Voice of the patient report

Dry Age-Related Macular Degeneration (AMD) Externally-Led Patient Focused Drug Development Meeting (EL-PFDD)

Meeting held virtually on March 1, 2024, 10 a.m. – 3 p.m. EST

Report date: May 17, 2024

Meeting Organizers

FOUNDATION FIGHTING BLINDNESS

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Dry Age-Related Macular Degeneration (AMD) Voice of the Patient Report

The mission of Foundation Fighting Blindness ("the Foundation") is to fund and drive the research that will lead to preventions, treatments, and vision restoration for the degenerative retinal diseases including retinitis pigmentosa, Usher syndrome, Stargardt disease, Leber congenital amaurosis, and dry AMD. This *Voice of the Patient* report was prepared on behalf of the Foundation as a summary of the input shared by patients living with dry Age-Related Macular Degeneration (AMD) during an Externally-Led Patient Focused Drug Development (EL-PFDD) meeting, conducted virtually on March 1, 2024.

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Consulting Partners were Larry Bauer, RN, MA, and James Valentine, JD, MHS from Hyman, Phelps & McNamara, P.C. (HPM).

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James Valentine, Esq. and Larry Bauer, RN, MA are employed by HPM, a law firm that represents patient advocacy organizations and companies that are developing therapeutics and technologies to advance health. The Foundation contracted Chrystal Palaty, PhD from Metaphase Health Research Consulting Inc. for assistance in writing this report.

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Thank you to the many FDA staff who attended our dry AMD EL-PFDD meeting on March 1, 2024, and who are taking the time to read this report. Thank you to Will Lewallen and Lyna Merzoug, and all others from the FDA's Patient Focused Drug Development Staff who skillfully guided us through this process. We are grateful to have this opportunity to ensure that patient and family perspectives are considered in the drug development and regulatory processes.

Thank you to our speakers, Ms. Tracy Gray from the FDA for sharing your perspectives, Dr. Emily Chew for your excellent clinical overview, and Dr. David Boyer for your presentation on treatments for dry AMD. Your eloquent presentations created a strong foundation for the rest of the day.

Thank you, Larry Bauer and James Valentine from Hyman, Phelps & McNamara P.C., for their expert assistance in planning and moderating our EL-PFDD meeting. Thank you to the Dudley Digital Works media team for all of their work, for the production planning and behind the scenes work that made our meeting a success.

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Thank you to all of our supporters and partner organizations including representatives from advocacy and professional organizations, drug companies, federal agencies, and universities from across the world for attending our meeting. This meeting would not have happened without your help.

Thank you to Apellis, Astellas, and Novartis for generously sponsoring our EL-PFDD meeting. Without you, our meeting and this report would not have been possible.

Our hope is that this meeting will have a lasting impact on the future of dry AMD research and medical product development, to help the millions living with dry AMD who urgently need treatment options.

Disclaimer: Foundation Fighting Blindness recommends that all individuals with dry age-related macular degeneration (AMD) consult their physician before starting or changing their treatments.

Key Dry AMD EL-PFDD Meeting Insights

- Dry age-related macular degeneration (AMD) is a progressive degenerative retinal disease, typically presenting with visual deficits in the central retina (macula). The disease can be caused by both lifestyle and genetic factors; many described how a parent also had dry AMD.
- **AMD is a condition affecting millions globally. In the United States, over 20 million were estimated to be living with the disease in 2019. Due to increasing lifespans, these numbers are expected to increase in the future.**
- Most living with dry AMD experience difficulties seeing in low light conditions, blurry/obstructed central vision, and eventually, severe vision loss. Individuals living with dry AMD can experience light sensitivity, flashes, visual distortions, and even visual hallucinations.
- Dry AMD has a heavy disease burden. Along with their vision, those living with dry AMD lose many important activities of life, which can impact identity. Many describe their life "before" and "after" dry AMD. As they lose the ability to recognize familiar faces, drive, read, watch TV, or use screens, they become increasingly dependent on others.
- Many living with dry AMD feel anxious and depressed as a result of their progressive vision loss and experience social isolation, and loneliness. They have many worries about the further loss of their independence, how the disease will progress, and losing more of their abilities and activities as their vision decreases.
- Until recently, most diagnosed with dry AMD were offered no treatment options except vitamins. Despite the very recent approval of two FDA-approved therapies for dry AMD, there is still a tremendous unmet medical need for treatment to stop the progression of dry AMD. Those living with dry AMD must rely on devices/technologies, adaptive strategies, and assistance from others. None of these approaches replaces vision.
- In the absence of a cure, individuals living with dry AMD want to stop or slow disease progression and vision loss. They need more effective ways to measure progression and treatment to address flashes. They highlighted the importance of earlier testing, more opportunities to participate in studies, and an acceleration of the drug development and approval process. Some want more public awareness about dry AMD.

Contents

Clinical Summary of Dry AMD[1]

What is dry age-related macular degeneration?

Age-related macular degeneration (AMD) is a progressive degenerative retinal disease, which typically presents with visual deficits in the central retina (macula). AMD is typically classified into two forms, dry and wet. This report focuses on the symptoms and treatments for dry AMD.

An early clinical sign of AMD is the presence of drusen, or yellow deposits in the back of the retina. Presenting symptoms of dry AMD are flashes and floaters, difficulty reading and driving, and difficulties seeing in low light. Symptoms vary from person to the next and may progress to blurry and/or distorted central vision, the loss of contrast sensitivity, blind spots, and the eventual loss of central vision. Peripheral vision usually persists.

Depending on the size and number of drusen, dry AMD is classified as early, intermediate, and late/advanced disease. Early AMD is defined by medium-sized drusen, while intermediate AMD is characterized by large and/or extensive drusen. Many patients are asymptomatic in the early and intermediate stages of the disease.

The progression of dry AMD to advanced disease is caused by the chronic progressive degeneration and loss of retinal tissue, in sharply defined areas, called geographic atrophy (GA). GA slowly increases in size over time, and as the atrophic area expands, vision is progressively lost. GA can take different shapes and can be located centrally as well as in other areas of the eye. A faster growth rate is seen in cases of bilateral presentation, non-central involvement, and larger and multifocal lesions.

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[1] Prepared from the presentations of Dr. Emily Chew, MD, Director of the Division of Epidemiology and Clinical Applications at the NIH's National Eye Institute, and Dr. David Boyer, a clinician, surgeon, and educator from the Retina-Vitreous Associates Medical Group.

Factors influencing the risk and progression rate of dry AMD include genetic and lifestyle factors. Positive lifestyle factors - not smoking, a healthy (Mediterranean) diet, and physical activity - are associated with 71% lower odds of developing AMD. Genetic factors are important, with 52 independent genetic variants identified to date on 34 loci, predominantly on chromosomes 1 and 10. Dry AMD-related gene variants influence the complement, collagen, and lipid pathways, implicating a disease pathogenesis involving the immune system, healing, and scar tissue formation. Some of the genetic variants are specifically associated with early and late macular degeneration.

How many people are affected?

In 2019 in the United States, an estimated 20 million individuals were living with AMD; 18.34 million with early-stage, and 1.49 million with late-stage disease. Dry AMD accounts for about half of the blindness in the US. Globally, the numbers are overwhelming; in 2020, an estimated 196 million people experienced AMD, with projected increases to 288 million globally in 2040. These projections are due to increasing lifespans.

What treatments are available?

Until recently, the only treatment was AREDS 2 nutritional supplements, developed by the National Eye Institute in response to the Age-Related Eye Disease Studies (AREDS and AREDS2). If taken daily, they can help reduce the risk of progression to advanced AMD, but do not prevent the formation of drusen or geographic atrophy formation.

In 2023 the FDA approved two products to slow the progression of geographic atrophy. Pegcetacoplan injection (Syfovre) and avacincaptad pegol intravitreal solution (Izervay) both decrease complement system activation by inhibiting C3 and C5, respectively. These medications are administered through intravitreal injections every four to eight weeks and must be continued indefinitely to get the best results. While these treatments offer a 14-17% reduction in GA growth after one year compared to natural history, some patients have demonstrated a 30-40% reduction after three years. Syfovre and Izervay are accompanied by side effects common to all intravitreal-administered medications including the potential for an infected eye (endophthalmitis), increased risk of floaters, posterior vitreous separation, subconjunctival hemorrhage, and post injection irritation. Evidence shows that these agents come with a very low risk of additional side effects, including ischemic optic neuropathy, occlusive vasculitis, and intraocular inflammation.

Several small molecule, gene, and cell-based therapies for GA secondary to AMD are under development or regulatory review. Some of these approaches focus on neuroprotection (reducing oxidative stress) through improving mitochondrial function, or by limiting toxic byproduct formation through visual cycle modulation. Stem cell therapy is an active area of research but does require surgical intervention which comes with risks and limitations. Methods to suppress complement-mediated inflammation are being tested including photobiomodulation using lights of different wavelengths, macrophage manipulation, and subthreshold laser.

Meeting Summary

The Dry Age-Related Macular Degeneration (AMD) Externally-Led Patient Focused Drug Development (EL-PFDD) was held virtually on March 1, 2024. The meeting was an important opportunity for people living with dry AMD, their spouses and other direct caregivers to share their perspectives regarding the symptoms and daily impact of dry AMD, as well as current and future approaches to therapies. The meeting was cohosted by Todd Durham, PhD, Senior Vice President of Clinical & Outcomes Research at the Foundation Fighting Blindness, and James Valentine, JD, MHS, from Hyman, Phelps & McNamara, P.C. The full meeting agenda is in **Appendix 1.**

The virtual meeting format allowed dry AMD community members to participate through live online polls, telephone call-ins, and by providing written comments through an online portal. One hundred and thirty-eight viewers attended the live stream meeting, including 25 individuals living with dry AMD, eight caregivers and family members, 21 friends, 28 members from the FDA, 22 scientists/researchers, 103 industry representatives, seven healthcare providers, twenty from non-profit organizations, and four others.

EL-PFDD meeting attendees used online polling to indicate demographics. Most attendees were from the continental United States, with half (50%) from the Eastern time zone, and the rest from the Central (27%), Pacific (15%) and Mountain time zones (4%). An additional 4% were from elsewhere in North America. The majority of attendees were female (62%) and the rest identified as male (24%) or preferred not to identify (14%). The prevalence of dry AMD increases with age and all of the attendees were over the age of 51 years, with strong representation from each age group: 51-60 years of age (23%), 61–70 years of age (31%), 71-80 years of age (15%) and 81 years of age or older (31%). Age at diagnosis was however lower: 8% diagnosed between 19-30 years of age, 17% diagnosed between 31-50 years of age, 33% diagnosed between 51–60 years of age, 25% diagnosed between 61-70 years of age and 17% diagnosed between 71-80 years of age. Half of the poll respondents had dry AMD in both eyes, 29%

had dry AMD in one eye and wet AMD in the other, and 21% selected "other". Not one individual reported experiencing dry AMD in only one eye. The results of demographic polling are shown in **Appendix 2.**

The number of live respondents was slightly lower than expected. However, as individuals living with dry AMD experience visual impairment, many had challenges when accessing the Zoom interface, polling app, the phone, and/or the comment interface. A list of meeting panelists and callers is listed in **Appendix 3,** and online polling results from topics 1 and 2 are presented in **Appendix 4.** To include as many patient voices and perspectives as possible, patient comments were collected through an online comment submission portal before, during, and for four weeks after the meeting, and are included in **Appendix 5**.

This *Voice of the Patient* report is provided to all dry AMD community supporters including the US FDA, other government agencies, regulatory authorities, medical products developers, academics, clinicians, and any other interested individuals. The input received from the March 1, 2024, EL-PFDD meeting reflects a wide range of experiences with dry AMD, however not all symptoms and impacts may be captured in this report. Please note that while this report includes descriptions of how individuals have treated or managed their dry AMD, **this information should not be interpreted as medical advice.** Please speak with your healthcare provider with questions about your current treatment.

The final *Voice of the Patient* report and the video recording of the meeting are available on the Foundation Fighting Blindness website at https://www.fightingblindness.org/.

Topic 1 – Living With Dry AMD: Symptoms and Daily Impact

Individuals living with dry AMD, spouses, and other caregivers described dry AMD-related health effects, the impacts on activities of daily living, and their worries and fears for the future. Several key insights emerged that were not captured in online polling and are highlighted throughout the report in **dark blue.**

Dry AMD is a progressive condition. Progression can happen at variable rates and is unyielding.

Patients described the first signs and symptoms of their disease. For many, the diagnosis of dry AMD diagnosis came as a shock and in all cases the subsequent vision loss was life-changing.

> *"Never in my wildest dreams did I think I would also be getting a diagnosis for a condition that - barring a treatment that is yet to be developed - will lead to blindness. … I was stunned. I never thought that going blind was something I would have to worry about. I didn't have any symptoms."* - Sean, living with dry AMD for eight years

> *"I was diagnosed with dry AMD two decades ago. Fortunately, the progression of my disease has been relatively slow. The gradual nature of the decline in my vision not only allowed me to keep most of my eyesight for a longer period of time, but it had me avoid the shock of going from perfect vision to near blindness overnight."* - David, age 74, living with dry AMD for over 20 years

> *"I was diagnosed with dry AMD with geographic atrophy about seven years ago. A little over two years ago, it got very aggressive and in a matter of two or three months, I lost almost all my central vision. …Usually you have five, seven, eight drusen in your macula. I have hundreds smaller ones, and they were very aggressive."* - Luiz, age 61, living with dry AMD for seven years

Dry AMD can run in families; many described how a parent also had this disease.

Many have seen a parent struggle with progressive vision loss as a result of dry AMD. Some found it hard not to project themselves into the same situation.

> *"As AMD runs in my family, the diagnosis was not a shock. What has shocking is the toll the disease has taken on my life and my sense of myself. The past decade has required adjustment after adjustment to new realities, new limits, and a much smaller life."* - Gail, age 73, living with both wet and advanced dry AMD for 14 years

> *"I was first diagnosed with dry AMD in 2009, and of course I was distressed to hear this diagnosis, but not at all surprised because my mother had been struggling with this crippling and life robbing disease and I had been navigating that journey with her."* - Patricia, age 75, living with dry AMD for 12 years

> *"I was diagnosed with possible AMD probably 30 years ago. I've been watching it carefully because both my mother and her sister, my aunt, went legally blind with it in their late-80s, early-90s, and now my younger sister has been diagnosed also with geographic atrophy and has started treatment with the Izervay. So, I know it's a hereditary disease."* – Pete, age 77, living with dry AMD for 30 years

Many of those living with dry AMD have other conditions that complicate their vision loss experience.

