**Macular Society Regional Newsletter Update from Adele Francis (Senior Regional Manager South Wales) April 2022.**

Hello, I hope you’re all keeping well.

**Groups Update**

**Ammanford -** Face- to- Face Group meeting, second Thursday of the month at 10.30am at Llandybie Public Memorial Village Hall Llandybie Ammanford SA18 3UR

**Royal Glamorgan** – Telephone support group call and quarterly café meetings

**Milford Haven** – Telephone support group call

**Monmouthshire (affiliated)** – Telephone support group and coffee group on third Thursday of the month at the Estero Lounge

**Swansea** – Bi-Monthly café meetings

**Llanelli** – Face- to- Face Group meeting, third Wednesday of the month 10am at The Lantern Centre Hall Street Church Llanelli SA15 3BB

**Carmarthen** – Face-to-Face Group meeting, fourth Thursday of the month 10.30am at Carmarthen Bowling Club, The Green, St. Peter's Car Park SA31 1QP

**Bridgend** – Face-to-Face Group meeting, third Friday of the month 10.30am at The Zone 46-48 Dunraven Place Bridgend, CF31 1JB

**Neath** – Face- to-Face Group meeting, fourth Tuesday of the month 1pm at Neath Library 35 Victoria Gardens, Neath SA11 1HE

**Ystradgynlais** – Face-to-Face Group meeting, fourth Monday of the month 10.30am at Welfare Hall Lesser hall Brecon Road Ystradgynlais SA9 1JJ

**Brecon** – Face-to-Face Group meeting, second Tuesday of the month 1pm at first Brecon Scout Hut, Scout Lane, Brecon, Powys, LD37DX

**Llandrindod Wells** – Face-to-Face Group meeting, third Thursday of the month 1pm at Wooden Blue Gate Middleton Street (in between Snap Cymru shop and Cefn Llys shop) Llandrindod Wells Powys

**Caerphilly** – Face-to-Face Group meeting, third Wednesday of the month at 10.30am at Caerphilly Library, 2, The Twyn, Caerphilly. CF83 1JL, in the reading room.

**Newport** – Telephone support group call

**Tenby** – Face to Face Group meeting, last Thursday of the month, at 2pm, Community Centre Augustus Place, Tenby, Wales, SA70 7DJ

**Lampeter** – Face-to-Face Group meeting, second Wednesday of the month 2pm at St Thomas Methodist Church, 7 St Thomas St, Lampeter SA48 7DQ

**Cardigan** – Face-to-Face Group meeting, third Tuesday of the month 1pm at St Marys Old school Hall, Cardigan.

**Cardiff Sightlife (affiliated)** – Supporting on a one to one basis as and when needed

**Bridgeviz (affiliated)** – Face-to-Face group meeting, first Friday of every month, 11:30am at St John's Ambulance Training Centre, Minerva Street, Bridgend, CF31 1TD

**Working Age and Young People and Connect by Tech Groups** – Zoom meeting on the fourth Friday of the month 10.30am

**All Wales Macular Telephone Support Group Call**

As the majority of groups in Wales are resuming face-to-face meetings, we have set up four weekly All Wales telephone calls to help those who are unable to make it to meetings in person. These will take place on:

First Wednesday of the Month 11am – 12pm - English Speaking

Second Wednesday of the Month 2pm – 3pm - Welsh speaking

Third Wednesday of the month 2pm – 3pm – English speaking

Fourth Wednesday of the month 11am – 12pm – English Speaking

At the required time please dial **01264 601 037** when asked press number 1 this is your pin number (all calls charged at local rate) we will all then be able to speak to each other. These will be hosted by, Adele Francis (South Wales) and Marian Williams (North Wales). Please feel free to join the calls even if you are attending the face-to-face meetings and need further information.

**Skills for seeing update**

One-to-one advice on how to make best use of the vision you have to continue doing the things you love. Combining vision know-how, magnification, lighting and, where it works for you, ‘eccentric viewing’ and ‘steady eye strategy’ techniques.

Skills for seeing continues to be in high demand so we will be recruiting new volunteers to deliver telephone and digital sessions later this year. If this role is of interest to you and you’d like to know more please contact Hannah Keegan on 01264 01264 560 201 or [Hannah.Keegan@macularsociety.org](mailto:Hannah.Keegan@macularsociety.org)

**Research Update**

Apellis Pharmaceuticals, a company we’ve been working with for a while, have announced that they are about to apply for a licence for their new drug for dry AMD. If approved, it will be the first drug treatment for this form of AMD. The company said: “On Wednesday, March 16, Apellis announced longer-term results from the Phase 3 DERBY and OAKS clinical studies, testing the efficacy and safety of intravitreal pegcetacoplan, an investigational medicine, in geographic atrophy (GA). GA is also known as advanced dry age-related macular degeneration. In an analysis conducted at month 18 of the clinical studies, treatment with both monthly and every-other-month pegcetacoplan continued to show reduced GA lesion growth compared to sham injections (no treatment). Pegcetacoplan continued to demonstrate a favorable safety profile in both studies. Overall, these longer-term data provide further evidence that pegcetacoplan has the potential to meaningfully slow disease progression and to preserve vision longer.” Apellis will first seek FDA approval in the US and then European Medicines Agency approval for the EU. As we’re not in the EU they’ll also have to apply to the MHRA for UK approval. It’s worth noting that this is not a cure, or even a drug that will stop progression of AMD. But it does look as though it may slow down progression which is its own progress and, as such, very welcome.

If you would like further information about any of the topics raised, please contact me on **07494 468 007** or you can ring the Advice and Information number on **0300 3030 111.**

Best wishes, Adele