InSIGHT

SPRING | 2023

A PUBLICATION OF THE CASEY EYE INSTITUTE
WOLD FAMILY MACULAR DEGENERATION CENTER

Casey researchers bring new insights, new options for age-related macular degeneration

One hundred years ago, average life expectancy in the U.S. was about 60, and the most common cause of vision loss was cataracts. No one was particularly worried about losing their sight from age-related macular degeneration (AMD), which tends to manifest itself in people over 50. Now that average life expectancy is roughly 76, it's more common for people to lose vision from AMD—and potentially live for 20 or more years. This phenomenon is not confined to the U.S. As the world population ages, and life-expectancy increases, AMD is expected to become even more common, with the number of estimated cases worldwide predicted to reach 288 million by 2040.

"That's why it's so important to improve early detection and develop new treatments," said David Wilson, M.D., former chair and director of OHSU Casey Eye Institute. "People are living with poor vision for many years, and it makes a big impact on their quality of life."

Casey has been at the forefront of AMD research and care for decades, creating increasingly better tools to diagnose and treat AMD. The new Wold Family Macular Degeneration Center is a central hub for the many research and clinical care efforts already underway, and a catalyst for further discovery and innovation by having research, clinical care and clinical trials all in one place.

Dr. Merina Thomas sees patients with retinal diseases, including age-related macular degeneration.

What we do and don't know about AMD

Eye doctors can diagnose AMD when they see small yellow deposits called drusen in the macula. These are relatively common in older patients and usually do not cause significant symptoms. However, having a lot of these drusen increases the risk of developing a more

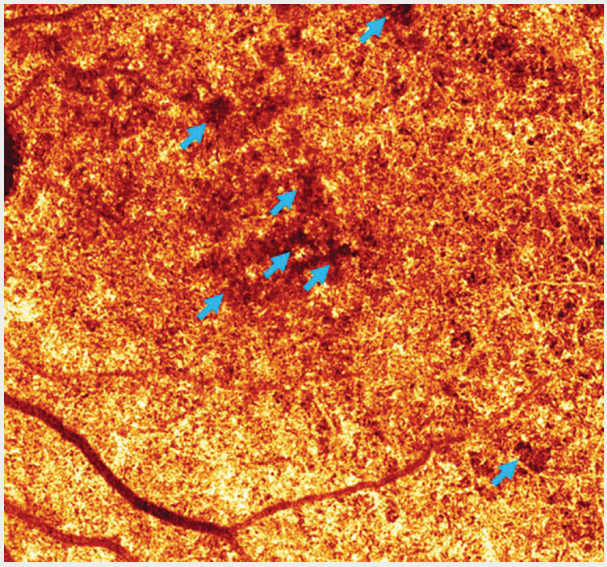
continued

In this issue

4 A note from the director
5 Current research studies
5 New faculty introduction: Benjamin Young, M.D.
6 New treatments
7 Exciting leadership changes
7 Honoring Joan Kahn's contributions

OHSU CASEY EYE *Institute*

Retinal capillaries



Choriocapillaris

Above: A state-of-the-art imaging prototype using optical coherence tomography angiography reveals normal retinal capillaries and choriocapillaris defect (blue arrows) in an eye with dry AMD. The unprecedented capillary details captured with this imaging technology will be very useful to discover the role of choriocapillaris in AMD.

advanced form of AMD, which can cause vision loss. One of those advanced forms is wet AMD, which is caused by the growth of abnormal blood vessels under the retina. This is the most common reason for vision loss, and fortunately, there are effective treatments that slow down and sometimes even reverse vision loss.

Another advanced form is a type of dry AMD called geographic atrophy, which happens when the cells that detect light (called photoreceptors) and the cells that support these photoreceptors die off. Currently, there are no treatments for this type of advanced AMD.

We know that certain lifestyle choices—such as smoking—increase the risk of advanced AMD. A healthy diet rich with fruits, vegetables, and fish has been shown to decrease the risk. For patients who have a lot of drusen, a supplement based on the Age-Related Eye Disease Study 2 (AREDS2) can also decrease the risk of wet AMD.

The Wold Family Macular Degeneration Center is a crucial clinical trial site for a promising treatment for AMD that gained FDA approval in the last year. Learn more about new treatments in the *New Drugs Available to Treat AMD* story on page 6 of this newsletter.

New treatments have the potential to not only slow the progression of AMD, but to also improve patients' quality of life because they could potentially extend the length of time between visits to every four months.

New hope for dry AMD patients

Historically, advanced dry AMD has been harder to treat than wet AMD, but new research could change that. One of the current clinical trials at the Wold Family Macular Degeneration Center is the Gallego study, which is testing a promising new drug designed to preserve retinal integrity and slow disease progression.

