



Merry  
Christmas



Caring for the cancer patient & their family

## OPA Christmas Newsletter 2021

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Welcome to the Christmas issue of the OPA Newsletter.  
We would like to wish you all a very Merry Christmas and a Happy New Year!

In this issue, you can catch up on all things new...



**London Marathon update**



**Changing to a CIO**



**Welcome back to a Trustee**



**AspECT EXcel Trial – New Project in preparation 2022**



**Newly revised Notes for a Carer Booklet**



**Christmas Cards**

**And much more, happy reading!**

# London Marathon 2021

## Siobhan Nugent In memory of Steve Hamper

At the beginning of this year, I jokingly said to my friends 'I want to marathon next year'. Little did I know that 8 months later, I would be doing just that. Lauren lost her dad, Steve, to Oesophageal cancer in October 2020. I'd known Steve for many years and we both loved music and specifically the band London Grammar. He was a great friend and used to love the different colours I dyed my hair; he would call me mad.

When Lauren, daughter of Steve, shared an Instagram post asking for people to help fundraise for the Oesophageal Patients Association (OPA) by running the virtual London Marathon, I thought why not and quickly signed myself up. I knew the OPA had helped Steve and his family quite a lot, so I thought it was a fantastic way to fundraise in his memory.

For anyone that knows me, they know that I am not a runner. However, once I put my mind to something, I am committed and determined. My training was hard and I suffered with so many blisters, but seeing Steve's memory page increase week by week with donations really motivated me. I wanted to see Steve's memory page reach £8000 by the time I'd completed the marathon.

The weather in the lead up to the marathon wasn't looking great and the entire week leading up to the marathon it was wet. I was really getting nervous but knew that I'd make it, even if I had to crawl!

When I woke up on marathon day, I was so happy to see that it was dry. I like to think it was Steve looking down on me and laughing at me for being silly enough to sign up to a marathon. I would be finishing the marathon at Steve's favourite pub, the Green Dragon, where all his family and friends had got together to host a tribute day in his memory. Before I set off, I saw that our £8000 target had been hit, which really spurred me on.



I wasn't fussed about my time and just wanted to get the marathon completed, but once I was running I really got into it. My friend Alex cycled the entire way with me and other friends cycled different parts with me and helped support and spur me on. It really pushed me on having everyone behind me.

By the time I hit mile 24, Lauren had to tell me to slow down so that she could get the finish line ready at the pub! I ended up running more than 26.2 miles as the route back to the pub was slightly longer than we thought.

Running down Higham Ferrers high street was amazing- cars were beeping and people were shouting me on. As I turned the corner into the pub, everyone was outside behind my finish line under a balloon arch. As I ran across the finish line, straight into hug Lauren and my friends, whilst being sprayed with champagne. It was a really emotional finish. The first thing I did was ask for a pint in Steve's memory.

Steve's tribute day raised over £3100. Knowing that I'd helped to fundraise such a huge amount was amazing. Overall, over £9600 has now been raised for the OPA in Steve's memory. I hope that this money lets the OPA continue the amazing work and support that they provide families. I know Steve would be laughing at me and wouldn't believe that I'd run it.

I'm so proud of myself, but I will never run another marathon again!



"I have to say what an incredible experience completing the virtual marathon was. I may have only walked it and it may have taken me 7 hours 26 mins, but I did it!

I had my husband and friends along the way to support me and carried out my marathon around the beautiful Warwickshire countryside, slightly less crowds than in London.

Thank you for giving me this opportunity to challenge myself, raise money for you and honour my dad's memory."



Sarah Parks



## Francesca Malanga

On the 27th of August our family lost Claudio, he was a special member of the family. We lost him to oesophageal cancer. He was taken from us too soon. Claudio was my dad's nephew, they weren't just uncle and nephew to each other they were brothers. There was only nine years difference between each other and grew up sharing a lot of cherished memories. There was never a moment at a family gathering/event that Claudio wasn't his smiley self, I always looked forward to seeing my cousin, those moments I spent with him will never be forgotten. He lifted the spirits and hearts of everyone that was in his life. He had so much more life to live. His soul will never be forgotten. Claudio's love for life, family and friends will live on through us. These words i am writing doesn't do justice for how amazing and special he was to me and my family. My dad is running the London marathon in memory of him he has chosen OPA cancer support. This is a very difficult and important run to my dad as he wants to do Claudio proud. He is also doing this for Claudio's mum, wife Linda, his two beautiful kids Alex and Elisa.

