment in

Photodynamic therapy, performed here by Dr. Michael Klein, can help many wet AMD patients who are not candidates for conventional laser therapy.

decades. “Photodynamic therapy can help many wet AMD patients who otherwise could not benefit from conventional laser therapy,” notes Dr. Andreas Lauer, a retina specialist at the Casey Eye Institute.

Photodynamic therapy is a two-step procedure in which a light-sensitive drug is injected into a patient’s arm, eventually reaching the eye. The drug is then activated by directing a non-thermal laser beam into the eye. Because a low-intensity laser is used, only abnormal vessels are destroyed, sparing surrounding healthy tissues. Although photodynamic therapy does not restore vision already lost to AMD, it can slow the progression of the disease. This treatment is now available at the Casey Eye Institute, which conducted clinical trials of the drug (verteporfin or Visudyne). Photodynamic therapy is evolving and newer light activated drugs are continuing to be tested. Related research is also underway on technologies to improve PDT and the delivery of other drugs within the body.

Genetics: Altering the expression of a person’s genes to treat, cure, or ultimately prevent disease is no longer the stuff of science fiction. Although gene therapy is in

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its infancy, scientists at Casey and elsewhere are moving closer to identifying the genes responsible for macular degeneration and developing techniques to deliver therapeutic genes to patients' cells.

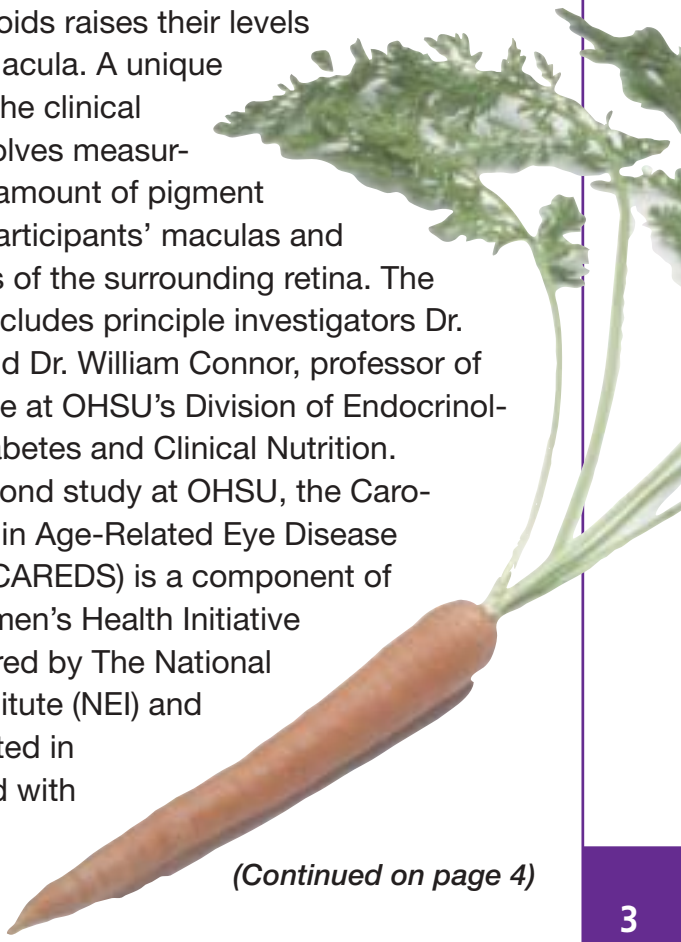
In the Genetics of AMD Study led by Dr. Klein and Dennis Schultz, Ph.D., researchers are analyzing the DNA of more than 100 families affected by the disease. Some promising locations are being found on several different chromosomes that might harbor genes associated with AMD. Four years ago, Casey scientists discovered the location of one macular degeneration gene as well as clues about others. Other research institutions have since confirmed that location, which has intensified even greater efforts to find these AMD genes. The project is complemented by the work of Dr. Tim Stout, a retinal specialist and geneticist at Casey who is conducting basic work on gene therapy and on genes that inhibit blood vessel growth in wet AMD.

Nutritional Supplements: For the first time, the benefits of vitamin therapy for AMD were proven in a landmark study called the Age-Related Eye Disease Study (AREDS). Results of the study, announced a year ago, found that a high dose combination of vitamins C, E, and beta-carotene, along with zinc and copper, could help people at high risk of developing advanced AMD. Faculty members from the Casey were investigators in this long-term trial in cooperation with the Devers Eye Institute at Legacy Health System.

Diet: Does eating all that spinach really stave off AMD? Although still unproven, recent research suggests that the carotenoids lutein and zeaxanthin (pigments found in green, yellow and orange fruits and vegetables) may help protect against macular degeneration. The pigmented compounds, which help maintain healthy cells and tissues in the eye, are concentrated in healthy maculas.

To better understand the role of lutein and zeaxanthin in AMD, OHSU researchers are studying whether eating a diet high in these carotenoids raises their levels in the macula. A unique part of the clinical trial involves measuring the amount of pigment in the participants' maculas and portions of the surrounding retina. The study includes principle investigators Dr. Klein and Dr. William Connor, professor of medicine at OHSU's Division of Endocrinology, Diabetes and Clinical Nutrition.

