



WE ALL MATTER

A monthly bulletin brought to you by OcuMel UK

Issue 12 : January 2019

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.

Welcome from Jo

As usual, it's been a busy time here at OcuMel UK and so I wanted to give an update on some of the work we have been involved in. For those of you who were able to attend our conference last year, you would have heard of our plans to:

- Recruit a nurse to support our help line
- Provide access to scans to patients experiencing difficulties and
- Encouraging research into a cure for ocular melanoma.

Piloting access to scans should go live next month and next week should see the position for our Care Coordinator Nurse being advertised. The job description has been circulated to our Clinical Advisory Panel and the Clinical Nurse Specialists so we can be sure to recruit the correct person for this role. This will be a major achievement and only possible because of all the support we have received over the years. Thank you to everyone who has contributed in one way or another.

OcuMel UK has certainly come a long way over recent years and so you will see below that we are looking for people to help us achieve our aims by joining our trustee board. Please do get in touch if you or someone else can help us in this way as it helps to keep our costs down.

I attended a meeting with Cancer 52 on Wednesday on the long-term strategy for the NHS which includes areas for people with rare diseases. More on this later, but it made me realise how many routes there are to achieving a set goal. We knew from the beginning of our journey that we didn't want others to experience what we went through as a family. Although we know we have been able to support others on similar paths, more is needed to stop losing more loved ones to this disease.

As we grew so rapidly, we had to take stock to develop our 5-year strategy so we could be focused on what and how we will achieve our aims as a charity. We hope to launch this to our members in the next couple of weeks and you will see it is packed with various ways that we can influence improvements in the future. I personally cannot thank our small team enough as they always go beyond what a normal job would ask of them and our supporters have constantly astounded me personally for the events, jumps, runs and very long walks that they are prepared to do to support our work. Thank you once again to everyone that is making this happen.

With the nurse in place to support people correctly, the next 12 months will see my focus shifting towards research. We need to understand the landscape better, see what is already in place and encourage the focused research we have spoken of previously. I am looking for people to join a Patient Advisory Group so that when views are needed from our community, we can make the best of those opportunities.

To really make a difference, we need to grow our advocacy network and so this will involve completing regular training modules which have already been tried and tested by larger patient advocacy organisations. More info will follow but if this is something that you are interested in, please do let me know.

Meeting with Cancer 52

For those of you on social media, you may have seen Jo Gumbs attended an All Member Meeting with Cancer 52 on Wednesday 23rd January. Cancer 52 is an organisation supporting over 100 rare disease communities and have been involved in influencing the long-term strategy for the NHS.

At the meeting, we heard from their keynote speaker David Fitzgerald, National Cancer Programme Director of NHS England. He presented 'the NHS Long Term Plan and what it means for people with rare and less common cancers'. Jo said, "It was great to see issues affecting people with rare diseases are now built into this plan and even more comforting to know that our voices are being heard and welcomed in this way." A question and answer session was held, where Jo was able to highlight the benefit of free eye tests for everyone in the UK and secondly how our issues aren't just about early diagnosis but also having the correct treatments in place to treat metastatic disease. She has suggested the NHS approve a model that can be adopted by all rare disease communities to encourage focused research. The audience seemed approving and so she is sending more about what this would look like in reality.

We do not know if it will be included in NHS plans but are hopeful that it may generate a focus so that future changes can be lead from above rather than small charities like ourselves trying to push up.

Dr Paul Catchpole also presented in the meeting. He is the Value & Access Director for the Association of the British Pharmaceutical Industry and spoke about the new 2019 Voluntary Scheme for Branded Medicines Pricing and Access. This is another important focus for us as we need to be sure that any research undertaken is then approved by people holding the purse strings. Again, two areas of concern were highlighted so they can be looked into ahead of any issues.

As Jo mentioned in her welcome message above, there are always many ways in which we can approach our work to achieve our aims but we are sure that by working alongside organisations like Cancer 52, Genetic Alliance UK and MPNE, it will set us on a better and quicker path

OcuMel UK Board of Trustees

Do you want to help the long-term future of OcuMel UK? Can you spare a couple of hours per month? We've identified some gaps in our Trustee Board and would really love to hear from you if you come from an accountancy, marketing or business background. By tapping into our members expertise we can keep costs low rather than outsourcing essential parts of our work. Please contact Nicolette on supporter.care@ocumeluk.org

Annual General Meeting

This year's AGM will be held on Monday 4th February from 12pm – 2pm:-

- Seminar Room 2, Heartbeat Education Centre, F Level North Wing, Southampton General Hospital, Tremona Road, Southampton SO16 6YD.

As with previous years, our members are invited to cast their vote by proxy, dial into the meeting or are welcome to attend. This will be a wonderful opportunity for our members to hear about the work we have undertaken over the past 12 months and our plans for the coming year.

If you haven't received your proxy vote form and wish to cast your vote please email supporter.care@ocumeluk.org to request a copy.

Rare Disease Day



OcuMel UK will once again be supporting Rare Disease Day on 28th February 2019. More information on how you can get involved can be found [here](#)

Eurordis Rare Disease Europe



Jo Gumbs is hoping to attend the 3rd Eurordis Multi Stakeholder Symposium on improving patients access to rare disease therapies in Brussels on February 13th – 14th. You can find more information about the symposium [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

Thank you...

We have 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.

Upcoming Fundraising Events

On 9th February *Catherine Hutchinson* is taking on the challenge of walking 100km of the Sahara Desert to raise awareness and funds for OcuMel UK following her husband's diagnosis. Catherine has achieved an incredible amount to date, for which we are truly thankful. If you would like to offer her your support you can find her fundraising page and read her story [here](#)

Maud Todd is taking on a year-long challenge of walking 2019km in 2019 – which is 14,400 steps every single day! Maud is fundraising for three charities, one of which is OcuMel UK! If you would like to follow Maud's efforts her fundraising page can be viewed [here](#) with a link to her Instagram account documenting her story.

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](#)

GDPR

OCUMEL UK WOULD LIKE TO KEEP YOUR CONTACT DETAILS IN THEIR DATABASE WHERE INFORMATION IS BACKED UP IN THE CLOUD AND STORED IN THE UK. WE USE YOUR DATA TO RECORD AND EVALUATE OUR SERVICE AND TO KEEP YOU INFORMED ABOUT ANY NEW DEVELOPMENTS, NEWS OR SERVICES THAT ARE APPROPRIATE TO YOU THROUGH OUR NEWSLETTERS, EMAIL OR TELEPHONE. WE NEVER PASS YOUR DETAILS ON TO A THIRD PARTY. YOU CAN WITHDRAW CONSENT AT ANY TIME. ALL COMMENTS, QUERIES AND REQUESTS RELATING TO OUR USE OF YOUR INFORMATION ARE WELCOMED AND SHOULD BE ADDRESSED TO JO@OCUMELUK.ORG

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