Casey Tests New AMD Treatment Method

Nearly every month, you’ll find Cecilia Tidlund at OHSU Casey Eye Institute, where she has been receiving injectable treatments for wet age-related macular degeneration (AMD), an advanced form of the disease. For patients with active wet AMD like Tidlund, repeated injections of anti-VEGF medications are required to keep her condition under control.

“I’m so grateful to get the injections I can’t tell you,” said the retired business owner, who has been coming to Casey for the past three years and says her vision has stabilized. “When I tell people I get a shot in my eye once a month, they say ‘wow,’” she said.

“In the real world, monthly treatments can be challenging,” acknowledged J. Peter Campbell, M.D., M.P.H., a retina specialist at OHSU Casey Eye Institute. “However, we’re now learning that if we wait longer between injections and don’t treat aggressively in the presence of active disease, we don’t see the initial gains in vision sustained later on.”

The treatment, injected into the eye’s vitreous (the clear substance inside the eye), blocks a protein called vascular endothelial growth factor — or VEGF — that spurs the growth of damaging blood vessels beneath the retina. The primary anti-VEGF medications currently used are ranibizumab (Lucentis), bevacizumab (Avastin) and aflibercept (Eylea).

The good news is that scientists at Casey and elsewhere are exploring innovative alternatives that may ease the burden of frequent injections while still maintaining its beneficial effects.

An Elegant Delivery Device

Casey is one of 50 sites in the U.S. conducting a new clinical trial to test an ocular...
Expo Offers Insight and Encouragement

The Macular Degeneration Center at OHSU Casey Eye Institute hosted its ninth Macular Degeneration and Low Vision Expo this spring – exactly 17 years since its first event was held on April 9, 1999. More than 950 people turned out for this year’s event at the Doubletree-Lloyd Center, which featured talks by Casey’s faculty and its community partners, hands-on exhibits of visual aids and assistive technology, and information about helpful resources. Guests also enjoyed a showcase of works by artists with sight impairment.

“Having macular degeneration or accompanying vision loss can be overwhelming for patients and their families. The goal of the expo is to help people better understand the disease, what’s being done in the lab and clinic, and to find emotional support from others,” said Casey retina specialist Christina Flaxel, M.D., director of the Macular Degeneration Center.

The program opened with presentations by Flaxel and fellow retina specialist Peter Campbell, M.D., M.P.H. The two experts provided a front-seat look at promising advances in macular degeneration, including clinical studies of new treatment approaches and groundbreaking imaging technology. Their talks were followed by a discussion of how lens tints and coatings protect and enhance vision, led by John Boyer, O.D., director of Casey’s Vision Rehabilitation Center. Boyer also highlighted innovations in assistive technology, such as head borne devices and glasses that assist or replace vision.

The morning ended on a high note with the inspirational story of guest speaker Robert Purvis, Ph.D., who described his experience with macular degeneration and his efforts to help others facing the same challenges. “As my vision loss increased, I had a decision to make,” recounted the retired educator, who regularly flies to Portland from his home in Sitka, Alaska for treatment at Casey. “I could continue saying to myself, ‘Why me?’ or I could be thankful for the life challenge and a new opportunity. I consciously chose the latter,” he said.

In the afternoon, attendees
learned about some of the remarkable capabilities of Apple mobile devices for people with visual disabilities. Richard Turner, M.S.W., a program director at the Oregon Commission for the Blind, introduced audiences to the built-in features and apps that can help users with vision loss read, communicate and get around.

Rounding out the day was a session on coping with the emotional and practical consequences of vision loss given by low vision consultant Mary Lee Turner. Using humor and a common sense approach, Turner upended the common notion that diminished sight means losing independence and the ability to live fully.

Watch and/or listen to video recordings of presentations from the 2016 Macular Degeneration and Low Vision Expo at www.caseyamd.com

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implant that slowly releases Lucentis into the eye’s vitreous. The device, about half the size of a dime, is implanted as part of an outpatient surgical procedure. Principal investigator at Casey is Andreas Lauer, M.D., Kenneth C. Swan Professor of Ophthalmology and chief of Casey’s Vitreoretinal Division.

Called LADDER, the Phase 2 study will compare the effects of three different doses of Lucentis to injections of the same drug.

“The study implant is quite elegant,” said Campbell, one of the clinical trial’s investigators. “Essentially it’s a reservoir with a filter at the edge that allows the drug to exit by passive diffusion, allowing for a constant concentrated level in the eye.” Comparing it to a car’s gas tank, the device can be refilled in the clinic in a sterile procedure that may be easier and less uncomfortable than a standard injection, he said. “We do not yet know how long the device may remain active without a refill; that is one of the goals of the study.”

“This method of continuous dosing has the potential to revolutionize the care for patients with wet AMD,” said Lauer. Moreover, if found to be safe and effective, it has great promise for the treatment of other retinal conditions, he said.

