DRWF
United Through Diabetes
21st September 2024

#### Berni Warren

Navigating the pathway of diabetic retinopathy, trials and triumphs and the vision for the future

### An introduction

My story so far .....

The future is bright

Let's talk about support

### My story so far ....

- Diagnosed in 2011
- I dropped my HbA1C too quickly when starting on an insulin pump
- at that time there was only one injection therapy for the eyes.
- Unfortunately for me treatment did not work, I lost my job and driving licence
- Started doing voluntary work with Universities, hosptials, HCPs and students to teach them about the impact of diabetes and sight loss
- On the committee that wrote the 'NICE diabetic retinopathy management and monitoring guidelines' and also a lay member for RCOphth and have been on NICE TA's helping to bringing new IVTs onto NHS.

### The future is bright

- When I first was diagnosed there was only 1 anti –vascular endothelial growth factor (anti-VEGF) available and now there are many (Avastin, Lucentis, Eylea) and also biosimilars and a bispecific (Faricimab) too as well as steroids such as Iluvien and Ozurdex.
- Research is going on behind the scenes more than we PLWD have ever known in the past
- Having worked with pharmaceutical companies such as Roche, Bayer, Boehringer Ingelheim, Abvie and others as well as NIHR BRC Moorfields I can safely say we are not being left behind!

## Let's talk about support

Support is out there and here is where to find it

### Macular Society - Macular Society Beating Macular Disease

 They have a DMO/DR support group which meets each month on Zoom and also a Whatts app group too .They also have 'Working age and young people' groups. Macular Society have a stand here today.

• have an 'Eye Health team' that can help explain info that's not understood they are also here today.

'Waiting Well team' do phone the RNIB to find out more

### Local Support groups and other support

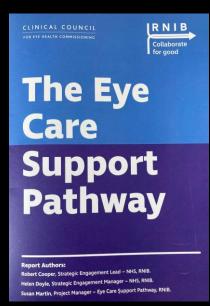
Local eye health charities e.g in this area Warwickshire Vision Support.

**ECLO** – Eye Clinic Liaison Officers

Most hospitals have these and can signpost you to support in your area and give lots of other

information

Eye Care Support Pathway public facing launched 18/09/24 It is a framework developed by the RNIB and others helping you to know what is needed at every stage of your journey. It covers having an initial appointment, having a diagnosis confirmed, support after your diagnosis and living well with your condition.



#### The Eye Care Support Pathway



With thanks to Helen Doyle for the slide

#### The Eye Care Support Pathway



















































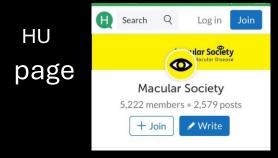
With thanks to Helen Doyle for the slide

# Online groups

- 1) Macular Society
- Have a Facebook group -
- 'Working age and young people'
- Also a Health Unlocked Page



Any other questions? do email me on balwtallyho@aol.com



https://healthunlocked.com/macularsociety

• 2) FB 'Diabetic Retinopathy UK support group'



### **Macular Society**

#### The Macular Society DMO/DR support group

Meets 3<sup>rd</sup> Wednesday every month on Zoom 7pm-8pm It also has a whatts app group too for added support Please phone the Macular Society or email balwtallyho@aol.com For more information.

# Emotional Support / counselling is really important for more information please phone

Macular Society - 0300 3030 111

RNIB - 0303 123 9999

Also local eye health charities can also offer emotional support /counselling too