Macular Disease Foundation AUSTRALIA

VisionVoice

Summer Edition 2021

Election '22: Your voice matters

MDFA continues to call for affordable eye injections as Australians prepare to go to the polls.

Many readers have been following with interest MDFA's work in advocating against a proposed cut to the Medicare rebate for eye injections. But the problem is bigger than the rebate.

This sight-saving treatment is primarily provided in private clinics with only 18–20% provided in a very limited number of public hospitals or bulk-billed services in private clinics.

Treatment costs vary but a recent MDFA survey has shown that patients receiving eye injections spend an average of $1,900 out-of-pocket costs per annum or $3,800 if both eyes need treatment (excluding travel costs for those living in rural or regional locations).

As most patients need up to six treatments per year, our surveys have consistently shown that the primary barrier to remaining on treatment is the ongoing out-of-pocket costs.

In our last survey, 29% of respondents considered delaying or stopping treatment while one in 20 had actually delayed or stopped treatment due to cost alone.

With the next Federal election expected between March and May 2022, there's no better time to amplify this issue so that the next 47th Parliament can address these challenges.

(continued page two)

Let's do this together – 47 Reasons

As the next Federal election will form the 47th Parliament, we want to bring to life the challenges of accessing sight-saving injections from every corner of Australia.

Our Parliamentarians understand the power of people and we want to share your stories with them, so we can make real change together.

We are looking for 47 of your stories – **47 Reasons** – why access to affordable eye injections is important to you.

We want to hear how you have benefited from treatment, and the struggles and sacrifices you make to afford ongoing treatment. Share your story, comments, testimonials, letters, audio messages or video footage with us.

While 47 stories will be the face of the MDFA campaign, every voice will be heard when we speak with Government.

You can choose to keep your story anonymous but we would like to share the State or Territory where you live.

(continued page two)

CEO Update

As we come to the close of another year navigating the challenges of the COVID-19 pandemic, I hope that we can all look towards the future with renewed hope for better times ahead.

At this time of the year, we often take the opportunity to review the past 12 months' achievements, many of which you will read about in this newsletter, and in our newly published 2020-21 Annual Report.

2021 also marks the end of our three-year strategic plan and we have developed an Impact Report which showcases our key achievements over this period of growth and development.

In writing this report, I could not help but be proud of the tremendous work of the MDFA team in delivering so many great results.

For a small organisation of 20 staff, we have done much to improve our technical capabilities to reach more people at risk of macular disease, and our ability to provide quality support for those living with macular conditions has been exemplary.

We have also made positive inroads to represent your voice to Government, and the collectively endorsed Strategic National Action Plan for Macular Disease now provides the blueprint for the eye health ecosystem to work together to fast-track better outcomes for the community.

I invite you to view the latest Annual Report and the three-year Impact Report 2018-2021 on our website at www.mdfoundation.com.au.

On behalf of the Board and staff of MDFA, we extend our sincerest thanks for your trust and your generous support over this year, and we wish you a happy and healthy festive season.

Dee Hopkins
CEO, Macular Disease Foundation Australia

Election '22 cont'd.

We want to ensure that more patients will benefit from sight-saving treatment and have the peace of mind to know they can retain their sight.

We invite you and your family to work with us and get behind our proposed campaign on this important issue.

If you're currently having trouble accessing treatment, please call our National Helpline on 1800 111 709.

"It's simply unacceptable that any Australian should need to stop treatment and risk blindness because of cost," says MDFA CEO Dee Hopkins.

47 Reasons cont'd.

MDFA will be creating a special 47th Parliament page on our website where all your stories, quotes, and videos will be displayed and shared with all the candidates of every political persuasion in the next election.

So we are ready in the event of an early election, we encourage you to get involved as soon as possible by emailing 47reasons@mdfoundation.com.au, or calling our National Helpline on 1800 111 709.

Farewell and welcome

After five years of dedicated service, we say goodbye to our retiring Chairman, Mr Robert Kaye SC. Robert has been a guiding force for MDFA and has opened many opportunities for growth and advancement.

We thank Robert for his guidance, commitment and support over the years and wish him well in all future endeavours. Longstanding Board member, Mr Neil Wykes OAM, is holding the position of Chair and we will share news on his replacement in the new year.