For more information about participating in this study, turn to page 6.

Phantom Visions Are Real Aspect of Vision Loss

Three years ago, Rena Tonkin was surprised to see grapes dangling from the trees as she and her daughter drove back to Portland from the Oregon Coast.

That unusual sight was Tonkin’s first experience with Charles Bonnet Syndrome (CBS), a common condition that causes “phantom” visions in people with reduced or poor vision. It is named after an 18th century Swiss philosopher and writer who described how his blind grandfather reported seeing detailed and fanciful patterns, buildings and people.

Tonkin, who has lost eyesight from age-related macular degeneration (AMD), continues to have visual hallucinations, but is no longer frightened by them. “I now see children wearing plaid clothing jumping around in front of me,” she said, joking that her long career in design may have something to do with the images.

Hallucinations from CBS usually pop up from memory and may be the brain’s way of compensating for the loss of visual input it gets from the eye’s photoreceptor cells, explained Thomas Hwang, M.D., a retina specialist at OHSU Casey Eye Institute. Studies show that the syndrome is more prevalent in older people and may affect about 10 to 15 percent of those with low vision. People with CBS may have frequent visual hallucinations at first, which can range from simple repeated patterns to complex images of landscapes, people dressed in elaborate costumes or animals. Over time, they usually taper off and may eventually stop.

Although CBS is physically harmless, it can be
Center Welcomes New Physician

A stunning night photo of Yosemite National Park’s Half Dome sits on the desk in Brandon Lujan, M.D.,’s office at OHSU Casey Eye Institute. Lujan, who recently joined Casey’s Retina faculty and took the photo of the park’s iconic rock formation, said he’s become captivated with night photography because it provides unique views not normally seen.

In a similar vein, Lujan is especially interested in Optical Coherence Tomography — or OCT — because of the uncommon perspective it provides. “OCT offers an unparalleled, three dimensional view of the living retina. For the first time, we can see changes at the cellular level and learn whether a treatment for macular degeneration is working,” said Lujan, who also is medical director of Casey’s Reading Center.

Originally from Minneapolis, Minn., Lujan earned his medical degree from Harvard Medical School, Boston, Mass. and completed his residency at the University of California, San Francisco. Fellowships in medical retina and retinal imaging followed at the Bascom Palmer Eye Institute in Miami, Fla. As medical director of the Reading Center, Lujan will oversee diagnostic imaging services for clinical trials here and nationally, including OCT, OCT angiography, autofluorescence and photography.

Lujan chose the field of ophthalmology because of its potential to greatly improve patients’ quality of life. He currently is seeing adult medical retina patients at Casey’s Marquam Hill and The Dalles locations.

emotionally wearing. Sufferers may be reluctant to tell their doctor or family about their visions because they are embarrassed or fear it is a sign of a mental health problem or dementia. There is no cure for CBS, but talking about it may help, said Hwang.

“Charles Bonnet needs to be talked about, especially to anyone experiencing rapid vision loss. Seeing things just adds to the anxiety of losing eyesight,” said Marja Byers, executive director of Blindskills, a Salem, Ore. organization that serves visually impaired and blind people. Byers said she experienced CBS soon after eye surgery, when she saw bushes, tall grasses and a weeping willow inside a restaurant. “I’m really glad I knew what it was before it happened. It would have been absolutely terrifying,” she said.

When members of Blindskills’ support group bring up CBS at meetings, “others are suddenly confessing that they also are experiencing visions. It’s very common but people don’t want to say anything,” said Byers.

Tonkin’s daughter Cheryl Tonkin also believes that family members need to be clued in about CBS. “It’s important for caregivers and family to know what it is so they can reassure their loved ones and realize it’s not a serious cognitive issue,” she said.

Coping with Charles Bonnet Syndrome

The Royal National Institute of Blind People offers a comprehensive explanation of CBS at http://www.rnib.org.uk Here are a few of their suggestions for making the images fade or disappear:

- Changing your environment may help. Turn on the TV or radio, move around or make the room brighter with lighting or by opening curtains.
- Look directly at the image, move your eyes or blink rapidly.
- Reach out and try to touch the hallucination.
Research at the Macular Degeneration Center

Wet Macular Degeneration

Ocular implant (LADDER Study)

**Purpose:** To compare the effects of an ocular implant that releases one of three different doses of ranibizumab (Lucentis) to injections of ranibizumab. The device releases the drug continuously for a prolonged period of time and can be refilled by your doctor when needed. This approach may decrease the need for frequent injections into the eye. This Phase 2 study is recruiting newly diagnosed wet AMD patients age 50 or older who meet other eligibility criteria.

