



St Luke's Cancer Centre Melanoma Support Group

Website: www.melanomore.net E-mail: melanomore@googlegroups.com

Annual Report & Accounts 2019 & 2020

Introduction

MelaNoMore was founded in 2018 by a small group of patients under treatment at that time and with the support and encouragement of Mr F Pakzad, Consultant Surgeon, Dr Mazhar Ajaz, Consultant Oncologist, and Delia Sworm, Cancer Nurse Specialist.

In those two years, we are pleased to note that we have become the first successful patient support group in the country for Melanoma sufferers, and are proud to be supporting our members through what is a very difficult time for them personally and also for the medical teams as we battle through the Covid 19 crisis. We have been fortunate to have strong support from the medical teams, and would particularly mention Delia Sworm and Kelly Smith, whose help has been immeasurable, both in introducing new patients to MelaNoMore and in supporting the group and its development. Delia always has time for MelaNoMore, no matter how busy she is.

During 2020, we have moved from "tea and chat" meetings to virtual cafes and built a strong website to disseminate our news and signpost further sources of support and information. We have accelerated our plans to introduce a new "buddy" system, providing valuable one-to-one support in these testing times.

None of these achievements would have been possible without the hard work and dedication of Paul Duhig – co-founder and Chairman from inception to January 2021. Everyone involved with MelaNoMore is acutely aware that we would not be where we are today without his leadership, and it is therefore with sadness that we have to report that Paul has decided to retire from MelaNoMore due to ill health. We wish him a full and speedy recovery.

It is again a testament to Paul that he leaves in his wake a strong and enthusiastic committee, well able to pick up the reins and drive the organisation forwards. Members of the existing Committee have agreed to cover the roles of Chairman, Secretary and Minutes Secretary until new Members are found to undertake these roles.

As this report demonstrates, we are in a reasonable financial position, and have ambitions to build on the impressive foundations we already have, looking forward to the time when we shall be able to meet again in person and organise wellbeing and social events. In the meantime, we will continue to do all of this virtually.

In Memoriam

Sadly, four of the founding group of seven patients have since passed away, Lisa Roberts, Kim Crawley, Godfrey Chapples and Simon Westcott, so this Report is in part in memory of them. Thanks go to all of them and their families for their parting gift of helping found MelaNoMore. The three remaining members have moved on to recover.

MelaNoMore-Structure and Aims

MelaNoMore was set up as an organisation to provide support for members and family members. It is not currently registered as a charity due to its current scope of activities and financial size. It is a small unincorporated group, managed by a Committee whose Members are appointed by the members each AGM. The Committee operating rules will generally reflect the approach to be taken if it were a Registered Charity. As such, all funds donated or generated will go to the funding of services to members as set out in the Constitution Aims. Financial records are maintained and are available for inspection.

The Aims of MelaNoMore, as set out in our constitution, are:

- (A) To promote and protect the physical and mental health of sufferers of melanoma and other skin cancer conditions - who attend St Luke's Cancer Centre, Guildford, are referred by linked Hospital Trusts (Ashford & St Peters, East Surrey, Frimley Park and Clinics), or other hospitals in the catchment area – through the provision of support, education and practical advice.
- (B) To promote the wellbeing of families and carers of sufferers as listed in purpose (A), again through the provision of support, education and practical advice.

To fulfil these aims, the following initial actions were agreed and taken:

- To hold Group meetings to allow Members and families to meet each other
- Set up information and education meetings on a range of issues
- Organise Social events for Members and their families
- Provide information through a Website and Facebook page
- Organise a Buddy System, allowing members to support each other on a one-to-one basis.

Membership

The Group currently has 69 active Patient members plus family members. We are indebted to the clinical nursing team, who include information about MelaNoMore with hospital information.

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).

There is no charge for membership as MelaNoMore is currently well funded.

Status of MelaNoMore

We are an unincorporated Members Association where all funds are used for the benefit and help of the members. We are too small to become a charity but operate along the guidelines set out by the Charity Commission.

Minutes of all meetings and decisions taken are recorded.

Our bankers are NatWest.

The Committee

List of Committee Members at 19th January 2021

Lay Members and Officers (5)

- Douglas Hollis – Treasurer & Acting Secretary
- Chris Caswell – Lead for MelaNoMore Buddy Scheme
- Gina Freeman – PR
- Neil Harrison
- Pam Walls (Pam is also a co-Founder and Chairman of Story FMR, details of which are on the website www.storyfmr.net . Story is primarily concerned with fundraising to support research into Melanoma and related Skin diseases. Story has just reached a target of raising £100,000 to support a Research Fellow at RSCH / St Luke's to work with Dr M Ajaz, Lead Oncologist)

St Luke's Clinical Members (6)

- Delia Sworm – Clinical Nurse Specialist & Clinical Lead For MelaNoMore (Delia is also Deputy Chair of The British Association of Skin Cancer Nurses (BASCSN's) www.bascsn.com)
- Elizabeth Clayton – Consultant Skin Cancer & Oncoplastic Surgeon
- Helena Emezue – Clinical Nurse Specialist
- Celia Harris – Research Nurse
- Kelly Smith – Skin Cancer Care Coordinator
- Kate Upshon - Clinical Nurse Specialist

All Clinical positions will renominate Dec 2021

Advisers (4) - Honorary

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

Virtual Cafe

Our group meetings started in late 2019 just before Covid-19 struck. We received a lot of help from The Fountain Centre which provided us with a Committee meeting room and then space for Group meetings in their area on Level B of St Luke's Cancer Centre.

Thanks go to Charlotte McDowell, Founder of the Fountain Centre and her very able team for their help and support in getting MelaNoMore set up.

