

Welcome to our March edition of We All Matter.

Below you will find a round up of the latest news in the world of OcuMel UK, we hope you find it informative.

Have Your Say

The National Cancer Research Institute are conducting a "Living With and Beyond Cancer - a James Lind Alliance Priority Setting Partnership Prioritisation Survey"

This could be one of the most influencing surveys we ask you to complete. It took 10-15 mins to complete but it gives us the opportunity to determine how research of over £1m is spent. Please select the areas of the most importance to you, but with questions being asked such as the two below, please please take the time to complete this.

- How do the support needs of people with rare cancers differ from people with more common cancers, and how are those needs best met?
- What is the optimal approach to follow-up to detect whether a cancer has come back?

We have fed back our thoughts on how it could include other priorities for people with a rare cancer but please complete this asap so our needs are captured.

[Living With and Beyond Cancer Survey](#)

Recent News

OcuMel UK is Charity of The Year at CSR Distribution Centre, Worksop

We are absolutely delighted that David Harris' colleagues have chosen us as their Charity of the Year in his memory. It was clear how much he meant to everyone he worked with.

They have amazing and creative ways of fundraising, from selling lightbulbs to priority parking spaces to half the cost of hiring meeting rooms. We are delighted to be working in partnership with such an amazing group of people, building much needed awareness and fundraising opportunities.

MPNE 2018 Annual Conference

Jo Gumbs was fortunate to attend Melanoma Patient Network for Europe

MPNE 2018 Annual Conference - cont.

Conference in Belgium. The whole conference was back-to-back with information about melanoma, how to influence change and with a separate stream for issues around ocular melanoma. It was incredible to see so many people working hard with a shared goal. Topics such as biopsies, treatments and of course surveillance were discussed. Jo will be summarising all new information and cascading it our membership shortly.

Eye Matter Too Campaign

Throughout March we have been running our latest campaign Eye Matter Too. This campaign is in memory of Lesley Kirkpatrick, who fought for many years to highlight the inequalities many with ocular melanoma face.

The Eye Matter Too Campaign gives a voice to those affected by ocular melanoma and aims to highlight how little this condition is understood and researched. If you would like to share your story, please contact jo@ocumeluk.org

I Patch For

This years I Patch For (formerly Eye Patch Day) will run from Friday May 18th - Friday May 25th.

The idea is simple; get your friends and family to pay you to wear an eye patch all day (except when driving/riding etc.) While you're wearing your eye patch, you will raise awareness amongst people you come in contact with.

Head to www.ipatchfor.com, a worldwide platform bringing everyone affected by ocular melanoma together. As well as providing more information about the campaign, downloads are available for people wanting to take part in the day with friends & family or tools to use on social media. The event is open to everybody.

To request a supporter pack (eye patch included), please email sonya@omuk.info

Treatment of uveal melanoma

Where are we now? A recently published overview on what we understand about ocular melanoma and the treatments to date can be read [here](#)

Awareness & Fundraising

If you have a fundraising event coming up that you would like to share, are looking for ideas or would like to see what others are doing and offer your support, please head over to our [Awareness & Fundraising Group](#) on Facebook.

Snowdon Challenge

On Saturday May 19th 2018 an amazing group from the ocular melanoma community are taking on the challenge of climbing Mount Snowdon in Wales.

If you would be interested in joining them or for more information, please email supporter.care@ocumeluk.org

Blogs

Two of our members write openly and honestly in their blogs, please follow the links below if you like to read them please go to:-

[Just and Eye](#) by Ruth Johnston

[OM - A whole new meaning of the word](#) by Joanne Morgan

Do you write a blog you would like us to mention? Please let Nicolette know on supporter.care@ocumeluk.org

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.

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

 **0300 790 0512**

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