During the EL-PFDD meeting, patients mentioned also having been diagnosed with other conditions including ankylosing spondylitis, retinoschisis, glaucoma, cataracts, Sjogren's syndrome and dementia. Some reported experiencing wet AMD in at least one eye.

“I have a rheumatoid arthritic condition called ankylosing spondylitis. The side effect of this, iritis in one or both eyes that was controlled until 2019 when it became chronic due to my age. I used steroid drops to control the iritis and pressure drops to counter the increased eye pressure. About 2016, I was diagnosed with age-related retinoschisis and referred to a retinal specialist.”- Tom C, age 74, living with dry AMD

“I did have cataracts a few years ago, and I'm not sure if mine is more because of my Sjogren's, and the dry eye, or if I'm headed down the AMD road like my mom. … My mom and I both also have Sjogren's syndrome … my eyes, they're severely dry.” - Wanda, age 66, living with dry AMD who is a caregiver for her mother, age 85, also living with dry AMD

“My retinal specialist assured me that cataract surgery would do nothing to harm my vision. When I went in for cataract surgery, left eye was 20/60, right eye was 20/50. Eight months later, my left eye was 20/200 and my right eye was 20/60. Did cataract surgery have anything to do with it? I don't know. It could have just been the progression of my vision.“ - Diane, age 77, living with dry AMD for 24 years

Poll 1&2

Most living with dry AMD experience difficulty seeing in low light, blurry central vision, and severe vision loss. Many suffer from anxiety and depression because of their dry AMD.

Meeting attendees first selected all of the dry AMD-related health concerns that they or their loved one(s) ever had, then selected their top three most troublesome. Most reported experiencing several visual challenges, and each individual selected an average of four different symptoms. Poll results are shown in **Appendix 5, Q1 and Q2.** Dry AMD-related health effects are listed in decreasing order of most troublesome and illustrated below with selected patient quotes.

Difficulty seeing in low light

Difficulty seeing in low light is one of the first symptoms of dry AMD and selected in the polls as the most troublesome symptom. Some described acute sensitivity to bright lights and difficulty adjusting to changes in light conditions. Rosana reminded everyone that difficulty seeing in low light is just the start, because dry AMD is progressive.

> *"Is only low light a problem? No! Things change during the development of this disease. It starts with low light, then, bright light, grey backgrounds, mix of light and shadow, until you realize you need to give up things that you are used to."* - Rosana, age 61, living with both wet and dry AMD for 16 years
>
> *"The low light condition … is a big issue for me. It impairs going downstairs safely sometimes. Hotel rooms don't have good lighting for reading unless it's a lighted screen. Sometimes meeting rooms are difficult."* - Susie, age 78, living with dry AMD
>
> The bright screens on computers or iPhones can be painful to look at. "*Obviously, when the light is bright, you can see better. But after I look at a bright light for a while, it really hurts my eyes."* - Wanda, age 66, living with dry AMD who is a caregiver for her mother, age 85, also living with dry AMD

Blurry central vision

Many patients have blurry central vision that eventually progresses to the total loss of central vision. Despite the impairment of central vision, many maintain excellent peripheral vision.

> Rob noticed his first dry AMD symptom when looking at his bedside clock. *"Part of an LED light numeral was missing and that's what sent me to the ophthalmologist. … If I look directly at something, it is gone, whether it's a letter in a word six inches in front of me while trying to read something, or whether it's a [vehicle] a hundred feet ahead of me*

> *on the highway. … That whole area is just absolutely gone. …If I want to look [directly] at something I don't see it."* - Rob, living with both wet and dry AMD for 12 years
>
> *"I was diagnosed about 20 years ago. … The loss of central vision is the most concerning thing, but that's only happened within the last four to five years."* - Robert, living with dry AMD for 20 years
>
> *"I'm very different than almost everybody I've heard on all the panels today…. My retinologist calls it a 'donut hole'. In the very center, I am 20/25 and 20/30, and when they put that white chart on the wall with the black letters, I can read almost to the bottom line, I'm really good, but I'm losing things around it. … So, mine is very different than everybody else."* - Pete, age 77, living with dry AMD for 30 years

Severe vision loss

Those with geographic atrophy eventually progress to severe vision loss.

> Diagnosed with dry AMD in 2008, Liz was stable for many years. "*About a year ago, I woke up and I lost almost all the vision in my right eye. I went to see my retina person and they said, 'You have developed geographic atrophy in that eye.'"* Liz was terrified. "*Things were stable for a few months and then in my left eye, I developed geographic atrophy also."* - Liz, living with dry AMD for 16 years
>
> *"Both eyes have lost central vision to geographic atrophy. I was diagnosed just before I turned 60, but the full impact has come with the onset of geographic atrophy in the last six years or so."* - Gail, age 73, living with both wet and advanced dry AMD for 14 years

Anxiety or depression

Vision loss leads to anxiety, depression and worry for the future for many. Some experienced trauma and despair.

> *“Well, depression and anxiety have taken up a lot of space in my head since my diagnosis. I've passed through periods of despair and loneliness full of fear for my future and grief for what I've lost. I regularly fight the feeling that a life worth living is over for me. Struggling for mental health is part of my new normal.”* - Gail, age 73, living with both wet and advanced dry AMD for 14 years
>
> *“The rate at which my vision is deteriorating is ongoing and scary. My grandmother and mother both lived to be in their late 90s and there's no reason to think that I won't live that long. But the prospect of being blind or nearly blind is depressing and such a waste.”* - Patricia, age 75, living with dry AMD for 12 years
>
> Wanda’s mother has already lost her vision. *“She is down and depressed about her eyesight because she's always been very independent. … You can see that she's depressed because she can't see. She can't read anymore. There are so many things that she can't do, and it's very frustrating for her.”* - Wanda, age 66, living with dry AMD who is a caregiver for her mother, age 85, also living with dry AMD

Additional dry AMD-related visual distortions

Individuals living with dry AMD described how **straight lines appear wavy or crooked, and how colors are not as bright as they once were.** Many experience **floaters, flashes, or visual hallucinations** which seem to intensify as the disease progresses. Others experience a **lack of depth perception, severe headaches**, and **dry eyes.**

> *“What I have noticed in my vision is where there are drusen deposits, I am perceiving an irregular grayish area that is translucent. This is making reading more difficult at times.”* - Tom C, age 74, living with dry AMD

“I also lost my capacity to distinguish colors, so I see almost everything in shades of gray and black and white.” - Luiz, age 61, living with dry AMD for seven years

“I had some floaters, but since nobody in my family has vision problems, I thought I would be fine. … Unfortunately, the floaters got bigger, and what I call a psychedelic experience took over. Lights started to flash inside my eyes and distortions began to happen. … My vision is now so deformed that I live in a curvy world, where the colors confuse me and shopping is no longer fun. The flashes are so intense that I dream about them.” - Rosana, age 61, living with dry AMD for 16 years

Poll 3

Dry AMD has a heavy disease burden. Many live with feelings of loss, social isolation, and loneliness.

Meeting attendees used online polling to select the top three activities that they or their loved one(s) are not able to do or struggle with due to dry AMD. Poll question results are shown in **Appendix 5, Q3,** and are illustrated below with selected patient quotes. A key insight emerged that was not captured in online polling and is highlighted throughout the report in **dark blue.**

Many with dry AMD live with a profound sense of loss for their vision, and for the many activities that made up their lives.

Many of the individuals who spoke at the EL-PFDD meeting are highly accomplished. Before dry AMD, many lived productive and independent lives as professional writers, CEOs, professors, and helicopter pilots. Several described a life "before" and "after" their progressive vision loss, where they were forced to let go of the skills and activities that defined them.

> *"When I look behind, I see a journey of loss. …I am a helicopter pilot, have a degree in art history, and would travel the world to see a good exhibition. Always loved outdoors and adventures."* Floaters and flashers meant, *"No more flying helicopters or playing tennis. I had … nothing else to do, but take vitamins and eat all the blueberries I could. I was wearing binocular glasses and started feeling insecure."*- Rosana, age 61, living with dry AMD for 16 years

> *"In the 12 years since my initial diagnosis, my vision has gone from not being able to tie a line on a fishhook to not reading well, to not seeing a semi-truck 100 yards ahead of me on the highway, to then not driving at all. These events are life-changing."* - Rob, living with both wet and dry AMD for 12 years

> *“AMD with atrophy caused me to give up singing in a semi-professional choral group, which I'd done for twenty years. If you can't read, you can't read music. This has been a major loss in my life.* **...** *I've had to revise my sense of who I am pretty radically. I got much older very quickly. I had to accept and understand myself as a disabled person, which takes humility and courage.”* - Gail, age 73, living with both wet and advanced dry AMD for 14 years

Inability to recognize faces

Recognizing facies is a top activity that people living with dry AMD are unable to do or struggle with. The inability to see faces has profound social impacts and changes how they relate to others and how others relate to them. Many described feeling stigmatized and judged when they didn’t recognize friends and students in a crowd.

> *“I can relate also to entering a room and I see a sea of faces. Those faces should be recognizable to me. I will see someone raise their hand as though they see me, but I can't tell who that person is until I get very close to them. ... I describe it as being browned out. I mean, I can see that there are probably eyes and the nose and a moving mouth, but that's very frustrating and can be embarrassing.”* - Patricia, age 75, living with dry AMD for 12 years

> *“When someone sees me, it's not obvious that I have vision problems. ‘How rude’, a neighbor may think he looked right at me and I didn't say hello. … It's complicated.”* - David, age 74, living with dry AMD for over 20 years

> *“Loss of central vision equals loss of faces, and that applies to TV and movies too. I never feel more disabled than in a room full of people I should know. I often decide that whatever the event has to offer is not worth the anxiety and stress, and I stay home. I work at keeping up connections because I know that withdrawal isn't a healthy way to go.”* - Gail, age 73, living with both wet and advanced dry AMD for 14 years

Losing the ability to drive

Driving is an important activity that people living with dry AMD are unable to do or struggle with and was mentioned repeatedly throughout the meeting. Some individuals with dry AMD first experience challenges with driving in poor light conditions or at night, while others described difficulties driving in bright light. Although many in the early stage of disease still drive, they choose to only drive during the day and to familiar locations. Once vision loss progresses, most stop driving completely. Independence and social life are affected and some struggle to attend events and medical appointments.

> *"One of the most significant impacts that this disease has had on my life is my inability to drive a vehicle. … My ability to perform simple tasks such as going to the grocery store has become increasingly difficult. I now rely on municipal transportation as much as possible."* - Ken, age 73, living with dry AMD for 23 years
>
> Lynne intentionally moved to a city where it is easy to walk. "*The biggest factor was that I couldn't drive anymore. … It's just a whole new life for me, and I love being able to walk. I still can go myself to the store, to museums though my sight isn't wonderful, but I'm doing everything I can right now, not waiting anymore."* - Lynne, age 85, living with dry AMD
>
> Since giving up driving, Robert has had to spend much more time planning and budgeting. *"Can a family member, or friend give me a ride, or do I have to budget for an Uber, or a car to take me? So you can't just say, 'Oh, I'm going to go do that'. You've got to really plan it out, and that makes it difficult."* - Robert, living with dry AMD for 20 years

Unable to read or watch TV or to use computers

As dry AMD-related vision loss progresses, many lose the ability to read, watch TV, or use computers. Some feel that their eyes have to work much harder to adjust. Others report that their vision is variable, changing from day to day. The inability to read or use computers impacts employment and hobbies.

> *“That sweet spot is getting harder and harder to find now. If I try and read, my eyes will jiggle and I'll get my magnifying glass out and I'll find a sweet spot where I can see a word at a time, but that's about all I can do right now. I can't read.“* - Tom H, living with dry AMD for more than 25 years

> *“I am currently unable to perform any type of reading or facial recognition, and it has become increasingly difficult to even watch television.”* - Ken, age 73, living with dry AMD for 23 years

> *“How can I explain what it means to a professional writer who was a teacher of literature for four decades to pick up a book and be unable to read it? All the eBooks and audiobooks in the world, precious as they are, won't compensate. I continue to write on screen, no longer on paper, but I write and rewrite much more slowly and laboriously. When I allow myself self-pity - and I do - it seems a brutal irony that the power of the written word, which I've lived by for seven decades is the one I'm losing.”* - Gail, age 73, living with both wet and advanced dry AMD for 14 years

Mobility/ambulating impacts

Many living with dry AMD described how the loss of vision impacts walking and ambulation. Depth perception and balance issues further complicate matters with the risk of falls when stepping off a curb or walking down the stairs.

> *“Everyone talks about loss of independence with vision loss, but that category contains multitudes. It has made me feel trapped, weak, elderly, and fearful. Loss of independence means restricted movement, not just driving and other kinds of travel, but finding my way around an*

> *office building, reading a street sign, or identifying an address.“* - Gail, age 73, living with both wet and advanced dry AMD for 14 years

> Susie became lost at a conference. *“And I went outside, couldn't see the door, couldn't see the street, it was all dark, went back inside and missed the session. …It was frustrating and disappointing, … I didn't go to the venue and it was really hard.”* - Susie, age 78, living with dry AMD

> Tom’s lost depth perception and glasses only made it worse. While on a cruise, *“I remember falling down the stairs, the last stair on one of the decks. … I thought I was stepping on the last step on the ground floor, on the deck, and I wasn't, so I fell.“* - Tom H, living with dry AMD for more than 25 years

Self-care/chores

Those living with dry AMD-related vision loss often depend on others to shop, assist with household chores, prepare meals, and select matching clothes for them. Some have difficulties with paying for merchandise, paying bills, or filling in forms. Vision loss undermines both independence and confidence.

> *“Despite that support and despite the gradual nature of my vision loss, I can't help but feel occasional self-pity, and even more so a concern for my devoted wife who shares the burden of my vision loss. …Many tasks that I previously managed myself now fall on her. Sometimes it seems like the disability is harder on her than it is on me.”* - David, age 74, living with dry AMD for over 20 years

> *“The burden on my family has increased due to the lack of my vision. I now rely on my wife and daughter to perform functions such as opening the mail, reading important documents, and even setting the dial on the washing machine so that I can perform daily household chores. …My ability to keep track of medical records, bank accounts, and even shopping lists have become a difficult task. … Of course, the*

> *lack of vision also inhibits my ability to pay for items using the new credit card machines, which are all different as far as how you insert and/or tap your credit card to process the purchase and or the transaction."* - Ken, age 73, living with dry AMD for 23 years
>
> *"The laundry room in my basement remained dark for three months because I couldn't change the ceiling light bulb. Any problem with technology from the TV remote to the computer, to the phone becomes twice as hard because reading instructions, messages and menus or identifying buttons is laborious, if not impossible. All of this mundane stuff requires help and I live alone. … I now pay to have things done for me that I used to do for myself, like having groceries delivered."* - Gail, age 73, living with both wet and advanced dry AMD for 14 years

Travel/vacationing

Many are afraid to leave a familiar environment.