MDFA welcomes Mr Peter Abrahamson B.Sc., FAICD, to the Board. Peter brings to the Board more than 20 years of senior executive experience as CEO and Board Director across the publicly listed and private for-profit sectors.

Peter has worked with large multinationals and start-ups across the pharmaceutical, medical device, and FMCG sectors. Peter's experience in health care will undoubtedly contribute greatly to the good governance of MDFA.

Your Voice

Submissions to Government

We continue our work to advocate on behalf of the macular disease community to Government and other key stakeholders.

Recent MDFA submissions include:

- Supporting the Port Delivery System application to the Medical Services Advisory Committee
- Review of Aged Care Quality Standards and recommendations for greater inclusion of people with low vision or blindness
- Endorsement of The Older Persons Advocacy Network joint statement in support of a rights-based Aged Care Act
- Review of the National Medicines Policy, advocating for equitable access and greater consumer involvement
- Contribution to the Medical Research Future Fund consultation, advocating for higher priority for research into eye diseases.

MDFA also contributed to policy submissions of organisations such as the Australian Patient Advocacy Alliance and Vision2020 Australia.

Have your say on new support project

We're working with community members and an external company, ThinkPlace, on a new project to shape our support services and be your journey expert.

As people living with AMD are the experts on what assistance and support is most useful, we're delighted that several members of our community have agreed to work with us on this new project to co-develop and inform new initiatives to better support our community.

They will also be testing some exciting innovations to better support people living with early and intermediate AMD and those living with wet (neovascular) AMD.

In this first stage of the project, we recruited six people of various ages and different stages of AMD and interviewed them about their experiences.

We proposed potential ideas then asked our six interviewees whether those solutions would impact their lives positively, and whether they'd actually use them.

"I found the workshop very useful," said one participant.

The feedback we received was invaluable, and is informing the direction of the project and any innovations moving forward.

We are now recruiting more volunteers for the next round of concept testing. If you're interested, please email education@mdfoundation.com.au – we'd love to hear from you.

Annual General Meeting

Please join us for MDFA's 2021 AGM, as we come together online to reflect on the year that was and share our priorities for the year ahead.

Date: Thursday, 9 December
Time: 11am
Venue: Online

To register, please contact MDFA:
Email: info@mdfoundation.com.au
Phone: 1800 111 709

We will distribute the online meeting link to people who registered closer to the event.

Our new office

MDFA has moved offices – by only 150 metres up the road. You can now find us in our new premises at:

Mezzanine level
383 Kent Street
Sydney NSW 2000

If you're in the Sydney CBD, please pop in and visit us.

Of course, you can always reach us via the National Helpline at 1800 111 709 and info@mdfoundation.com.au.

Education

Don't miss our free webinars

These are the free online education sessions we've got coming up.

Topic	Date & Time	Presenter
Low vision aids: Something for everyone	Tue, 30 Nov 2-3pm AEDT	Rob Drummond from Quantum RLV
Nutrition and AMD: A research update	Wed, 8 Dec 2-3pm AEDT	Diana Tang from Macquarie University
The role of the optometrist in your eye care journey	Wed, 19 Jan 2-3pm AEDT	Hamdy Amrizal from MDFA
Support for people who are blind or vision impaired	Wed, 16 Feb 2-3pm AEDT	Jane Britt from Blind Citizens Australia

To register:

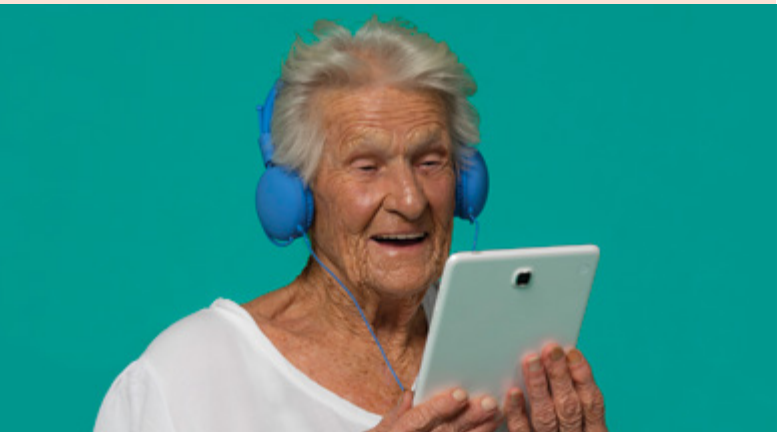
P: 1800 111 709

E: education@mdfoundation.com.au

W: **www.mdfoundation.com.au/education-sessions**

or scan this QR code.

