

St Luke's Cancer Centre Melanoma Support Group

Website: [www.melanomore.net](http://www.melanomore.net) E-mail: [melanomore@googlegroups.com](mailto:melanomore@googlegroups.com)

## Annual Report and Accounts 2021

### Introduction

Despite another difficult year beset by Covid restrictions, MelaNoMore has continued to build on its services to members, communicating and supporting in four main ways:

1. As we have been unable to meet in person, we have continued our programme of Virtual Cafés. In hosting these zoom meetings, we have attempted to strike a balance between wellbeing/informative meetings and sociability, including quizzes and general conversation, and our thanks are due to all those who have contributed and attended.
2. Our monthly Newsletter, which again seeks to balance melanoma news and interviews with more light-hearted content, has proved extremely popular with our members.
3. Work has been undertaken this year to simplify and focus our website which now provides a strong resource for our membership, including links to many other helpful organisations. All our events and future programme are featured on the website – [www.melanomore.net](http://www.melanomore.net) – which also provides links to sign up for our Buddy Scheme and to make contact with the committee.
4. The “Buddy” scheme has been extremely successful this year, providing one-to-one support between members.

### Virtual Café Programme

As we all know it has been a difficult year with Covid preventing face to face or group meetings in person. The next best thing is our Virtual Café meetings via Zoom. During the year we have endeavoured to bring you a variety of guest speakers and the 2021 round-up was as follows:

- **Mr Farrokh Pakzad**, Consultant Melanoma & Breast Surgeon, gave a fascinating talk on the Surgical Management of Melanoma. Of note was that 80% of melanomas can be cured by surgery alone. He spoke amongst other things about AI tools for diagnosis, Breslow thicknesses and size of margins, adjuvant treatments and future treatments being very personalised.
- **Dr Mazhar Ajaz**, PHD MRCP FRCR, Consultant Oncologist, focused on immunotherapy Development and provided an absorbing talk on some of the science behind the development of immunotherapy drugs, enlightening us as to why and how they work.
- During a Talking Heads presentation, **Ms Elizabeth Clayton** - Consultant Oncoplastic Breast & Skin Cancer, FRCS, provided us with a thought provoking and interesting discussion covering the workings of the MDT (Multi Disciplined Team, a look back on why Melanoma patients continue to increase and introduced us to BAD (British Association of Dermatology) who provide invaluable skin advice. We also discussed how to educate the great British public on how to mitigate melanoma.

- **Delia Sworm**, Macmillan CNS - Skin Cancers - responded to our many questions in her “Ask the Nurse” session. Anything from; Is the hospital free from Covid?; What vitamin supplements should I take?; Is there any further engagement with the surgical or oncology teams after the 5-year mandatory period?; Is there any help available for “cording” after removal of sentinel lymph nodes? And many more.
- Guest Speaker **Sarah Browne**, Healthwatch Community Engagement Lead from Healthwatch Surrey explained that Healthwatch was set up to ensure that the views and experiences of people across the country were heard clearly by people who run and plan health and social care services. Healthwatch Surrey is an independent organisation that gives people a voice to improve and shape services and get the best out of local health and social care services.
- **Boba Rangelov**, SSCA Patient and Public Engagement Manager from the Surrey and Sussex Cancer Alliance explained that her organisation was established as a part of the NHS to work in partnership with the local healthcare organisations (hospitals, community health services etc.) to enable them to provide excellent cancer services across Surrey and Sussex. Boba gave a detailed presentation to the Café introducing the SSCA and encouraging us to get involved.
- **Mark Witcomb**, Macmillan Cancer Support, Engagement Lead for Surrey & Sussex spoke about Support for people living with Cancer. Mark was instrumental in supporting MelaNoMore during the start-up phase and Macmillan provided the “seed” money in order for the local support group to flourish. This money has now been repaid and has again been put to use to support other new start-up support groups related to cancer. The focus of the talk was to explain the support Macmillan can provide for people living with cancer, including melanoma.
- **Chris Caswell**, MelaNoMore Committee & Buddies Lead, entitled his talk “Beating the Odds”. He gave us a fascinating, moving and very personal account of his journey through the melanoma pathway. Our thanks go to Chris for sharing his remarkable story. Reading it in print in no way did it justice, as to the way he told it. We wish him a long, healthy and happy life. From feedback we know this story has prompted others to write their own stories — We look forward to hearing them.