> *"Once my flight was delayed and the airport was hit by a storm, everybody runs to get their hotel rooms or flight changes, and I find myself not knowing where to go or how to get help. I had to sleep at the airport, where the person pushing my wheelchair left me."* - Rosana, age 61, living with dry AMD for 16 years
>
> *"I've become much more reticent to strike out across the state, let alone the globe and no more solo travel for me. My world is shrinking despite the fact that I'm in excellent physical shape other than my eyes."* - Patricia, age 75, living with dry AMD for 12 years
>
> *"Now that I'm retired, independent travel is becoming more difficult by myself."* - Tom C, age 74, living with dry AMD

Other activities impacted by dry AMD

During the meeting, individuals living with dry AMD described the other activities that they were unable to do or struggle with because of dry AMD.

This includes **changing jobs or losing employment**, **socializing and participating in family events**, **sports, exercise, and hobbies**. Other things mentioned during the meeting include increased accidents and not being able to find dropped objects.

Changing jobs and losing employment. Some had to change work roles or even retire from work because of their vision.

> *"My work at Disney was fine for at least 10, 15 of the years I worked there. But toward the end, my vision had failed so that... At some point, everybody that's failing from AMD will understand the sweet spot concept. Toward the end, I would have to find a sweet spot to see distance. I could drive the boats, I knew where I was going, I knew what to do, but in order to make sure I was seeing correctly, you may have to jiggle your eyes a little bit."* - Tom H, living with dry AMD for more than 25 years
>
> Robert described his vision loss, *"It got to the point where I just can't drive and I can't read. I can't read handwriting. And I was a teacher. And so it's taken away quite a few of those activities."* - Robert, living with dry AMD for 20 years

Many have challenges socializing and being part of family events.

> *"In order to go out to a restaurant now with friends, I first review the menu online to decide ahead what to order, is becoming more difficult for me to know I can attend my granddaughter's school recitals and other events at night. Going to family events out of town for the day becomes more difficult as I don't want to drive at night or in bad weather."* - Tom C, age 74, living with dry AMD
>
> *"She doesn't like to go out at night, which I can understand because I kind of feel like that myself. But she's become more fearful of being left alone; if I need to take her to the doctor and drop her off at the door and then go and park the car, she's very fearful of that."* - Wanda, age 66,

> living with dry AMD who is a caregiver for her mother, age 85, also living with dry AMD

Sports, exercise, and hobbies. Many lost the ability to do their favorite things.

> *"Lack of my ability to see clearly, it has also impacted my ability to perform recreational activities such as biking, hiking, and even playing catch with a grandchild."* - Ken, age 73, living with dry AMD for 23 years

> *"My favorite activity is playing Bridge and I'm a pretty damn good Bridge player. …I quite often cannot identify a card just put down across the table from me, whether it's a spade or a club. Hearts and diamonds are a little bit easier, so I have to be extremely careful about that. I can still score a Bridge game, but adding up numbers is very difficult."* - Liz, living with dry AMD for 16 years

> *"I worry how long I'm going to be able to do some of the things that I'm doing right now. I know, from experience, I've already cut back on what I'm doing. I no longer can work in the shared shop because I don't feel safe using power tools with my limited vision."* - Robert, living with dry AMD for 20 years

Poll 4

Individuals living with dry AMD worry about losing their independence, about how dry AMD will progress, about losing the ability to read or watch TV.

Meeting participants used online polling to select their top three worries about themselves or their loved one's condition in the future. Results are in **Appendix 5, Q4** and are illustrated with patient quotes below. Patients shared many other worries during the meeting as well.

Worries about loss of independence and not being able to care for their family

Individuals living with dry AMD shared many closely related worries: the worry about losing their independence and burdening their families, the worry about no longer being able to care for their families, and the worry about needing to move to assisted living.

> *“The possible loss of independence is what scares me the most. I don't want to be a burden on my family and friends. I want to lead an active lifestyle for as long as possible, want to continue to do the activities that bring me so much joy, from skiing to sailing, to playing squash. I worry that again, that I'm going to be a burden.”* - Sean, living with dry AMD for eight years

> *“The loss of my independence by not being able to come and go as I need to do in exercising my abilities to repair things and perform normal daily duties as a father and as a husband, has become very challenging as the result of AMD. …I have always been a very independent person and have not relied on others to help me perform daily chores. As my wife continues to get older as well, I am sure her medical needs will increase, and I am not sure how much help I can be to her as well as myself. As my current condition continues to worsen with time, my biggest fear will be my ability to perform the most common daily functions that I am still able to do today.”* - Ken, age 73, living with dry AMD for 23 years

> *“I looked into giving up my house and moving to a retirement center. I went and I was petrified of being trapped with these people in this place, not having freedom to do things. And so right now I'm planning to stay in my house. I figure I can hire people to drive me places if I need to.”* - Liz, living with dry AMD for 16 years

Worries about not knowing how dry AMD will progress

Most living with dry AMD worry about losing their remaining vision, about their disease progressing, and how that will impact being able to do the things they enjoy.

> *"I was stable for so many years that I'm hoping I'm going to be stable now for a number of years … But you just don't know what the future's going to hold. And it just sort of dark cloud hanging over your head."* - Liz, living with dry AMD for 16 years

> *"Well, I'm petrified on one hand, after seeing what my mom's gone through. But on the other hand, I'm trying not to worry, and be optimistic that this is just the beginning stages for me. And hopefully, it will not progress fast."* - Wanda, age 66, living with dry AMD who is a caregiver for her mother, age 85, also living with dry AMD

> *"The warning words of my retina specialists are, 'Your condition could go from dry to wet at any moment.'. … I have no idea what the progression is going to be. It is a degenerative disease, so the expectation is that it's going to get worse."* - Patricia, age 75, living with dry AMD for 12 years

Worries about losing the ability to read/watch TV and use computers

Not only do individuals living with AMD worry about losing the ability to read and watch TV, but they worry about losing the ability to use the devices that they depend on.

> *"One of my greatest worries is not being able to use the devices because those are what allow me to read, and communicate, participate in things like this. And I've noticed that it's becoming more, and more difficult. And I have to keep learning new accessibility controls on my devices."* - Robert, living with dry AMD for 20 years

> *“What can we do to prepare for some loss of vision? It is true with this condition, in most cases unless really severe, you don't lose all of your vision. But I guess that's not impossible. So not really knowing, ‘will I be able to take a trip this year? Will I be able to take care of somebody? Will I be able to take care of myself? Am I going to have to move?’”* - Patricia, age 75, living with dry AMD for 12 years

Worries about losing the ability to drive

Worries about losing the ability to drive are closely related to worries about losing independence. Many are already making plans for how to get around once they are no longer able to drive themselves.

> Susie is focused on planning for the future, *“I can still drive, but I think a lot about who will I ask? Am I going to do an Uber, or am I going to do a family member? Very active planning is really important, I think, for people who have the condition. … I think about transportation a lot.”* - Susie, age 78, living with dry AMD
>
> Liz worries about the impacts of not being able to drive. *“Loss of freedom. Loss of being able to drive. Loss of being able to do things on your own. …My driver's license is good for another year plus, but then I have to get my driver's license renewed.”* She described all the things she wouldn’t be able to do if she stopped driving. *“Grocery shopping, going and playing Bridge, driving in to see my grandchildren, my daughter. Having to get rides to do all that.”* - Liz, living with dry AMD for 16 years

Worries about having to change jobs or stop working/going to school

Many of the individuals living with dry AMD were diagnosed at the pinnacle of their careers and worry about whether they can continue to work.

> *“I'm an interior designer, so I'm petrified of losing my sight.“* - Wanda, age 66, living with dry AMD who is a caregiver for her mother, age 85, also living with dry AMD

> Susie’s shared her top worry. *“The loss of the ability to work. I can do much of my work at home, but if I lose the ability to read, I can't do the work that I'm doing.”* Dry AMD already interferes with lectures because when she is in the audience, she can’t *“see somebody's PowerPoint, if it's the wrong colors or if the room is completely dark, even if though that's a lighted screen. ... And if I'm in the speaker position, then it's difficult to see the faces.”* - Susie, age 78, living with dry AMD

Other Worries

Individuals living with dry AMD shared other worries not included in the poll options, but which reflected the impacts described in earlier sections. This includes **worries about increasing social isolation**, **falls and injuries**, and **worries about being unable to travel**.

> *“It's unbelievable to me that I had never met a blind person really before I got involved with the foundation Fighting Blindness, and I felt terrible about that. It just made me think about how lonely and isolating this condition must be, just blindness in general. I think it's the isolation really more than the loss of independence that scares me the most. It's terrifying.”* - Sean, living with dry AMD for eight years

> *“As the perimeter of my life narrows, I worry about my increasing solitariness. I've come to avoid meetings and social engagements because transportation is hard or because I'm wary of being out at night when it's so easy to lose my footing or because when I get there, I won't recognize people.”* - Gail, age 73, living with both wet and advanced dry AMD for 14 years

“I think I'm more aware [of my vision failing] and as one gets older, the fear of falling down the stairs when you can't see the bottom stair as distinct from the next.” - Susie, age 78, living with dry AMD

Topic 2 - Current & Future Approaches to Treatment for Dry AMD

Those living with dry AMD as well as their spouses and other direct caregivers described all the different medications, medical treatments as well as non-medical approaches that they had tried for dry AMD-related symptom management. They discussed the most significant drawbacks associated with each approach and articulated their hopes for future dry AMD treatments. Several key insights emerged that were not captured in online polling and are highlighted below in **dark blue**.

Dry AMD continues to have a tremendous unmet medical need, and those diagnosed with the disease will do anything to prevent further vision loss.

Until recently, most diagnosed with dry AMD were offered no treatment except vitamins. They were forced to adapt to vision loss on their own.

> *"It has been so distressing to hear again and again, 'There is just nothing we can do for you.' …Ophthalmologists, retina specialists are not schooled or very helpful. They diagnose and treat where there is a treatment."* Patricia had a hard time finding resources on her own. *"We do all of those things, but then it's a lonely road and to get to finding these solutions. That's one of the biggest challenges that I think all of us have."* - Patricia, age 75, living with dry AMD for 12 years

> *"[Dry AMD] is something that's always on my mind and I do just about everything, or at least try to do everything I can to delay the progression of the disease. I wear my sunglasses. I take my AREDS vitamins twice daily, try to eat a healthy diet and exercise regularly."* - Sean, living with dry AMD for eight years

Poll 5

AREDS vitamins are used by almost all dry AMD patients, followed by Syfovre or Izervay. Few other treatment options are available.

Using online polling, EL-PFDD meeting attendees selected all the medications or medical treatments that they or their loved one used (currently or previously) to treat symptoms associated with dry AMD. Poll responses are in **Appendix 5, Q5** and illustrated below with patient quotes.

AREDS vitamins

The AREDS and AREDS2 vitamins were the top medication approach, selected by most EL-PFDD attendees in the polls. If taken daily, these nutritional supplements help reduce the risk of progression to advanced AMD, but do not prevent the formation of drusen or geographic atrophy formation. Some also indicated following a healthy diet and taking other dietary supplements like fish oil.

> *"When I was first diagnosed, they just told me to take vitamins. And then later when I said, 'Well, I'm having trouble seeing it at night or in low-light situations,' they said, "That's part of aging.' But I wasn't really informed it was part of this progression."* – Robert, living with dry AMD for 20 years
>
> After her diagnosis, *"I began taking the AREDS eye vitamins, eating even more leafy greens, yellow and orange vegetables, and wearing sunglasses that block harmful rays. It's beyond belief to me that in all these years, this regimen is the only treatment available to most of us with dry AMD. Unless of course, my dry AMD progresses to the blinding - if untreated - wet kind, there's just nothing else to do."* - Patricia, age 75, living with dry AMD for 12 years

Vitamins have few side effects or downsides, apart from the fact that most people who take them don’t really know if they are effective at preventing vision loss.

> *"While I can't say for certain, it's possible that AREDS did prevent my dry AMD from becoming wet, or even though I've never seen any research suggesting the effectiveness in this regard. Maybe it contributed to the slow progression of my vision loss. In any event, I experienced no discernible side effects from taking the vitamins.”* - David, age 74, living with dry AMD for over 20 years

Syfovre (pegcetacoplan injection) or Izervay (avacincaptad pegol)

Syfovre and Izervay were approved by the FDA in 2023. Many individuals living with dry AMD did a lot of research and reading to find out more about these treatments.

> *“I've just started taking Izervay in my right eye, … just to see if that can help stabilize it.”* - Liz, living with dry AMD for 16 years

> *“I had a private retinal specialist. They could see some wet activity and some bleeding, and so he said, ‘Well, I can give you a shot.’ … Now, I'm getting shots to slow the progression down and I get it in my left eye. My right eye has changed dramatically recently. I asked him if he could maybe put the slowing procedure in both eyes. He wasn't sure whether he could talk the [health insurance] into it.”* - Tom H, living with dry AMD for more than 25 years

> *“My retinologist offered [Syfovre] in both eyes the very first time. …I've had six shots now. I'm a year into it. … I'm doing that because it's proactive. Whether it's working and whether it's going to work long range, I don't know, but I saw what happened to my mother, my aunt, I want to try it. … I'm willing to take the risk and I really do think it is slowing it down, but I have no way to prove it.”* - Pete, age 77, living with dry AMD for 30 years

Syfovre or Izervay are accompanied by a long list of downsides including the risk of side effects, an increased risk of developing wet AMD, and some are apprehensive about the thought of intravitreal injection. Although these medications are most appropriate for those with rapidly progressing GA, sometimes dry AMD progresses faster than the drugs can slow vision loss progression. At the meeting, it was clear that many don't care about the downsides if there is any chance to preserve their vision.

> Diane's vision loss progressed rapidly despite having multiple treatments. "*I could barely read the chart. … My retinal specialist said, 'I don't believe that it is the injections that are causing this. I think it's the progression of your vision loss, which does happen sometimes very quickly.'*" - Diane, age 77, living with dry AMD for 24 years
>
> Rob overcame his worries about administration, risks of the dry eye turning to wet, injection infections and other complications. *"Keep in mind, those complications are all real but statistically insignificant. No other choices are available and there is 100% chance it will get worse if nothing is done. After six months of deliberation, I decided to quit being afraid, toughen up and start going for the shot. … I feel I wasted six months of potential help."* - Rob, living with both wet and dry AMD for 12 years

Investigational medicine in a clinical trial

Many living with dry AMD are very keen to participate in clinical studies, and some actively seek clinical trial opportunities, not necessarily for themselves, but to help others suffering from the condition.