Another investigational treatment builds on Casey's experience as a national leader in gene therapy for retinal diseases. Casey is one of the sites conducting

> "Wyoming philanthropist John Wold's generosity, and that of the Wold Foundation, established the Wold Family Macular Degeneration Center that is making it possible for us to speed progress toward a cure."
>
> – **David Wilson, M.D., former chair and director of OHSU Casey Eye Institute**

an international gene therapy study involving surgical treatment for dry AMD. The study entails a procedure in which surgeons replace or augment a gene associated with dry AMD.

In patients with AMD, the cells in the retina start to degenerate and disappear. A research team at Casey is exploring cell-based therapy to restore function, by transplanting cells back into the retina. The research is still in its early stages, but there is reason to be optimistic about this cutting-edge treatment.

Advanced imaging improves diagnosis and treatment

Long heralded as leaders in ophthalmic imaging, Casey is constantly improving its ability to visualize and track changes in areas of the eye affected by AMD. Today's primary tools for detecting AMD are optical coherence tomography (OCT) and OCT angiography, areas where Casey researchers are at the forefront of innovation.

"With OCT angiography, we can detect the onset and progression of wet AMD before fluid leakage occurs. For dry AMD we can visualize the degeneration of the layers in the retina, before vision is affected," said Dr. Huang. "Detecting changes in these layers is key to early diagnosis as well as assessing the effectiveness of potential new drugs to treat dry AMD."

Slow and steady progress

Progress can be slow and painstaking, but today's AMD patients have much better options than they did only 20 years ago.

"I have patients who were in the original studies when I started here, close to 20 years ago, who are still able to see. So that's amazing progress. We have treatment options now that mean people don't have to worry about going completely blind, at least with the wet form of AMD. As long as they can get the injections and can come in, they are often able to maintain their vision, which is amazing," said Christina Flaxel, M.D., Bula Buck Arveson and Charles C. Arveson Professor of Macular Degeneration Research and director of the Wold Family Macular Degeneration Center.

This holds true for dozens of other eye conditions, and underlines the importance of basic science and clinical trials. One small research breakthrough leads to another and, eventually, a meaningful new option for patients.

A personal commitment

Wyoming philanthropist John Wold developed macular degeneration in his early 80s and lived with declining vision until his death at 100. "He had two decades in which his independence was quite limited. He knew first-hand how serious AMD could be," said Dr. Wilson. "His generosity, and that of the Wold Foundation, established the Wold Family Macular Degeneration Center that is making it possible for us to speed progress toward a cure."

Note from the director

Christina Flaxel, M.D.

Bula Buck Arveson and Charles C. Arveson Professor of Macular Degeneration Research; Director of the Wold Family Macular Degeneration Center

Greetings from the Wold Family Macular Degeneration Center. We have lots of good news to report since our last newsletter from 2020. In October of 2022 we celebrated the long-delayed grand opening of our new headquarters, housed inside the new Elks Children's Eye Clinic building. Our beautiful new space makes it possible for research and patient care to happen all in one place, and I'm excited by the potential I see.

> "It's gratifying to look back and realize that I have patients who were in the original studies when I started here, close to 20 years ago, who are still able to see. That's amazing progress."

Our new facility opened for staff and patients in 2020 — right in the middle of the pandemic. Despite the challenges, we were able to maintain uninterrupted care for our patients. Some of our most regular visitors were our macular degeneration patients who receive monthly injections. They overcame many obstacles to keep these appointments, because they knew we were taking maximum safety precautions— and the treatments work.

Casey has participated in research studies for many of the most effective AMD treatments available today, and we're on the cusp of developing even more effective treatments. The Wold Center was a crucial clinical trial site for promising treatments for wet AMD, one of which gained FDA approval in 2022. New treatments have the potential to not only slow the progression of wet AMD, but to also improve our patients' quality of life.

It's gratifying to look back and realize that I have patients who were in the original studies when I started here, close to 20 years ago, who are still able to see. That's amazing progress.

As we head into 2023, I am excited about this new era for research and patient care. Thanks to our brilliant staff and dedicated community of supporters, the prospects for people at risk of and living with AMD are improving every year.

