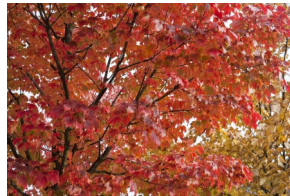


In this issue:

- Optimistic October
- VC—Chris Caswell's story
- The Interview—Dr. Koliou
- The World of Melanoma
- Buddies report
-and more.



..... and before
you know it Autumn has
arrived!



I'd like to say after a heady summer..... but summer was far from spectacular. September showed much early promise which soon fizzled out but come October the weather is virtually guaranteed. It can be mild or chilly, dry or rainy, calm or windy, even an odd sunny day. Autumn is now in it's first throes and the leaves are changing colours and beginning to fall, lawns are getting their final pre-winter cuts. There's something special about autumn, as the nights draw in and the colours begin to change. Autumn means mugs of hot chocolate, long walks with crunching leaves underfoot and bonfire night, not to mention Halloween!



The harvest is plentiful at this time of year and we should take advantage of the fresh fruit and vegetables to enhance our microbiome.



Optimistic October



Can you believe we're at the spookiest month of the year already and we have less than 100 days until Christmas!



As the nights draw in, a drop in temperature, and with the gradual return of people to offices, shops, recreational events, restaurants, pubs and bars it's time to look after yourself. You might be feeling down, worried, or anxious. It is OK to feel like this - these are normal reactions to uncertainty and the change of seasons.

Action for Happiness focus on **Optimism for October** – this can come from setting personal goals or looking at how far you've come through the challenging past 18 months with a brighter future. It doesn't matter if you set a goal for the day which is something small, the important thing is to give yourself the opportunity to feel like you've achieved something and to remember to celebrate that – no matter how big or small!

This month's "Action for Happiness" calendar is full of ideas to help you think about how you can put this into practice.

Optimistic October 2021

MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY	SUNDAY
				1 Write down three things you can look forward to this month	2 Find something to be optimistic about (even if it's a difficult time)	3 Take a small step towards a goal that really matters to you
4 Start your day with the most important thing on your to-do list	5 Be a realistic optimist. See life as it is, but focus on what's good	6 Remind yourself that things can change for the better	7 Look for the good in people around you today	8 Make some progress on a project or task you have been avoiding	9 Share an important goal with someone you trust	10 Take time to reflect on what you have accomplished this week
11 Avoid blaming yourself or others. Find a helpful way forward	12 Look out for positive news and reasons to be cheerful today	13 Ask for help to overcome an obstacle you are facing	14 Do something constructive to improve a difficult situation	15 Thank yourself for achieving the things you often take for granted	16 Put down your to-do list and do something fun or uplifting	17 Take a small step towards a positive change you want to see in society
18 Set hopeful but realistic goals for the week ahead	19 Identify one of your positive qualities that will be helpful in the future	20 Find joy in tackling a task you've put off for some time	21 Let go of the expectations of others and focus on what matters to you	22 Share a hopeful quote, picture or video with a friend or colleague	23 Recognise that you have a choice about what to prioritise	24 Write down three specific things that have gone well recently
25 You can't do everything! What are your three priorities this week?	26 Find a new perspective on a problem you face	27 Be kind to yourself today. Remember, progress takes time	28 Ask yourself, will this still matter a year from now?	29 Plan a fun or exciting activity to look forward to	30 Identify three things that give you hope for the future	31 Set a goal that brings a sense of purpose for the coming month

ACTION FOR HAPPINESS

Happier · Kinder · Together




NEWSLETTER

MelaNoMore

Buddies

Let's talk

The Virtual Café



22nd September



Attendance: 16



Guest Speaker: Chris Caswell

Topic: Beating the Odds—A fascinating, moving and very personal account of Chris' journey through the melanoma pathway.

I first want to remind us that most skin cancer is caused by exposure to excessive Ultra-Violet (UV) light levels, leading to un-controlled growth of skin cells.

As a child I was brought up in Johannesburg, South Africa. Like most middle-class families there, the garden swimming pool was in constant use for at least eight months of the year. 60 years ago, sun-cream was not of the standard we have today and whilst used, it was not so effective.