> *"I'm being treated by a doctor at the Columbia Eye Institute and I am on a trial at the NIH where they are producing a new macula for me based on my stem cells, but basically I think this is very early trial because we still don't know how to implant that."* - Luiz, age 61, living with dry AMD for seven years

> Patricia is currently participating in a sibling study. *"Even though my brother and I share similar genetic material, he does not have AMD. In fact, he's still working as an instructor airline pilot. Go figure. In this study, they will analyze why only I have AMD."* The study also involves emerging stem cell approaches. *"I realize that the study progression will be slow and maybe years before outcomes can be applied. Regardless, this is the very first time I have had any hope at all for a treatment for Dry AMD. And frankly, if it doesn't work for me, I appreciate being part of an effort to solve the problem."* - Patricia, age 75, living with dry AMD for 12 years

Several panelists expressed their disappointment when they did not qualify to participate in clinical trials, and cited other downsides such as experimental treatments that involve placebos or treatments that only target one eye.

> *"My retinologist is very active in trials and offered me three or four trials. I looked at those trials, chose not to go with the trials because the rules around the trials was that you get it in one eye. I'm equal in both eyes, almost exactly equal in both eyes. You get it in one eye and there's about a 50% chance that you're getting a placebo."* - Pete, age 77, living with dry AMD for 30 years

> *"I went in for an interview in my doctor's office and I spent five hours there going through paperwork, and more photos of my eyes. By the time all of that was done, I no longer qualified [for the trial] because it had progressed to the point past where I [was no longer eligible]. I'd been so hopeful, and it really brought me down. I was pretty low for a while."* - Diane, age 77, living with dry AMD for 24 years

> Lynne was excited about the chance to be part of a clinical trial. *"I was so encouraged, not so much that I thought it would help me, but that it might help somebody. … And then I got a call saying they were sorry, but now that one of the other researchers had looked at both of my eyes, I would not be able to fit into the study. And I was heartbroken*

> *for about a week. I didn't think it was going to make me better, but I just felt like I was doing something [to help].”* - Lynne, age 85, living with dry AMD

Other medications or supplements as well as monitoring

In addition to take high dose anti-inflammatories and experimental compounds, some individuals with dry AMD are monitoring their vision daily with **amsler grids** and other **home monitoring devices,** and some are **regularly monitored by their specialists**.

> Because of aggressive disease, “*I'm also recommended to me to take doxycycline and basically doxycyline is an anti-inflammatory and we're trying that. It's high doses that I'm taking and we don't know if it's still working or not. I started this mid last year. More recently I changed to acetanilide, which is basically to help me with dark and light because that's what's bothering me.”* - Luiz, age 61, living with dry AMD for seven years

> *“I went to my retinal doctor where I learned I did have dry AMD in both eyes. There was nothing to be done except continue to follow a good diet and use the Amsler grid. The next year I had to get a new retinal specialist, who put me on AREDS 2 and prescribed a Notal Vision ForeseeHome device to help catch an early change to wet AMD. … I had to stop using the device completely because they could no longer establish a baseline for my left eye. This left me only using the Amsler grid.“* - Tom C, age 74, living with dry AMD

Other medications that were included as poll response options but were not selected and were not discussed during the meeting include **medications to aid with sleep**, **medications to manage behaviors, anxiety, or depression**, and **vitamin A**.

Have not used medications or medical treatments recently

Some individuals diagnosed with dry AMD are not offered any treatment, and others decline treatment because of the risks of side effects.

> *“The [ophthalmologist] confirmed the diagnosis [of dry AMD] in both eyes, but gave me no hope that I could really do anything to slow down the progression, and basically left it up to me as to whether I wanted to have a follow-up visit the next year. So that was really tough to hear, and I definitely wanted more advice, expertise, and, really, support. AMD hasn't impacted my vision yet, in some ways my diagnosis seems like something ambiguous and hopefully the distant future.”* - Sean, living with dry AMD for eight years

> Rosana doesn’t want to take any risks with her vision. *“I need to be very cautious on what I'm going to use because there is such a small vision left that we don't want to progress the speed of the blindness. We know it's going to come, but for now it's better do nothing, and that's what I'm doing.”* - Rosana, age 61, living with both wet and dry AMD for 16 years

Poll 6

In the absence of a treatment that could stop the progression of dry AMD, patients must rely on devices/technologies, adaptive strategies, and assistance from others.

Meeting attendees used online polling to select all the approaches used to help manage symptoms of dry AMD, in addition to medications and treatments that they were using currently or had used in the past. The poll results are shown in **Appendix 5, Q6**. During the EL-PFDD meeting, participants shared a wide range of approaches for adapting to vision loss. Approaches have been sorted into the categories of **devices/technologies**, **adaptive strategies**, and **assistance from others** and illustrated with patient quotes. A key point is illustrated below in **dark blue.**

Most use many different approaches, which change as vision loss progresses.

Some of the devices and approaches can become less useful with time.

> *"Today, I use all sorts of aids to help me live my life fairly independently. My digital tools are able to read or light and magnify the words on a screen or paper. I listen to my books."* - Patricia, age 75, living with dry AMD for 12 years

> *"At the beginning of my journey 17 years ago, I was like Batman. I had the utility belt filled up with the things that I need to have. I don't use them anymore. The yellow lens, orange lens, all the devices, I tried all of them, even the Apple Pro. They might help a little in one specific situation. It's very difficult. They are all very expensive."* - Rosana, age 61, living with both wet and dry AMD for 16 years

Devices/Technologies

Individuals living with dry AMD rely on many different devices and technologies to live with their vision loss including portable lighting devices such as flashlights, magnifiers, screen readers, video amplifiers, and closed-circuit TVs. Many living with dry AMD have been forced to embrace new technology and are more technologically adept than their peers.

Portable lighting devices / flashlights. Extra lighting is one of the first adaptations that people with dry AMD embrace.

> *"I travel with a portable light."* - Susie, age 78, living with dry AMD

> *"I have a drawer that has workout clothes that are black, and sweaters that are black. I can't see what's what. I have to get a flashlight. I've noticed that I'm starting to use flashlights more. … Even at home when the light is going down, I try to use a flashlight so that I can see better."* - Wanda, age 66, living with dry AMD who is a caregiver for her mother, age 85, also living with dry AMD

> *"You learn to use your iPhone as a magnifier and also the light on it all the time. You go to a restaurant, you have to use your iPhone in order to read the menu."* - Liz, living with dry AMD for 16 years

Magnifiers and magnifying technologies can include iPhones, devices such as Clover Book and closed captioning TV, as well as wearable devices.

> *"If I'm looking at my tablet, and a lot of times I'm using both a magnifying glass and my cell phone as a magnifying glass to read a word or the back of a frozen meal, how long to cook it."* - Rob, living with both wet and dry AMD for 12 years
>
> *"For devices, it has been helpful to have the CCTV screen where I project. I'm an avid cook and baker and entertainer. ... I have six shelves of cookbooks, so I can still at least do that because I can put it there and read my ingredients. … I have one of the handheld things that I can take with me to magnify in the grocery store"* - Joann, living with dry AMD for 25 years
>
> Robert uses wearable video magnifiers and portable magnifying devices out in public. *"When I go to my grandchildren's concerts or graduations, I don't just see a blur of people in the distance ... I can zoom in far enough, so that I can just see them sitting in there and playing their music while I'm listening to the group perform, and that makes the experience that much more enjoyable. Worth the money that I had to spend."* He uses the magnifier at home. *"I can zoom in on the buttons on the oven or I can zoom in on the screw that I'm trying to tighten. So, it does work for me and I use it whenever I can."* - Robert, living with dry AMD for 20 years

Downsides: Portable magnifying devices can be costly and confining, especially the ones that look like VR headsets. Magnifying devices don't necessary provide enough contrast for reading.

> *“Magnifiers do not help me a lot because I prefer to see everything white on black. Any other alternative in terms of contrast doesn't work for me.”* - Luiz, age 61, living with dry AMD for seven years

Audiobooks, screen readers, devices/software including apps for vision loss. Many enjoy audiobooks, read with the assistance of an Apple device or OrCam, and some use apps such as Seeing AI for the visually impaired.

> *“Audiobooks, thank God, I can still belong to my book club.”* - Joann, living with dry AMD for 25 years

> *“All my media devices have become audible so that I can still continue to perform some of my daily functions.”* - Ken, age 73, living with dry AMD for 23 years

> *“I just recently discovered something called AppleVis, … they list all of the different applications that are being put on iPhones and iPads. …I just got an email from them earlier this week that probably added 30 or 40 new apps. I look for those. I find those very helpful.”*- Pete, age 77, living with dry AMD for 30 years

Downsides: many find it hard to adapt and adjust to new technologies and require assistance with device updates and adjustments. Video amplifiers have a delay and can strain existing vision.

> *“I'm trying to use technology to supplement that loss of vision, but even that is now hard. I know what to do, but sometimes I can't get to do it because I can't see it. And other people don't always know about how to set it for me. … Whether it's the color contrast, or the brightness. But to have somebody that can sit with you, and help you with your device, and set it up. And then, be willing to come back, or to meet with you again because it'll change over time as the disease progresses.”* - Robert, living with dry AMD for 20 years

> Luiz shared a downside of video amplifiers. *“I cannot use them for more than 15 or 20 minutes because it's too bright and your eyes, you*

> *cannot use that too much, and second that they get very dangerous because the delay between the camera and what you see, there are a couple milliseconds, but it's enough for you to have an accident. So, you got to be careful in using that."* - Luiz, age 61, living with dry AMD for seven years

Glasses and blue light blocking glasses. Glasses can't compensate for a lack of central vision and for some, they distort depth perception.

> *"I do have glasses. Sometimes the glasses are useful if I'm on my iPad and want to scan my emails. I can scan a group of words and get the concept out of it if I've got my glasses on."* - Tom H, living with dry AMD for more than 25 years

> *"I went and ordered blocking blue light glasses, because when I'm on my phone or I'm watching TV after a while, my eyes severely ache and they're dry. And I think the blue light has a lot to do with me*." - Wanda, age 66, living with dry AMD who is a caregiver for her mother, age 85, also living with dry AMD

While **experimental device in a clinical trial** and **retinal prosthesis** were listed as poll response options, these were not selected in the polls or mentioned during the meeting.

Adaptive strategies

Individuals living with dry AMD use many different strategies to help them adapt to vision loss and to plan and prepare for worsening vision loss in the future. These include **maintaining a positive mindset**, **identifying novel resources**, **mobility training, white canes, and learning braille**.

Maintaining a positive mindset. This includes staying hopeful.

> *"You have to figure out clever ways of dealing with things, and how to keep going and not let it get you down."* - Liz, living with dry AMD for 16 years

> *"I'm hoping technology, and time will be ahead of me, where there are options, things in the future, that will help before it gets that bad. I'm just trying to think positive as much as I can because [although] I am not at the stage that everybody else on the panel is at, but it is scary at this point."* - Wanda, age 66, living with dry AMD who is a caregiver for her mother, age 85, also living with dry AMD

Identifying novel resources. Some listen to podcasts and others have depended on a low vision therapist - an occupational therapist with a specialty in low vision – to find new strategies, tools, and tricks.

> *"Something that has been very useful for me, and informative, is finding an occupational therapist who has a specialty in low vision. … Going into their office, they had a variety of different lights, magnifiers, colored lenses to put over your glasses. And how to use my iPad, how to use my phone, how to find all of these things. ... It would've taken me forever to find [by myself]."* - Patricia, age 75, living with dry AMD for 12 years

> *"The Foundation for Fighting Blindness podcasts are absolutely great. It has been very helpful for me and I encourage everybody to listen to them."* - Luiz, age 61, living with dry AMD for seven years

> "*So, you find little tricks. Now I do all my food prep or my hobbies on cafeteria trays, because if I drop something they'll stay in the tray and then I'll be able to feel them and find them. And I don't worry about messes that I don't see on the counter or on the floor because they stay on the tray. So, you have to make adaptations*." - Robert, living with dry AMD for 20 years

Mobility training, white canes, braille. Some who are further in their dry AMD progression have started to learn to use the traditional tools of the blind.

> *"I am a great fan of a white cane. I think it's very important because when people look at you, they don't know you are blind or visually*

> *impaired, and it's a mark that will show that sometimes you do need help."* - Rosana, age 61, living with both wet and dry AMD for 16 years

> *"It's been recommended to me that I take mobility training, so I'm learning to walk with a mobility cane. … At my age, tripping is a problem, so I use the cane to see the two, three feet in front of me, and use whatever vision I get to see the general direction I'm going."* - Robert, living with dry AMD for 20 years

> *"I am quite visually impaired right now. ... I'm even just enrolled in introductory braille classes just so that I can label things and get labels in braille. Because I can't take notes anymore, so I use audio notes, but I'm learning the braille. I figure that'll be a way to keep my brain alive while I'm doing that."* – Robert, living with dry AMD for 20 years

Assistance from others

Many individuals living with dry AMD rely on their friends and family, support groups, and others who have similar issues.

Asking for help from family and friends. Individuals living with dry AMD increase their reliance on friends and family as their vision and independence diminish.

> *"I've also told my circle, my family, my friends, about my condition. And so frequently, when I am with others they offer an arm, an elbow or something. They see something ahead. And so I really try to get support as much as possible."* - Patricia, age 75, living with dry AMD for 12 years years

> *"My husband orders my books for my phone and I can make my phone calls. Fred puts my contacts in the phone, and so I can do that with Siri. … It's all about having help of my husband that is here. That keeps me going on and on and not much more."* - Joann, living with dry AMD for 25 years

Support groups and connecting with others who share similar issues. Many spoke of how important it is to connect with others with similar lived experience, not just for support but to learn new strategies as well.

> *"One of the things that I have found very useful is to find an in-person support group for low vision. So that's how I learned about a lot of the things that I use. And knowing that there are other people going through the same thing, and you can share your story, and learn how they've done adaptations. … It's nice to have a team behind you."* - Robert, living with dry AMD for 20 years

> *"In the early days of my diagnosis, I looked for support from others facing similar challenges. Unfortunately, there were no local support groups available, so I co-founded the Mid-South Chapter of the Foundation Fighting Blindness. The relationships and support that I received through this group went a long way toward helping me adapt to my situation."* - David, age 74, living with dry AMD for over 20 years

> *"I met a friend with the same problem. So we share experiences, like how to put toothpaste on a toothbrush, or how to know what's on my plate when dining out. … I think it's really important to [know someone else] that counts steps all the way because you feel you are not alone."* - Rosana, age 61, living with both wet and dry AMD for 16 years

Poll 7 & 8

An enormous unmet need exists for treatments that stop the progression of dry AMD.

