



- In this issue:**
- Fools & Daffodils
 - Celebrating MelaNoMore
 - Mr Pakzad's VC
 - Aga goes to Poland
 - News from the World of Melanoma
 - Buddies report

April

The month of fools and daffodils

The origins of April Fools Day are not clear but it is known that the tradition of practical joking and mischief-making dates back to Ancient Roman times.

It would appear that the festival is closely related to the coming of Spring.

Ancient Romans and Celts celebrated a festival of practical joking at about the time of the Vernal Equinox, as do millions of India's Hindus.

The French also mark 1 April but instead of April Fools they call it Poisson d'Avril (April Fish).



Some of you may remember the April fool's prank played on the BBC in 1957.

The hoax Panorama programme, narrated by distinguished broadcaster Richard Dimbleby, featured a family from Ticino in Switzerland carrying out their annual spaghetti harvest.

It showed women carefully plucking strands of spaghetti from a tree and laying them in the sun to dry.

But some viewers failed to see the funny side of the broadcast and criticised the BBC for airing the item on what is supposed to be a serious factual programme.

Others, however, were so intrigued they wanted to find out where they could purchase their very own spaghetti bush.

Spaghetti was not a widely-eaten food in the UK in 1957 and was considered by many as an exotic delicacy.

Mr Dimbleby explained at each year the end of March is a very anxious time for Spaghetti harvesters all over Europe as severe frost can impair the flavour of the spaghetti.

He also explained how each strand of spaghetti always grows to the same length thanks to years of hard work by generations of growers.

This is believed to be one of the first times the medium of television has been used to stage an April Fools Day hoax.



Celebrating MelaNoMore — 27th April 2022



We are delighted to report that 78 people will attend this event in person and we look forward to seeing everyone at the tithe barn, set in the wonderful Loseley Park; a splendid location. We are so pleased to be able to hold this event, to celebrate MelaNoMore’s achievements and to remember Lisa, whose vision brought the organisation into being.

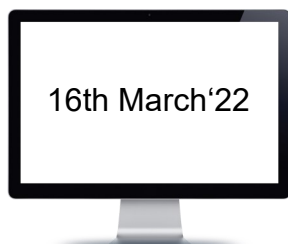
The Loseley Park grounds are available to walk around from 4pm and the main event, including a glass of bubbly and a served buffet, begins at 6pm.

We are very much looking forward to hearing from our guest speakers, from a company called “Skin Analytics” who are going to talk to us about the role of artificial intelligence in early detection of skin cancers.

Our thanks go to Gina Freeman who has spread the word amongst local shops and service providers and has a grand list of prizes which have been donated to our cause. Please bring along cash (no cards) to take part in the raffle.



The Virtual Café



Guest Speaker: **Mr Farrokh Pakzad, Consultant Melanoma Surgeon**

Topic: **Management of locally advanced Melanoma—current and future perspectives**

Following last year's talk on Surgical Management of Melanoma, we were delighted to welcome back Mr Pakzad to provide further incites into his trade. We apologise for the picture as there is no available media showing his magnificent beard.

Mr Pakzad pointed out that the interaction between Surgeons and Doctors will be paramount to future melanoma treatments.

We need to understand the terms Local; Regional and Systemic: **Localised**—Cancer is limited to the place where it started, with no sign that it has spread. **Regional**—Cancer has spread to nearby lymph nodes, tissues, or organs. **Systemic**—Cancer has spread to distant parts of the body.

As we are focussing on local advanced Melanoma it is useful to define what a local relapse is :

A **local relapse** of melanoma is a deposit less than 2 cm from the original melanoma. Anything beyond that is classed as either:

- In transit metastasis
- Nodal Matastasis (regional)
- Systemic metastasis.

It is important they we self-manage our skin regularly and look for the following:

- ◆ Changing pigmentation around the scar
- ◆ Lumps within or under the skin close to the scar
- ◆ Lumps within the or under the skin away from the primary site
- ◆ Lumps in lymph nodes, neck, armpit or groin
- ◆ New persistent or worsening systemic infections

Why do we get a local recurrence?

Sometimes melanoma can come back in the same area after treatment (recurrent/relapse melanoma). This can be months or years later. This can happen if cancer cells are left behind after treatment. The cells are too small to be seen with the naked eye or on scans. Over time, these cancer cells can begin to grow again.

Sometimes, melanomas come back as 'clusters' of melanomas. The clusters are near where the original melanoma (primary) first started. Doctors sometimes call these satellites or in-transit metastases.

The Virtual Café



Options for Management:

- ◆ Surgery
- ◆ Systemic therapy (BRAF targeted or immunotherapy)
- ◆ Radiotherapy
- ◆ T-VEC +/- radiotherapy
- ◆ Electrochemotherapy
- ◆ Isolated limb infusion or perfusion of chemotherapy

Surgery, BRAF targeted or immunotherapy and radiotherapy most of us are familiar with and apart from the first tend to be the domain of the oncologists. We will review the remaining three options.