The insidious nature of skin cancer is such that it can be many years or decades before it reveals itself. My family re-settled back in England and I became a chartered accountant. It was not until 2018 that I noticed a small lump on the top of my head which itched and bled when scratched. I went to the GP who immediately referred me to Frimley Park Hospital. At my first consultation the lump was about the size of a penny piece (decimal version). A week later it had grown to the size of a 2p piece. The surgeon was quite matter of fact – “We’ll cut it out and put a skin graft over it, just a local anaesthetic and should take about 40 minutes”.

Two hours later the surgeon emerged from behind me bloodied and looked somewhat concerned. He had cut a square out from the top of the head approximately 10 x 10 cm in size, to clean out any residual cancer cells around the visible lump. He had then taken an equivalent sized skin graft from the upper thigh area and heavily bandaged both wounds. I remember being asked how was I getting home and I said by car as I thought it was just a minor op and it would be fine. It was not a comfortable journey. Imagine wrapping a cone – thigh to knee, the inevitable consequence is that the bandages will slide down, as they did and by the time I got home, blood was everywhere soaking my trousers.

A couple of weeks later, I noticed little black raisin bubbles forming all around the skin graft site on my head. I immediately rang the Hospital who referred me to the Royal Surrey where a second surgeon told me that they could not operate further - the cancer was too far gone and the only things that could be offered was a course of immunotherapy and if necessary, palliative care. At that time, I had no idea what immunotherapy was but I had heard of palliative care and I certainly wasn't ready for that. Imagine getting told all this over the phone at work!

The cancer had now spread from my head to neck and other parts of my body. A PET CT scan lit up like a Christmas tree showing all the hot spots and sites of cancer tumours within the body. The prognosis was not good and I now started a course of immunotherapy, a cocktail of two drugs; Nivolumab and Ipilimumab.

NEWSLETTER

The Virtual Café



Guest Speaker: Chris Caswell

Topic: Beating the Odds—A fascinating, moving and very personal account of Chris' journey through the melanoma pathway.

Nivolumab works by binding to and blocking the activation of PD-1 by PD-L1, essentially releasing the brakes on the car (immune system) so that it can fight the cancer. Essentially, Nivolumab works by taking the mask off of cancer cells so that they can no longer hide from the immune system, and end up being destroyed by our body's own immune response

Ipilimumab is medication that works to activate the immune system by targeting CTLA-4, a protein receptor that downregulates the immune system. Cytotoxic T lymphocytes (CTLs) can recognize and destroy cancer cells. However, an inhibitory mechanism interrupts this destruction. Ipilimumab turns off this inhibitory mechanism and boosts the body's immune response against cancer cells.

After my first immunotherapy injection, the inevitable side effects took hold. It felt as if I had a nettle rash within my body. I had an uncontrollable urge to scratch my skin, full eight finger scratches which were so intense they resulted in bleeding. I suffered chronic fatigue and would sleep up to 20 hours a day. Scratch and sleep was all I was capable of doing. I felt so bad I told the oncologist that I wanted to give up the treatment to which his response was "Take the course of treatment or die". That sort of response certainly focusses the mind. I resolved to continue.

Since the first injection, I had lost 2 stone just by lying in bed. Relatives from South Africa and Sweden arrived and stayed at the house for 4 days and I barely have any recollection of them being there, except perhaps having a cup of mushroom soup with them.

After my second immunotherapy injection, further scans revealed I had 10 cancer sites in my body. After my scan I collapsed to the floor in the hospital. I was taken straight to the Onslow Ward and stayed there for 8 days. The oncologist said "I've good news and bad news. The bad news is we've blown up your pituitary gland and the good news is we've got pills to fix that." After the eighth day I was discharged to the Chiltern ward.

The next day I received my 3rd infusion of "Nivo & Ipi". I had lost every single hair on my body and the pigment was coming out of my skin – this was good news apparently. Diarrhoea was the new normal, resulting in 2-hour WC sessions and serious colitis. To be any further than 8 paces from a WC was a ward hazard. The brain was in a permanent fog – I was barely functioning.

Since the start of the immunotherapy, I was encouraged to keep a diary of all the side effects I was experiencing.

NEWSLETTER

The Virtual Café



Guest Speaker: Chris Caswell

Topic: Beating the Odds—A fascinating, moving and very personal account of Chris' journey through the melanoma pathway.

