

HELLO Spring!



Caring for the cancer patient & their family

OPA Spring Newsletter 2021

Welcome to the Spring issue of the OPA Newsletter. What a year we had in 2020, here's hoping for a better future ahead. In this issue you can catch up on all things new...

- ✿ New Trustee
- ✿ New Carer Advisor
- ✿ London Marathon (a couple of places left)
- ✿ Barrett's Oesophagus and the launch of the Cytosponge
- ✿ Can daily aspirin stop oesophageal cancer from returning?

New & Improved Website!

We are delighted to announce the launch of our updated website www.opa.org.uk. This has been a massive piece of work but going forward this means we will have the ability to add more interactive features to the website including videos, questionnaires and social media. Our site is fully mobile compatible and is responsive for mobile and tablet devices to keep you up to date with the latest news and advice from OPA on the move, so you don't have to miss a thing.

Don't forget, you can also donate via your phone, to keep up the valuable support work we do to help our patients, carers and their families.



New Trustee: Will Docherty

Born in Inverness, I have a German wife and a teenage stepdaughter. I am a Chartered Quantity Surveyor and having worked for over 33 years for two firms, I set up my own company in 2020. I am now familiar with the steep learning curve associated with starting out in business!

Through my career I have lived and worked in various locations in the UK as well as Canada and the United Arab Emirates. Whilst I was living in the UAE, I was diagnosed with stage 3 adenocarcinoma of the oesophagus. As an expat, I was fortunate that my employer's medical insurance policy allowed me to have the initial diagnosis and neoadjuvant radiochemotherapy treatment at home in the UAE, before undergoing oesophagectomy surgery by Professor Arnulf Hölischer in Germany.

As I recently passed the five-year anniversary of my diagnosis, I wrote a post on social media and it is staggering to see the size of the team involved in diagnosis, treatment and rehabilitation. In my case, it involved many teams from five hospitals in three countries - and that is just the people I saw. In addition, there are countless more behind the scenes, each making a valuable contribution to the team effort, albeit often without acknowledgement.

The excellent medical support was supplemented by family, friends and colleagues, which was paramount in allowing me to focus on recovery and I thank them all.

As a Trustee of the OPA, I want to increase awareness of this disease to allow more early diagnosis and therefore improving the prognosis of those who will be affected in future.

New Carer's Advisor: Philip Wright

Philip retired after four years as a Trustee of the OPA, but has continued his association with the charity by hosting occasional meetings for carers. He himself has been a carer for his partner who had surgery for oesophageal cancer in 2005. He has found that informal exchanges of ideas and suggestions for helping partners of those who are about to undergo or who have had surgery for this cancer can be reassuring and beneficial.

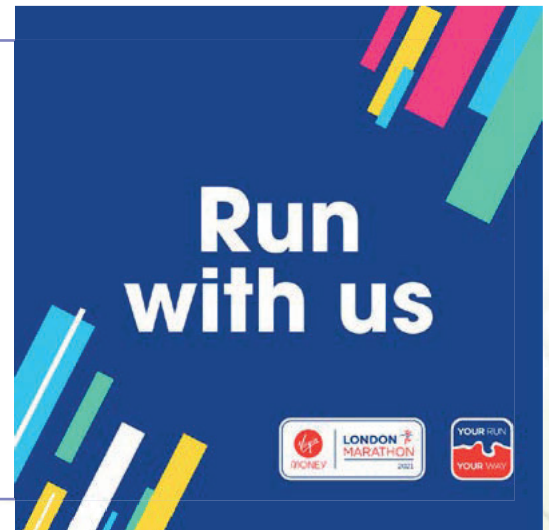


London Marathon

The OPA has a couple of places left to participate in the Virtual 2021 London Marathon!

Thank you to everyone who has decided to take on this challenge for the OPA. We are so excited and cannot wait to hear about your experiences later this year!

Good Luck to you all!!!



OPA Carer's Meeting: Report

In contrast to our first set of Zoom meetings for Carers last November, where the most pressing topic had been coping with the Dumping Syndrome, both of the meetings in March seemed to centre around controlling Reflux. As well as encouraging continuing the use of PPI's (Omeprazole and others), reducing meat intake, taking supper early, and even regular exercise, as tolerated, were suggested.



One patient had been able to control successfully months-long nausea and vomiting with Erythromycin, a GP-prescribed antibiotic. Besides the better known recommendation of taking regular probiotics (such as the Yakult drink) to help with digestion, some had found that fermented foods such as Kefir, Sauerkraut or Kombucha, cooking foods with sauces, and using lactose-free milk products such as Creamy Oat, provided relief from persistent digestive discomfort.



