

# WE ALL MATTER

A monthly bulletin brought to you by OcuMel UK

ISSUE 1



## Top stories in this newsletter

Understanding  
Patient Journeys

First Member  
Meet Up

Jenni Lewis Makes  
The Headlines!

We All Matter

## Understanding Patient Journeys



We need to hear from all our members to understand more about how you were diagnosed and about your care going forward.

A survey has been created and we invite you to spend 5-10 minutes letting us know about who manages your care, how frequently and how this is done.

Results will only be published anonymously and we won't know your name unless you provide it to us in one of the comments

[CLICK HERE TO COMPLETE THIS SURVEY NOW](#)

We have also asked for 3 things you have learnt from your experiences in the hope your responses will help those newly diagnosed or further down their journey.

Some of the data we gain will also be used to support Jenni's petition to the Scottish government. You can read more about this below and this may trigger a review of the Uveal Melanoma Guidelines in England.

## First Member Meet Up



Following on from our latest newsletter, ForSight. The amazing Ruth Johnston has organized our first meet up in London **THIS SUNDAY!!!**

It's not too late to join but she will need to know final numbers by **Thursday**. They plan to meet at La Regina, 9 Euston Road, London, NW1 2SA at 12.45.

To ensure space is available, please email [jo@ocumeluk.org](mailto:jo@ocumeluk.org) if you are interested in meeting fellow members.

Early results from last months survey are that you feel there should be member meetups held monthly or quarterly and so we need your help to make this happen.

Are you able to choose a date and find a location that is easy to get to? It can be a restaurant, coffee shop, conference room or a picnic in a park as the weather starts to improve. We'd love to hear from you.

## Jenni Lewis makes the headlines!



"If you don't do it, no-one else will" fits the bill perfectly here.

Unhappy with receiving yearly ultrasounds to her liver, Jenni Lewis started an online petition for ocular melanoma to be recognised in Scotland and enable patients to receive enhanced MRI scans with contrast of the liver in an attempt to detect early metastatic disease.

Jenni was then asked to join a meeting with the Public Petitions Committee—Scottish Parliament, which she attended with Iain Galloway (representing OcuMel UK), so their views could be heard.

A consultation process is underway with patient groups & hospitals being asked if they offer MRI's or ultrasounds and their reasons for doing so. We are preparing our response and will keep you informed on the developments in this area.

You can watch Jenni and Iain [here](#). They start 56 minutes in.

## Rare Disease Day



OcuMel UK has applied to join Eurodis, Rare Disease Europe and hope to raise the profile of rare conditions by taking part in

Rare Disease Day on the **28th February**.

Please see our website and Facebook page next week for more info how you can help.

## Upcoming Events

Our annual Eye Patch Day is fast approaching, with this years date set for Friday 19th May. If you would like to register your interest and receive a free sponsor pack, please email Nicolette.



The KP24 Foundation are organising #ride4ocumeluk, a bike ride mirroring Kevin Pieterse's journey through English County Cricket, cycling 300 miles over three days from 3 July 2017. For more information <http://www.kp24foundation.com/bike-ride/>

If you or anyone you know might be interested in taking part, please contact Jo and Nic directly, rather than The KP24 Foundation.



In connection with this event, OcuMel UK would like to "cycle round the world"! By members and supporters each pledging to cycle an amount of miles beginning from 1 July 2017 until we have reached our target of 24,902 miles. Contact us for further details.

Do you have any events coming up you would like us to share on our next edition of "We All Matter?"

---

## We All Matter



Our trustee Ben Richardson, an Optometrist for Vision Express, spent a day last week volunteering his time at a Crisis Centre in East London performing eye tests on homeless people of all ages and backgrounds. Out of the 11 people he saw, 2 were referred on to query ocular issues. This highlights the importance of EVERYONE getting their eyes tested so abnormalities such of ocular melanoma, can be picked up promptly. Read more [here](#).

---

## AGM



A huge thank you to everyone who voted in person, proxy or joined by conference call.

As per previous years our conference call demon raised it's head and so we were faced with some challenges but it didn't stop a great meeting. Minutes will be circulated shortly to all our members by email where we hold valid addresses and by post to anyone not online.

Next year we plan to make the AGM a larger event by inviting speakers to attend and so if there's anyone you would like to hear from, please let us know.

---

## St Paul's Eye Unit Open Afternoon



On Wednesday 5th March 2017 PPIER (Patient and Public Involvement in Eye Research) are hosting an open afternoon at St Paul's Eye Unit, Royal Liverpool Hospital from 1.30—4.30pm. Everyone is welcome to attend. Talks will be held on Diabetic Retinopathy, Glaucoma & AMD. There will also be information and patient support stands. Our member and Patient Representative, Keith Tanner will be there with an OcuMel UK Stand. If you can, pop in and say hello.

OcuMel UK—139 Langley Road, Slough SL3 7DZ—01753 357771  
Registered Charity No 1147506

Jo Gumbs—[jo@ocumeluk.org](mailto:jo@ocumeluk.org)  
Nicolette—[supporter.care@ocumeluk.org](mailto:supporter.care@ocumeluk.org)