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**Volunteer Newsletter Update from Adele Francis (Senior Regional Manager South Wales) January 2023.**

Hello everyone’ Happy New Year, I hope this newsletter finds you well and rested after the Christmas period.

**Macular Group meetings Update**

* Ammanford - Second Thursday of the month, 10.30am at Llandybie Public Memorial Village Hall Llandybie Ammanford SA18 3UR contact Lloyd on 07814 198 286
* Royal Glamorgan – First Wednesday of the month 2pm at The Pavillion, 52 Lanelay Road, Talbot Green Pontyclun, CF72 8HY contact Julie Parker 07531 498 967
* Milford Haven – First Thursday of the month, 2pm at Milford Haven Library, Cedar Court, Haven's Head Business Park, Milford Haven, Pembrokeshire, SA73 3LS contact Maddy on 07584 836524
* Monmouthshire – First Thursday of the month, 2pm Wyesham Christian Fellowship, Chapel Close, Wyesham, Monmouth NP25 3NN contact David on 07951 869 586
* Swansea – Bi-Monthly (Jan, March, May, July, Sept, Nov) First Thursday of the month 11.30am at the Grand Theatre Conservatory, Singleton St, Swansea SA1 3QJ contact Kate on 01792 401 450
* Llanelli – Third Wednesday of the month 10am at The Lantern Centre Hall Street Church Llanelli SA15 3BB contact Adele on 07494 468 007
* Carmarthen – Fourth Thursday of the month 10.30am at Carmarthen Bowling Club, The Green, St. Peter's Car Park SA31 1QP contact Janice on 07975 728 405
* Bridgend – Third Friday of the month 10.30am at Halo Bridgend Life Centre Angel St, Bridgend CF31 4AH contact Joy on 07985 028 212
* Neath – Fourth Tuesday of the month 1pm at Neath Library 35 Victoria Gardens, Neath SA11 1HE contact Adele on 07494 468 007
* Ystradgynlais – Fourth Monday of the month 10.30am at Welfare Hall, Lesser hall, Brecon Road, Ystradgynlais SA9 1JJ contact Adele on 07494 468 007
* Brecon – Second Monday of the month 10.30am at Brecon Town Council Offices (rear entrance), The Guildhall, Brecon Powys LD3 7AL contact Nick on 07837 562 364
* Llandrindod Wells – Temporary suspended until February 2023 contact Mary on 07974 580 083
* Caerphilly – Third Wednesday of the month at 10.30am at Caerphilly Library, 2, The Twyn, Caerphilly. CF83 1JL, in the reading room contact Denise on 07812 052 836
* Newport – Telephone support group call, last Thursday of the month 2pm contact Mary on 01633 400 464
* Tenby – Last Thursday of the month, at 2pm, Community Centre Augustus Place, Tenby, Wales, SA70 7DJ contact Val on 07452 888 287
* Lampeter – Second Wednesday of the month 2pm at St Thomas Methodist Church, 7 St Thomas St, Lampeter SA48 7DQ contact Diana on 07933 778 725
* Cardigan – Temporary suspended until February 2023 contact Adele on 07494 468 007
* Solva and St David – Second Tuesday of the month at 2pm at St David’s Drop In Centre, City Hall, High Street, St. David’s, Haverfordwest
* Dyfed, SA62 6SD contact Margaret Hughes on 07815 729 856.
* Bridgeviz (affiliated) – 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**

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

Please call Adele on 07494 468 007 for joining instructions (all calls charged at local rate) These will be hosted by Adele or Marian.

**How to tackle treatment delays**

The Macular Society’s Advice and Information Service is here to help if you are experiencing delays in sight-saving treatment.

Any delays to injections, for patients with wet age-related macular degeneration (AMD) and other macular conditions such as diabetic macular oedema (DMO), could lead to unnecessary sight loss. It is therefore vital that treatment is received on a regular, and timely, basis.

**So, what should you do if you are experiencing delays?**

Determine the reason for the delay

Ophthalmology is the busiest outpatient service in the NHS and patients do occasionally experience delays to treatment. However, there can be legitimate reasons for any delays, including extensions to treatment regimens.

If you feel you are waiting longer for treatment, the first thing we would advise you to do is talk to your ophthalmologist. They can tell you how often you should be expecting to wait between injections. If you are responding well to treatment your ophthalmologist may be happy for you to go for longer periods without treatment so a delay may not always be a cause for concern.”