We held one successful 'Tea & Chat' session in the Fountain Centre into 2020, but once Covid-19 arrived we had to change plans. We set up monthly MelaNoMore Virtual Café events from June 2020 with a combination of speakers from the medical profession talking on an aspect of Cancer Care followed by a social time including quizzes, and discussion about current topics which are of interest to members.

Our December 2020 Café was a virtual Christmas Party – it was well attended and everyone agreed was very enjoyable - thanks are due to Gina Freeman for organising this and to Sharon Harrison for entertaining us.

Wellbeing Programme

The original plan was to hold one or two one day seminars annually on Wellbeing topics relating to Melanoma. The Hospital Clinical Team held one of these in Spring 2018, and MelaNoMore organised another in September 2019 as part of the MelaNoMore launch.

Both were well attended with over 50 people at each meeting, attracted by a strong panel of speakers from Royal Surrey County Hospital NHS Trust and St Luke's Cancer Centre, Guildford supported by external speakers.

The September meeting also gave us an opportunity to work with Melanoma Focus and The Fountain Centre and give them more exposure to Guildford patients.

Since this time and with the onset of Covid, we have amalgamated the Wellbeing Programme within the Virtual Café. We have received a lot of support from the Clinical & Professional teams at Royal Surrey NHS Trust, who have given their time to speak at Virtual Café on a wide range of Wellbeing topics. The Programme is set out on our Website.

We have tried to provide information that we would have hoped to give in a one-day Wellbeing seminar, but in instalments. A Newsletter follows each meeting for those who were not able to attend. They have been popular and successful.

We have also received contributions from external local care providers or commissioning bodies operating in Surrey, NW Sussex, NE Hants, and Southwest London, updating the Group.

Website development

Our website philosophy is to give helpful information on issues and to signpost our members to other online resources to help them on the many practical issues that arise through treatment. It is an evolving and constantly improving service. All our events and future programme are featured on the website – www.melanomore.net – which also provides links to sign up for our Buddy Scheme and to make contact with the committee.

The website development has been ably led by Doug Hollis, who also acts as our Treasurer and is currently covering the role of Secretary. He has received wonderful support from Chantal Elgie-

Peters of Canterbury Website Design who gave a lot of her time free in memory of her brother-in-law Derrick Watterson.

Buddy Scheme

The aim is to pair “Buddys” who are people who have had treatment and more experience of the disease, with “Friends”, who are just starting on their journey. The Buddy/Friend pairing enables Buddies to pass in information, to talk about their own experiences, and provide a listening ear, away from the focused appointment meetings with the Oncology Team.

Under the leadership of Chris Caswell, a new recruit, and a small group comprising Gina Freeman, Neil Harrison (another new recruit), and Pam Walls, assisted by Doug Hollis, The MelaNoMore Buddy system was set up and operational within three months. The onset of Covid-19 has led to more isolation for some of us and it was the incentive for us to provide more immediate support for our Members.

The service launched in October 2020 and has already agreed 9 pairs of Buddy and Friend combinations. The success of the scheme was acknowledged in one of our Virtual Cafés in January 2021; and we are delighted that our members are finding this a useful and helpful service.

Financial Information

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

Fundraising & Supporters

Macmillan Support

Initially in 2017/18 we had no funds so to help us of get off the ground we applied to Macmillan Cancer Support for a Support Grant in late 2018. This was supported by Mark Witcomb, Macmillan Lead for Surrey and Sussex. The grant application was successful and we received £2,840.00 on 23rd May 2019.

The funding was divided into categories, but we only spent half of the overall Grant because:

- (1) the initial design of our website & its ongoing hosting are being undertaken for free, with subsequent maintenance handled in-house;
- (2) meeting costs have been reduced due to the need to hold later ones over Zoom;
- (3) there have been no costs for speakers as they were either our clinicians or representatives of Melanoma charities;
- (4) our very generous donors meant we did not need to organise fundraising.

Although only contractually obliged to return £1,438.60 of the Grant to Macmillan, the Committee decided that because we find ourselves reasonably comfortable financially, MelaNoMore would repay the full Support Grant of £2,840.00 with our thanks to Macmillan for the support which helped to get us going.

Our particular thanks go to Mark Witcomb, and other Macmillan Colleagues, who has given a lot of his time to helping us, and continues to do so.

Funds raised by Friends

MelaMoMore has the benefit of the support of 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.

This amounts to £5,678.61 over 2019 & 20.

The immense generosity of those who put so much into raising these funds is humbling. We realise we are the custodians of the funds and will do everything we can to make good use of this great gift.

It allows us to take a long-term view and to be able to offer several options going forward in Future Plans as set out below.

We hope Lisa would be pleased with what we are doing.

Future Plans

Looking forward into 2021, it is our fervent hope that we shall be able to re-start our social and wellbeing education programmes, with members meeting again, for various events (a brewery visit was arranged in the summer of 2020 when restrictions were briefly relaxed, but this was not well attended). Other ideas will be welcomed, and we are particularly keen to include family and friends in these events

In the meantime, we plan to continue our successful Virtual Café with Wellbeing Programme.

Our Buddy System is set to expand, with more members supporting each other on a one-to-one basis.

We will continue to develop our website – www.melanomore.net – to offer more information and further links to useful sites.

We will welcome more members from affiliated sites, including representation on our committee.

Above all, we would like to hear from our members with ideas on how we can develop MelaNoMore further.

It's been an exciting year and we are continually looking for new members to join the committee and be a part of shaping MelaNoMore into the future. Please let us know if you are able to join us.

PD/PW/CC/DH/2021