

# WE ALL MATTER

A monthly bulletin brought to you by OcuMel UK

ISSUE 2

MARCH 2017



## Top stories in this newsletter

Patient Journeys

Member Meet Up

Stronger Together

We All Matter

## Understanding Patient Journeys

Thank you to everyone who were able to complete our Understanding Patient Journey survey. It has given us a great insight and based on your feedback we will be implementing a surveillance guide for patients based on the NICE approved Uveal Melanoma Guidelines. We have also featured information taken from this survey into Jenni Lewis' Petition to the Scottish Government.



There is still time to complete the survey using the link below if you haven't already.

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

Part of the survey captured the advice you would give to a newly diagnosed patient. We will collate and publish the comments once the survey closes.

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## First Member Meet Up

Our first member meet up went ahead last month in London! Feedback was overwhelmingly positive. Thank you to Ruth Johnston for getting the ball rolling and to those who took the time to attend.



Keith Tanner is currently arranging a North Region member meet up in the south Manchester area. For more information, please contact Keith direct via [north@omuk.info](mailto:north@omuk.info) or call the helpline and we can pass on your details.

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.

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## Jenni Lewis' Scottish Parliament Petition

This petition is currently under review and responses can be seen [here](#).



OcuMel UK have submitted our response explaining why we support the petition and have followed this up with further information, which you should be able to view in the next few days.

We know some of our members are in similar situations. Please be assured that we are looking at ways we, as a charity, can assist you.

The first of these initiatives will be a Managing Your Follow Up leaflet clearly stating current information from the Guidelines and the options available to you.

We are also in discussion with relevant bodies regarding another avenue for patients and more on this will hopefully be announced next month.

OcuMel UK are here to support our members, and thanks to your feedback surveillance is an area we are working hard to improve.

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## Stronger Together

One of our members, Iain Galloway, started an online pan-European patient group in early 2016. Melanoma Patient Network Europe Ocular/Rare, or MPNE Ocular/Rare for short, are a sister network to the already established MPNE who deal mainly with the much more common skin melanoma. Now they'd like your help!"



"As we all know Ocular Melanoma is a 'rare cancer', this means fewer patients which makes it tricky to run trials.

Now, it appears there are \*a lot\* of new treatments on the horizon and it is key that trials can be conducted. Having a large enough number of European OM patients looking for a clinical trial is a very strong argument to get a trial off the ground. So, PLEASE- if you could make sure this very short sign-up reaches as many patients with Ocular Melanoma as possible, this would be very much appreciated...and don't forget to fill it in yourself too" Click [here](#) to complete this now.

For more information about the work of MPNE, please see [here](#).

## Fundraising and Events



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.

Some of our members are organising local raffles as part of Eye Patch Day and are approaching local & national businesses for prize donations. This is a great way to raise funds, please let us know if this is something you would like to arrange yourself.

Last year Jenni Lewis sourced a signed Glasgow Rangers Football shirt to auction. If you are able to obtain any special items that we could auction, please contact Nicolette.



Andrew Coombes will be walking 44 miles along The Test Way on Saturday 17th and Sunday 18th June. If you would like to join him, please contact Nicolette who will pass your details on, if you would like to support him, please click [here](#) for his page.

Matt Jeavons of Beverley Holidays has been a long running supporter of OcuMel UK and his help has been an immense support to us. Beverley Holidays have this year nominated OcuMel UK as one of their chosen charities to support. [www.beverley-holidays.co.uk](http://www.beverley-holidays.co.uk) have three holiday parks located in beautiful South Devon. They will be donating a proportion of the funds they raise from various activities.



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

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## Contacting your Local OcuMel UK Regional Representative



You may have noticed a new email address for Keith Tanner mentioned earlier. He's not alone, all our Reps now have new email addresses, ending @omuk.info.

If you would like to contact your Rep, please click [here](#) for their contact information.

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## We All Matter



Keith Tanner represented OcuMel UK at the PPIER (Patient and Public Involvement in Eye Research) open afternoon at St Pauls's Eye Unit, Royal Liverpool Hospital. One of the amazing new innovations shown at the event was the OrCam MyEye. A glasses-mounted device that can read text, recognize faces, and identify products for people who are blind or partially sighted. View the product here <http://uk2.orcam.com/>

The product is also available through [www.henshaws.org.uk](http://www.henshaws.org.uk), a charity supporting people with sight loss and a range of other disabilities.

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We would like to take a moment to remember those we have sadly lost. Each loss is heartbreaking for their family and friends, but also felt by the wider OM community.

Anyone needing support please reach out someone. Please remember you are not alone in this journey.

<a href="#">OcuMel UK Helpline</a>	(Mon, Tues, Thurs & Fri - 11am-1pm)	0300 790 0512
<a href="#">Samaritans</a>	(open 24 hours a day, 365 days a year)	Freephone 116 123
<a href="#">MacMillan</a>	(Monday to Friday 9-8pm)	0808 808 00 00
<a href="#">Cruse Bereavement</a>	(Mon & Fri 9.30-5pm, Tues, Weds & Thurs 9.30-8pm)	0808 808 1677
<a href="#">MIND</a>	(Monday to Friday 9-6pm)	0300 123 3393

- 0300 790 0512
- [www.omuk.info](http://www.omuk.info)
- [info@ocumeluk.org](mailto:info@ocumeluk.org)
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Charity Registered in England No. 1147506  
139 Langley Road, Slough, Berkshire, SL3 7DZ