Even though I was ill and hardly there at times this diary idea resonated with me and I kept it religiously. Some days would be gibberish and subsequently I often found entries that repeated themselves up to ten times for a single day.

On a later visit to the ward the oncologist asked to see my diary and I showed him where it was. He slowly turned the pages and absorbed every entry. It seemed an age before he looked up and said "Right you have suffered enough, I am going to put you out of your misery."

With that he dropped 8 magic pills into my hand. "I want you to go home tonight to sleep and, in the morning, I want you to take all 8 pills." The effect was almost instant, within days the itching had stopped and other side effects diminished. I couldn't stop eating – wake at 4:30 am for a little snack, at 6:30 a pre-breakfast meal, at 9:00 a full breakfast and so it went on throughout the day. I put on 3 stone in a matter of weeks.

The body was awake but the mind was still blurred and foggy.

I had another PET CT scan and my partner and I booked a week in the IoW, selected as it was only 2 hours from RSCH. I thought this might be my last holiday.

After returning from my holiday, I had another appointment with the oncologist. To this day I don't know who was more surprised, him or me. He just looked at me and said "We can't see any cancer, there is nothing on the scan, you are clear." I later found out that when the oncology team began to treat me, I had a prognosis of about 4 weeks. The "Nivo" treatment continued to the 2-year point.

This is a remarkable outcome and demonstrates that with perseverance and despite the immense amount of discomfort, the treatment works.

During my treatment I had:

3 doses of Ipilimumab	23 doses of Nivolumab
14 PET CT scans	7 MRI scans
and 100 plus injections or bloods taken.	

NEWSLETTER

The Virtual Café



Guest Speaker: Chris Caswell

Topic: Beating the Odds—A fascinating, moving and very personal account of Chris' journey through the melanoma pathway.

The "jet lag" and the fatigue has become less. I still have days when the brain fogs up a bit. I enjoy motorcycling and sometimes I just forget how to get home!

I am truly indebted to all the surgeons, doctors and nursing staff who looked after me. They saved my life and will continue to monitor me through to the end of my days. I am very positive about life and the one thing I learnt from this, was that family and friends are the most important things in life.

My Christmas present this year will be a trip to the barbers. Yes, my hair is growing back everywhere. All white as I no longer have any melatonin in my skin.

So, yes – I Beat the Odds and if there is ever a need, you will too.

Our thanks go to Chris for sharing his remarkable story. Reading it here in black and white in no way does it justice as to the way he told it. We wish you a long, healthy and happy life.

MelaNoMore Activities

It has been noted that there has been a drop off in numbers attending the Virtual Café and Happy Hour.

This is not wholly unexpected as we recognise that people tend to stay or be active within the Group when they are learning about their diagnosis or wish to learn more through the website, or speakers at the Virtual Café, or from other members at the Happy Hour or via the Newsletter. The comfort provided through the Buddy and Friend scheme is also a big help to many. As people become familiar with their situation they tend to drop off the MelaNoMore radar or a return to work from covid lockdown prevents attendance.

With this in mind we will be suspending our VC and Happy Hour activities until the new year when we expect to have a new cohort of patients which will be on the start of the melanoma pathway.

The next Newsletter will be published early December as a Christmas Special

If you have any suggestions regarding any activities you would like the group to provide please contact us at:

melanomore@googlegroups.com

THE INTERVIEW



This month we talk to:

Dr. Panagiotis Koliou

Consultant Medical Oncologist – Breast and Melanoma

St Luke's Cancer Centre, RSCH

Q: Can you tell us a little bit about yourself?

I was born and brought up on the Greek island of Rhodes. If you read my CV it would appear I have been a perpetual student. I spent 10 years in further education, earning a BSc, MSc, and a MD (Doctor of Medicine). In 2016 I completed my PhD specialising in Oncology.

Degree/Certificate	Institution	Specialty	Year Completed
PhD in Biochemistry	School of Chemistry, University of Ioannina, Greece	Oncology	2016
MD	School of Medicine, University of Ioannina Greece		2005-2009
Masters of Science	University of Surrey, Guildford, Surrey, UK	Clinical Biochemistry & Molecular Biology	2001-2003
Bachelors of Science	Benedictine University, USA	Health Science & Biochemistry with Distinction	1997-2001

My mother's relatives emigrated to the United States, so I was able to stay with them whilst studying for my first degree. I had an enjoyable stay in Guildford whilst studying for my Masters. So much so, I'm back again!