## Newsletter/Website

During the year we introduced you to a number of charities that deal with melanoma cancer:

- In March we were proud to record an important endorsement for MelaNoMore, in reporting that **Macmillan** had published an article in their Newsletter regarding the successful launch of MelaNoMore, initially backed by Macmillan start-up grants.
- We introduced **Melanoma Focus** and the **British Association of Dermatology** (BAD) to the MelaNoMore Members in April, and in May we looked at the **Skcin** charity and also **Melanoma UK**.
- In July we introduced you to **Cancer Support UK** and **The British Skin Foundation**, while in August we looked at **Cancer Research UK**.
- In September, following the fine talk by Mark Witcomb outlining all the different ways Macmillan support people with cancer, we followed this up with a look into the history of **Macmillan** and how they spend their money.

- Finally, In October we supported a local alliance between **Royal Surrey NHS** and **Surrey FA** who provided a free service of Walking Football.

During the year we interviewed a number of key medical staff, which most of you will have met at some time or other during your treatments, for features within the Newsletter:

- In March we talked to **Delia Sworm** - Macmillan Skin Cancer Nurse Specialist at St Luke's Cancer Centre, Royal Surrey Hospital, Guildford. Delia is also the Lead Clinician on the MelaNoMore Committee.
- In April we talked to **Kelly Smith** - Skin Cancer Care Coordinator at St Luke's Cancer Centre, Royal Surrey County Hospital, Guildford. Kelly is the co-ordinator between patients and MelaNoMore.
- In June we interviewed **Kate Upshon**, Lead Macmillan Clinical Nurse Specialist Skin Cancer and founder clinical member of MelaNoMore.
- In May we interviewed **Dr Sarah S Qureshi**, MBBS, FCPS (Med Oncology), MRCP (UK), Associate Specialist Oncology, St Luke's Cancer Centre and she shared with us some of her life in how she arrived at her current role.
- In October we spoke with **Dr. Panagiotis Koliou**, Consultant Medical Oncologist – Breast and Melanoma, St Luke's Cancer Centre, RSCH

All our monthly newsletters, with Virtual Café presentations and interviews in full, may be found on the website – [www.melanomore.net](http://www.melanomore.net)

## Buddy Scheme

The idea of the Buddy scheme is to pair a “Buddy” with a “Friend” on a one to one basis, to give support away from the focused appointment meetings with the Oncology Team. A Buddy who possibly has more experience and is further down the melanoma path, can provide a listening ear and support to a “Friend” who is newer and perhaps just starting on their journey, and may also be experiencing a roller coaster of emotions. Buddies can pass in information about their own experiences, and many, both Buddies and Friends, have reported beneficial discussions including topics even non melanoma based!

Buddy/Friend contacts are mostly by longer phone calls on a more frequent basis than clinical appointments, probably weekly or more, and interspersed with shorter ad hoc text or WhatsApp messages.

Since the Buddy scheme was launched in October 2020, just over a year ago, there have been 314 contacts between 10 Buddies and 15 Friends, which is a substantial achievement.

Thank you to all Buddies who have given their time to provide this personal support.

## Membership

Membership is open to all patients and their family members being treated at St Luke's Cancer Centre in Guildford or are referred by linked Hospital Trusts (Ashford & St Peters, East Surrey, Frimley Park and Clinics). As MelaNoMore is currently well funded, no charge is currently made for membership.