## David Spencer

Fit, active, in perfect health, and into healthy organic eating, you can imagine the shock as things changed forever. As fate would have it, this year's London Marathon is on the 3rd October; the exact same day I woke up 3 years ago in excruciating agony. The relief waking up cancer free helped numb some of the pain. Waking up after 14 hours with a shorter oesophagus and half a stomach missing was odd. Learning how to walk again, step by step; the thought of ever running again was laughable.



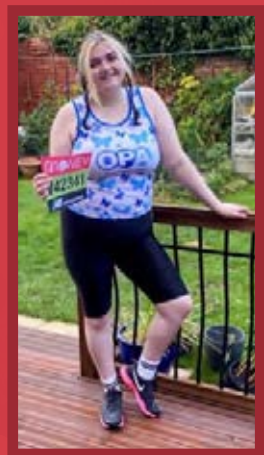
Despite my tiny little tumour, the statistics for oesophageal cancer are unforgiving, and for the first time I acknowledged my own mortality amidst a dizzy, painful blur.

I have always had incredible family support and this fund raiser is for the many many people I have met who are in a much less fortunate position than myself and need help. The Oesophagus Patients Association do a great job supporting this.

## Rebecca Cook

My grandad was diagnosed in March this year with oesophageal cancer. He had been suffering from acid reflux for many years since childhood but was noticing it getting worse from around Christmas time last year, as well as struggling to eat more and more. So in the new year he was booked in for his endoscopy. He was very cautious as he lost his own father to oesophageal cancer, but it was detected when it was too late and he only had weeks left.

After his first round of FLOT chemo and his successful oesophagectomy we have just received the news that there is only cancer in one of the nodes they took away during surgery! Showing great success rates with the chemo he has undergone – showing there really is hope with this cancer. It is no longer always a death sentence. He is opting for some last FLOT chemo in the next few weeks to really make sure this awful illness is gone for good. I cannot wait to see him ring the bell early next year!



# AspECT EXcel Trial New Project in preparation 2022

Professor Janusz Jankowski - University College London



## Background.

The AspECT Trial successfully followed up 2557 patients with Barrett's oesophagus (BM) for a mean of ~9 years, showing that high dose proton pump inhibitors (PPI) significantly reduced the bad outcomes of the Barrett's oesophagus, namely death, occurrence of precancerous high grade dysplasia (HGD) and oesophageal adenocarcinoma (BA). High dose PPI appeared remarkably safe, despite reports from several large cohort studies of increased vascular events and other proposed complications.

The data also suggested that aspirin reduced these endpoints although this was only statistically significant if non-steroidal anti-inflammatory drug users were excluded. Interestingly, the combination of high dose PPI and aspirin appears more effective than either alone. Neither agent showed an effect in preventing BA and the main decrease in endpoints were in non-cardiac death with PPI and HGD with aspirin (and to a lesser extent PPI too). In this regard since these agents reduce the precursor lesions, HGD, longer follow up would be expected to show a decrease BA. AspECT is one of the few cancer prevention trials in the world to show a synergistic combination between two agents.

The Women's AspECT study (WASP) embedded in AspECT trial confirmed that when comparing the endpoints between the sexes, men indeed have a higher incidence all of the endpoints of HGD, BA and early death, including when all the unrelated variables

are considered; the effect of high dose PPI was very clear in men but less so in women.

However, since fewer women were recruited, additional follow up will allow us to address this issue too as the power will increase by at least 65%.

## For more information on this trial:



Please visit the OPA website -  
AspECT EXcel Trial - The OPA

*We have helped the following trusts  
this year with research...*

- **University College London**
- **University Hospital Southampton**
- **Lancaster University**
- **Imperial College London**
- **University of Bristol**
- **Guys and St Thomas' Hospital**



# Awareness Week 2021



The OPA are happy to announce that due to their first and very successful UK Reflux Awareness Week that they are holding the second campaign this year!

**Running from 22nd – 28th November 2021,** the OPA will continue to urge people to Get Educated, Get Evaluated and Get Treated for Acid Reflux. Working in collaboration with their Patron, Fiona Wade who plays Priya Sharma in Emmerdale, is OPA's Patron after losing her father to Oesophageal Cancer who suffered from acid reflux for some time.

Our campaign centres around three core messages:

## GET EDUCATED

About the symptoms and complications. We would like to educate people that Reflux disease is more than just heartburn and raise awareness of more symptoms.

**LEARN MORE** with the link:  
<https://opa.org.uk/get-educated/>

## GET EVALUATED

To find out if you have Gastro-oesophageal reflux disease (GORD): The first and most important step in treating your reflux symptoms is to accurately diagnose the cause. There are a range of diagnostic tests available to understand your own individual case and we will be raising awareness of all the different tests and what to expect.

