



## **WE ALL MATTER**

**A monthly bulletin brought to you by OcuMel UK**

**Issue 10 : July 2018**

**Welcome to the latest 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.**

### **A Message From Jo**

As expected, the past few months have been a busy time for us as we prepare for our annual conference with MPNEocular, our gala dinner to fund a Care Coordinator Nurse, a meeting to bring our clinical advisory panel together and the preparation for a larger meeting where we want to bring ocular melanoma leaders throughout Europe together.

NHS England recently invited us to attend a meeting about their cancer strategy and how they can include people with rare cancers. We are also working with

Genetic Alliance UK to see how we can better support two main difficulties our members have faced lately - surveillance and accessing clinical trials.

We have also submitted our proposal for patients to access MRI scans through OcuMel UK if they are unable to access them and we should have more details on this soon.

We understand the impact that having a rare cancer can have on emotional well-being and the results of Genetic Alliance's recent survey have highlighted the growing need for us to support our members in this area. To gain a better understanding of this, we will shortly be issuing a survey to understand some of the difficulties you all experience.

During this very busy time, we have tried to ensure patient support hasn't been affected and we hope that is the case. One crucial point it has highlighted is the absolute need for a dedicated person to support you all so that we can continue to push for change. Please know we are here working for you, but please do get in touch if you need any help or if there are any areas that you feel you may be able to help us.

## Helpline - 0300 790 0512

If there is anything concerning you, or there is something you want to talk about, including Stage IV treatments, please do contact Jo via the helpline or on [jo@ocumeluk.org](mailto:jo@ocumeluk.org).

## Awareness & Fundraising

This year has seen an incredible increase in our members proactively raising awareness and fundraising for us, both independently and through organised events. Whether you choose to contact your local opticians to introduce us and leave information leaflets, take part in one of our national awareness campaigns, take part in a sporting challenge or place static collection tins in your local area – everyone's support is immensely appreciated and collectively will make a huge difference to our work.

### AmazonSmile

Do you shop with Amazon? Have you heard about AmazonSmile?

AmazonSmile is a partner of Amazon (bringing you the same shopping experience) with the added benefit of Amazon donating a percentage of the net purchase price to your chosen charity!

There is no additional cost or charge to customers or charities, it simply allows customers to choose a charity to support before they start shopping and this will generate a donation for their chosen charity. OcuMel UK are part of this fantastic service so please consider supporting us whilst shopping with AmazonSmile!

[Sign up for Amazon Smile here](#)

### Give As You Live

Give as you Live is an online fundraising platform allowing you to shop at over 4,200 top stores and raise free funds for charity. The store pays Give as you Live a percentage of your total purchase price in commission and of this, 50% is passed on to the charity of your choice. [Join Give as You Live here and support OcuMel UK](#)

## Awareness & Fundraising Cont'd

### Static Collection Tins

In February we launched a new incentive to place 400 static collection tins in 12 months. With thanks to the many members that have supported us by placing tins in their local area this incentive has seen a great start. We are pleased to update you with our efforts so far.

28 collection tins have been successfully placed during June 2018.

1. 98 collection tins have been successfully placed in total since February 2018.
2. An income of £1,306.53 has been generated since February 2018.
3. We have 97 collection tins out with our members, waiting to be placed.

If you would like to get involved or hear more about the awareness and fundraising opportunities available, please get in touch with Sonya by e-mailing [sonya@omuk.info](mailto:sonya@omuk.info) or 07921 163835

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.

## Events

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**We are so excited to announce OcuMel UK's first annual Gala Dinner will be held on Thursday 27<sup>th</sup> September from 7pm – 1am at the stunning Wardolf Hilton, in buzzing Covent Garden.**  
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Guests can expect an evening of unforgettable performances and entertainment along with fabulous food and drinks. This night to remember will include the chance to win some wonderful auction prizes, all in aid of those affected by ocular melanoma.

OcuMel UK are incredibly grateful that this Gala dinner is being organised with the support of patient, Joanna Morgan, with the intention that all funds raised will go directly towards funding a OcuMel UK specialist nurse to support you, our members.

## Events cont'd

We are reaching out to all our members for your support to help make this event as memorable and profitable as possible. Perhaps you have connections or can support the event in any of the following ways:

**--SPONSORSHIP—AUCTION PRIZES—HOLIDAYS & EXPERIENCES—  
LUXURY GOODS & SERVICES—TABLE BOOKINGS—**

FOR INFORMATION ON CORPORATE SPONSORSHIP PACKAGES OR TO DISCUSS HOW YOU MIGHT BE ABLE TO HELP, PLEASE GET IN TOUCH WITH:

Sonya: [sonya@omuk.info](mailto:sonya@omuk.info) or 07921 163835

[Click here to view event details](#)

[Book tickets here](#)

## Press Release & Patient Stories

Press releases can be a valuable and effective way of promoting the work of Ocu-Mel UK and publicising campaigns, fundraising events and individual patient stories.

We are delighted to share the following stories which have been featured since our last E-bulletin and take this opportunity to thank our members that featured in these.

An article published by Molsom & Associates showing how important regular eye testing is - [Eye exam save Spalding woman's life](#)

Thank you to our members Sophie and Andrew for featuring in this [video](#) helping people understand more about one of the treatments for ocular melanoma. We were fortunate to meet the lovely team at

Clatterbridge and can see why so many people speak highly of the care they receive when undergoing proton beam therapy.

## Blogs

[A Ripple Effect](#) by Jo Gumbs

[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](mailto:supporter.care@ocumeluk.org)

## Staying Updated

Our social media pages, e-bulletins and newsletters are in place to keep you all updated and provide you with opportunities for support and/ or signposting.

As well as keeping you updated, we have recently learnt that the number of OcuMel UK members and social media followers have a real impact on our position when applying for any future sponsorship and funding. The impact of GDPR has also led to a dip in these numbers across the board.

To strengthen our position for any future applications we are asking everyone to 'subscribe', 'follow' and 'like' everything!

[Join us a member here](#)

**Find us on Facebook:**

[Main page](#)

**Support groups:**

[OcuMel UK Patient Support](#)

[OcuMel UK Family Support](#)

[OcuMel UK Awareness & Fundraising Group](#)

**Follow us on [Twitter](#)**