Meeting attendees used online polling to first indicate how well their current treatment regimen addresses the most significant dry AMD symptoms, and then to select the top three biggest drawbacks of current treatment approaches. The results of both polls are shown in **Appendix 5 Q7 & Q8**. Poll responses for both Q7 and Q8 are consolidated below.

Not very effective at treating the target symptom

Not very effective at treating the target symptom was a top downside selected in the poll. This aligns closely with the top response to the poll question, “How well does your current treatment regimen control the condition overall?”, which was **somewhat**. Throughout the meeting, many individuals spoke about how **they were not offered any treatments** and **could not tell if treatments were working**. Even if treatments or other approaches do work, it **isn’t the same as having your vision**.

> Joann is seen at a large ophthalmology practice every four to six months. *”I can’t say that I really get a lot of help. …My ophthalmologist a few years ago tried several ... injections, and I have no idea what it was, but it obviously did not result in any kind of improvement.”* – Joann, living with dry AMD for 25 years
>
> Despite several Syfovre injections, the dry AMD in Diane’s left eye progressed rapidly from 20/200 to 20/300. “*That was so hard to hear. I mean, I knew it was getting worse but it was frightening. I could barely read the chart.”* Four weeks later, *“My vision was then 20/350. It was progressing.”* – Diane, age 77, living with dry AMD for 24 years

Although many have positive experiences with assistive devices such as wearable video magnifiers, these do not replace vision.

> *“Well, they help in some ways. You get the idea that if you get new glasses or you get some new device and it’s going to return everything the way it used to be when you remembered you have good vision and it’s not quite true.”* – Robert, living with dry AMD for 20 years

Route of administration

Route of administration ranked high as a treatment downside in the poll responses. This was mostly related to the fear of receiving intravitreal injections, however, most individuals who received the injections reported that they were painless.

> *“The idea of getting monthly shots in my eyes is really quite terrifying.”* - Patricia, age 75, living with dry AMD for 12 years

> Rob originally thought that the idea of getting injections was “abhorrent” but changed his mind after experiencing them. “*The injections in the eye are tolerable. The washing and desensitizing are annoying, and the shot - though is psychologically difficult - is not a big deal. Shame on me for thinking it was. If a flu shot is a ‘one’, this is a ‘two’.”* - Rob, living with both wet and dry AMD for 12 years

> Although Pete is someone who is extremely sensitive about his eyes, “*I went in and gosh, it really isn't that bad.*" - Pete, age 77, living with dry AMD for 30 years

Limited availability or accessibility of treatments

There are few treatments available for dry AMD. Many living with dry AMD have disease that has progressed too far to be eligible for recently approved treatments. Others find it hard to get to the treatment because of the distances that they need to travel and can no longer drive. For some, the treatment options are costly.

> David’s eye specialist wouldn’t recommend injections for him. *“She wouldn't recommend the treatment, feeling that the efficacy didn't outweigh the risks, at least for me. ... I'm not aware of any other treatments for AMD. I sure wish there were.”* - David, age 74, living with dry AMD for over 20 years

> Rob finds it hard to travel for treatment. *“In my case, access to the specialist giving the drug is a real problem. He's about an hour and a half away, so between the commuting and the office visit, it just about ruins the entire day. Not to mention the cost of the Ubers.”* - Rob, living with both wet and dry AMD for 12 years

> *“There are two choices. One costs a couple thousand dollars each shot and the other one's like $50.”* - Tom H, living with dry AMD for more than 25 years

Other downsides selected in the polls

Meeting attendees using online polling to select other drawbacks to treatment options include **only treats some but not all symptoms, requires too much effort and/or time commitment**, **side effects**, and **not applicable as I am not using any treatments**. A downside mentioned throughout the meeting was that individuals **can’t tell if treatment is working or not.**

> *“Recently, my doctor said that I should retire AREDS because it was not making any impact, and in fact because I started losing [my central vision]. …It's very hard to see what's helping or not. At the end of the day, what you want is at least to delay the process. In my case, [dry AMD] is very aggressive, … so I don't know [if the vitamins are] helping or not.”* - Luiz, age 61, living with dry AMD for seven years

> *“I'm about three months into the eye injections. Are they working? That's a good question as it is far too early to tell. I only hope that what was proven during the clinical trial works for me. The good news is my specialist says the effectiveness numbers [from clinical trials] are coming in even better now. And even more encouraging, a friend in Texas reports that after six months, his specialists think disease has stopped or seriously stalled. That gives me even more hope.”* - Rob, living with both wet and dry AMD for 12 years

> *“I am fortunate that I've been on Syfovre for a full year. … I don't know how well I'm doing. … I tell my wife one day ‘I feel really good’, another day, ‘gosh, everything seems to be going worse on me’, and because all it's doing is slowing progression and I don't know what progression would be, it kind of leaves me kind of hanging.”* - Pete, age 77, living with dry AMD for 30 years

Poll 9

Short of complete restoration of their vision, people living with dry AMD have many wishes for future treatments, including stopping or slowing progression and preventing further vision loss.

Throughout the meeting, individuals living with dry AMD described what they wished for in future treatments and also identified some gaps in the dry AMD management landscapes that need to be addressed. While some described their hopes, they also acknowledged that these new treatments were unlikely to appear in their lifetimes.

> *"One of the ophthalmologists told me probably 25 years ago, 'Pete, there's going to be a cure for this, just not in your lifetime,' and I'm 77. I'm seeing my lifetime get shorter, but I'm seeing the distance between those cures or other things coming. So, I'm excited to see what's coming."* - Pete, age 77, living with dry AMD for 30 years
>
> Diane's vision is diminishing faster than the drugs can help. *"I'm a realist and I think hope is important, but again, with all the research that I've done, I've read about gene therapy, stem cell therapy... They're way down the line. At 77, I don't think there will be a treatment available for me."* - Diane, age 77, living with dry AMD for 24 years

To stop or slow progression and further vision loss

Most want to slow vision loss and prevent further macular deterioration. Several even hope that their vision can be restored.

> *"I have started on a shot for only my left eye. ... But right now, the hope is that it just slows down the aggregation of the macula. And if it does that, I'd be happy…If [dry AMD] would stop now, it means I could continue to live the way I'm doing right now."* - Lynne, age 85, living with dry AMD

Luiz wants to slow or even reverse vision loss. *"Of course that's the dream of everybody. But I'm optimistic. I still hope I'll see the face of my grandkids and I'll be able to look at myself in the mirror and I'll be able to pick my clothes and make color matching in a better way."* - Luiz, age 61, living with dry AMD for seven years

Better ways to measure both progression and the slowing of progression

"I'd like to see a way to measure [the slowing of progression] better. My doctor said that if I hadn't had [Syfovre], I would have been legally blind in five years. 'With this, you might have a couple more years.' I'd like to be able to measure that." - Pete, age 77, living with dry AMD for 30 years

Treatment to address flashes

"I am too late in the process to wish for [progression] stopping or the cure. ...I would love to get rid of the flashes that are flashing 24/7, either if my eyes are open or closed, I sleep with flashes, everything flashes. It's too psychedelic for me. I would love to get rid of that."- Rosana, age 61, living with both wet and dry AMD for 16 years

A cure and a way to prevent dry AMD for future generations

"My dream would be that using our own stem cells would reverse and grow back those photoreceptors. That's quite a dream, but that would be miraculous and wonderful if something like that could happen. …I know it's not going to come in time for me, but if I pass this [gene] on to any of my grandchildren, I say by then, I think there will be something that would counteract [dry AMD]." - Joann, living with dry AMD for 25 years

An alternate administration strategy

> *"A pill to replace the injections and if nothing else, a more powerful drug to lessen the frequency of injections."* - Rob, living with both wet and dry AMD for 12 years

Opportunities to participate in studies and clinical trials

Many living with dry AMD would like to accelerate clinical development for treatments that would help stop the progression. Several patients discussed the amount of risk that they were willing to undertake in clinical trials.

> *"I continue to be on the lookout for studies or clinical trials related to Dry AMD. …My criteria though for evaluating the risk versus rewards when experimenting with these treatments probably has changed over the years. Previously, I would've been more anxious to try treatments that would slow the progression. However, given the more advanced stage of my disease now, I'll focus more on treatments that might halt or reverse the progression. With so many people suffering from this disease at each of its stages, desperately hoping for help, new treatments are needed to attack the disease from every angle. I continue to hope and pray."* - David, age 74, living with dry AMD for over 20 years

> *"If I had my two eyes with dry AMD, I would try whatever in one eye. I don't have that. So I'm pretty much conservative now. I prefer to not do any trial. My personal opinion."* - Rosana, age 61, living with both wet and dry AMD for 16 years

Earlier testing and identification of dry AMD

> *"I was asked what else I would like if I can't have a cure. The first thing would be a test to find this problem much earlier."* - Rob, living with both wet and dry AMD for 12 years

> *“One of the things that I think is really important is early testing. …And so, early testing by a retinologist particularly, would be important for people whose family has the condition.”* - Susie, age 78, living with dry AMD

More public education and awareness of dry AMD

> *“I'd like to see more public education. [Dry AMD] is growing so much and yet nobody I really talk to understands what all of us here are going through. I mention it to somebody and the standard comment is, ‘Oh yeah, my 90-year-old grandmother had that. Oh, she was fine.’ And that's all I ever get about macular degeneration and nobody knows what geographic atrophy is.”* - Pete, age 77, living with dry AMD for 30 years

Incorporating Patient Input into a Benefit-Risk Assessment Framework

The dry AMD EL-PFDD meeting helped to increase the understanding of how this disease impacts those living with the disease and their loved ones. The meeting also reinforced the continued unmet medical need in this community. **Table 1** speaks to the disease burden that patients living with dry AMD endure. It serves as the proposed introductory framework for the Analysis of Condition and Current Treatment Options to be adapted and incorporated into the FDA's Benefit-Risk Assessment. This may enable a more comprehensive understanding of these disorders for key reviewers in the FDA Centers and Divisions who would be evaluating new treatments for dry AMD. The data resulting from this meeting may help inform the development of dry AMD-specific, clinically meaningful endpoints for current and future clinical trials, as well as encourage researchers and industry to investigate better treatment.

The information presented captures the perspectives and collective hopes of people living with dry AMD for future research and successful new product development. Note that the information in this sample framework is likely to evolve over time.

> *"How is it that a disabling disease continues unabated despite robbing sight from some 20 million people in the United States and over 200 million worldwide? And taking into consideration the lost useful productivity of this population, it represents huge opportunity costs to individuals, families, and society. … It's a loss. All of us still have good minds, and we want to be good participants in society, in our communities."* - Patricia, age 75, living with dry AMD for 12 years

> *"I work in healthcare and I've seen miracles that happen. I believe in science and our ability to find effective and safe treatments, but I also know how hard it is. My hope is just that a medical breakthrough is on the near horizon for me and all those who suffer from retinal disease."* - Sean, living with dry AMD for eight years

TABLE 1: Benefit-Risk Table for Dry Age-Related Macular Degeneration (AMD)

	EVIDENCE AND UNCERTAINTIES
ANALYSIS OF CONDITION/ IMPACTS ON ACTIVITIES OF DAILY LIVING	Dry age-related macular degeneration (AMD) is a progressive degenerative retinal disease, typically presenting with visual deficits in the central retina (macula). The disease can be caused by both lifestyle and genetic factors; many described how a parent also had dry AMD. **AMD is a condition affecting millions globally. In the United States, over 20 million were estimated to be living with the disease in 2019. Due to increasing lifespans, these numbers are expected to increase in the future.** Most living with dry AMD experience difficulties seeing in low light conditions, blurry/obstructed central vision, and eventually, severe vision loss. They can experience light sensitivity, flashes, visual distortions, and even visual hallucinations.
CURRENT TREATMENT OPTIONS/ PROSPECTS FOR FUTURE TREATMENTS	Until recently, most diagnosed with dry AMD were offered no treatment except vitamins. Despite the very recent approval of two FDA-approved therapies for dry AMD, there is still a tremendous unmet medical need for treatment to stop the progression of dry AMD. Those living with dry AMD must rely on devices/technologies, adaptive strategies, and assistance from others. None of these approaches replaces vision.

TABLE 1: Continued

	CONCLUSIONS AND REASONS
ANALYSIS OF CONDITION/ IMPACTS ON ACTIVITIES OF DAILY LIVING	Dry AMD has a heavy disease burden. Along with their vision, those living with dry AMD lose many important activities of life, which can impact identity. Many describe their life "before" and "after" dry AMD. As they lose the ability to recognize familiar faces, drive, read, watch TV, or use screens, they become increasingly dependent on others. Many living with dry AMD feel anxious and depressed as a result of their progressive vision loss, and experience social isolation, and loneliness. They have many worries about the further loss of their independence, how the disease will progress, and losing more of their abilities and activities as their vision diminishes.
CURRENT TREATMENT OPTIONS/ PROSPECTS FOR FUTURE TREATMENTS	In the absence of a cure, individuals living with dry AMD want to stop or slow disease progression and further vision loss. They need better ways to measure progression and a treatment to address flashes. They highlighted the need for earlier testing, more opportunities to participate in studies, and an acceleration of the drug development and approval process. Some want more public awareness about dry AMD.