After receiving my MD, I started work based in Chania, Crete at St George's Hospital. There I was assigned as Research Fellow to the Oncology Department, undertook my foundation training and speciality training in internal medicine/haematology and medical oncology. I left there at the end of 2014 and continued my medical oncology training at Papageorgiou General Hospital, Thessaloniki, Greece. I joined University College London Hospital (UCLH) as a Clinical Fellow Medical Oncology from 2016 to 2018. After this I practiced as a Locum Consultant in Medical Oncology, initially at UCLH with Teenage and Young Adults (TYA) Sarcoma patients and the Acute Oncology Service and subsequently at the RSCH with Breast, Melanoma & the Acute Oncology Service.

In Sep 2020 I accepted the post of Consultant Medical Oncology for Breast Cancer and Melanoma at the RSCH.

Q: Why did you choose cancer as your specialism?

Interestingly, most people I knew at the School of Medicine steered clear of cancer speciality as there were few treatments other than surgical back then, particularly in melanoma cancers. For me, I saw this as a great opportunity both from a research point of view and also to assist in early trials. As a humanitarian I was convinced I could be part of the break-through for treating melanoma patients.

THE INTERVIEW



This month we talk to:

Dr. Panagiotis Koliou

Consultant Medical Oncologist – Breast and Melanoma

St Luke's Cancer Centre, RSCH

Q: What are the best and worst aspects of your job?

The best aspect of my job is the multi-tasking which is needed to support all my patients. I am continually looking for new treatments and monitoring how patients react to them. The speed of change is fast with many new trials underway and this makes me excited about the future.

The worst is too much work and the stress factor involved. I am continually aware of the need to get the best outcomes for my patients and I work tirelessly to achieve this.

Q: Do you have any concerns about the rising Covid rates?

I feel the biggest threat comes from school kids getting infected and passing it on to elderly family, despite the fact they are likely to be vaccinated the elders are never a 100% safe.

Even though we are now a highly vaccinated country, the risk still remains and if a new strain develops then we may have to react quickly with a modified vaccine. We need to monitor trends, particularly in our own communities and react accordingly.

The protocols at the Hospital here remain in place and I feel quite safe coming to work.

Q: How do you relax?

With having a stressful job, relaxation is very important to me and I love to cycle. The solitude and rhythmic action of the bike just empties the mind. I also like to swim but not so much in the English seas. When I go home to Rhodes, I can happily spend 2 hours a day in the warm sea.

Q: What is your favourite food and tittle?

I am happy to eat anything and everything. But if pushed my mother's Dolmades (stuffed vine leaves) are my favourite. She makes them without meat and included wheat grains, many herbs and spinach, other leaves and they are delicious. I never order them in Greek restaurants as I know I will be disappointed. Generally, I have cut down on meat and have a flexitarian type of diet. I don't really drink but occasionally I might be persuaded to take a glass of red wine at a special occasion.

THE INTERVIEW



This month we talk to:

Dr. Panagiotis Koliou

Consultant Medical Oncologist – Breast and Melanoma

St Luke's Cancer Centre, RSCH

Q: what do you dream of doing that is achievable?

Establishing treatments for all melanoma patients, particularly the 50% who don't respond to drugs.

Already I am involved with academic research on this front at the University of Surry and I wish to continue this to provide the best treatments for patients.

Q: How do you see your job changing in the next 3-5 years?

We will continue to see increasing number of melanoma patients over the next 5 years. New drugs and different combinations of drugs are already in clinical trials and I wish to stay and expand in the job to be able to offer new treatments to patients with better outcomes.

The next big thing is the microbiome - The microbiome is defined as the collective genomes of the microbes (composed of bacteria, bacteriophage, fungi, protozoa and viruses) that live inside and on the human body. What researchers are looking at is the effect that the microbiome may have on the development of cancer and how it may be enhanced to enable the body to fight cancer cells and aid treatments.