Ring your ophthalmologist

Many people start by ringing the appointments clerk, however, they may not appreciate the urgency of the situation. Our advice is always to try ringing your ophthalmologist who will understand the importance of your timely treatment; this can usually be done via their secretary.

However, if you are waiting for a macular hole or cataract procedure, it may be that the eye clinic is operating according to guidelines, or according to their clinical based decision. If you call your ophthalmologist and determine that you are experiencing a delay, please contact the Macular Society for support.

Find out if your hospital has an Eye Clinic Liaison Officer (ECLO)

Having an Eye Clinic Liaison Officer (ECLO) is a really effective way for eye clinics to help patients. An ECLO works closely with the eye clinic and the staff; there are some external services such as the Sensory Team to help support patients with their sight loss.

Eye clinic staff may be unable to answer questions and provide emotional support to someone who has just been diagnosed. This is where the ECLO can step in and help. They can also help you with your treatment schedule, when you have an appointment and liaise with the eye clinic to help get an appointment when you need one. Unfortunately, not every eye clinic has an ECLO. However, it is important for you to find out if there is one at your eye clinic, and if so, what are their contact details and working hours.

Before ringing, it is important to have your hospital number if possible, sometimes your date of birth will suffice. It is also useful to have the date of your last injection, a note of how far apart your injections should be, and therefore the date that your next injection is due.

Contact the Macular Society’s Advice and Information Service

If these routes do not result in a timely appointment ring our Advice and Information Service. The Advice and Information team has an advocacy service, which can help.

Our Advocacy Service has been set up to help people with macular disease who are finding it difficult to access the treatment or care that they are entitled. We also help friends, family and carers acting on behalf of people with macular disease.

If you are calling the service, we will need your full name, address, contact telephone number, date of birth, hospital number (if possible), plus details of the concern, including the relevant dates.

We will need to know who you have already contacted and their responses. It is useful to know the reason for the delay, if this has been given, for example staffing shortages or an incorrect referral.

Contact the Advice and Information Service on 0300 3030 111.

Advice for someone newly diagnosed with wet AMD

If you are newly diagnosed with wet AMD and are waiting for your first appointment, it is important to know how quickly this should be received. The National Institute for Health and Care Excellence (NICE) Clinical Guideline recommends that people with suspected wet AMD should be referred to a retinal specialist immediately. If treatment is needed, it should be given within 14 days of the initial referral. Optometrists should refer you directly to a retinal specialist at a hospital and not via a GP.

If you haven’t heard from the eye clinic within the first few days after referral, then we would recommend giving the macular clinic a ring to check if they have received your referral. You can then establish if an appointment has been scheduled, and if there are going to be any delays. If the macular clinic has not received your referral, then contact the person that has referred you in the first instance e.g. your optician, as they may need to follow it up.

For any further questions or support contact our Advice and Information Service, which is open Monday to Friday 9am to 5pm on 0300 3030 111 or email help@macularsociety.org

If you have faced or are facing delays and are willing to share your experiences, we would love to hear from you at stories@macularsociety.org

**Volunteering for the Macular Society**

Do you have family or friends with some spare time? How about introducing them to volunteer for the Macular Society?

The Macular Society is the UK’s leading charity determined to beat the fear and isolation of macular disease with world-class research, and the best advice and support. By giving your time, you will help us to reach the thousands of people living with macular disease and sight loss in your area and provide life-changing support.

Join our team of volunteers and help us make a difference to thousands of people with macular disease. Whether you can spare a few hours or a couple of days a week, you’ll be doing something great to help people with macular disease.

Everyone has a reason for volunteering. Perhaps you know someone who has macular disease, are currently supporting a loved one, or want to give something back to support your community. If you want to gain experience or develop new skills, we are sure we have something for you too.

You might work directly with our members within your local community or volunteer as a telephone befriender from the comfort of your own home. It is an exciting time to be part of the Macular Society, so join today and you’ll receive a warm welcome from our fantastic team and volunteer community.

If you’d like to have a chat about volunteering, give us a call on 01264 326 622. Please spread the word, it could have such an impact for a very worthwhile cause.

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

Kind regards, Adele