**LEARN MORE** with the link:  
<https://opa.org.uk/get-evaluated/>

## GET TREATED

Learn about treatment options for GORD: Once the cause of your symptoms have been established by your healthcare professional, there are a range of different treatment options available to you. We aim to raise awareness of these different options so you can have an informed conversation with your healthcare professional about what might be the best treatment for you.

**LEARN MORE** with the link:  
<https://opa.org.uk/get-treated/>

**Watch this space for an update in the Spring 2022 Newsletter!**



You can order this poster on the OPA Shop to display in your local Hospital, GP Surgery, Community Centre:  
<https://opa.org.uk/product/gp-surgery-poster-awareness-week-2021/>

# Functional Gut Clinic



## The Functional Gut Clinic – Helping people take control of their gut health

Gut symptoms can be troubling and difficult to live with, not being able to enjoy certain foods or having repeated symptoms can cause real unhappiness. At the Functional Gut Clinic we help people take control of their gut health with the very latest diagnostic technology and a team of dedicated specialists to offer a trusted, proven and reliable service that swiftly identifies the problem with the patients' gut health; then connects patients with precisely the right treatment to alleviate symptoms or put things right. We cover the full range of gut symptoms; heartburn, dyspepsia, constipation, diarrhoea, bloating, pain, belching, flatulence and incontinence.

Many people with gut symptoms find themselves being passed around from GP to specialist without getting a definitive diagnosis and treatment plan. With our state of the art diagnostic tests and our highly trained, qualified and experienced team of experts, we can really understand what's happening with the patient's gut and help them on their journey to a resolution.

## Why choose The Functional Gut Clinic?

- We're the only practice to be IQIPS accredited and COC approved and adhere to the highest standards – ensuring a framework for our practices which are independently assessed.
- No waiting lists, no waiting times and therefore no frustration or anxiety.
- We work in a highly efficient way to ensure we deliver both the clarity and quality of care you need in a highly efficient manner.
- We focus solely on gut health.
- We are the only practice that analyses the interaction and function of the gut in relation to the patient's symptoms. We continually build our business around the needs of our patients. We offer the best quality tests and, where possible, allow the patient to choose whether to do their tests at the clinic or in the comfort of their own home. Whenever possible, we offer the patient a choice.
- We have a comprehensive range of testing equipment and expertise to ensure we can put our patients and their gut health at the centre of our care approach

For more information visit us at <https://thefunctionalgutclinic.com/>



# Reflux UK

Mr Nick Boyle, Medical Director of RefluxUK, has just returned from the inaugural hybrid conference of the European Foregut Society in Vienna.

The attendees came from all over Europe and the US and enabled participants to discuss the latest ideas and innovations in the world of reflux. Talks ranged from diagnostic and technical challenges, GORD and its interventions and evolution in treatments, patient work ups and treatment for those with Barrett's Oesophagus and lastly achalasia.

# R=flux

This was a great opportunity to debate, discuss, and network and was very well attended bringing together surgeons and Gastroenterologists and other specialists for some fabulous talks. This conference has allowed participants to collaborate and exchange ideas throughout Europe and the US, across disciplines and between clinicians in the management of patients with benign Foregut disease and pre-malignancy.

## Putnams Bed Wedge Pillow Special Offer

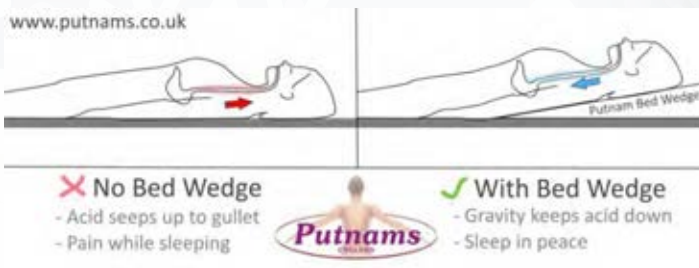
Many people with Acid Reflux Disease have to sleep propped up. This can be difficult but some find a wedge pillow helpful. These can be quite expensive. The standard retail price is £72.67.

**So, the OPA has teamed up with Putnam Pillows to provide their standard Bed Wedge - Acid Reflux at an affordable price with a £24.01 discount, so you will only pay £48.66.**

For more information, please visit <https://opa.org.uk/bed-wedge-special-offer/>



**ONLY  
£48.66**



## Welcome back Professor Grant Fullerton - OPA Trustee

Grant is the former lead Oesophago-Gastric Consultant Surgeon in Glasgow Royal Infirmary with major interests in management of malignant and complex benign upper GI disease. Grant is a former Associate Professor of Clinical Surgery with extensive research interest in benign and malignant upper GI disease. His particular interest is in the field of Barrett's oesophagus including its role in cancer development and treatment with Radiofrequency Ablation.