Our thanks go to Dr. Koliou for talking to us, we wish him a long and successful career and look forward to him addressing the Virtual Café in the new year.

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.

Have you had a cancer diagnosis? Would you like to try Walking Football?

Royal Surrey County Hospital and Surrey FA are piloting a Walking Football project for men and women who are living with and beyond cancer.

Walking Football is an inclusive, fun and sociable 5-a-side version of the game played at walking pace, but with the same excitement of the original game.

Start a new healthy activity with others who have similar experience as part of your overall health plan. Come along and join in, you don't have to know anything about football.

Who?

Anyone who has had a diagnosis of cancer (families are welcome).

Cost?

Free.

When?

Every Friday at 11am.

Where?

Surrey Sports Park, University of Surrey.

To find out more and sign up, please contact Rob Bryant at Surrey FA:



rob.bryant@surreyfa.com



07740 724 832



www.royalsurrey.nhs.uk/walking-football



Jill and Paul



I have arthritis and my husband was worried about me taking part following my cancer treatment. Once we saw the sessions and how calm they were, I felt I could play and so did he. So much so that he started joining in himself!

Bill



I stoppped playing football back when I was 41. These sessions gave me an opportunity to play again and share my cancer story with a fantastic group that I now consider friends.

Marie



When I saw the cancer walking football group advertised, I thought it was a wonderful opportunity. I feel physically stronger and motivated to exercise. For me, it's been a goal to keep coming back.

Stephen



Coming out and meeting new people initially can be quite scary. Cancer walking football sessions have no pressure, it's a good chat and we all get on really well. I'd encourage others to come and give it a go!

Buddies and Friends



Have you just received your diagnosis?

Are you still on the road to recovery?

Are you undertaking treatment?

MelaNoMore

Buddies

Let's talk

Are you feeling Anxious, Fearful, Apprehensive?
Does your family/carer need help to understand your situation?
Do you just want to chat with someone who understands what you're going through?

MelaNoMore has now established '**Melanomore Buddies**' allowing Buddies and Friends to get together

For further information visit www.melanomore.net (click on Support Icon) or email: melanomore.buddy@gmail.com



Chris Caswell, Lead –
MelaNoMore Buddies

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 may be of quick ad hoc text or WhatsApp messages, interspersed with longer possibly weekly phone calls.

We currently have 6 Buddy /Friend pairs operating, and in total Buddies and Friends have shared 139 phone calls, and sent 123 texts, WhatsApps or emails. Additionally there have been 4 face to face meetings! So total contacts now run at 266 since the Buddy Scheme was launch last October, just less than a year 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

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

October— Autumn sets in and the Spooks and Ghouls come out at night. A few witticisms to cheer us up. Share them with your, kids, grandkids, nephews, nieces, friends etc..

What happens when winter arrives?
Autumn leaves!

What do the trees say when they start getting their leaves back in spring? What a re-leaf!

*** The Winning Joke ***

You're a bus driver on an autumn tour through the park. At the first bus stop two people get on, at the second stop four people get on, at the third stop one person gets off and at the fourth stop everyone gets off. The question is, what colour are the bus drivers eyes?

The same colour as yours, you're the bus driver!

What did one autumn leaf say to another?
I'm falling for you!

Why do trees like to try new things each year?
Because every autumn they turn over a new leaf!

What do you get if you drop a pumpkin?
Squash!

How do trees get on the internet?
They log in!

What do you call a very large pile of leaves?
The Great Barrier Leaf!

Knock Knock
Who's there?
Wool

What did the bird say on Halloween?
Tick or tweet!

Wool who?
Wool you grab me a sweater? It's getting cold outside!

Knock Knock
Who's there?
Water
Water who?
Water you going to dress up as for Halloween?

What do you get when you cross a vampire and a snow man?
Frostbite

Why didn't the skeleton go to see a scary movie?
He didn't have the guts

Why are vampires like false teeth?
They all come out at night

What do you call a witch who lives at the beach?
A sand-witch.

Which ghost is the best dancer?
The Boogie Man!

Why did the ghost go into the bar?
For the boos.

Why are graveyards noisy?
Because of all the coffin!

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
- *Linked sites project
- *Health & Wellbeing lead
- *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

melanomore@googlegroups.com

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

