



WE ALL MATTER

A monthly bulletin brought to you by OcuMel UK

Issue 11 : November 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.

OcuMel UK & MPNE Ocular/Rare Conference 2018

Back in early October, along with MPNE, we brought together a community of people with a rare disease and raised our knowledge in so many areas by inviting amazing doctors, nurses, patients and other professionals to speak.



Thank you so much for all those who were able to attend and for your positive feedback. If you were unable to attend, or would like to refresh your memory, videos from the talks on the day are available to watch on our YouTube Channel [here](#)

Local Meet-ups

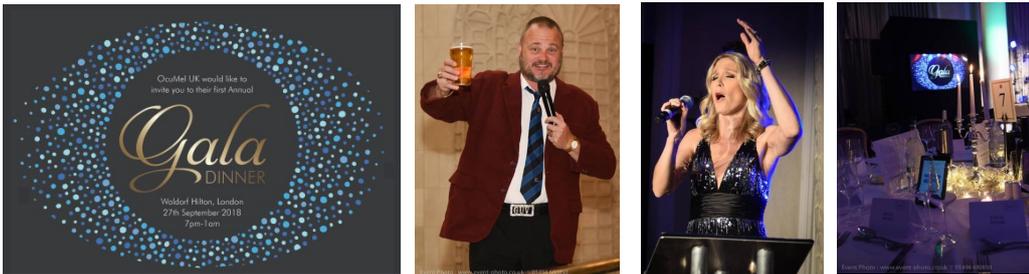
Aside from the knowledge gained during our Conference, the feedback we receive is that the friendships formed are one of the many positives taken away from attending. We understand though, that not everyone is able to attend our conferences and with this in mind, we feel it would be a great idea to try to organise some regional meet ups. If this is something you would like, please let Nicolette know on supporter.care@ocumeluk.org

OcuMel UK Gala Dinner

We held our first Gala Dinner on 27th September, and cannot thank patient and Trustee Joanne Morgan enough for all of her hard work in bringing this event together. We are also incredibly grateful to all those who sponsored the event, donated auction prizes and attended in person to ensure the night was such a huge success!

We were delighted to receive incredible feedback received from guests from the night and to confirm the evening raised a profit of almost £20,000 which will go towards the recruitment of our specialist care coordinator nurse.

To view the Gala's plea video featuring Joanne Morgan and Neil Hutchison click [here](#)



Challenge Events

We have also started working on putting together a challenge event package which we hope to launch before Christmas for spring 2019. We are currently looking at several options for locations in the UK and aim to organise a fundraising challenge that will incorporate lots of socialising so that this provides everyone with an experience that is memorable for many reasons. If anyone would like to support this or has an ideas they would like to discuss, please get in touch with sonya@omuk.info

In the News

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.

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.

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.

[Cancer sufferer hosts celebrity Gala Night](#)

[Optometry Today - Make-up Artist hosts Gala](#)

[Daughter's quest to quicken results after father's cancer death](#)

[Meet the runners fundraising to change lives at Oxford Half Marathon](#)

Do you have a message you would like to share with people? Please contact sonya@omuk.info if you would like to be featured in one of our press releases.

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.

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

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](#)

Like and follow us on Facebook:

[OcuMel UK's main page](#)

Support groups:

[OcuMel UK Patient Support](#)

[OcuMel UK Family Support](#)

[OcuMel UK Awareness & Fundraising Group](#)

Follow us on [Twitter](#)