Grant has now taken up an advisory post with the Scottish Government as the Clinical Lead for General Surgery. Grant has managed to get the Cytosponge introduced in NHS Scotland as a National Service. The Cytosponge is a new technique to screen Barrett's oesophagus patients which has been a great recovery tool during this pandemic.



## We're now a Charitable Incorporated Organisation (CIO)

In 2021 our Trustees made the decision to transition from our current legal status as an unincorporated charitable association to a Charitable Incorporated Organisation. Our new registered charity number is: 1194327

What are the benefits of being a Charitable Incorporated Organisation and why did we change to this structure?

A Charitable Incorporated Organisation is a legal entity and can enter into contracts in its own right. Our old unincorporated

charity structure meant that our Trustees were personally liable for any debts, property or transactions on behalf of the charity. A CIO may also hold property and contracts in its own name, rather than in the name of a staff member or Trustee, which has advantages with regard to succession of the charity. With our plans to develop our charity in the upcoming years, we felt that this new CIO structure was the best fit for our growing organisation.





## Revised Notes for a Carer Booklet

This booklet offers help and advice for Carers about what may be involved in preparing to support and care for someone before and after their surgery for oesophageal or gastric cancer. As the well-known author Kate Mosse, herself a carer, wrote recently in Saga Magazine: "It is about having a parallel life running alongside your own." Carers need to learn about, and learn to anticipate, all the pains and discomforts, and the often irreversible changes in lifestyle that surviving this cancer involves, even though they themselves will not experience these directly.

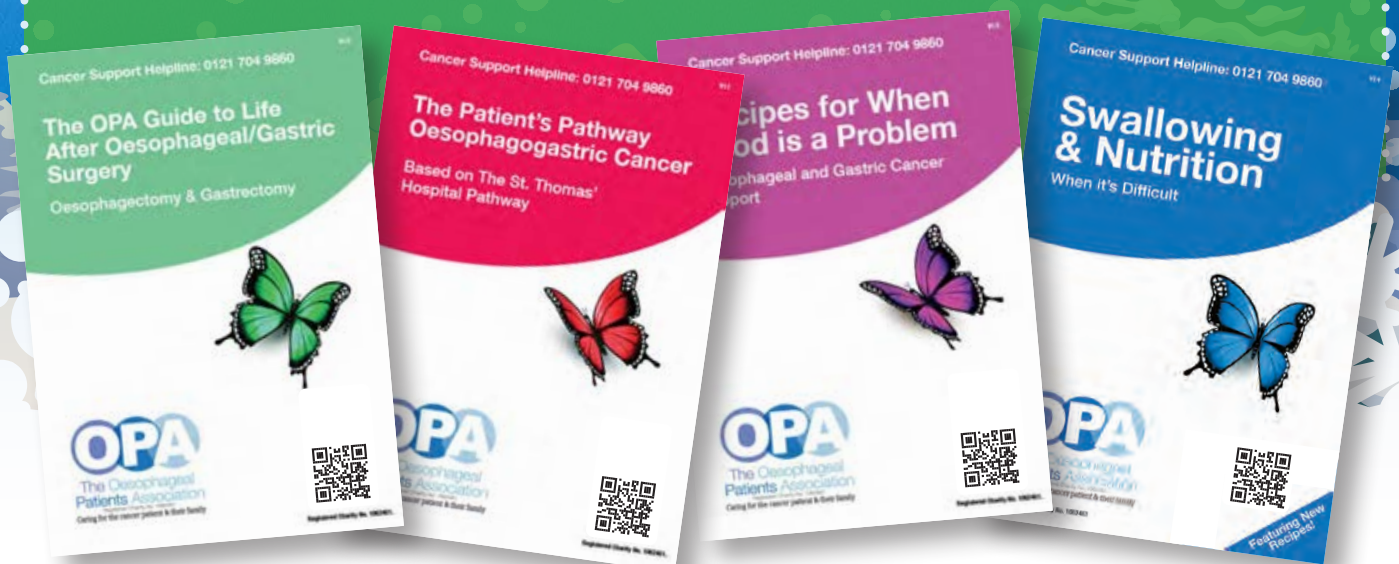
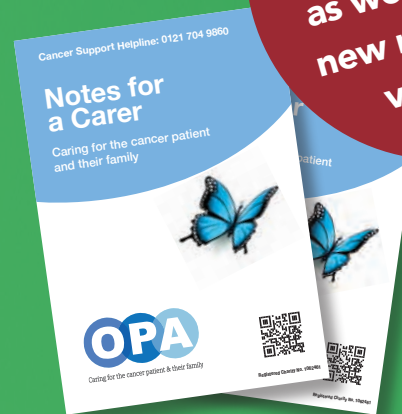
The booklet explains what the OPA can offer in the way of support through its helpline, website, social media, publications and buddying service. It lists other charities' useful websites and publications, and explains what extra financial support may be available for Carers themselves, who is eligible, and how to apply. It gives advice on basic legal matters for Carers who need to assume responsibility for the personal matters of someone who is, however temporarily, incapacitated.