A second study at OHSU, the Carotenoids in Age-Related Eye Disease Study (CAREDS) is a component of the Women's Health Initiative sponsored by The National Eye Institute (NEI) and conducted in Portland with



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Genetics of Age-Related Macular Degeneration Study

If your family has three or more living blood relatives with macular degeneration, you may be eligible to participate in a research study of genetics and age-related macular degeneration conducted by Casey Eye Institute and supported by the National Eye Institute. Volunteers receive eye photography and DNA analysis at no cost. Tests are performed in your local area with no travel necessary. For more information call Mitchell Schain, study coordinator at 503-494-3064.

Study coordinators Layla Dudley (top) and Debbie Vahrenwald (below) demonstrate a device used to measure macular pigment density.

Kaiser Permanente. This long-term study has tracked the health and lifestyle of participants for 15 years. The ocular portion involves participants answering questions about their sunlight exposure, lifestyle and diet as well as testing their macular pigment levels. These factors, along with smoking and high blood pressure, have been linked to the development of AMD and are being studied further.

Laser for Drusen: Studies are underway to find out if certain types of laser treatments can prevent dry AMD from progressing to the more serious wet form. For example, Dr. Klein and his team at Casey are conducting the Complications of Age-Related Macular Degeneration Trial (CAPT) to learn whether low-intensity laser can prevent vision loss in patients with large drusen in both eyes. Drusen are fatty deposits in the retina that can lead to severe AMD. Sponsored by the National Eye Institute, the study has completed enrollment and will be evaluating patients over the next several years.

Surgery: Surgical techniques are being developed to delicately remove blood and abnormal vessels from the eye in wet AMD. In the Submacular Surgical Trials conducted at Casey by Dr. David Wilson, this procedure was performed to learn if further vision loss could be prevented. Enrollment has also been completed in the study, and patients are being assessed.

Other Experimental Therapies: Transpupillary thermotherapy, rheotherapy and macular translocation are among other treatments being investigated elsewhere for AMD. At this time, they have yet to be clinically proven as effective.

What You Can Do Now

If you are at risk for age-related macular degeneration or have the disease, there are some steps you can take to keep your eyes as healthy as possible:

- Be sure to have an annual dilated exam. Early detection offers the best chance of success with today's treatments.
- Check your Amsler Grid daily to notice subtle changes to your vision.
- Eat a healthy diet with plenty of fruits and leafy vegetables
- Wear sunglasses with UV protection
- Quit smoking
- Exercise regularly, watch your blood pressure and maintain a healthy lifestyle

Hallucinations Not Uncommon Among AMD Patients

Henry*, a retired 75-year old attorney, was visually impaired from age-related macular degeneration. As his sight began to deteriorate over a two-year period, he began to experience unusual visual hallucinations. He told his doctor he would see "people coming and going, dressed in costumes like football or soldier uniforms ... they put on galas, drive vehicles and are very busy outside my house."

Understandably, Henry was disturbed by these images, which disappeared when he blinked his eyes quickly or turned his head. He knew they were figments of his imagination, but hesitated to mention them to others, fearing they were caused by a mental illness.

Henry, whose case is described in the June 2002 issue of the medical journal *Geriatrics*, was experiencing a little discussed but not uncommon condition called Charles Bonnet syndrome. It was named after a Swiss philosopher who described visual hallucinations in his elderly grandfather after cataract surgery in the mid 1700s.

For some patients, the images involve elaborate pictures of people or places, while others might see detailed patterns and lines. "Usually, these visions are not scary," notes Dr. Robert Egan, a neuro-ophthalmologist at the Casey Eye Institute. "Patients are sometimes amused by them," he says, adding that the vivid images often involve people dressed in costumes or animals.

Charles Bonnet syndrome usually occurs in older patients whose vision diminishes relatively quickly, such as from the wet form of age-related macular degeneration. Although patients may be reluctant to discuss these episodes, their physician can reassure them that they're not suffering from a mental disorder, says Dr. Egan, who has had a number of patients with this condition.

At this time, it is uncertain why visual hallucinations develop in people with sight loss. Scientists suspect it may be caused when there is an absence of normal visual impulses to the brain. The brain may "fill in" this void with familiar, stored images, explains Dr. Egan.

There is no cure for Charles Bonnet syndrome, but some patients find relief by knowing it's not a mental disorder that is causing the hallucinations. Generally, these images will disappear after about a year or 18 months. You may also alleviate the condition by altering the circumstances in which the images appear. For example, if the visions tend to appear when it's dark, switch on a light.

"I had one patient who kept seeing a man in his door. When he shut the door, the image disappeared," says Dr. Egan.

For patients especially distressed by the hallucinations, medication may be prescribed. If you are experiencing vivid hallucinations after a decline in vision, talk to your doctor. He or she can give you the reassurance you need and rule out other health problems that may be causing these visual disturbances.