Catch up on our past webinars on YouTube. Visit **YouTube.com/MDFoundationAus** or simply scan this QR code.



Want a speaker?

Your community group could host a free AMD education session – as either an in-person seminar or an online webinar.

As we return to face-to-face gatherings, we'd love to invite any group to book an MDFA speaker.

To book an MDFA speaker – free of charge – please email education@mdfoundation.com.au or call our National Helpline on 1800 111 709.

Survey volunteers needed: AMD and quality of life

If you have age-related macular degeneration (AMD), you could help this MDFA-funded study measuring how AMD affects quality of life.

The study will lead to the development of a technologically advanced, computerised questionnaire that can be used to evaluate the effectiveness of AMD treatments from the patients' perspective.

Researchers at the University of New South Wales (UNSW), led by MDFA Research Grant recipient Dr Sheela Kumaran, are looking for people with AMD over the age of 50 to complete:

- An online/paper/telephone survey about the impacts of AMD on quality of life
- A diary to record costs associated with AMD for 30 days

To learn more, please visit **https://redcap.link/AMDQoLproject** or scan this QR code.

That link will take you to the participant information sheet, a screening questionnaire to see if you're eligible to participate, then an online consent process.

If you have any questions, please contact the chief investigator Dr Sheela Kumaran, Research Fellow on 02 9065 9964 or sheela.kumaran@unsw.edu.au.

Macular Disease Foundation AUSTRALIA

Macular Disease Research Update

November 2021

Potential treatment for late-stage dry AMD on the horizon

Apellis reports initial findings from two phase III studies in geographic atrophy

Geographic atrophy (GA) is a leading cause of severe visual loss and unlike wet AMD there is no effective treatment for GA currently available.

The prospect of a treatment for advanced dry AMD or GA moved closer in recent weeks. Results from two large clinical trials show that monthly or every-other-month eye injections of pegcetacoplan (being developed by Apellis) can slow the progression of GA.

Pegcetacoplan is designed to control excessive activation of the immune system, which is known to play a part in many diseases including dry AMD. The drug inhibits part of the immune system called complement component 3 (C3) which forms part of our defences against infectious organisms.

The two phase III clinical trials – OAKS and DERBY – include 1258 people with GA. After 12 months, pegcetacoplan reduced the growth of GA lesions by 14% (every-other-month injections) and 17% (monthly injections) compared with no treatment when the data from the two studies were combined.

The two clinical trials showed some differences in their results. While OAKS showed significant results, DERBY was less positive. Participants will continue in the studies until they have received dosing for 24 months. Researchers will then gain a better understanding of the longer term benefits and safety of treatment with pegcetacoplan.

Injection of pegcetacoplan into the eye appeared to be well tolerated and have similar risks to injections for the approved treatments for wet AMD.

Apellis plans to submit the clinical trial results to regulatory authorities in the USA in 2022. There are still many steps before pegcetacoplan could be approved for use in Australia.

KEY

- Geographic atrophy secondary to age-related macular degeneration
- Neovascular (wet) age-related macular degeneration
- Diabetic macular oedema
- Retinal vein occlusion
- Diabetic retinopathy
- Choroidal neovascularisation
- Genetic disorders
- Other macular disease

Clinical trials in humans aim to find better ways to manage disease while establishing correct dosage, safety and efficacy when compared with other treatments. They are designed to minimise the possibility of bias or incorrect conclusions.

Clinical research is lengthy, rigorous and expensive. Some agents described in this update are years from completion and others may not result in effective treatments even late in their development.

Approved in Australia

Several treatments are approved and funded in Australia for macular diseases. Your ophthalmologist will determine whether treatment is right for you.