Simplified advice is also included on food and eating problems, topics which are more fully set out in two other OPA booklets: 'Swallowing and Nutrition - when it's difficult' and 'Recipes for when food is a problem.

<https://opa.org.uk/shop/>

In 2021 the OPA held six Zoom meetings for Carers, with between 5 and 10 participants each time. Some of those who chose to join had actually had the operation themselves, but since they were either single or no longer had a partner, were in fact their own carer as well. The main topics for discussion were, as anticipated, on eating problems post-surgery, adapting to the habit of 'grazing', consequent weight loss, and coping with the distressing 'Dumping Syndrome' sometimes experienced after eating. Several participants had also noticed that, occasionally, the necessary follow-up hospital appointments tended not to get made, even when they were still needed. Carers were therefore encouraged to be more 'assertive' on behalf of those they were caring for, to ensure these post-surgery reviews were not missed.

Keep an eye out on the OPA Shop as we are adding new merchandise very soon!



# Thank you to all of our Fundraisers



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



# Place your Christmas Card Order Here...

You can order your OPA Christmas Cards by posting this order form and sending with a cheque to:  
 OPA, 6 & 7 Umberslade Business Centre, Pound House Lane, Hockley Heath, Solihull B94 5DF. Or via the OPA Shop online here -  
<https://opa.org.uk/shop/>. All prices include postage and packaging.

## Christmas Penguin

- 5 Cards £7.50
- 10 Cards £15.00
- 20 Cards £30.00
- 50 Cards £60.00



## Seasonal Snowflake

- 5 Cards £7.50
- 10 Cards £15.00
- 20 Cards £30.00
- 50 Cards £60.00



## Robin and Wreath

- 5 Cards £7.50
- 10 Cards £15.00
- 20 Cards £30.00
- 50 Cards £60.00



## Toys and Baubles

- 5 Cards £7.50
- 10 Cards £15.00
- 20 Cards £30.00
- 50 Cards £60.00

## The Royal Christmas Tree

- 5 Cards £7.50
- 10 Cards £15.00
- 20 Cards £30.00
- 50 Cards £60.00



## Snowy Mountains

- 5 Cards £7.50
- 10 Cards £15.00
- 20 Cards £30.00
- 50 Cards £60.00



## Full set of designs

- 6 Cards (one of each Design) £9.00
- 12 Cards (two of each Design) £18.00
- 24 Cards (four of each Design) £36.00
- 48 Cards (eight of each Design) £58.00

Please send your payment together with a tick against the card(s) you wish to order to: OPA, 6 & 7 Umberslade Business Centre, Pound House Lane, Hockley Heath, Solihull B94 5DF.

Please make all cheques payable to the OPA, or pay online: Account number: 02301636 Sort Code: 40-42-12, or via our website:  
<https://opa.org.uk/shop/>

### Christmas Card Order Form

Name:.....  
 Address:.....  
 ..... Tel:.....  
 Email:.....  
 Amount enclosed for order:..... I would also like to donate £..... to the OPA.

OPA, 6 & 7 Umberslade Business Centre, Pound House Lane, Hockley Heath, Solihull B94 5DF.

Registered charity No. 1194327



# I would love to make a donation



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: \_\_\_\_ / \_\_\_\_ / \_\_\_\_

For online donations – Account number: 51354981 Sort Code: 40-42-12

## For Standing Order Donations

### By bank transfer

Recipient bank: HSBC Bank

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: \_\_\_\_ / \_\_\_\_ / \_\_\_\_

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](mailto:enquiries@opa.org.uk)

For further information please contact The OPA on 0121 704 9860 or email [charity@opa.org.uk](mailto:charity@opa.org.uk).



**Make a donation today!**  
Scan the QR code

