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Vote on MRI's



As mentioned in previous E-Bulletins, Jenni Lewis began a petition for patients in Scotland to receive MRI scans as part of their follow up care.

An update on this can be found below but in advance of the review to the Uveal Melanoma Guidelines, we would like to understand and document whether MRI scans are better at detecting metastases in the liver compared to scanning by ultrasound.

We would like you to decide whether OcuMel UK should fund a project providing & evaluating twice yearly MRI scans. This would be for:-

- Patients thought to be potentially at higher risk of developing metastasis or unaware of their risk.
- Patients not currently receiving this follow-up.
- A limited period, for example three years, subject to funding.

You will receive an online questionnaire at 2.30pm to cast your vote.

We will close the survey in 2 weeks and take your responses to our Board of Trustees to determine whether this is something we could potentially offer.

If you have any questions or comments regarding this, please call or email Jo.

I Patch For



Thank you to everyone who has baked, raced, decorated, tweeted and Facebook'd in the name of I Patch For. Your efforts have been truly amazing and will no doubt have made more people think about the health of their eyes.

So far this year's I Patch For campaign has seen a record number of supporters. We have sent out 28 supporter packs, with many more making use of the online downloads.

I Patch For - cont.



Eye patches and I Patch For signs can be downloaded [here](#). A photo can spread your message across social media to literally hundreds of people.

It's not too late to take part, in fact there are a couple of events during June, continuing to raise awareness of ocular melanoma.

[Pinnacle Internet Marketing](#) kindly arranged our Facebook frame for this campaign and for those of you on Facebook you can change your profile picture [here](#).

Our site www.ipatchfor.com will serve as a platform for future years and should help patients find support in their local countries. We are confident this will continue to grow with many more organisations joining us.

Funding



We have a new volunteer, Carolyn Tweed who has taken on the mammoth task of applying to Trusts and Foundations for funding on our behalf. Up until now we have been solely reliant on your generosity, but to enable OcuMel UK to grow and further support our members, funding is essential.

One of the ways we feel we can support you better is by funding a qualified nurse to manage the support line, meet patients, act as an advocate and help to develop the support groups.

Whilst we are hopeful we will receive some funding towards this, it is likely there will be a shortfall, and so we may have to look to alternative fundraising options.

Jenni Lewis' Scottish Parliament Petition



The Chief Medical Officer has given a response to the petition, which can be viewed [here](#).

The committee are due to evaluate all the information submitted next month and we will keep you updated as we hear from them.

Text Donate



If you are happy to make a contribution to our work or are happy to encourage others to do, text donate can be a quick easy way for many. To do so, text OMUK20 space and the amount you'd like to donate to 70070.

For example, if you wanted to donate £5, you would write OMUK20 £5 and send this by text to 70070. Thank you.

Patient Stories



Please remember we have a Patient Story section on our website, available to view [here](#).

If any of you have written a blog, or have any video diaries you would be happy for us to share on this page, please get in touch.

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**

 **www.omuk.info**

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