

Welcome to our October edition of We All Matter.

“Where there’s a will, there’s a way”, is the saying running through Jo’s mind on a frequent basis. Since OcuMel UK was founded we have worked hard towards achieving its aims, but with every passing week there is more and more we can do to help people affected by ocular melanoma.

OcuMel UK 2017 Annual Conference

Our Ocular Melanoma Patient Conference took place on Friday 22nd September, and it was lovely to welcome so many of our members. We were able to secure some fantastic speakers again this year, and we hope everyone found the day informative and enjoyable.

We received great feedback from the day but this quote sums them up “Brilliant and very informative”.

For those of you who were unable to attend, the videos of the speakers will be on our YouTube Channel. Click [here](#) to view.

Surveillance - MRI vs Ultrasounds

In 2015 we saw the launch of the National Guidelines for Uveal Melanoma ([full report](#)). There is more clarity around many aspects of the management of this condition, but Surveillance is one area of uncertainty we hear about on the helpline and from our members. “Should I receive an MRI scan or an ultrasound scan? Which scan is better?”

The guidelines state, “Patients judged at high-risk (see Section 6.3.2) of developing metastases should have 6-monthly life-long surveillance incorporating a clinical review, nurse specialist support and liver-specific imaging by a non-ionising modality.” An non-ionising modality is an ultrasound or an MRI.

For a patient with liver disease who is receiving treatment with curative intent, the guidelines state “patients should receive regular (3-4 monthly) hepatic MRI and CT of chest, abdomen and pelvis.”

We know there are patients in the UK who are being offered an ultrasound scan but would prefer to receive an MRI scan.

We (OcuMel UK) cannot say which scan a patient should receive, whether an MRI or an Ultrasound. Every person is an individual but the guidelines to state “All patients, irrespective of risk, should have a holistic assessment to discuss the risk,

Surveillance - MRI vs Ultrasounds - cont.

benefits and consequences of entry into a surveillance programme. The discussion should consider risk of false positives, the emotional impact of screening as well as the frequency and duration of screening. An individual plan should be developed.”

So what can we do?

We asked our membership base, whether they would be in support of OcuMel UK funding a project to provide and evaluate twice yearly MRI scans for patients. The majority - 86% - were in favour, 10% were undecided and 4% were against. Cost was a concern for some who were undecided.

We will shortly be surveying our membership to find out just how many have asked their doctor for an MRI scan and been refused. We have a plan of what can be offered but this will depend on how many would opt in to such a scheme. If you would like to be included in this survey, please sign up as a member - details below.

Help us win £2,000! Make us your favourite charity on eBay

This October, eBay for Charity will be counting every time a charity is selected as a favourite. The charities with the most favourites at the end of the month will win cash prizes.

£2,000 for a small charity like ours, will make a huge difference. Please visit our profile page on eBay [here](#) and click “Add to My favourites”.

You can also search for us by going to charity.ebay.co.uk/search.

The charities with the most favourites at the end of the month will win cash prizes. So please make the most of social media and spread the word with your family and friends and encourage them to do the same.

Every vote counts! Thank you for your support

Volunteer for OcuMel UK

We know our supporters have an amazing variety of skills and knowledge, and we know many of you may want to help but are unsure how. Please email sonya@omuk.info if you would like to help out in some way.

This is so important as lack of time and resource is delaying so much of what we want to achieve.

Sonya is our Volunteer Co-ordinator and will be responsible for looking after and expanding our existing volunteer base, and organising fundraising events. She comes to us with a wealth of experience both from working within the charitable sector and from volunteering herself, and would love to hear from you.

Melanoma Taskforce Meeting

Back in September, Jo attended a Melanoma Taskforce meeting in Westminster, chaired by Pauline Latham OBE MP.

Many of the UK's melanoma charities were present and plans how they could work together were discussed. They also discussed how the Taskforce could use its platform in Parliament to assist the charities in achieving shared aims or projects.

Although some of the difficulties our members face are unique to ocular melanoma, there will be some common ground and these meetings will enable us to have a voice and to share best practise with other similar organisations.

Snowden

Our member Gemma Whitchurch is organising a member's walk up Mount Snowdon early next year. Gemma says it has three aims; to give everyone a focus, improve fitness and to raise sponsorship for OcuMel UK. She will be issuing training plans to help to those of us who have never taken on such a challenge.

We are amazed by the amount of people who have already signed up for this event, and so if you would be interested in joining them, please email Nicolette on supporter.care@ocumeluk.org so your details can be passed on.

MPNE Meeting

Jo Gumbs attended MPNE's conference last weekend Leiden, Netherlands. Iain Galloway and his team have worked hard to develop an amazing programme. Please visit [MPNE's website](#) for the latest information.

Fundraising

We have mentioned previously our aim to employ a nurse to run our helpline, and also visit hospitals to meet patients and the medical team on a regular basis. We've also been asked to fund a Fellow so they can work on really pushing through the larger projects, this is something for us to look into for the future.

We are always reluctant to ask our supporters to fundraise for us but want to give you all an idea of how money will be used. We'd love to hear from you if you can help us in any way.

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.

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This journey is difficult at times and so it can take strength to reach out for help. If you need support, please talk to someone.

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

 **0300 790 0512**

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