Appendix 1: EL-PFDD for Dry AMD Meeting Agenda

March 1, 2024, 10:00 AM-3:00 PM EST

10:00 – 10:05 AM	Welcome and Opening Remarks: Todd Durham, Ph.D., Senior Vice President, Clinical & Outcomes Research, Foundation Fighting Blindness
10:05 – 10:15 AM	FDA Remarks - The Role of Patients in Drug Development: Tracy Gray, Health Scientist, Patient Engagement Lead, Patient Science & Engagement, CDRH
10:15 – 10:30 AM	Clinical Overview of Dry AMD: Emily Chew, M.D, Director of the Division of Epidemiology and Clinical Applications, National Eye Institute, National Institutes of Health
10:30 – 10:35 AM	Overview of Discussion Format: James Valentine, J.D., M.H.S., HPM, Meeting moderator
10:35 – 10:40 AM	Audience Demographic Polling Questions

Morning Session: Living with Dry AMD - Symptoms and Daily Impact

10:40 – 11:05 AM	Panel 1: Patient & caregiver perspectives on symptoms and daily impacts - 5 prerecorded panelists
11:05 – 12:30 PM including:	Audience Discussion and remote polling on Topic 1 • 5 Discussion starters via Zoom • Audience remote polling • Moderated audience discussion
12:30 – 1:00 PM	Break

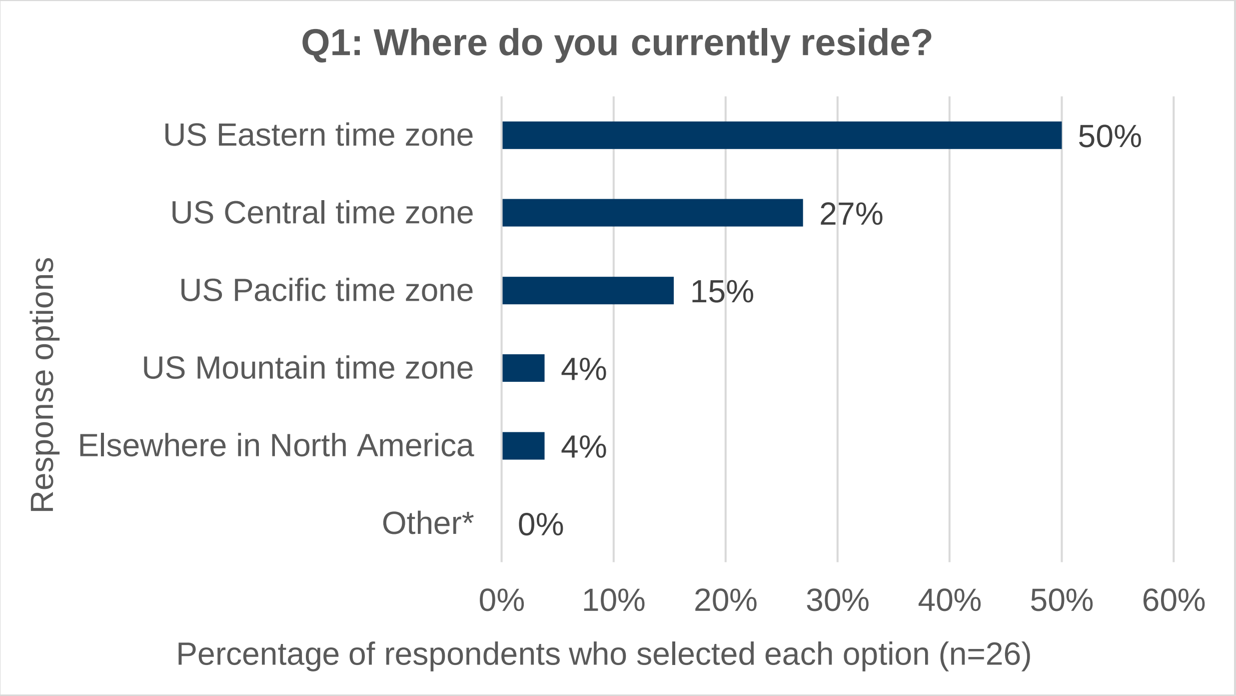
Afternoon Session: Current & Future Approaches to Treatment for Dry AMD

1:00 – 1:05 PM	Introduction to Session 2
1:05 – 1:15 PM	Treatment and Management of Dry AMD: David S. Boyer, M.D., Retina-Vitreous Associates Medical Group
1:05 – 1:15 PM	Panel 2: Patient & caregiver perspectives on current and future treatments - 5 prerecorded panelists
1:30 – 2:45 PM including:	Audience Discussion and remote polling on Topic 2 • 5 Discussion starters via Zoom • Audience remote polling • Moderated audience discussion
2:45 – 2:55 PM	Meeting Summary: Larry Bauer, RN, MA, HPM
2:55 – 3:00 PM	Wrap Up and Thank You: Todd Durham, Ph.D., Foundation Fighting Blindness

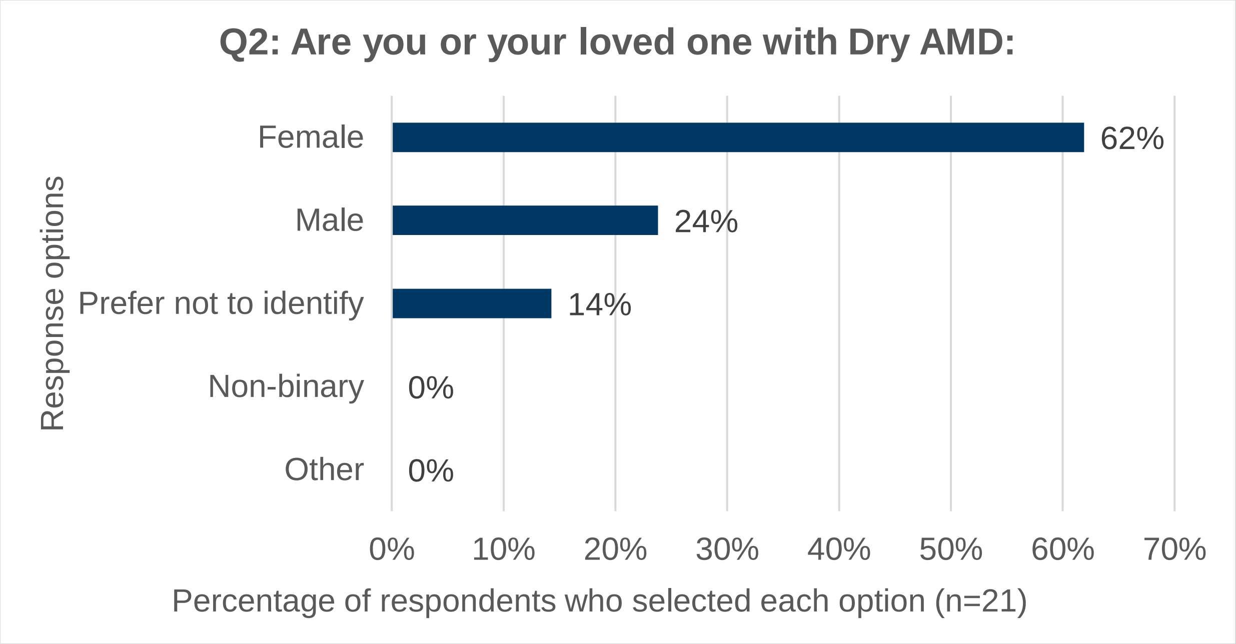
Appendix 2: Demographic questions

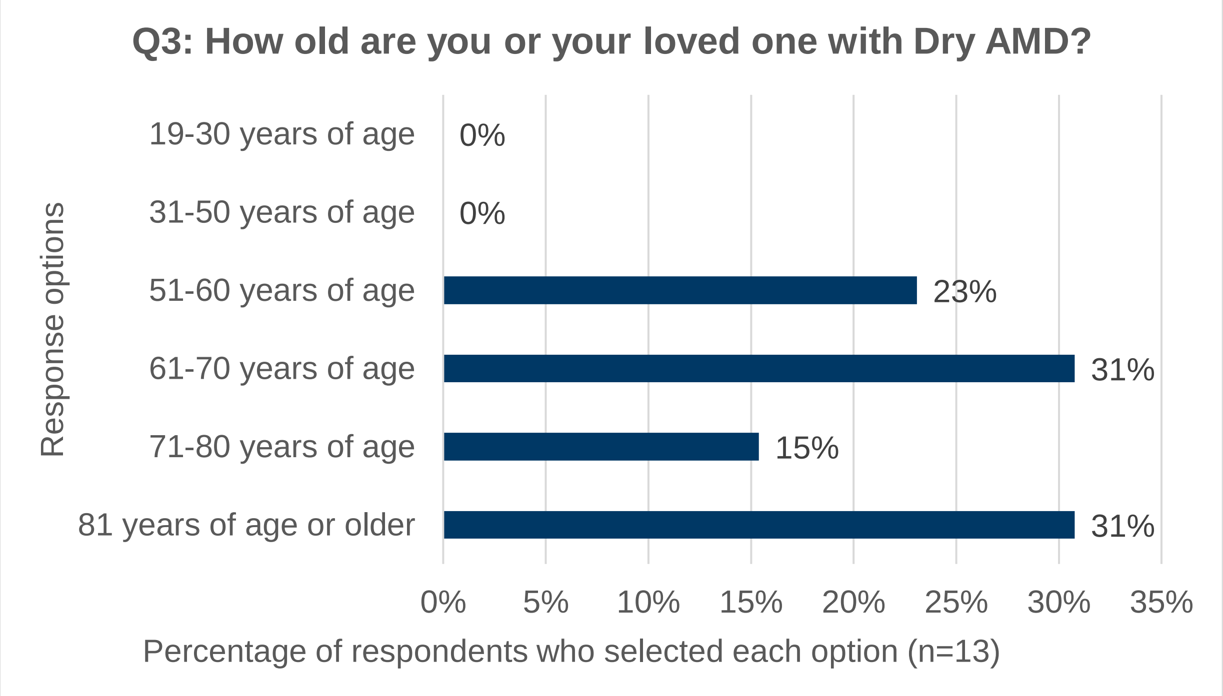
The graphs below include patients, parents and caregivers who chose to participate in online polling at the March 1, 2024, meeting. The number of individuals who responded to each polling question is shown below the X axis (N=x).

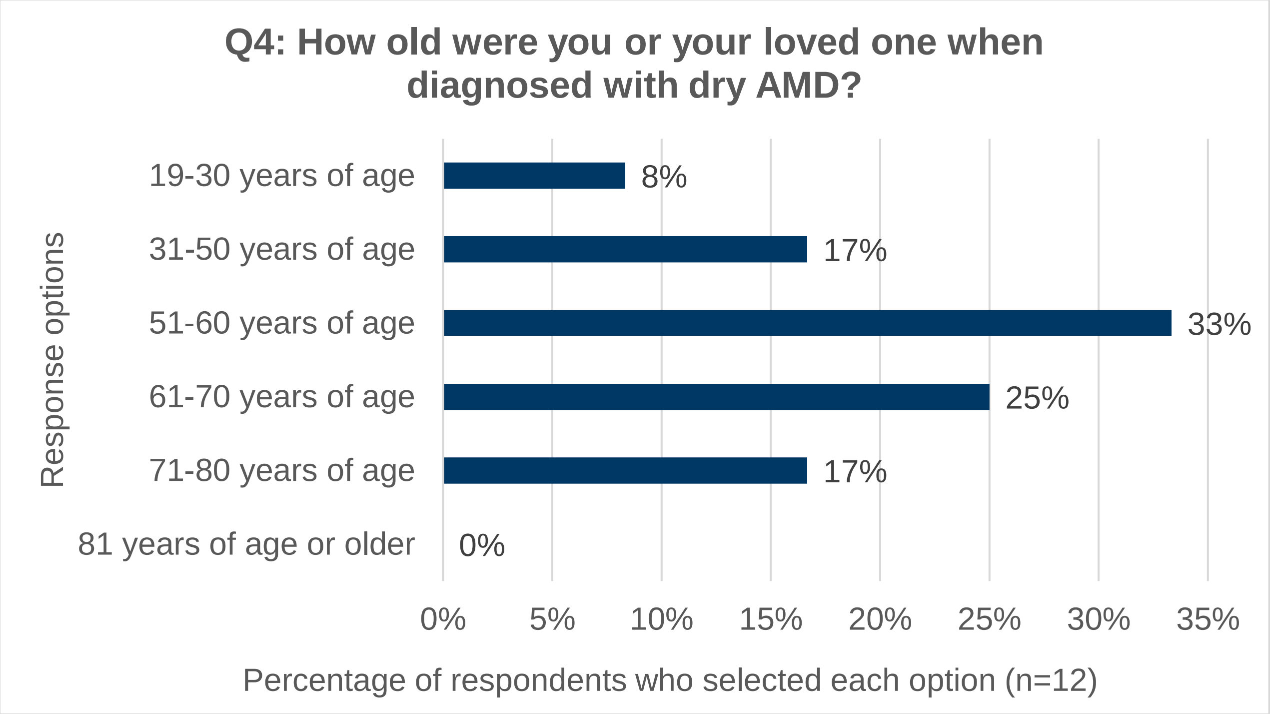
While the response rates for these polling questions is not considered scientific data, it provides a snapshot of those who participated in the DRY AMD EL-PFDD meeting. Note that meeting demographics are dynamic and may have changed as more individuals joined the meeting.



*Includes US Alaska or Hawaii time zones and Europe.


Q2: Are you or your loved one with Dry AMD:
Response options
Female
62%
Male
24%
Prefer not to identify
14%
Non-binary
0%
Other
0%
0%
10%
20%
30%
40%
50%
60%
70%
Percentage of respondents who selected each option (n=21)


Q3: How old are you or your loved one with Dry AMD?
Response options
19-30 years of age
0%
31-50 years of age
0%
51-60 years of age
23%
61-70 years of age
31%
71-80 years of age
15%
81 years of age or older
31%
0%
5%
10%
15%
20%
25%
30%
35%
Percentage of respondents who selected each option (n=13)


Q4: How old were you or your loved one when diagnosed with dry AMD?
Response options
19-30 years of age
31-50 years of age
51-60 years of age
61-70 years of age
71-80 years of age
81 years of age or older
8%
17%
33%
25%
17%
0%
0%
5%
10%
15%
20%
25%
30%
35%
Percentage of respondents who selected each option (n=12)

Appendix 3: EL-PFDD Panelist and Callers

Session 1: Pre-Recorded Panelists
- Rosana, age 61, living with both wet and dry AMD for 16 years
- Sean, living with dry AMD for eight years
- Gail, age 73, living with both wet and advanced dry AMD for 14 years
- Tom C, age 74, living with dry AMD
- Ken, age 73, living with dry AMD for 23 years

Session 1: Zoom Panel
- Susie, age 78, living with dry AMD
- Patricia, age 75, living with dry AMD for 12 years
- Robert, living with dry AMD for 20 years.
- Liz, living with dry AMD for 16 years
- Wanda, age 66, living with dry AMD who is a caregiver for her mother, age 85, also living with dry AMD

Session 1: Callers
- Rob, living with both wet and dry AMD for 12 years

Session 2: Pre-Recorded Panelists
- Tom H, living with dry AMD for more than 25 years
- Diane, age 77, living with dry AMD for 24 years
- David, age 74, living with dry AMD for over 20 years
- Patricia, age 75, living with dry AMD for 12 years
- Rob, living with both wet and dry AMD for 12 years

