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**Volunteer Newsletter Update from Marian Williams (Regional Manager North Wales) July 2022.**

Hello everyone,

Such sad news about the Her Majesty the Queen passing away aged 96 on the 8th September 2022.

Queen Elizabeth II was renowned for her support of charitable causes. As a patron of a number of sight loss charities, she showed a tremendous amount of dedication and support to those living with visual impairment, as well as a great understanding of the challenges they face.

Cathy Yelf, chief executive of the Macular Society, said: “Many of us have not known a life without our Queen and this will be a great loss for the entire country. Many of our supporters who have grown up around a similar time to Queen Elizabeth II will no doubt feel this loss very deeply. We are so thankful to her for a lifetime of dedication to great causes, not least her support for sight loss charities. Our thoughts remain with her family at this incredibly sad time.”

**Wales Eye care Conference**

Annual Wales Eye care Conference - Bookings are now open

We are pleased to announce that bookings are now open for this year's Annual Wales Eye Care Conference, which will be held on Monday 7th November 2022 (registration from 9am) at SWALEC Stadium, Sophia Walk, Pontcanna, Cardiff, CF11 9XR. The theme for the conference will be 'Future Approach to Eye Care: Reform and Recovery'.

Please call Wales Council of the Blind +442920 473954 if you need to book.

**National Eye Health Week**

The Macular Society’s online tool to estimate your risk of developing the biggest cause of sight loss in the UK.

The tool allows you to see how likely you are to lose your sight to macular disease, which affects nearly 1.5m people in the UK, even children.

The online tool asks users to answer just five simple questions to estimate their risk. It also suggests easy and practical things they can do to drive down their own risk and protect their eyes.

Macular Society will be running a set of Facebook adverts for the Risk Checker, those interested will click through to our website or visit www.macularsociety.org/riskchecker and complete the questionnaire to find out your risk of macular disease. If you would like your report emailed to you, you can fill in your details (name and email) and you will be sent on an email journey before being added to our enews lists.

**Vision Express**

As you will know, we are working in partnership with Vision Express to help raise awareness of macular disease and also raise vital funds. As an example of this, you might well have seen the very loveable, cuddly Marvin the Mole soft toy in stores over the last few months?! To coincide with this year National Eye Health Week (though continuing over the next six weeks or so) they are also doing some fundraising in stores for the Macular Society and CHECT, their other charity partner. If you are passing a Vision Express store, please do pop in to say thank you and tell them a bit about the difference their support is making. Sarah Jarman in our fundraising team is managing our partnership with Vision Express and I know she would love to hear from you if you are able to pop into a store and if possible take a picture of yourself and the staff of Vision Express. Please get in touch with her at sarah.jarman@macularsociety.org.

**Macular Society Conference September 2022**

Over 2,500 people registered for the annual Macular Disease conference last Saturday and what an amazing day it was! All of the presentations were received with huge interest and have received some great feedback. People joined online from all over the UK. We also had worldwide participation with supporters joining from France, USA, Romania, New Zealand, Australia, Menorca, Turkey, India and Italy. Peak viewing figures showed over 1,200 viewers on line at the start of both the morning and afternoon sessions, plus 34 joining via the telephone conference lines. Those that joined the online chat boxes (150+ at times) were enthusiastic and very engaged, with plenty of questions for the speakers and Q&A panellists. The feedback both online and from the conference survey so far has been, extremely positive.

**Faricimab - all you need to know about the new treatment for wet AMD and DMO**

In our recent webinar, as part of the My Macular and Me series, consultant ophthalmologist and retinal surgeon at Ian Pearce revealed more about Roche’s new drug Faricimab (Vabysmo).

**Why do we need more drugs for wet AMD?**

Talking about the prevalence of wet AMD, Pearce highlighted that 35,000 to 40,000 patients are diagnosed every year – that is five patients every hour. “With this growing number of patient’s health services are stretched,” he said. “How can we adapt to it? There’s a lot of interest in how to get treatment that lasts longer than four or eight weeks, which is where the interest in Faricimab has come in.”

He added: “Four monthly injections are three times a year, so if we can move the pendulum and instead of coming every month or two months get patients with extended intervals, then that is a significant benefit, not only for us as a health service to provide care, but if we can cut the number of times a patient visits it means we free-up slots to make sure those visits occur on time. It’s critical that when we give you an appointment, we have capacity to get you in for any treatment.”

**Who can access Faricimab?**

While Pearce predicted that Faricimab will become the ‘primary treatment’ for new and existing patients with wet AMD and DMO, it won’t be for everyone. “That isn’t to say if you’re having existing treatment that you need to change,” he said.

However, Pearce encouraged patients to speak to their eye specialist about the new drug, to discuss if it would be the right option for them. As a physician, he said patients should be able to trust their eye specialist enough to ask questions. “Medicine for the 1,000 years has relied on trust,” he said. “You have to trust and believe in the physician. I think what’s important is to raise it. As a physician if we’ve got lots of patients coming through, the easiest thing is to keep you on the same drug if I have to change you to another drug then it takes time. When you’re in a busy clinic it’s very easy to want to get you in and out with the same drug and there’s a bit of an incentive not to change. So, by you asking ‘I have heard about Faricimab (Vabysmo), do you think that will help me?’.”

He added: “If you’re not happy, raise it again the next month. A lot of time we make decisions and patients think that decision is forever and it isn’t. The way I treat patients compared to 20 years ago is completely different. I’ve got lots of new drugs, so keep asking.”

**When is treatment most effective?**

Some people with wet AMD respond better to treatments than others. The reasons for this are not currently known, but Pearce highlighted the importance of receiving treatment as soon as possible.

He said: “The most important thing is if you notice a sudden distortion in your vision, get seen straight away. The quickest and easiest way at the moment is via a high street optician. I am an eye specialist and my eye unit is open 24 hours, but the reality for most patients is you don’t have that facility. High street opticians who are highly trained and very attuned to picking up early signs of wet macular degeneration.”

He added: “If you have good vision there’s 80 to 90 per cent chance I’m going to keep you with great vision for the next five years and that’s where we want to be.”

**What is the future of treatments for wet and dry AMD?**

Pearce shared his hopes and excitement for the future treatment of wet AMD and DMO.

“For the last 10 years wet macular degeneration treatment has pretty much stood still,” he said. “We’ve had these false starts and nothing’s changed. I think the next five years will be a big difference. We’ve got Faricimab now, it’s available now, you can go and have it tomorrow. But, there are other agents that are in the pipeline which will be working more effectively.”

While there is currently no treatment for dry AMD, Pearce said there was a ‘revolution’ for treating the advanced stages of the disease in the near future. He said: “There are many, many patients who have very advanced dry who suffer significantly with loss of vision and at the moment for those advanced dry forms we don’t have treatments. However, there are treatments coming online and there’s probably going to be a revolution in treating very advanced dry AMD in the next 12 – 18 months.”

**Health Boards Update**

Last Friday the Hywel Dda Eye Care Collaboration Group met. The health board continues to report concerns around staff shortages and lack of accommodation. There is little progress on reducing waiting lists and workforce development is key. They reported two new recruitments in Amman Valley to perform cataract surgery but are aware more is needed.

AMD clinics remain a concern as they are struggling with capacity; some weekend clinics have been run but the health board is still losing staff. The health board has agreed a Biosimilar switch and is looking at using Faricimab for those suitable patients (so is Swansea Bay). The health board is also employing a new nurse injector (30-hours per week).

If you would like further information about any of the topics raised in the newsletter, please contact me on **07495 054 053** or you can ring the Advice and Information number on **0300 3030 111**.

Kind regards, Marian.