Although these meetings were mainly meant for Carers, some participants were joined by their partners who had had oesophagectomies, and their direct input was helpful, too.

NOGCA | National Oesophago-Gastric
Cancer Audit

NOGCA 2020 Report for Public and Patients

The National Oesophago-Gastric Cancer Audit (NOGCA) evaluates the quality of care for patients with oesophago-gastric (OG) cancer in England and Wales.

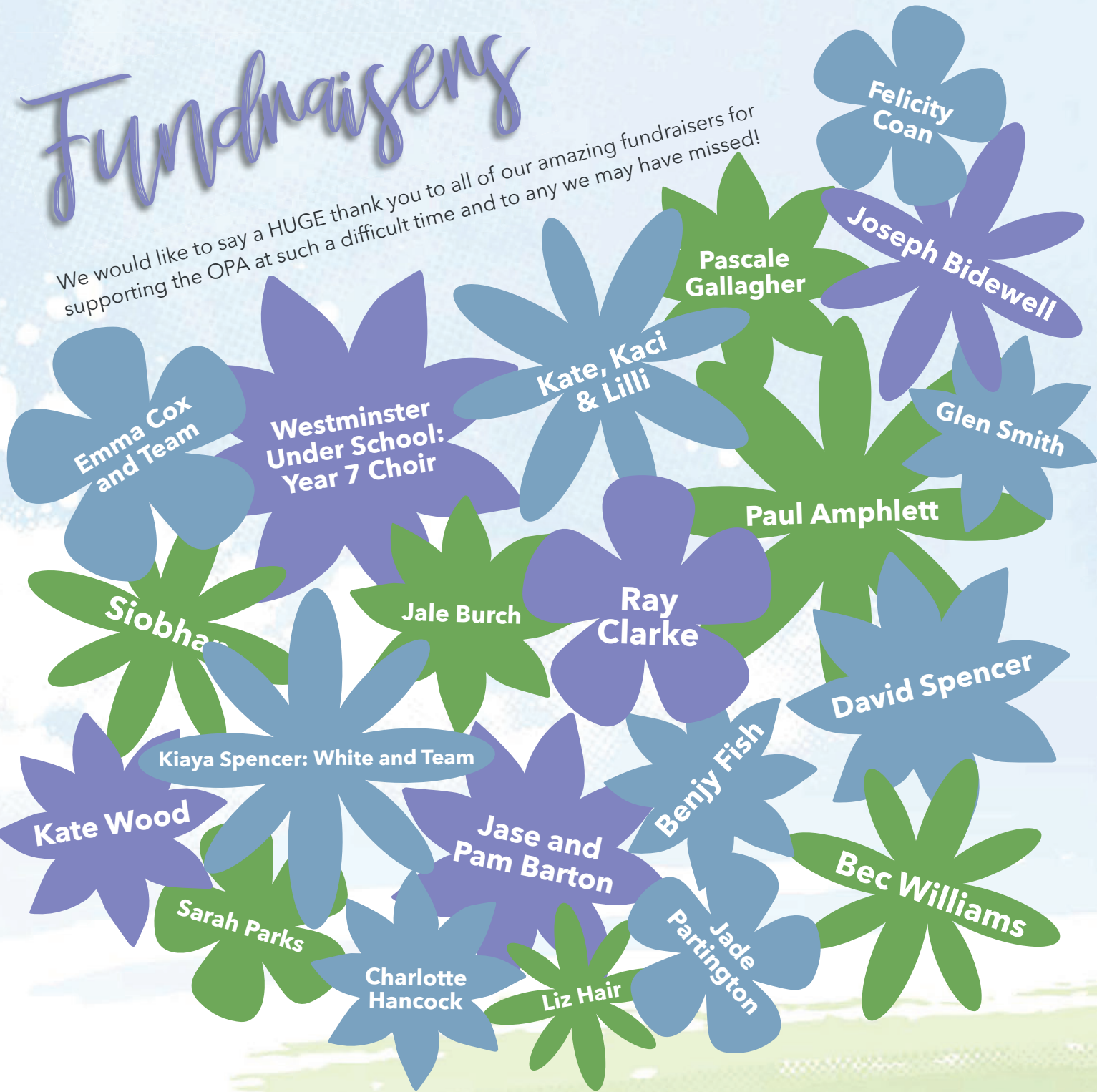
The audit provides information that enables NHS cancer services to compare their performance and to identify areas of care that could be improved.

Since 2012, the audit has also included patients with high grade dysplasia (HGD) of the oesophagus, which is a condition that increases a person's risk of developing cancer.

You can read the report here: https://www.nogca.org.uk/content/uploads/2021/03/NOGCA2020_patient-report_FINAL.pdf

Fundraisers

We would like to say a HUGE thank you to all of our amazing fundraisers for supporting the OPA at such a difficult time and to any we may have missed!