Talimogene laherparepvec (T-VEC)

Talimogene laherparepvec (T-VEC) is a type of immunotherapy. It is also called Imlygic. For more than a century, doctors have been interested in using viruses to treat cancer. Some viruses tend to infect and kill tumour cells. Known as **oncolytic viruses**, this group includes viruses found in nature as well as viruses modified in the laboratory to reproduce efficiently in cancer cells without harming healthy cells. To date, only one oncolytic virus—a genetically modified form of a herpesvirus for treating melanoma—has been approved.

For melanoma skin cancer it's a treatment for cancer that has spread to other areas of the skin, soft tissue or the lymph nodes, and can't be removed with surgery.

T-VEC is a treatment using a weakened form of the cold sore virus. The changed virus grows in the cancer cells and destroys them. It also works by helping the immune system recognise and attack cancer cells. You have T-VEC as an injection directly into the tumour.

39% of patients achieved a complete local response and 18% had a partial response with follow up times between 3—18 months.

Note: Funding on the NHS is NOT available for this treatment.

Electrochemotherapy

Electrochemotherapy is a treatment that combines chemotherapy with a small electrical current. It is used to treat cancers that:

- started in the skin
- started elsewhere in the body and have spread to the skin

Chemotherapy uses anti cancer (cytotoxic) drugs to destroy cancer cells. Electrochemotherapy is a way of getting chemotherapy into cancer cells.

The Virtual Café



It is a combination of:

- chemotherapy injected into the tumour or bloodstream
- an electric pulse to send the chemotherapy into the cancer cells (called electroporation)

A special probe sends an electric pulse to the tumour. The electric pulse changes the outer layer of the cancer cell. This makes it easier for the chemotherapy to get inside the cell.

73% have an overall response after 60+ days and the one year survival rate is 67%
This treatment is very well tolerated.

Isolated limb infusion or perfusion of chemotherapy

A procedure that may be used to deliver anticancer drugs directly to an arm or leg. The flow of blood to and from the limb is temporarily stopped with a tourniquet (a tight band around the limb), and anticancer drugs are put directly into the blood of the limb. This allows the person to receive a high dose of drugs in the area where the cancer occurred. Also called limb perfusion.

Questions followed which Mr Pakzad addressed.

Our thanks go to Mr Pakzad for taking the time and trouble to address the group as we know he has a very busy schedule. As always we all learned a little bit more, which helps with our understanding of the disease and the options available to combat or mitigate it.

Aga Goes to Poland



Aga Kehinde, Chair of MelaNoMore and two of her colleagues are going to Poland in response to the Ukrainian refugee crisis. Aga's skills in trauma management will be used to teach the Polish support groups how to offer meaningful support and comfort to the Ukrainians.

We wish her every success in her mission which will last about 3 months, She will continue to chair MelaNoMore through regular meetings via the internet.

Aga has set up a fund raising page to contribute to the expenses of being in Poland for a 3 month period. She has provided a comprehensive write up of what she and her colleagues will be doing on this page. Should you wish to learn more and/or contribute then please go to:

<https://gofundme/dfc42c4d>

MelaNoMore
Let's talk



Virtual Café

13th April 10am via zoom

Topic:

Stress Management and
Resilience building

WITH

Aga kehinde

CLINICAL CANCER NURSE
CANCER EDUCATOR AND
MEDICAL COACH



NEWSLETTER

News From The World of Melanoma

We are intending to provide information on this page of what other charities and support groups are doing within the world of melanoma.

This month we are focussing on Action for Happiness

Action For Happiness

Active April 2022

MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY	SUNDAY
 4 Eat healthy and natural food today and drink lots of water	 5 Turn a regular activity into a playful game today	 6 Do a body-scan meditation and really notice how your body feels	 7 Get natural light early in the day. Dim the lights in the evening	1 Commit to being more active this month, starting today	2 Spend as much time as possible outdoors today	3 Listen to your body and be grateful for what it can do
11 Set yourself an exercise goal or sign up to an activity challenge	12 Move as much as possible, even if you're stuck inside	13 Make sleep a priority and go to bed in good time	14 Relax your body & mind with yoga, tai chi or meditation	8 Give your body a boost by laughing or making someone laugh	9 Turn your housework or chores into a fun form of exercise	10 Have a day free from TV or screens and get moving instead
18 Try a new online exercise, activity or dance class	19 Spend less time sitting today. Get up and move more often	20 Focus on 'eating a rainbow' of multi-coloured vegetables today	21 Regularly pause to stretch and breathe during the day	15 Get active by singing today (even if you think you can't sing!)	16 Go exploring around your local area and notice new things	17 Be active outside. Dig up weeds or plant some seeds
25 Have a 'no screens' night and take time to recharge yourself	26 Take an extra break in your day and walk outside for 15 minutes	27 Find a fun exercise to do while waiting for the kettle to boil	28 Meet a friend outside for a walk and a chat	22 Enjoy moving to your favourite music. Really go for it	23 Go out and do an errand for a loved one or neighbour	24 Get active in nature. Feed the birds or go wildlife-spotting

ACTION FOR HAPPINESS

Happier · Kinder · Together

News From The World of Melanoma

Action For Happiness

10 Keys to Happier Living

Everyone's path to happiness is different. Based on the latest research, we have identified 10 Keys that tend to make life happier and more fulfilling.