Resources on the web

STAYING INFORMED

- National Eye Institute: www.nei.nih.gov
- American Academy of Ophthalmology: www.aao.org/eye-health
- National Eye Institute events: www.nei.nih.gov/about/news-and-events/events
- Accessible statistic tracker: cvstats.net

STAYING CONNECTED

- American Council of the blind: acb.org

PHYSICAL ACTIVITY

- NW Association of Blind Athletes and Eyes Free Fitness both have workout routines on YouTube
- Down Dog yoga app

SHOPPING

- Store to Door: storetodooroforegon.org
- TriMet Lift Grocery Delivery: trimte.org/lift.delivery

SIGHTED ASSISTANCE

- Be My Eyes: bemyeyes.com
- Aira: aira.io

VIRTUAL MEETINGS

- Guide to Zoom Cloud Meetings from a Blindness Perspective: mosen.org/zoom
- Google Meet: meet.google.com (scroll down the page for link to accessibility features)
- Hadley School for the Blind: hadley.edu/InstructionalVideos

RESEARCH AT THE WOLD FAMILY MACULAR DEGENERATION CENTER

Clinical trials for AMD at Casey Eye Institute

For more information about the following studies contact Jennifer "Scottie" Maykoski
Phone: 503-494-3064

SHORE – A study for treatment-naïve wet AMD
All patients who enroll in this study will receive 2 years of monthly ranibizumab (Lucentis) injections either with or without a second injection of the study drug. The hope is that when combined with ranibizumab, vision will improve more than what is possible with just the VEGF-A inhibitor. Participants must be age 50 or older, be newly diagnosed with wet AMD, not yet treated, and meet additional study criteria. Participation includes monthly visits to Portland for about two years. All transportation arrangements and cost will be covered by the study, as well as cost of study treatment and care.

DAVIO2 – A Study for Subjects with recent diagnosis Wet AMD (CNV)
The purpose of this study is to evaluate the efficacy and safety of an Intravitreal Insert pellet as a sustained release drug delivery system in the treatment of people with wet AMD. The study drug is given as a onetime injection in the eye. Participants will come to Portland monthly for about one year, or up to 17 visits. All transportation costs will be covered by the study, as well as cost of study treatment and care. To be eligible, participants must have received a diagnosis and treatment for CNV within four years and done well after previous treatment with anti-VEGF injections.

HONU – An observational study of progression of intermediate AMD (Drusen)
The purpose of this study is to follow the natural history of the progression of intermediate dry AMD (Drusen) and identify genetic biomarkers for disease. There is no treatment provided as part of this study. Participants will come to Portland every 12 weeks for about three years for a total of 13 scheduled visits. They will receive study specific vision testing, imaging and laboratory testing at no cost. All transportation arrangements and cost will be covered by the study. Participants must be over the age of 50, have early to intermediate dry AMD, and cannot have diabetes or glaucoma.

Welcome Dr. Benjamin Young, who has joined OHSU Casey Eye Institute as a retina specialist.

After completing medical school at Brown University, Dr. Young went to Yale University for residency, followed by the University of Michigan for a fellowship in adult and pediatric vitreoretinal surgery. His research interests include age-related macular degeneration, diabetic retinopathy, and retinopathy of prematurity.

Originally from Omaha, Nebraska, Dr. Young enjoys reading, playing tennis, spending time with his wife, and working on his podcast “Eyes For Ears.”

New drugs available to treat AMD

VABYSMO | FDA approved Jan. 2022, available at OHSU Casey Eye Institute since Oct. 2022

VABYSMO (faricimab-svoa) is a medicine given by injection into the eye to treat adults with wet AMD and diabetic macular edema. It is different from the previously approved drugs, as it does not only target vascular endothelial growth factor (VEGF), but also angiopoietin. It is thought that blocking angiopoietin may make the blood vessels less sensitive to VEGF and lead to better control of the disease. In the studies, some patients were able to go up to 4 months between injections without compromising their vision.

SUSVIMO | FDA approved Oct. 2021

SUSVIMO is a system of long-term medication delivery used to treat adults with wet AMD who have received anti-VGF injections in the past. A reservoir is surgically implanted in the eye and filled with ranibizumab (the same medicine as Lucentis™), allowing a slow release of the medication. In the studies, most patients with the implant did not require any injections before 24 weeks with good visual outcomes. While this is an exciting development, unfortunately, there was a significantly higher complication rate in this group, including infection and bleeding in the eye. While these important safety issues are being worked out, we are not offering this treatment at OHSU at this time outside the clinical trial.

BYOOVIZ and CIMERLI | BYOOVIZ was FDA approved Sept. 2021, commercially available July 2022; CIMERLI was FDA approved Aug., 2022 and became commercially available Oct. 2022

BYOOVIZ and **CIMERLI** are "biosimilar" drugs, designed not only to be molecularly similar to the reference drug—in this case, ranibizumab (Lucentis™)—but also without clinically meaningful difference between itself and the reference drug. They work the same way as ranibizumab, targeting VEGF molecules in wet AMD, slowing down the growth and leakage of blood vessels in the eye. These drugs demonstrated that they work just as well as ranibizumab for wet macular degeneration with comparable side effects.