Also, thanks for the continued support of our charitable trusts and foundations.

In memory of



RefluxUK

Cytosponge™

We are thrilled to be offering the new minimally invasive test to diagnose Barrett's Oesophagus in at risk patients. It has been developed in the UK and is accurate, less invasive, and relatively inexpensive compared to endoscopy.

Barrett's is caused by reflux and is the precursor of most oesophageal cancers in the UK. However, only about 20% of patients with Barrett's oesophagus are diagnosed and therefore most people who develop oesophageal adenocarcinoma were unaware they had Barrett's.

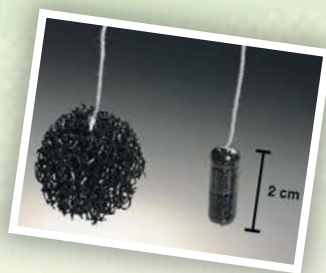
We will be using Cytosponge™ as a screening tool in patients potentially at risk of developing Barrett's Oesophagus, these people include those with heartburn, and on PPI'S (Omeprazole or Nexium) for longer than 6 months. For those who test positive an endoscopy will be recommended.

The test takes about 15 minutes and is undertaken as an outpatient procedure by a trained specialist. Cytosponge™ consists of a small gelatin capsule. This contains a compressed spherical polyester sponge which is attached to string. The capsule is swallowed and after 5 minutes the capsule dissolves allowing the sponge to expand. Using the string a nurse then pulls the sponge from the stomach through the oesophagus and out of the mouth. As it travels up the oesophagus it collects cells including some from Barrett's if its present. The sample is put into a preservative and sent to the lab where it is analysed using immunohistochemical staining for trefoil factor 3 (TFF3). This is a biomarker for Barrett's and when identified in the cells contained in the sample during examination under a microscope it indicates that Barrett's is present.

Evidence from clinical trials suggests that at risk patients offered Cytosponge™ are significantly more likely to be diagnosed with Barrett's than those offered standard care.

<https://refluxuk.com/symptoms-and-diagnosis/diagnostic-tests/cytosponge/>

Article courtesy of Reflux UK



How to use Zoom

Due to the ongoing COVID-19 crisis, remote and home working continue to be the 'new normal'.

This means that many charities are relying on Zoom as they pivot their meetings and events online.

In this article, we examine what Zoom is, how it can be used and some of the main features that charities can take advantage of. We will also offer some key tips and tricks for charities to use when using Zoom to keep in touch with staff, beneficiaries and stakeholders.

<https://charitydigital.org.uk/topics/topics/how-to-use-zoom-8095>



Can daily aspirin help to stop oesophageal cancer from coming back?



We all know aspirin as a painkiller and a drug used to prevent and treat heart attacks and strokes, but does it also have a part to play in the fight against cancer? Some research has suggested that people who regularly take aspirin may be less likely to be diagnosed with cancer than those who don't. In studies testing the beneficial effect of aspirin on heart disease, aspirin appeared to reduce the number of people who developed cancer and, in those that did develop cancer, it was less likely to spread. So researchers believe that, for people who have had treatment for some types of early stage cancer, aspirin may offer the hope of stopping the cancer from coming back. Importantly though, this idea still needs to be tested and proven. The best way to do this is with a clinical trial.

When oesophageal cancer is diagnosed at an early stage, it can normally be successfully treated with surgery and/or a combination of chemotherapy and radiotherapy. However, there is always a risk of the cancer returning. The Add-Aspirin clinical trial is for people who have had treatment for a range of common cancers, including oesophageal and stomach cancer, as well as breast, prostate and bowel cancer. The aim of the study is to test whether taking aspirin daily for 5 years after treatment for early stage cancer can stop or delay the cancer from coming back.

A clinical trial is the best way to answer this question because it will provide a fair test, and will look at both the benefits and the side-effects of taking aspirin in a large group of people who have had cancer. It is important to do this before aspirin can be

recommended for people who have been treated for cancer previously. The study is testing two different doses of aspirin, so that we can learn more about how much aspirin may be needed to have an effect, if any, against cancer. Some people will receive one of the two aspirin doses to take every day, and others will receive a dummy drug (placebo) which looks the same as the aspirin tablet but does not contain any medicine. Participants will not know which tablets they have been given - this creates a fair test. Over a number of years, researchers will look at how often people's cancer came back in the aspirin groups compared with the placebo group. They will also look at how well people took the tablets and how many people experienced side effects.