 <p>Giving Do kind things for others</p>	 <p>Relating Connect with people</p>	 <p>Exercising Take care of your body</p>	 <p>Awareness Live life mindfully</p>	 <p>Trying Out Keep learning new things</p>
 <p>Direction Have goals to look forward to</p>	 <p>Resilience Find ways to bounce back</p>	 <p>Emotions Look for what's good</p>	 <p>Acceptance Be comfortable with who you are</p>	 <p>Meaning Be part of something bigger</p>

MelaNoMore's Buddies and Friends

Join the conversation – we are looking for both “friends” and “buddies” to match together

“it is so good just to talk – we discuss all sorts of different subjects and have formed a real friendship”

MelaNoMore
Buddies Let's talk

Whether you have just received your diagnosis, are undertaking treatments, still on the road to recovery, or a family member trying to make sense of it all, you may be feeling anxious, fearful, apprehensive. MelaNoMore is here to help. We cannot give medical advice, but we can give a listening ear and the chance to chat with someone who understands what you're going through.

A 2020 study of 100,000 Brits found that confiding in others appears to reduce the risk of depression by 21%

For further information: visit www.melanomore.net/buddies/ or email: melanomore.buddy@gmail.com



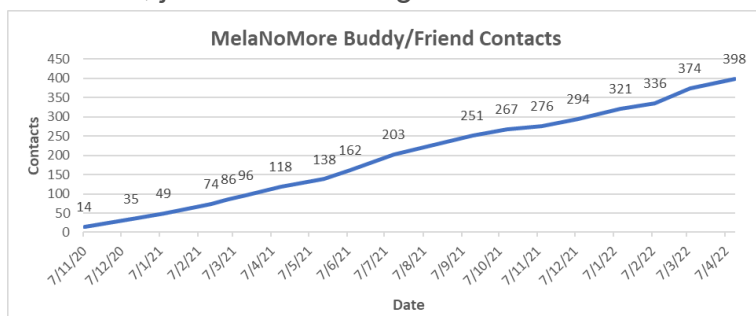
The MelaNoMore Buddies system continues to offer support via the Buddy / Friend one to one pairing. A Buddy, who perhaps has had more experience of the melanoma path and process, is paired with a Friend, who is possibly newer and in need of support and a listening ear.

This pairing offers support to share information, to discuss worries and concerns on a one to one basis, without the constraints of appointment time slots. This support pairing is away from the standard clinical appointments, on a more frequent basis, probably weekly or more.

Contacts are mostly by longer phone calls and interspersed with shorter ad hoc text or WhatsApp messages.

So far Buddies have been in contact with 19 Friends to give support, shared 195 phone calls and 197 texts, WhatsApps or emails. There have also been 6 face to face meetings, giving a total of 398 support contacts

This is a substantial achievement considering the Buddy / Friend scheme was only launched in October 2020, just 18 months ago.



If you wish to join this support group, as either a Buddy or a Friend, please send an email to [**Melanomore.buddies@gmail.com**](mailto:Melanomore.buddies@gmail.com)

This page is for your contributions to the Newsletter. There are no limits on content.

Following on with our April theme on the front page we thought you might like to try these jokes on your friends and family .

Q: Mike was born on March 31st and he's the easiest person to pull an April Fools' joke on. Why?

A: Because he was born yesterday.

*** JOKE OF THE MONTH ***

Q: Henry's mother had four kids. The first three were named April, Fools, and Day. What was the fourth one named?

A: Henry

Q: Carrie's birthday is in April, which is in the fall. How is this possible?

A: Carrie lives in Australia

Q: What did the tree say when April began:

A: What a re-leaf

Q: What makes April jump so high?

A: It's Spring

Q: What was the Easter Bunny's favourite vegetable

A: EGG-plant

Q: Which monster plays the most April Fool's jokes

A: Prankenstein

Q: Which day of the year do diesel engines like most?

A: April Fuels Day

Q: What can be seen in the middle of "March" and "April", but can't be seen in the beginning or end of either one?

A: The letter "r"

Q: What do you say when it's raining chickens and ducks in April?

A: FOUL spring weather.

We hope you enjoy this Newsletter. Please let us know or if you have any suggestions for improvement or any articles may wish to publish. You can contact us on: melanomore@googlegroups.com



MelaNoMore Vacancies

We continue to have vacancies on the Committee and are also in need of volunteers to assist the Committee with tasks or roles - such as:

- *Website designer
- *Deputy Newsletter Editor
- *Linked Site leads

If you are interested in helping out with any of these roles or wish to join the Committee, then drop a line to

group@melanomore.net

Include your phone number and we will ring you back to discuss with you.

