

For Sight Newsletter

Welcome to the annual newsletter for OcuMel UK. We sincerely hope you will find this both useful and insightful.

Dear Members,

I cannot believe it's been a year since our last newsletter. So many exciting developments have happened during the past year, which we would now like to share with you. One of our main developments is that we are now moving into encouraging research into treatments for ocular melanoma, which I am sure you will agree is a direction we need to take. However, this important development has put a strain on our resources and we have had to prioritise our work carefully.

As many of you know, my connection to ocular melanoma was through my dad. I felt he should have received more information and support throughout his diagnosis. More importantly he needed a better treatment plan as his cancer progressed.

I recently learnt that only £36,000 was spent researching ocular melanoma in 15/16, which I felt wasn't good enough. I drafted a press release and contacted various organisations - including the larger cancer charities - but I was left disappointed and disheartened with their responses. It was then I knew we needed to take control and create opportunities for research that can't be ignored.

My dad was an incredible man, he would always say things to me in Italian and I have to say, I didn't understand most of them. Fortunately, I met Bettina Ryll from the Melanoma Patient Network Europe who said, "If you don't do it, no-one else will". That one sentence from Bettina made all the difference and I understood if I wanted change then we at OcuMel UK had to make it happen. We didn't want to see any more families suffering an ordeal like mine did.

Since then, we have been involved in a ridiculous amount of work and we have much more ahead of us. However, my team and I are truly buzzing about the fact we are making real breakthroughs, which can improve the lives of people with ocular melanoma, their carers and families.

Jo Gumbs – National Director for OcuMel UK

How do we bring the treatment of ocular melanoma in line with other more common cancers?

We have identified various ways in which we can help to achieve better treatment of ocular melanoma patients.

1. Clinical Advisory Panel

We are fortunate to have a representation from some of the main ocular melanoma specialists in the UK. With lower resources last year, we couldn't bring these doctors together as much as we wanted to. This year we are planning meetings in June and November to look at areas affecting patients in the UK from the feedback you have given us.

2. National Guidelines Review

The uveal melanoma guidelines are due to be reviewed this year. We need to ensure the relevant people including patients, are brought together and their voices are heard. If anyone is interested in being part of this, please do get in touch.

3. Bring key people together throughout Europe

This is our most ambitious and influential piece of work. It is only with collaborating with others that we will find a cure for this condition in a focused and timely fashion. Largely speaking, if you spend enough money on finding a cure, eventually it will happen. Unfortunately, we do not have the luxury of spending vast amounts of money, so we must manage our resources carefully to ensure it they directly help patients. We couldn't do this on our own and so have enrolled the help of a gentleman, Eric Low, founder of Myeloma UK. He has since worked with other rare cancer groups to introduce focused research. We are very grateful to him for giving us his time and feel we have the right people around us to make this happen as quickly as possible.

4. Using the powers that be

Jo attended a meeting at Westminster recently to learn the various ways in which our MP's, government petitions, select committees and early day motions can help with our work. This is a new area for us and so we are looking into what has worked for others and will be in touch with an update. We are also involved in a Melanoma Taskforce group which is a parliamentary forum chaired by Pauline Latham MP. Historically, it has been made up of a panel of skin cancer experts, patient groups, GPs, skin cancer nurses, and oncologists. The Taskforce was set up to make practical recommendations as to how the prevention and treatment of skin cancer, and particularly melanoma, could be improved. We have been invited to join this group so that ocular melanoma is represented and so may need a patient representative for this. Please let us know if you are interested.

Helpline plans

As we grow, it has become clear that patients and their families need dedicated support and we are in the process of recruiting a nurse to oversee our helpline. The nurse will be available to support people throughout their diagnosis over the phone and hopefully in healthcare settings. The long-term plan is to recruit two nurses to cover both the north and the south of the country.

Donations & Fundraising

As a charity with limited funds we rely heavily on donations and fundraising activities to help us continue to deliver the vital support and research we provide. How much we can achieve is always dependent on funding, so we ask you to consider supporting us. If we can place a further 200 collection tins in local shops and outlets we could raise around £48,000 per year, which will help us secure our nursing positions.

OcuMel UK Pin badge

For anyone attending hospital appointments, please do wear the OcuMel UK pin badge, as these can help strike up a conversation. If you feel comfortable telling someone about our work, please do so we can reach out to more people with this condition.

For more information go to www.omuk.info or email info@ocumeluk.org

You can also contact by telephone on 0300 790 0512.

GDPR

The deadline to be compliant is 25th May. We will be contacting our members with a consent form so you can tell us how you would like us to keep in touch with us and to confirm membership.

Membership is hugely important to us, so we really would appreciate everyone returning the enclosed form. When we explain the views of our membership, it makes a huge difference if we are representing 50 or 3000 people.

If you think your families or friends would like to become a member of ours, please do tell them about our work and direct them over to our website www.ocumeluk.org.

We can post them a form if easier.

Dates to watch out for

I Patch For

18th – 25th May 2018

Our Eye Patch For initiative is taking the world by storm, okay not quite, but we are getting there. The idea of the initiative is to encourage people to have regular eye tests and to create more awareness of ocular melanoma.

Gala Dinner

27th September 2018

One of our members who has been diagnosed with ocular melanoma, Joanne Morgan, is holding a Gala Dinner at the Waldorf Hotel in London. Money raised will go towards the funding of our nurse.

Annual Patient Conference

5th-7th October 2018

This year we are hosting our conference with MPNE Ocular, so that our community can hear from a wide variety of speakers. We are looking to run dual streams throughout the conference so that people can choose which sessions they attend.

Candle Light Walk

November 2018

We would like to hold several candlelight walks around the UK for our members who have lost loved ones. If anyone has any ideas for dates and locations, we urge you to get in touch with us. Please look on our website for more information on all these events.

<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**

 **info@ocumeluk.org**

 **facebook.com/OcuMelUK**

 **[@OcuMelUK](https://twitter.com/OcuMelUK)**

 **[OcuMelUK](https://www.instagram.com/OcuMelUK)**



139 Langley Road, Slough, Berkshire, SL3 7DZ