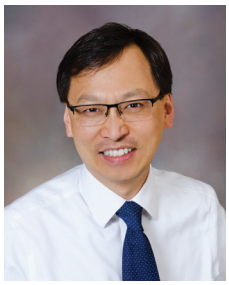
Join the Vision Loss Support Group!

The Vision Loss Support Group held every third Wednesday of the month from 1-2:15 pm, virtually. It is for patients who are experiencing changes to their vision, vision loss or low vision and want to receive additional support and information. Supported by a licensed social worker, the support group is a great place to:

- Connect with others experiencing similar challenges
- Learn about adaptive skills to manage the impact of changes in vision on functioning
- Share your personal story and strategies for dealing with vision loss and changes to vision
- Learn about helpful tools, resources and tips to live life to the fullest from professionals from Casey and the community

Wish to learn more? Contact Tara Albury, MSW, LCSW, at 503-730-5550.

Andreas Lauer, M.D.



Thomas Hwang, M.D.

Christina Flaxel, M.D.

New leadership guides macular degeneration care and research

Since the last issue of InSight in 2020, there have been some exciting changes to the leadership team at OHSU Casey Eye Institute, within the retina division, and in the Wold Family Macular Degeneration Center.

In October 2022, **Andreas Lauer, M.D.**, was appointed director of the Casey Eye Institute, succeeding David Wilson, M.D., who retired in June 2022. Lauer is a professor of ophthalmology and a retina specialist, and a world-renowned surgeon leading the field in gene therapy clinical trials for inherited retinal diseases.

Thomas Hwang, M.D. has stepped into the role as retina division head. Hwang is a professor of ophthalmology and has held other leadership positions within Casey Eye Institute, including serving as the ophthalmology residency program director and vice-chair for education. Hwang is a well-respected, dedicated and accomplished retina specialist, and we are very excited to have him leading the division.

Christina Flaxel, M.D., has also stepped into a leadership role, becoming the director of the Wold Family Macular Degeneration Center in 2021. She is well suited to take the reigns of the center and guide Casey Eye Institute's age-related macular degeneration research into the future. She is an investigator on many basic research studies and clinical trials, and is a dedicated retina specialist with unparalleled experience taking care of patients with medical and surgical diseases of the retina and vitreous.

Celebrating Joan Kahn's contributions

For more than 20 years, Joan Kahn worked as the program coordinator for the Wold Family Macular Degeneration Center at Casey Eye Institute. Though she retired in 2021, we are pleased to have this opportunity to honor her for her many contributions to the center.

Kahn served as an invaluable resource to center directors, starting with Michael Klein. M.D. "Joan's skills and dedication were very instrumental to the success of the Macular Degeneration Center," said Klein. Kahn managed education programs, communications and events for the center, which served as an important educational resource for those with age-related macular degeneration and low vision at Casey Eye Institute and in the community.

Joan Kahn, M.D.

"She has earned our eternal gratitude and appreciation for her tolerance, grace under fire, creativity and journalistic professionalism," said John Boyer, O.D., who worked with Joan on the Low Vision Expo, a free education event held every other year that attracted about 1,000 people.

Joan also assisted the Macular Degeneration Advisory Board, building long-term relationships with members in their joint effort to support the fundraising and educational activities of the center.

"I am so pleased to recognize someone who did so much good for so many Oregonians in need of access to unbiased, science-based facts about macular degeneration," said Boyer.

We wish to extend a heartfelt thank you to Joan for her many years of service research and education at the Wold Family Macular Degeneration Center.

Wold Family Macular Degeneration Center
515 S.W. Campus Dr.
Portland, OR 97239

InSight is published twice a year by the Wold Family Macular Degeneration Center at OHSU. To be added or removed from the mailing list, please call 503-494-3537.

OHSU is an affirmative action, equal opportunity institution. 2/23

Vision rehabilitation services at Casey

There are many tools available to assist you when vision loss impacts your daily life. The Vision Rehabilitation Center offers treatments, education and occupational therapy services for adults and children to make the most of your remaining vision. Call 503-494-3098 to learn more.

Support the Wold Family Macular Degeneration Center

To make a gift, please contact Liz Arrington, Senior Director of Development at the OHSU Foundation: arringtl@ohsu.edu or 503-552-0716

ohsufoundation.org/eye-vision

Wold Family Macular Degeneration Center
OHSU Casey Eye Institute
515 S.W. Campus Dr.
Portland, OR 97034
503-494-3537
www.ohsu.edu/amd