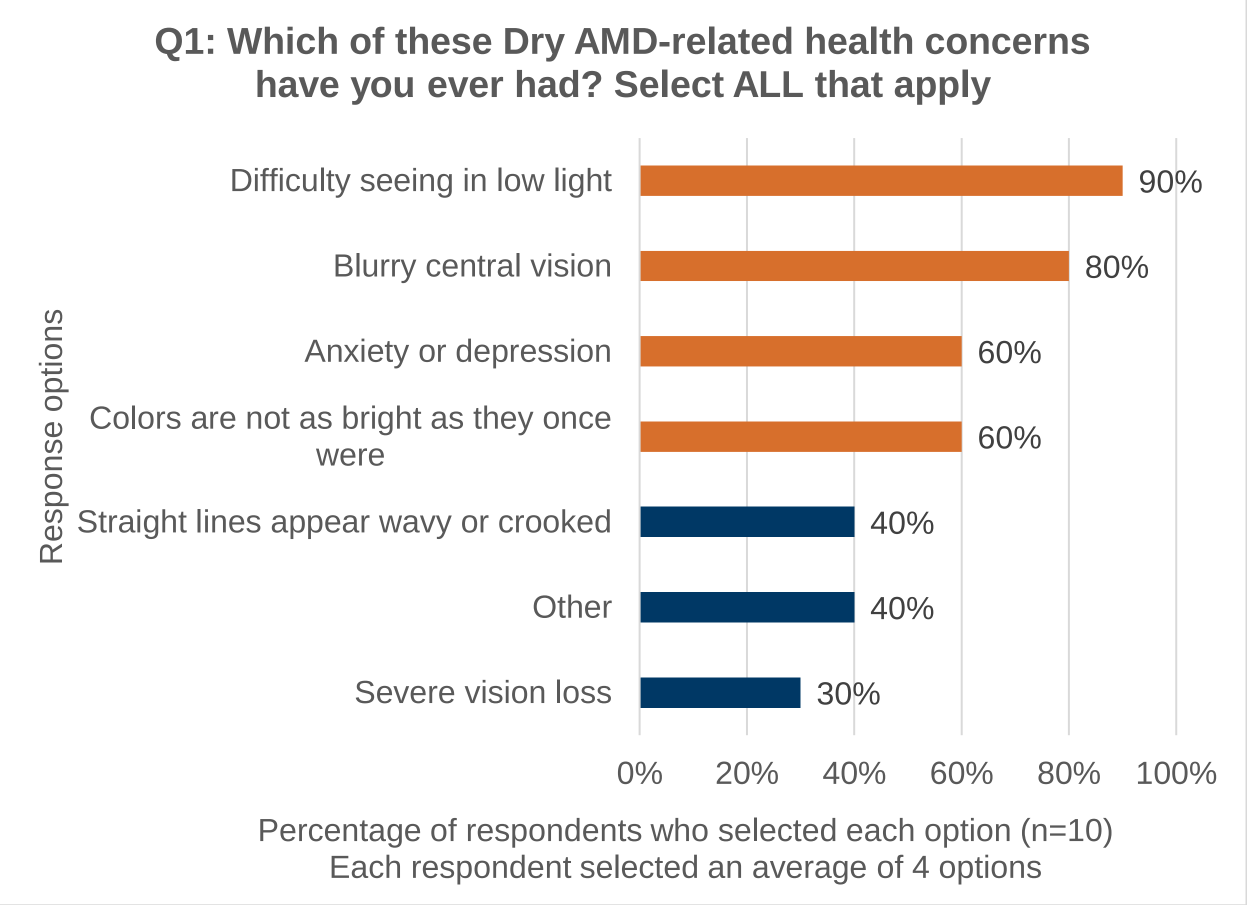
Session 2: Zoom Panel
- Lynne, age 85, living with dry AMD
- Luiz, age 61, living with dry AMD for seven years
- Pete, age 77, living with dry AMD for 30 years
- Joann, living with dry AMD for 25 years and her husband Fred
- Rosana, age 61, living with both wet and dry AMD for 16 years

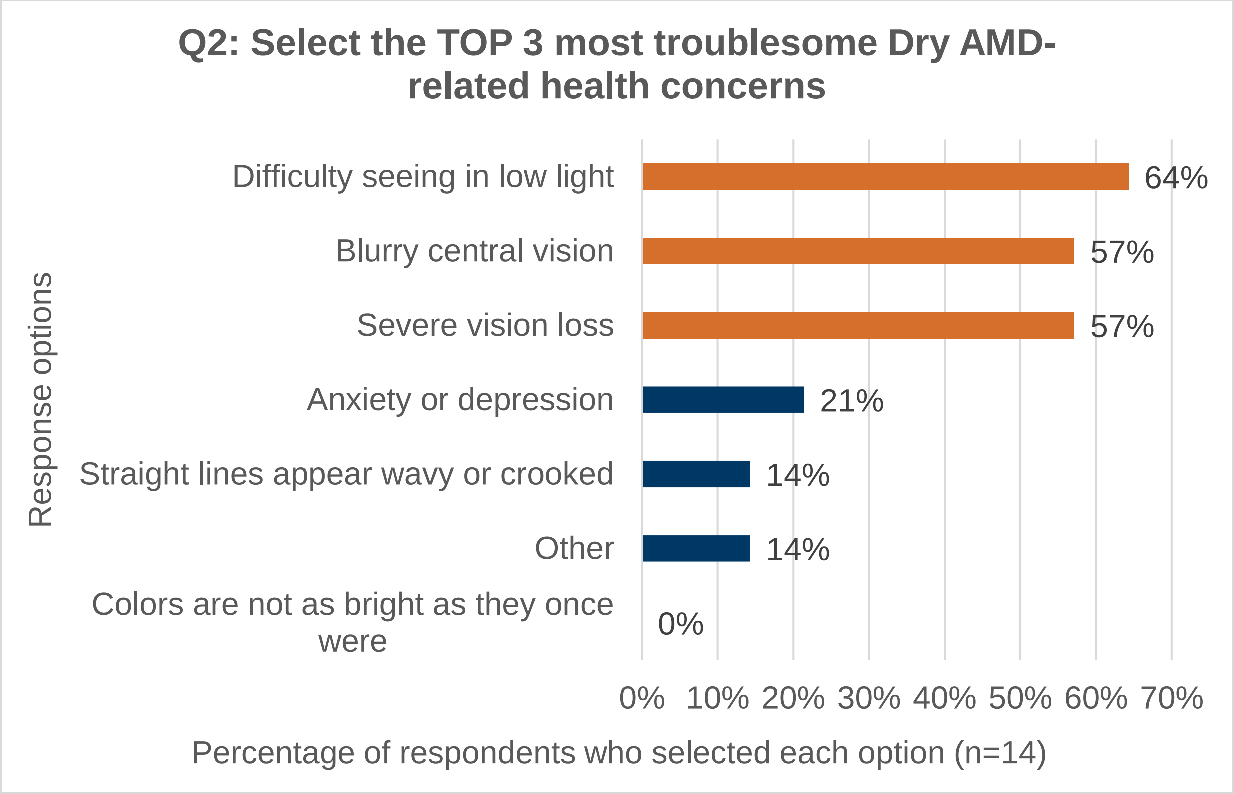
Session 2: Callers
- Robert, living with dry AMD for 20 years

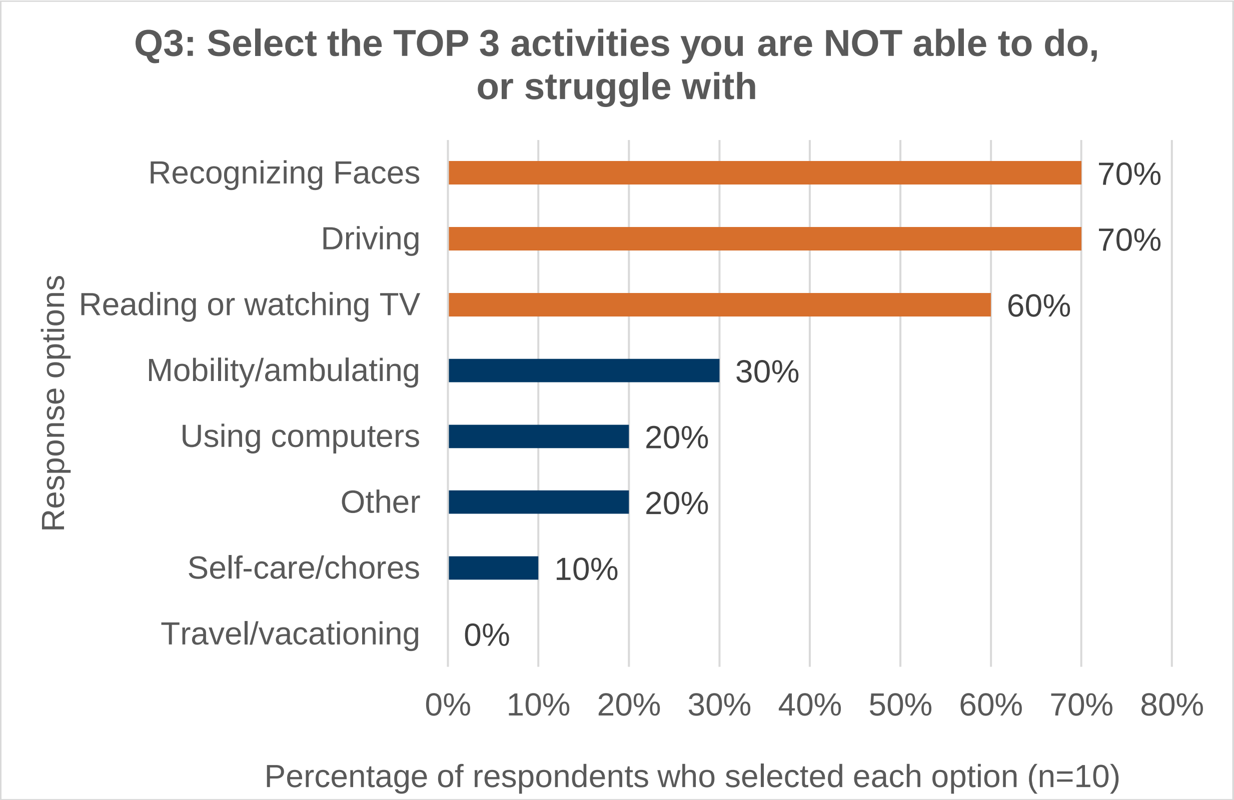
Appendix 4: Meeting Poll Results

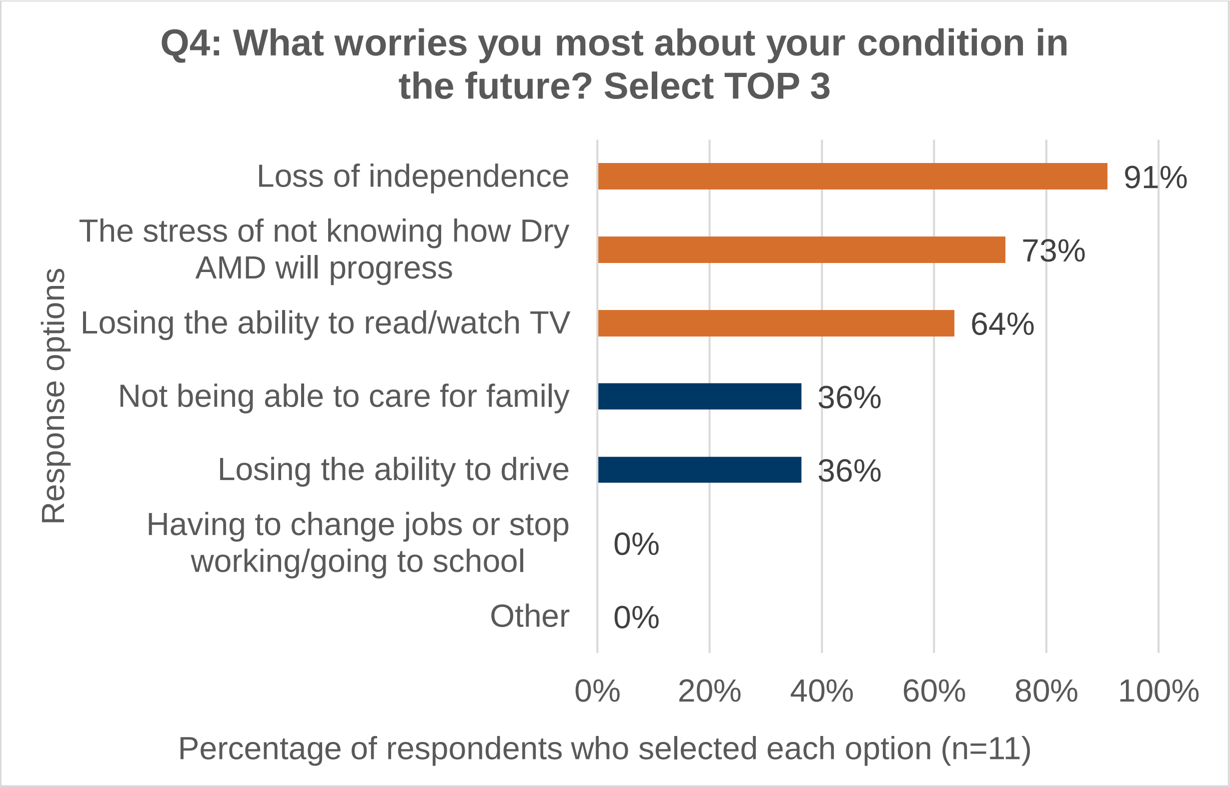
The graphs below include patients, parents and caregivers who chose to participate in online polling during sessions 1 and 2. The number of individuals who responded to each polling question is shown below the X axis (N=x). The responses for these polling questions are not considered scientific data. These are intended to complement the patient comments made during and after the meeting.