**Contact:** Ann Lundquist, 503 494-6364

Injectable medication for wet AMD (SEQUOIA Study)

**Purpose:** To compare the safety and effectiveness of the study drug abicipar pegol to ranibizumab (Lucentis) in patients with newly diagnosed wet AMD. Abicipar pegol is an anti-VEGF agent that may be more long lasting than some current therapies for wet AMD. This Phase 3 study will be recruiting patients age 50 or older who have at least one eye with wet AMD that has not been treated. Other eligibility requirements also apply.

**Contact:** Shelley Hanel, 503 494-1986

Dry Macular Degeneration

Lampalizumab for advanced dry AMD

**Purpose:** To evaluate the effectiveness and safety of lampalizumab in patients with geographic atrophy (GA), an advanced form of dry AMD. The medication, given by injection into the eye, targets an enzyme that may encourage dry AMD to develop. The study will examine the change in the area of GA and changes in vision. Enrollment is completed and patients are being followed.

**Contact:** Mitchell Schain, 503 494-3115

Implantable medication for dry AMD (BEACON Study)

**Purpose:** To learn if an implantable medication, Brimonidine, is safe and effective for treating advanced dry AMD. In this Phase 2 study, a tiny pellet is implanted into the eye’s vitreous that releases the medication to the retina over a sustained period of time. Eligible participants must be 55 years or older and have advanced dry AMD in the study eye that results in moderate vision loss, in addition to other eligibility criteria.

**Contact:** Ann Lundquist, 503 494-6364

Gene-based Treatment Shown to be Safe and Well-Tolerated

A Phase 1 study of a gene-based therapy for wet macular degeneration has been found to be safe and well-tolerated – with signs of effectiveness, according to Andreas K. Lauer, M.D., a principal investigator and Kenneth C. Swan Professor of Ophthalmology and chief, Vitreoretinal Division at Casey Eye Institute.

Casey is one of three clinical sites conducting the clinical trial of RetinoStat, in which two genes are delivered to a specific location beneath the retina, where they trigger proteins that block abnormal blood vessel growth in a sustained manner. “This approach may offer a much more long-lasting effect than current therapies, which require repeated injections to stabilize wet AMD,” said Lauer. The study is closed to enrollment and continues to follow participants.
Other studies

Advanced imaging trials
Purpose: To test the capabilities of optical coherence tomography (OCT) angiography in patients with dry or wet AMD. Investigators are studying whether this new version of OCT can visualize and measure blood vessel growth as well as fluorescein angiography, which involves the injection of a contrasting agent to highlight the problem vessels.

Contact: Denny Romfh, 503 494-4351 or Omkar Thaware, 503 494-7398

Genetics of Age-Related Macular Degeneration Study
Purpose: To find genetic mechanisms associated with AMD, which will lead to more accurate early detection and precise treatments. Researchers are using advanced whole genome sequencing technology to find gene variations in large families and other populations affected by AMD. The study is supported in part by a major grant from the National Eye Institute.

Contact: Jennifer Maykoski, 503 494-3064

Association between advanced AMD and alterations in the gut microbiome
Purpose: To learn whether associations exist between gastrointestinal tract gut bacteria and AMD. Researchers will also explore the connection between an individual’s genes and the activity of the gut bacteria. The study is limited to a select group of participants enrolled in the Genetics of Age-Related Macular Degeneration Study.

Contact: Jennifer Maykoski, 503 494-3064

A Note from the Director

For this issue of Insight, our biggest challenge was finding enough space to adequately cover many of the Macular Degeneration Center’s current activities. As you flip through the pages, you will read about a number of promising clinical trials, a new addition to our faculty and the recent Macular Degeneration and Low Vision Expo.

Similarly, our flourishing research, patient care and outreach efforts have prompted the need to expand our physical space. Plans are underway to build a new facility next to Casey Eye Institute’s current structure on Marquam Hill. With ground breaking expected next summer, the enlarged space will enable the center to serve more patients with better options and accelerate discovery.

The Macular Degeneration Center’s remarkable growth and accomplishments are a result of the dedicated and forward-thinking leadership of its founding director, Dr. Michael Klein. Now, after two decades heading this successful program, he is transitioning to an "emeritus" role as I take on the position of director. Although he is stepping back, we are very thankful that he will maintain an active presence at the center, offering guidance and support as we move forward in fighting this disease.

Christina J. Flaxel, M.D.
Director, Macular Degeneration Center
Connect with the Macular Degeneration Center!

Education and outreach is a top priority of Casey Eye Institute's Macular Degeneration Center, a national leader in research and patient care for age-related macular degeneration (AMD). If you'd like to be on our mailing list to receive the Insight newsletter and other information — or have a speaker for your group, please contact the center at 503 494-3537 or at kahnj@ohsu.edu.

Learn more about AMD and the work of the Macular Degeneration Center at www.caseyamd.com