*Name changed to protect confidentiality

Keeping Up With Leal

Sunlight streams into Leal Whittlesey's spacious living room, where the beginning stitches of her latest knitting project lay on the sofa. Next to the knitting needles is one of Leal's favorite gadgets – a lighted magnifier she found at a local needlecraft store.

"I love to knit. I've been doing it all my life," she says, as she demonstrates the hands-free device that enables her to work with greater ease. Three years ago, Leal might have abandoned her favorite hobby when she abruptly experienced vision loss from age-related macular degeneration. "It came on suddenly," says Leal, who was diagnosed with wet AMD, the less common but more severe form of the disease. "I felt I was sunk and didn't know what I was going to do," she says, adding a doctor told her she would no longer be able to live independently.

"I love to knit. I've been doing it all my life."

Her son, who had been a patient at the Casey Eye Institute, recommended she visit the Casey for care. After being assured she would be able to remain in her home of 52 years, Leal regained her confidence and began to learn how to adapt to her visual impairment.

"You've got to get up and do something," says the mother of four grown children. As part of her "can do" attitude, Leal says she will "buy anything that can help me." In addition to her lighted magnifier, her collection of low vision aids includes a talking clock, a talking key chain that tells time (which she uses as a watch) and talking scale. She also has a large print calendar, checkbook and playing cards. An avid bridge player, she's played with some of the same people for 50 years. During games, she sets one lamp on the bridge table and one behind her to help her see. "I can't see faces, but I can see the cards," says Leal, who plays as often as three times a week.

At mealtime, Leal uses a small penlight to help identify the food on her plate. "After I ate a quarter of a lemon one night, I decided I needed to do something," she says, laughing. A video magnifier has also become indispensable.

Leal, who has lived in Portland all her life, often acts as a resource to others facing vision loss. Friends and acquaintances often call on her for helpful tips and recommendations of low vision aids. She also serves on the Advisory Board of the Casey's Macular Degeneration Center and attends low vision support group meetings sponsored by Vision Northwest.

Her main advice to those challenged by visual impairment is to "try to help yourself as best you can." It's apparent that Leal follows her own counsel – and then some.

Low Vision Suggestions From Leal Whittlesey

Talking "Helpers"

- Watches and clocks
- Scales
- Calculator
- Indoor-outdoor thermometer
- Glucometer and blood pressure monitors

Large Print or Oversized

- Calendar
- Television remote
- Telephone with large numbers
- Large print checks (available at banks)
- Playing cards with oversized faces (the cards are normal sized)

Phone

- Call 411 for directory assistance or to have the operator dial for you. This service is free with a physician's verification. Contact Qwest for more information.

Other Tips

- Apply raised buttons on the microwave, furnace, stovetop and washer/dryer – available at stationery stores.
- Video magnifiers or "readers" are marvelous (also known as CCTVs).
- Talking books abd descriptive videos are available from the Oregon State Library, 503-224-0610 or 800-452-0292
- Low vision support groups meet throughout Oregon and Southwest Washington, and are sponsored by Vision Northwest, 503-684-8389 or 800-448-2232.

The following low vision resources compiled by the Macular Degeneration Center may also prove helpful:

Low Vision Rehabilitation Clinic
Casey Eye Institute, OHSU 503-494-3098
Provides low-vision evaluations, training in use of adaptive equipment, counseling for patients and families and prescriptions for adaptive lenses and magnifiers

Oregon Commission for the Blind 503-224-0610 888-202-5463
Assistance and training for employment and activities of daily living – doctor's referral needed

Oregon State Library 503-224-0610 800-452-0292
Talking books and descriptive videos

Vision Northwest 503-684-8389 800-448-2232
Offers vision loss support groups, a specialized retail store and other services

The Macular Degeneration Partnership
On-line only www.amd.org
Coalition of patients & health care providers

LS&S Group 800-468-4789
Catalog of low-vision products

Ann Morris Enterprises 800-454-3175
Catalog of innovative low vision products

Thorndike Large Print Readers Guild
Large print books by mail 800-223-6121

Reader's Digest 800-877-5293
Large-type edition

Descriptive Video Service 800-333-1203
Current VHS videos with narration

Support Macular Degeneration Research

With macular degeneration now recognized as the leading cause of adult new blindness in the United States, there is much that needs to be done. As most patients and their families know, current treatments cannot help everyone and newer methods are urgently needed. The answer lies in research. You have an opportunity to make a real difference by supporting macular degeneration research at the Casey Eye Institute.

How you can help

Donations of any size for macular degeneration research are greatly appreciated. You may send contributions in the enclosed envelope to:

Macular Degeneration
Center Fund
Casey Eye Institute
3375 SW Terwilliger Blvd.
Portland, OR, 97239

For more information, call the Macular Degeneration Center at 503-494-3537

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Editor: Joan Kahn
Designer: Ottley Design Group

This Newsletter is published twice a year by the CEI Macular Degeneration Center at Oregon Health & Science University. Questions or comments are welcome and should be directed to the Macular Degeneration Center Program Coordinator by calling 503-494-3537 or emailing mdc@ohsu.edu.

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