The study is currently recruiting participants in a large number of hospitals across the UK, as well as in the Republic of Ireland and India. More than 8000 people have joined the trial so far, and 11,000 are needed in total. Individuals interested in taking part in Add-Aspirin should speak to their doctor at the hospital where they are receiving their cancer treatment, who will be able to consider their suitability for the trial. You can also find out more about the study here: <http://www.addaspirintrial.org/patients-public/>.

If the trial is successful, this simple and cheap drug could offer hope to people across the world who have had treatment for oesophageal cancers.

This article was submitted from Chris Jones - Trainee Representative for NCRI Oesophagogastric Research Group.

A message of support from a Patient, Carer and Fundraiser



Thank you so much to Justine Wilson for sharing her story and for the very generous donation from Justine and her company Cardano Risk Management.

"My husband Peter, at just 48, was diagnosed with cancer. I wanted to take a few minutes to share our story and hopefully help someone else by doing so.

Peter was having difficulty swallowing food and after two weeks of antibiotics, the symptoms persisted so he was referred for a Barium Swallow test. The tests revealed a suspected throat hernia, which at the time, made perfect sense.

A follow-up Endoscopy and biopsies really took us by surprise. We had an incredibly difficult conversation with the nurse regarding the results. Peter simply asked, "is it cancer?". The thought of cancer hadn't even occurred to me! The nurse dropped her head and replied, "it might be". In that moment, my world fell apart. I was shocked. I felt like my husband had been served a death sentence.

Peter, at only 48, was diagnosed with Stage 3-4 Oesophageal Cancer. This cancer, whilst it does affect more men than women, it's usually with people in their 60s and above.

A treatment schedule was quickly put in place. After two cycles of intense Chemotherapy, Peter was booked in for a 10-hour operation, the Ivor

Lewis procedure. Thankfully, the operation went well and the cancer removed, along with 52 lymph nodes (only two had cancerous cells).

I am pleased to say that Peter is in good health eight years on. He returned to work a year later, but he lost around six stone in weight and despite amazing progress, he still has his daily struggles with food - a constant reminder of what he has been through. But Peter is incredibly strong and positive and is living a full life again!

Cardano Risk Management, who I work for, have been incredibly supportive. They have an excellent scheme for employees when they reach their five-year work anniversary and make a £5,000 donation to the employees' charity of choice, which is absolutely amazing! I want to thank them for this generous donation and support. It has meant an awful lot.

I have chosen the charity OPA (The Oesophageal Patients Association), who are a fantastic charity, supporting patients and their families whilst raising awareness of this cancer. They were of huge support to and continue to be there for us.

More information about this great charity can be found here <https://www.opa.org.uk>, but please help raise awareness of this cruel disease so we can help others catch their symptoms early."

- Justine Wilson

Thank you!

London Zoom Meeting

The proposed London Zoom Meeting will be held in May, further details will follow shortly. If you would like to receive an invite, please subscribe here: <https://opa.org.uk/register/>



Please will you help us?

By bank transfer

Recipient bank: HSBC Bank,
34 Poplar Road, Solihull, B91 3AF
Sort Code: 40 - 42 - 12
Account Number: 02301636

To make an online donation visit:

<https://www.opa.org.uk/donations.html>

By regular Standing Order payment –

Sort Code: 40-42-12

Account Number: 51354981

I wish to make regular donations to the Oesophageal Patients Association of (tick appropriate box)

£2 £5 £10 £25 £100,

or other amount:

Please state amount in words:

every (tick appropriate box) Week Month Year starting on ___ / ___ / ___ until further notice.

Your bank details

To: (insert name and address of your bank) _____

Sort Code: ____-____-____

Account Number: _____

Boost your donation by 25p of Gift Aid for every £1 you donate

Gift Aid is reclaimed by the charity from the tax you pay for the current tax year. Your address is needed to identify you as a current UK taxpayer.

In order to Gift Aid your donation you must tick the box below:

I want to Gift Aid my donation of £_____ and any donations I make in the future or have made in the past 4 years to the OPA.

I am a UK taxpayer and understand that if I pay less income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay.

Your Details

Title: (Mr/Mrs/Dr etc.) _____ Name: _____

Address: _____

Tel: _____ Email: _____

Signature: _____ Date: ___ / ___ / ___

Any other Donations

I am pleased to send a donation of £_____ Please tick here if this is to be treated as a Gift Aid donation.

Title: (Mr/Mrs/Dr etc.) _____ Name: _____

Address: _____

Tel: _____ Email: _____

Signature: _____ Date: ___ / ___ / ___

Please send this form to: Fundraising Dept. The OPA, 6 & 7 Umberslade Business Centre, Pound House Lane, Hockley Heath, Solihull B94 5DF. Or email to: enquiries@opa.org.uk

For further information please contact The OPA on 0121 704 9860 or email charity@opa.org.uk

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