Ranibizumab (Lucentis®)

Ranibizumab (Lucentis®), sold by Novartis, is an anti-VEGF molecule first approved in Australia in 2007.

In 2021, a ranibizumab biosimilar (Byooviz®), developed by Samsung Bioepis, was approved in the USA and Europe. Biosimilar products aim to have comparable safety and efficacy to the original branded product.

Aflibercept (EYLEA®)

Aflibercept (EYLEA®), sold by Bayer, developed by REGENERON, is an anti-VEGF trap fusion protein first approved in Australia in 2011.

In 2021, REGENERON announced phase II study results that showed a high dose of aflibercept gave better outcomes in patients with nAMD. Trials are under way in nAMD (phase III PULSAR) and DMO (phase II/III PHOTON) to test efficacy with treatment intervals up to 16 weeks. Results are expected late 2022.

Voretigene neparvovec (Luxturna®)

Voretigene neparvovec (Luxturna®) is a gene transfer vector, developed by Spark Therapeutics, sold by Novartis, to treat inherited retinal dystrophy caused by a pair of faulty RPE65 genes.

In a clinical trial published in 2017, the treatment was shown to improve visual function in this previously untreatable disease.

In 2020, Luxturna® became the first gene therapy approved in Australia.

Brolucizumab (Beovu®)

Brolucizumab (Beovu®), developed by Novartis, is an anti-VEGF molecule recently listed for PBS subsidy in Australia.

Brolucizumab is only available for patients who have received ranibizumab (Lucentis®) and/or aflibercept (EYLEA®) for at least six months and have not responded to first-line treatment.

The decision to switch between anti-VEGF therapies requires careful consideration of risks and benefits. For patients currently receiving eye injections for nAMD, your ophthalmologist will be able to discuss with you whether the treatment may be appropriate or not.

Pending approval

Upon successful completion of phase III trials, companies must apply to regulatory authorities (such as the Therapeutics Goods Administration and Pharmaceutical Benefits Scheme in Australia) for approval to offer the treatment for patients.

Port Delivery System (Susvimo®)

The Port Delivery System (PDS), developed by Roche, is a refillable drug implant that delivers ranibizumab (Susvimo®) into the eye.

The phase III ARCHWAY study compared the PDS refilled every six months with monthly eye injections of ranibizumab. Patients using the device had similar vision outcomes and safety to patients treated with monthly ranibizumab, although the risk of inflammation within the eye was increased in patients with the implant.

In October 2021, the system was approved by the US FDA for patients with nAMD who responded to two or more previous anti-VEGF injections. It is under review in Europe.

Studies continue to evaluate the system in DMO (PAGODA) and DR (PAVILION), long-term safety in nAMD (PORTAL) and extended dosing intervals in nAMD (VELODROME).

Faricimab

Faricimab, developed by Roche and Genentech, is an antibody treatment that blocks the activity of VEGF-A and antiopoietin-2. Both are involved in the formation of new blood vessels, disruption of blood vessel stability, and inflammation.

Two trials in DMO (YOSEMITE, RHINE) showed faricimab had similar efficacy and safety to aflibercept with the potential for longer treatment intervals. Faricimab reduced the severity of diabetic retinopathy.

In nAMD, two phase III clinical trials (TENAYA, LUCERNE) showed efficacy similar to aflibercept with extended dosing intervals.

In August 2021, Roche announced the clinical results have been submitted to the FDA for review.

Late-stage developments

Late-stage (phase III) clinical development tests potential treatments in large groups of patients

to evaluate safety and efficacy, often compared with current standard of care. At least two successful studies are generally required before a treatment can be submitted for approval.

KSI-301

KSI-301, developed by Kodiak Sciences, is an anti-VEGF antibody attached to a biopolymer, which is expected to offer longer intervals between eye injections.

A phase I study demonstrated tolerability and suggested a durable effect in patients with nAMD, DMO and RVO with injection intervals from two to five or more months.

Kodiak Sciences have multiple phase III studies ongoing, including over 2700 patients. First results are expected early 2022.

