



St Luke's Cancer Centre Melanoma Support Group

RSCH, Guildford, Egerton Road, Guildford, GU2 7XX

**Website: [www.melanomore.net](http://www.melanomore.net)**

**E-mail: [melanomore@googlegroups.com](mailto:melanomore@googlegroups.com)**

**Hello**

This is a note of the **Virtual Cafe held on Wednesday 1<sup>st</sup> July 2002 10.00am.**

There were 9 members, 5 Committee members, and 3 outside speakers on the call.

**Sarah Browne and Catherine Malins from Surrey Healthwatch**

talked about a project they are running to seek the help of patients and families about the effects of Covid- 19 on local care services in the area (Preferably for services in Surrey, but out of area comments will be reviewed). Comments can cover GP services, Other community services, and Hospital Services, whether provided face to face or virtually.

Several Points were fed back to Sarah by members.

RSCH / St Luke's

- Blood test appointments at RSCH were now online and this was a good improvement to Hospital services and should be maintained.
- Ease of parking was helpful, but would no doubt go back to the old situation as numbers of patients increase.
- Video consultations were welcomed, although the feeling is that face to face appointments are preferable, particularly at key times in the treatment course.
- Telephone appointments were generally accepted but there are limitations both with GP and Hospital appointments. It is sometimes difficult to get the exact nature of how a patient is feeling across in this type of communication.
- Some felt it was difficult to get a face to face appointment if this was strongly desired in the current situation. This was under constant review

by the hospital. If a patient felt it was an issue to get an appointment a conversation with your CNS was advised.

- Isolation during the Covid -19 lockdown was an issue, although everyone on the call had coped. It would be important to re-establish relationships over time, and for people to feel comfortable in coming into the hospital.
- Frustration was expressed at the short notice given on some cancellations of clinic appointments and the associated concerns of delay in treatment or monitoring this could infer. One member had four appointments cancelled and re-arranged, which has been very frustrating , even taking onto account the situation.
- Overall, the feeling of the Group was that services had been maintained well, but that the much-valued personal contact with staff members has been missed.

**Sarah thanked the members for their contribution and she would give feedback on the projects findings when completed.**

IF ANY MEMBER WANTS TO PASS ON FURTHER COMMENTS PLEASE SEND THESE TO SARAH

[sarah.browne@healthwatchsurrey.co.uk](mailto:sarah.browne@healthwatchsurrey.co.uk)

[www.healthwatchsurrey.co.uk/your-views/share-your-experiece/](http://www.healthwatchsurrey.co.uk/your-views/share-your-experiece/)

Reference: Covid -19 Survey

### **Susanna Daniels, Deputy CEO, Melanoma Focus**

gave a very lively review of services being offered by the Charity on-line. Attached are the slides she used which are for your information.

Susanna stressed that they are trying to improve services all the time so comments are welcome.

- She spoke about The Patient Decision Aid, a tool to help patients navigate the Melanoma care pathway.

<https://melanomafocus.com/information-portal/pda/>

Melanoma Focus are looking to update the Patient Decision Aid and initially wish to gain patient feedback via a virtual workshop. If you are interested,

Susanna welcomes volunteers contacting her to offer to make more detailed input in due course on [susanna@melanomafocus.com](mailto:susanna@melanomafocus.com)

**Susanna also talked about the Melanoma Focus Melanoma Helpline which is manned by professionals in the field and is available on**

**0808 801 0777 or [www.melanomafocus.com/support/helpline](http://www.melanomafocus.com/support/helpline)**

Information on **Sun Awareness** is also available on the website, an issue discussed in the last Virtual Café in June.

Melanoma Focus is also developing a detailed, searchable resource of all UK melanoma **Clinical Trials** to advance patient care. This is obviously a dynamic field and requires constant update. More information will appear on the website shortly. If you find a trial you are interested in please make sure you talk to your CNS.

**Mole mapping** information is being sent to the hospital in paper format shortly and will be available through Kelly Smith [kelly.smith11@nhs.net](mailto:kelly.smith11@nhs.net) . It will ultimately be an electronic link on Melanoma Focus website also be posted on [www.melanomore.net](http://www.melanomore.net)

More details on all of this are in the slides and on the Melanoma Focus website.

**Our thanks go to Susanna for her time and interest. Melanoma Focus has been a good friend to MelaNoMore and we will maintain contacts.**

## **Other Information and points raised**

### **Events**

The Education Wellbeing Day is still under consideration for the autumn, but we are still waiting to see if we can set up such a meeting . We are also looking at a virtual style of meeting. More details to follow.

Others social events are on hold, again until we are clear as to what is permitted?

### **Facebook page**

We are nearly there setting this up but still need someone to “manage” it on our behalf. If you are interested please let Paul Duhig know via the email address [mealnomore@googlegroups.com](mailto:mealnomore@googlegroups.com) .

As a sub issue we discussed the need for a **Younger Age Group** communication system. This needs other social media outlets but we need help on getting this up and running. There are links on [www.melanomore.net](http://www.melanomore.net) in the Support section / Useful contacts.

We also briefly touched on the setting up of **The Buddy System** and it was agreed that for the next Café we would have a proposal to talk about.

The Virtual Café ended at about 11.15am after a final convivial chat. I look forward to seeing you at the next one.

Kind Regards

*Paul*

Paul Duhig, Chairman

### **MacMillan Care Pathway Survey Reminder**

**Alex Greenway, Macmillan Cancer Pathway Programme Manager, Guildford & Waverley CCG** approached **MelaNoMore** to publicise a survey she is carrying out with Macmillan on how cancer care in particular has been affected in recent months and to talk about possible changes to improve the service.

A link to the Cancer Interface Questionnaire Survey Form are attached from **Alex Greenway, Macmillan Cancer Pathway Manager**, if you would like to participate?

<https://www.smartsurvey.co.uk/s/CancerInterfacePatientCarer/>

or go to the Home page of the website, [www.melanomore.net](http://www.melanomore.net)

and click the Macmillan Pathway box

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### **Future MelaNoMore Virtual Cafe Gatherings using Zoom**

Wednesday 29<sup>th</sup> July 2020 at 10.00am

Wednesday 26<sup>th</sup> August 2020 at 10.00am