We recognise that membership of MelaNoMore is variable and may be transient. Whilst we have some members who are keen to support us now and into the future, we have others who, once they have undergone their particular course(s) of treatment, wish to "move on" and drop out of active membership. To try to understand the impact of this, we began an extensive review of our membership in the last quarter of 2021, contacting our membership list by telephone as well as email, to ascertain those still keen to attend our events, Virtual Cafes, receive our regular Newsletters and/or benefit from our Buddy service. This exercise is ongoing, and our current membership stands at approximately 50, including committee members.

It would help us greatly if, at some point in the future, you wish to step away from membership, you would kindly let us know.

## MelaNoMore Committee

During 2021 we have co-opted two new Members onto the committee, Sarah Pleass (Secretary) and Aga Kehinde (Chair).

We are indebted to the clinical nursing team, who include information about MelaNoMore with hospital information.

Below is a list of our current Committee Members,

### **Lay Members and Officers**

- Aga Kehinde – Chair
- Douglas Hollis – Treasurer
- Sarah Pleass – Secretary
- Chris Caswell – Lead for MelaNoMore Buddy Scheme
- Neil Harrison – Editor of Newsletter
- Pam Walls – Events and Governance
- Gina Freeman (on sabbatical for first half of 2022)

### **St Luke's Clinical Members**

- Delia Sworm – Trainee Advanced Clinical Practitioner - Skin cancers (Oncology) & Clinical Lead for MelaNoMore
- Elizabeth Clayton – Consultant Skin Cancer & Oncoplastic Surgeon
- Kelly Smith – Skin Cancer Care Coordinator
- Kate Upshon -Lead Clinical Nurse Specialist
- Dr Panagiotis Koliou
- Helena Emzue

We are also fortunate to have four honorary advisors, and would like to reiterate our thanks for their time and support to MelaNoMore:

- Dr Mazhar Ajaz – Clinical Consultant Oncologist
- Mr Farrokh Pakzad – Consultant Oncoplastic Breast and Skin Cancer Surgeon
- Mark Witcomb – Lead for Macmillan in Surrey & Sussex
- Dr George McGavin - patient

## Financial Information

MelaNoMore has continued to receive support from the Bailey family and the friends of Edward and Lisa Roberts who have raised significant and generous amounts of money for us in memory of Lisa Roberts, one of our founders. A further £5000 was received from the family at the beginning of the year.

Expenditure has involved one of our reserves have been spent on events this year, in view of the Covid crisis. Looking forward to 2022, we do plan to run physical events and will therefore include an element of fundraising in our activities moving forward.

A summarised record of our financial status is attached as Appendix A to this Report.

## Future Plans

Now that restrictions are lifting, we are planning to hold a celebration evening on Wednesday 27<sup>th</sup> April. This will be held in memory of founder member Lisa Roberts, whose family have been so generous in raising money for us. We are in the process of contacting members personally with an invitation to join us for a served buffet meal while listening to a number of talks from members of the medical team as well as a special guest. This will be free to members and their guests, and the reaction to date is one of excitement that, after all this time, we are finally able to meet together.

Following this event, we will of course look to run more face-to-face meetings/small events during the year.

We will, at the same time, continue with our successful Virtual Café programme, concentrating chiefly on Wellbeing subjects. We are fortunate to be in the process of recruiting a professional Wellbeing Lead to take this forward, and our new Chair also has considerable experience in this field.

Our Buddy System will continue with members supporting each other on a one-to-one basis. It is our hope that perhaps some meetings will be face-to-face (over a real coffee?!) during the year, but that is of course subject to individual preferences.

We will continue to develop our website – [www.melanomore.net](http://www.melanomore.net) – to offer more information and further links to useful sites.

As a Committee, we are proud of our achievements in 2021, despite Covid keeping us apart. We are always looking for new Committee Members, so please volunteer if you would like to join us. As always, your ideas for further developing MelaNoMore, and particularly for social events, will always be welcomed – please do get in touch.

**MelaNoMore Committee**  
**February 2022**