In nAMD, the DAZZLE trial is studying KSI-301 dosed every three months; the DAYLIGHT study is evaluating monthly KSI-301 dosing. Both compare KSI-301 against aflibercept dosed every other month.

The GLIMMER and GLEAM studies are enrolling patients with DMO to compare extended dosing intervals of KSI-301 against aflibercept every other month.

In RVO, the BEACON study is enrolling patients with macular oedema due to RVO who are injected with KSI-301 every other month or aflibercept dosed monthly.

Finally, KSI-301 is being studied in patients with moderate to severe diabetic retinopathy in the GLOW study. Patients will be injected every 24 weeks with active drug or a sham treatment.

OPT-302

OPT-302, developed by Opthea, is an anti-VEGF C/D trap fusion protein. VEGF-C and -D are involved in abnormal blood vessel growth and leakage which occurs in nAMD, DMO and other macular diseases.

OPT-302 is injected into the eye and is being studied as an add-on therapy to approved anti-VEGF agents. In a phase II trial, visual acuity gains with OPT-302 plus ranibizumab were greater than with ranibizumab alone.

Two phase III trials are now recruiting Australian nAMD patients. The ShORe trial compares OPT-302 monthly or every other month plus monthly ranibizumab with monthly ranibizumab alone.

The COAST study has the same design but includes aflibercept instead of ranibizumab.

Both ShORe and COAST will report results after 52 weeks (late 2023) and continue to 100 weeks to assess longer term efficacy and safety.

A phase II trial in DMO studied monthly injections of OPT-302 plus aflibercept and showed the combination offered better visual outcomes than aflibercept alone.

MOSAIC
A GA BURDEN OF ILLNESS STUDY

Invitation for Patients and Carers to Participate in a Survey about Dry Age- Related Macular Degeneration/Geographic Atrophy

Modus Outcomes, a scientific research company, will be doing a global survey later this year for the MOSAIC study. The study explores people's experiences with geographic atrophy (GA), which is also known as advanced **dry** age-related macular degeneration (AMD).

We are interested in understanding how GA/advanced dry AMD impacts daily life for people with GA and those who help them.

People aged 60 or older living with GA/advanced dry age-related AMD and their main, non-paid carer (unpaid person who cares for a person with GA/advanced dry AMD or whose life is affected by a person with GA/advanced dry AMD) living in the US, UK, Australia, Germany, and France are invited to participate.

Patients and carers who qualify will be asked to complete a 30–45 minute electronic or telephone survey later this year; participants will be compensated. **No medical treatment will be provided as part of this study.**

If you or someone you know may qualify (patients or carers) please contact **contact@global-patients.com**. When the survey is available later this year, the research team will contact you!

RGX-314 ● ●

RGX-314, being developed by REGENXBIO, uses a viral vector to deliver a ranibizumab gene into the eye. This is expected to inhibit new blood vessel formation and leakage which is the cause of several macular diseases.

The phase II/III ATMOSPHERE study is currently enrolling nAMD patients. Two doses of RGX-314 injected under the retina will be compared with monthly ranibuzumab over two years. Initial results are expected in 2023.

In nAMD, the phase II AAVIATE study will evaluate the efficacy of two different doses of RGX-314 injected into the white of the eye using a novel micro-injector developed by Clearside Bioscience.

In DR, the phase II ALTITUDE study will test two doses of RGX-314 injected using the novel micro-injector. Results from both studies are expected in 2022.

Avacincaptad (Zimura®) ● ●

Avacincaptad, developed by Iveric Bio, is designed to inhibit complement C5, part of the immune system implicated in many diseases including GA.

The phase II/III GATHER-1 trial showed monthly eye injections of avacincaptad reduced the growth of GA by 27% over 12 months. (*Note: this result cannot be compared with pegcetacoplan outcomes in OAKS and DERBY.*) Injection of avacincaptad into the eye appeared to be well tolerated.

GATHER-2 is an ongoing phase III study in GA to assess the efficacy and safety of monthly intravitreal injection of avacincaptad versus sham over 12 months. For the second year, monthly versus every-other-month injection will be compared. Results are expected in 2022, and the study will continue into 2023.

