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**Volunteer Newsletter Update from Marian Williams   
(Regional Manager North 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**

* Llandudno Support Group – First Monday of every month at 11am at the Danoon Hotel, Llandudno.
* Newtown Support Group – First Monday of every month at 2pm at the MCRA, Plas Dolerw, Milford Road, NEWTOWN
* Abergele Support Group – Third Monday of every month at 1.30pm at the Hafod y Park, Abergele.
* Dolgellau Support Group – Third Wednesday of every month at 1.30pm at the Theatre Fach, Dolgellau, Gwynedd.
* Llangollen Support Group – Fourth Monday of every month at 11am at the Hand Hotel, Llangollen.
* Bangor Town Support Group – Second Monday of every month at 11am at the Quaker House, Bangor, Gwynedd
* Aberystwyth Support Group – Fourth Wednesday of every month at 11am at the Tesco Community Room, Park Avenue, Aberystwyth
* Llanbedr Support Group – Fourth Thursday of every month at 1.30pm at the Llanbedr Community Hall, Llanbedr, Gwynedd.
* Ruthin Support Group – Second Thursday of every month at 11am at the Canolfan Naylor Leyland Centre, Ruthin.
* Tywyn Support Group – First Tuesday of every month at 11am at the Neuadd Pendre, Tywyn, Gwynedd.
* Welshpool Support Group – Second and Fourth Tuesday of every month at 2pm at the Methodist Church, Welshpool, Powys.
* Holyhead, Pwllheli and Wrexham Groups - These groups are temporary suspended until April 2023. For further information please contact Marian on 07495 054053.

**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

These will be hosted by Adele Francis (South Wales) or Marian Williams (North Wales).

**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 an 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 have not 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 07495 054053 or you can ring the Advice and Information number on 0300 3030 111.

Kind regards

Marian.