Response options selected by more than 50% of poll respondents are shown in **orange.**

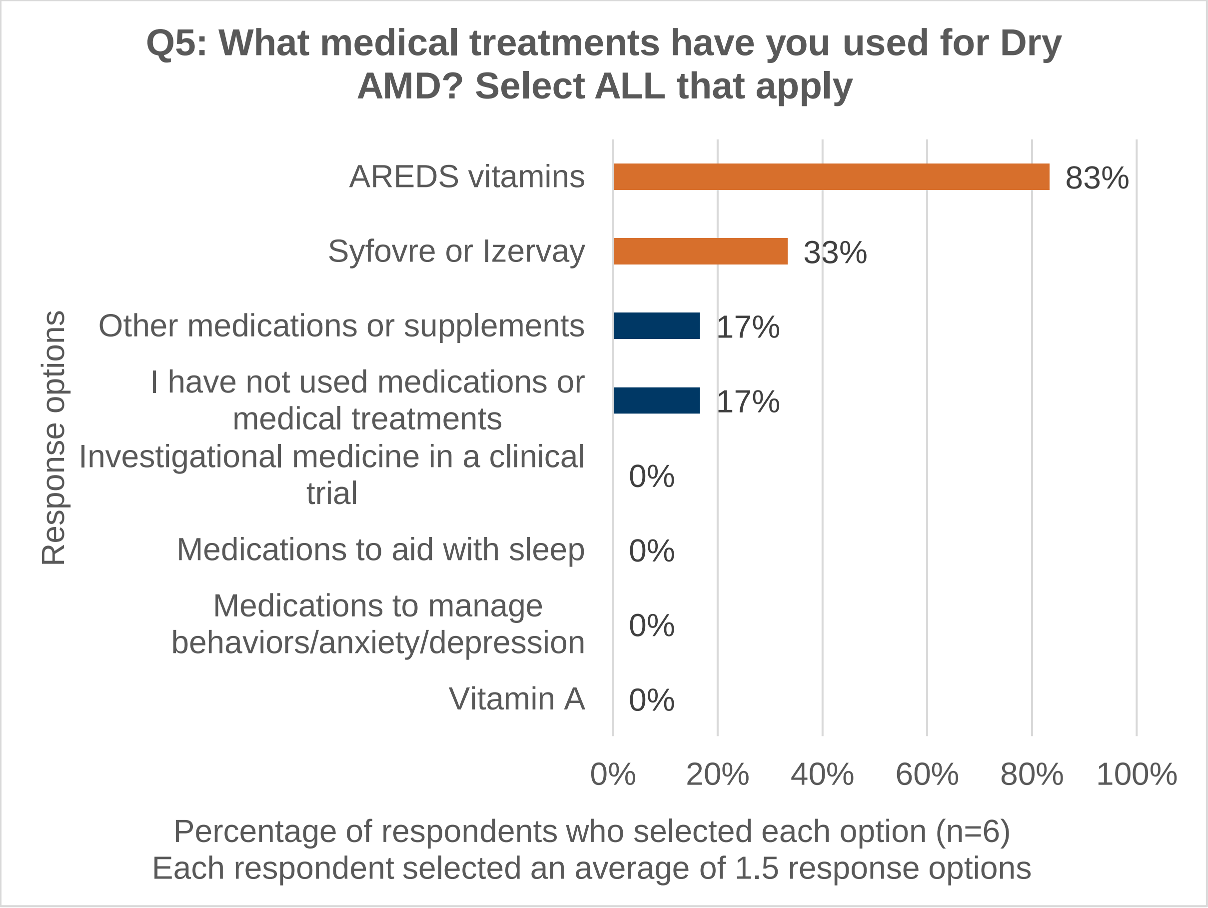



Q2: Select the TOP 3 most troublesome Dry AMD-related health concerns

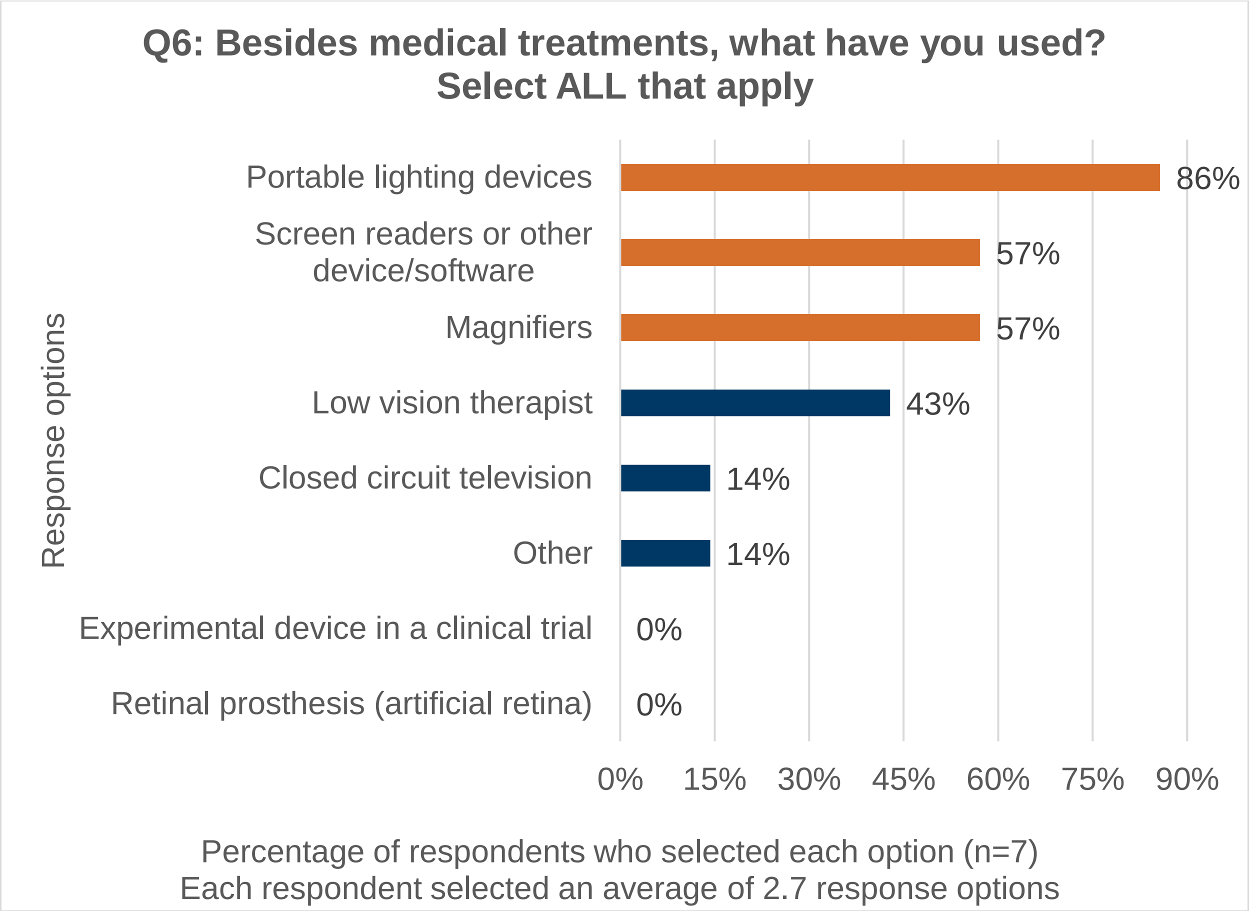

Q3: Select the TOP 3 activities you are NOT able to do, or struggle with



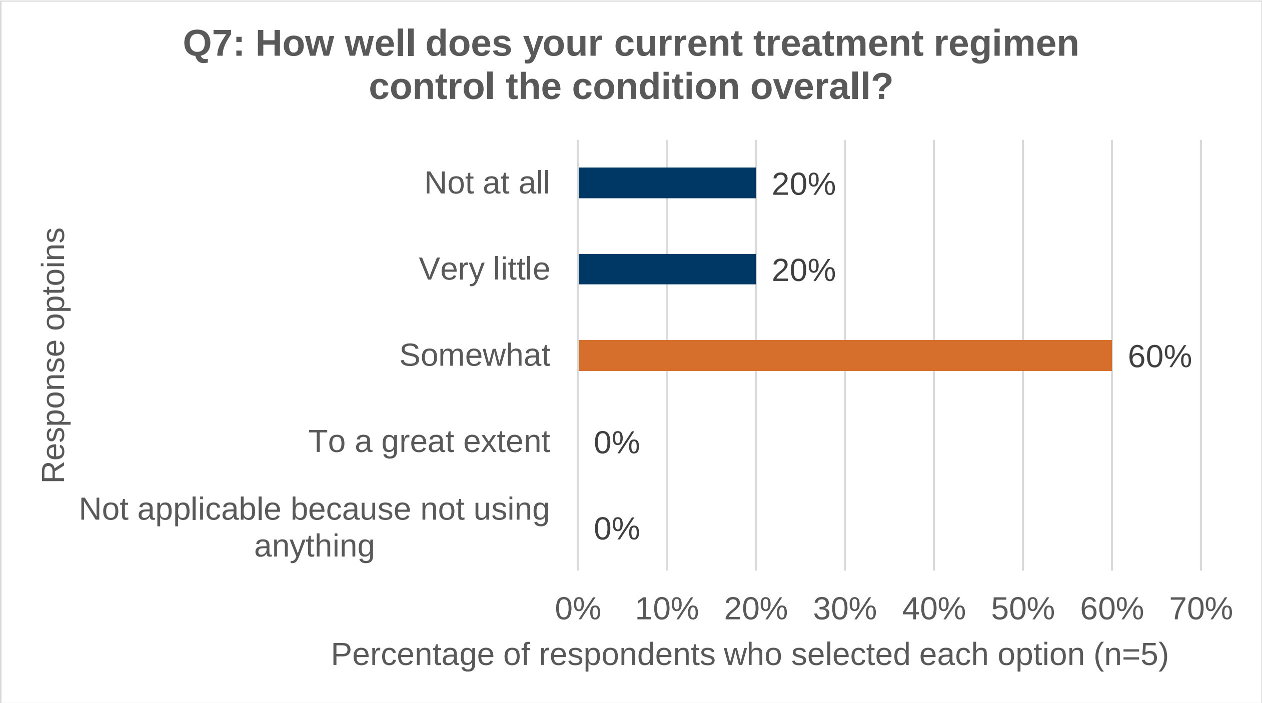
Q4: What worries you most about your condition in the future? Select TOP 3



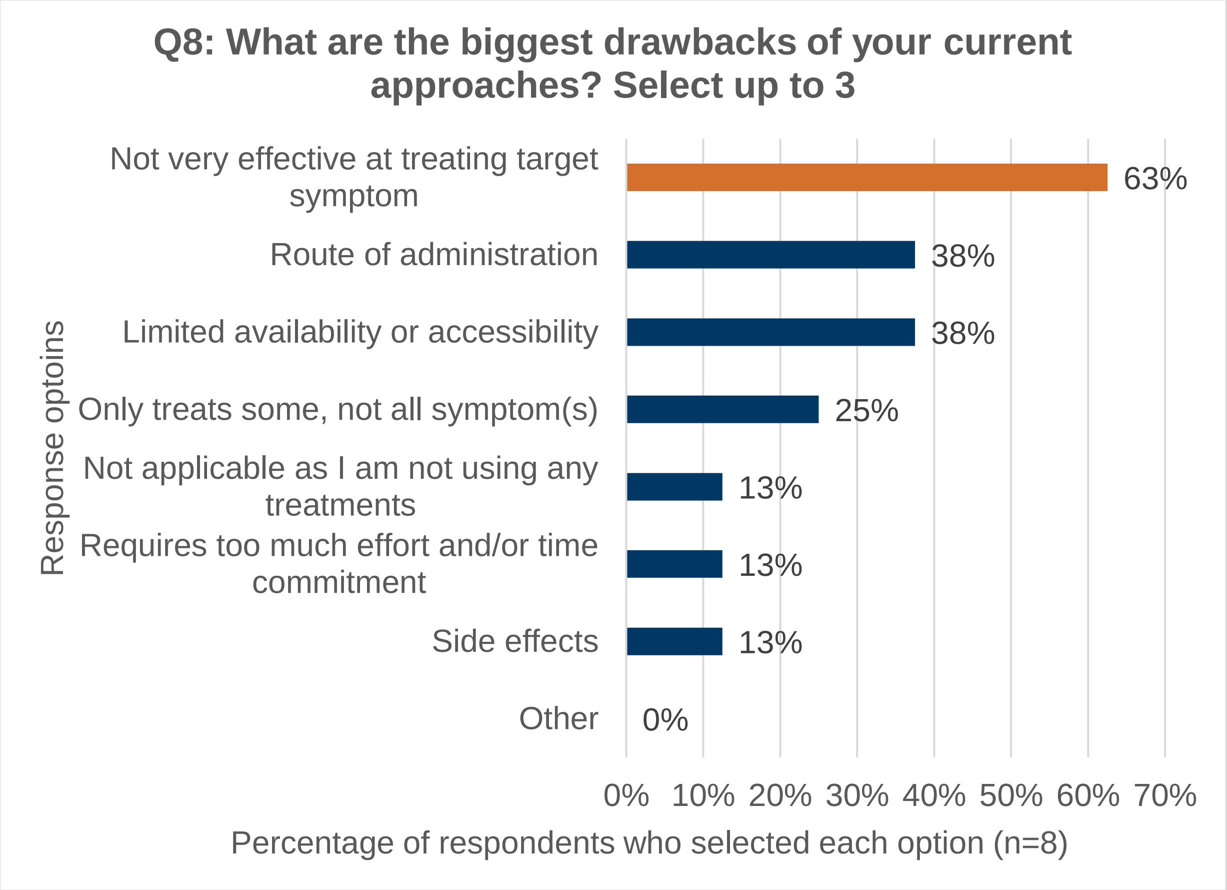
Q5: What medical treatments have you used for Dry AMD? Select ALL that apply



Q6: Besides medical treatments, what have you used? Select ALL that apply



Q7: How well does your current treatment regimen control the condition overall?


Q8: What are the biggest drawbacks of your current approaches? Select up to 3
Response optoins
Not very effective at treating target symptom
Route of administration
Limited availability or accessibility
Only treats some, not all symptom(s)
Not applicable as I am not using any treatments
Requires too much effort and/or time commitment
Side effects
Other
63%
38%
38%
25%
13%
13%
13%
0%
0%
10%
20%
30%
40%
50%
60%
70%
Percentage of respondents who selected each option (n=8)

Appendix 5: Additional Patient Comments

To include as many patient voices and perspectives as possible, patient comments were collected through an online comment submission portal before, during and for four weeks after the meeting. All submitted patient comments are compiled in this appendix, with selected comments included in the main body of the *Voice of the Patient* report.

Robert, living with dry AMD for 20 years

For years my eye care professionals said the only thing to do was to take a supplement. Finding assistive devices and technology was never suggested. Now I depend on the support of others with low vision for support and to maintain an independent life.

Rosana, age 61, living with both wet and dry AMD for 16 years

IS ONLY LOW LIGHT A PROBLEM? NO! THINGS CHANGE DURING THE DEVELOPMENT OF THIS DISEASE

IT STARTS WITH LOW LIGHT, THEN, BRIGHT LIGHT, GREY BACKGROUNDS, MIX OF LIGHT AND SHADOW, UNTIL YOU REALIZE YOU NEED TO GIVE UP THINGS YOU ARE USED TO.

Gail, age 73, living with both wet and advanced dry AMD for 14 years

Hi, it's Gail, who you already know from my video. I didn't mention that AMD with atrophy caused me to give up singing in a semi-professional choral group, which I'd done for twenty years. If you can't read, you can't read music. This has been a major loss in my life.

Pete, age 77, living with dry AMD for 30 years

Everyone so far seems to have central vision issues. I’m completely different. I have what was called non-central GA or my RS donut hole GA. I see very well in the very central but difficulties in other areas.

Thomas, family member of someone living with wet AMD

Someone mentioned seeing something that is not really there. My sister-in-law has RP and has severe vision loss. She experiences Charle Bonnet Syndrome and has hallucinations. My 95 yo Aunt has wet AWD in both eyes and late at night will see someone in the room with her or suddenly flowers on the wall. Her retinal doctor discussed with her to her relief.