Avacincaptad is also being studied in autosomal recessive Stargardt disease in the phase II STAR study. The study is currently enrolling and due to report in 2023.

Early-stage developments

For further information on early stage treatments, check out the information on our website (**www.mdfoundation.com.au**) or by scanning this QR code.

Uncertain future

Even after extensive clinical development and investment, treatments may fail to be approved. The future for two otherwise promising agents is now uncertain.

Abicipar pegol ●

Abicipar pegol, developed by Allergan and Molecular Partners, is a novel anti-VEGF molecule. Unlike approved treatments, abicipar is a designed protein (DARPin) which was expected to offer extended dosing intervals for people with nAMD.

In 2020, the FDA rejected Allergan's application for approval due to high rates of eye inflammation. Applications were subsequently withdrawn from the Japanese and European regulatory agencies.

In August 2021, Molecular Partners took back control of the development program and are considering next steps.

Conbercept (Lumitin®) ●

Conbercept (Lumitin®), developed by Chengdu Kanghong Biotechnology, is an anti-VEGF trap fusion molecule similar to aflibercept. In 2013, the Chinese food and drug administration approved the product for use for nAMD and other macular diseases based on two small clinical trials (AURORA, PHOENIX).

Two international trials (PANDA-1, PANDA-2) were started to support approval outside China. The studies were designed to evaluate the efficacy and safety of conbercept injected into the eye every eight or 12 weeks compared with aflibercept injected every eight weeks.

In April 2021, Chengdu Kanghong announced the PANDA trials had been impacted by the COVID-19 pandemic and would not achieve their goals. The two studies have been stopped and the future of the product outside China is unclear.

Medical Costs Finder: New tool to help you understand out-of-pocket costs

The Australian Government has launched the Medical Costs Finder, a new online tool to help Australians find out more about the cost of specialist medical services such as eye injections.

The Medical Costs Finder allows you to search for treatments you receive, the estimated fees for specialists and other health providers, and compare typical costs for the same service.

This helps you better understand what is typically paid and whether your likely out-of-pocket costs are high or low, compared with what others have paid for the same service.

The Medical Costs Finder lists Australia's common medical procedures – and will shortly include ophthalmology fees including eye injections – and will continue to add more services over time.

The website aims to address better transparency around the cost of medical treatments by letting you know how your out-of-pocket costs compared to what other people are paying.

You can also search services by the Medicare Benefits Schedule (MBS) item number, and filter results by postcode to see what fees are like near you.

You can also refine your search by whether you're in or out of hospital, whether the hospital is private or public, and whether you're privately insured.

Access the Medical Costs Finder at **www.health.gov.au/resources/apps-and-tools/medical-costs-finder** or by scanning this QR code.

Healthy Choices

Turkey and mango salad

This cold Christmas salad is loaded with two vital nutrients for eye health: Vitamin C in the mango, and selenium in the turkey.

Salad ingredients

500g turkey, sliced
100g baby spinach
50g herbs (coriander, mint, basil)
1 large mango, peeled and sliced
2 tbsp seasoned rice vinegar
1 tbsp caster sugar
1 garlic clove, crushed
1 small red chilli, finely chopped with seeds removed
Black sesame seeds, to sprinkle

Dressing

100ml honey
60ml rice vinegar
100ml peanut oil
2 tsp sesame oil

Instructions

Mix the rice vinegar, sugar, garlic and chilli, and stir until the sugar has dissolved. Pour over the sliced turkey and set aside.

To make the dressing, place the honey and vinegar in a food processor and process to combine. With the motor running, slowly add the peanut and sesame oils until a thickish dressing forms.

Place a pile of spinach on each plate and top with a handful of herbs, followed by some turkey. Lay slices of mango on top, drizzle with the dressing and sprinkle with the black sesame seeds.

For more delicious and eye-friendly recipes this festive season, download your free Christmas Macula Menu e-cookbook from our website: **www.mdfoundation.com.au/resources/macula-menu-christmas-recipes**

Meet the author: Dymphna Stella Rees

When Dymphna began digging through her legendary parents' literary archive to write a book of her own, she was also diagnosed with wet AMD. But eye injections have saved Dymphna's sight, helping her publish 'A Paper Inheritance' a decade later.

Dymphna Stella Rees is Australian literary royalty. Her parents are Leslie Rees and Coralie Clarke Rees, a pair of award-winning authors and broadcasters in mid-20th Century Sydney.

Leslie wrote more than 50 books in his life, leaving his daughter a treasure trove of literary artefacts when he passed away in 2000.

In 2012, Dymphna discovered bundles of love letters buried in this archive – the inspiration for her to write 'A Paper Inheritance', a memoir of Leslie and Coralie's creative and romantic partnership.

"My love of language – my love of beautiful writing – was always a part of me," Dymphna tells MDFA.

"And then I thought 'I must write this book' in 2012, which was exactly the year I was diagnosed with wet macular degeneration."

Despite no family history of macular disease, Dymphna first noticed signs of her AMD at the computer, when she saw lines of text bending like a parabola. She quickly saw her optometrist and was diagnosed with late AMD in her right eye.

Dymphna did two things straightaway: begin anti-VEGF eye injections with her ophthalmologist, and reach out to MDFA for support.

"I very much appreciate the work that the Foundation does. Immediately when I was diagnosed, I wanted to get more information, and I went straight to the Foundation," Dymphna says.

"I'm an online researcher, and I wanted to read all about the eye injections. The work the Foundation does in disseminating that information, it is a great help."

Dymphna received monthly eye injections for three years until the vision stabilised in her right eye. More recently, her ophthalmologist also picked up AMD in her left eye, which is now being treated.

"Because I had the scans and I have regular treatment, it was picked up quickly and it's going very well now," she explains.

"It's sort of miraculous, because writing this book required so much research into old, frail documents.

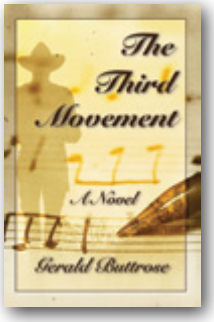
"When you consider that to write 90,000 words and then pore over ancient documents and transcribe and read newspaper articles and handwriting from up to 90 years ago, it's a lot of expectation of one's sight!

"And it was just absolutely remarkable that I was able to have treatment all that time, and it has allowed me to bring out this book."

'A Paper Inheritance' by Dymphna Stella Rees is available now through **uqp.com.au**

Book Club

Meet three authors who haven't let vision loss stop them from penning these great reads.



'The Third Movement' by Gerald Buttrose

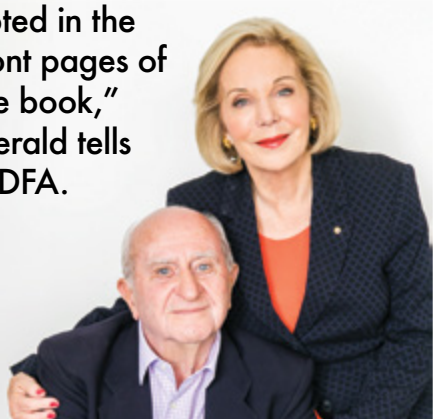
Gerald Buttrose – the beloved uncle of MDFA Patron Ita Buttrose AC OBE – has published a poignant novel about a young musical prodigy caught up in World War Two.

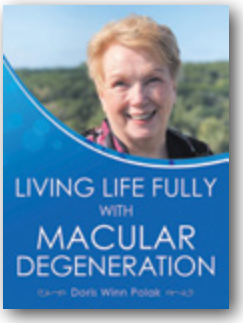
'Uncle Gerald', 98, has lived with AMD for almost two decades. But regular eye injections have maintained his sight well enough to continue writing well into his 90s.

Gerald's new book follows Patrick Sheridan, a budding pianist from country New South Wales forced to choose between his promising music career and joining the fight for his country.

Gerald served in the Australian Army during World War Two, and his new novel reflects on how conflict affects not only combatants, but their families, friends and communities.

"I could not have written it had it not been for the Foundation's timely and expert advice, through Ita, which enabled me to retain my sight. This is noted in the front pages of the book," Gerald tells MDFA.

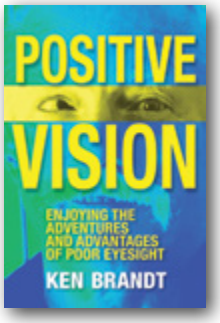




'Living Life Fully with Macular Degeneration' by Doris Winn Polak

Doris – a retired music and English teacher from the United States – was diagnosed with AMD in 2014. In this guidebook, the author shares the tools and techniques she's used to adjust to her condition.

"If you are newly diagnosed and would like to understand what you and your eyes can expect over the next weeks, months and years, pour yourself some coffee, pull up a chair and get started reading my story," Doris writes.



'Positive Vision' by Ken Brandt

'Positive Vision: Enjoying the Adventures and Advantages of Poor Eyesight' is full of inspiring anecdotes about Ken Brandt's roller-coaster journey with low vision.

Ken – a New York native who now calls Melbourne home – provides an amusing account of his life with various eye conditions, regaling the reader with tales of parachuting out of planes, battling arson blazes and chasing thieves through the streets of the Big Apple.

Clare's 15 years of voluntary support

A message from her fellow volunteers

"Working with Clare has been a joy for all of us. Clare is a fiercely independent person who is always friendly and helpful, caring and thoughtful towards everyone.

"She is an excellent communicator and has always liked to keep in touch with people. Her sense of humour is legendary – especially the need to have hot chips for lunch!

"Clare is very committed to whatever she undertakes and has shared her extensive knowledge and understanding of MDFA with us all. During the COVID-19 lockdown Clare has continued to work from home on the Peer-to-Peer program.

"Congratulations, Clare, on completing 15 years of volunteer service to the Macular Disease Foundation Australia."

MDFA launches new Eye Health video series

Lights, camera, action!

Macular Disease Foundation Australia has released a new series of educational videos to help Australians better understand macular disease.

Coinciding with the one-year anniversary of the online Check My Macula quiz, our new Eye Health video series features dozens of bite-sized videos that answer some of the most common questions people ask about their eye health.

Throughout the COVID-19 pandemic, the macular disease community told us that they're looking for short, sharp video content – and we've listened.

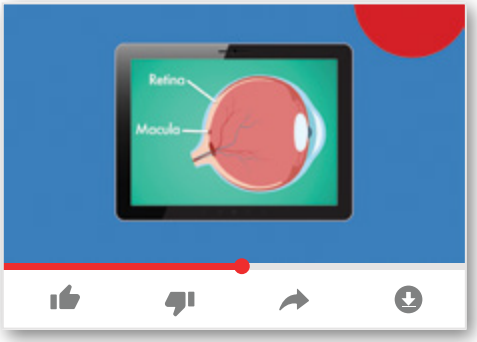
Each video is only one or two minutes long, sharing important health advice in a simple, easy-to-understand way.

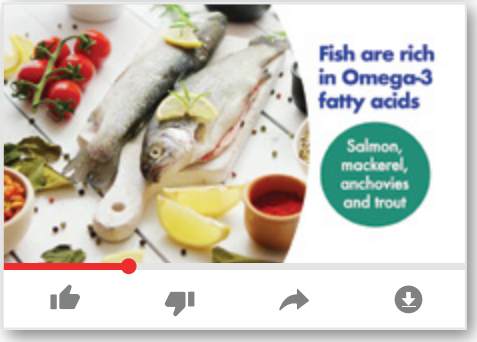
The Eye Health video series aims to improve your understanding of various macular conditions, possible treatments and preventions, lifestyle changes you can make to protect your sight, and tips to live well with vision loss.

These are some of the topics covered:

- How does the eye work?
- What foods are good for my eyes?
- What are the risk factors for AMD?
- How do eye injections work?
- I've been diagnosed with AMD, what do I need to tell my family?
- Can diabetes affect my eyes?
- How can I take care of my mental health with vision loss?
- What low vision aids could help me?

You can watch the Eye Health video series on YouTube (**www.YouTube.com/MDFoundationAus**), MDFA's website (**www.mdfoundation.com.au**), or by scanning this QR code.





Contact Us: 1800 111 709 info@mdfoundation.com.au @maculardisease
@MacularDiseaseFoundationAustralia Mezzanine level, 383 Kent Street, Sydney 2000