

NEWS AND EVENTS FROM AROUND THE COUNTRY

SUMMER 2024



- WINNER -



In the world of cancer charities, OPA Cancer Charity stands as a beacon of hope and support for those affected by oesophageal and gastric cancer.

The organisation goes far beyond the ordinary – raising awareness, providing exceptional support, serving as a firstclass research resource and showcasing the dedication of their highly qualified team. Whether patients are in the early stages or further along in their journey, the OPA is committed to making their experience as straightforward and uncomplicated as possible.

Judges' comments

The judges were particularly impressed by the OPA's comprehensive support services, which have been devised specifically to offer a diverse selection of assistance. The variety of provisions include patient buddy service, support groups and guidance on navigating complex cancer treatments and are flexible and versatile enough to provide a personalised service to any and all patients who arrive at the door. With their efforts, they're changing the narrative for those affected by these challenging cancers. They offer not just hope but a concrete path to improved health and wellbeing in the face of adversity – something that can be transformative in the lived experience of so many patients.

Welcome

We are delighted to share our Summer Newsletter with you, including heartfelt stories, exciting updates, and essential information from the OPA Cancer Charity. Our dedication to raising awareness of acid reflux and supporting those impacted by oesophageal and gastric cancers has been unwavering throughout the year, inspiring us to make a significant difference in the lives of many individuals and their families.

OPA was a chosen charity of the year for Women On the Move Against Cancer (WOMAC)!

"Women On the Move Against Cancer (WOMAC) recently held its annual fundraising event at an exclusive private members club in London, raising £15,100 for its chosen charities for 2024. WOMAC pledged to donate £7,500 to each of the charities but thanks to the sell-out event and generosity of its guests on the night, it was able to achieve that target in the first fundraising event for the year. Further donations will be secured via other fundraising initiatives in 2024, including a friend taking part in the London Marathon, the Southern Group of Motoring Writers karting event and 'WOMAC weeks' later in the year."- WOMAC

Carolyn Harrison, OPA Ambassador: "We are so grateful to WOMAC for choosing OPA as one of its charities for 2024 and for hosting us at such a prestigious venue. The funds raised from the party and other events it has run throughout the year will help us support and guide more patients, caregivers and their families through difficult times and uncertainty."



Claire's Story

Hi, I'm Claire, I'm an oesophageal cancer patient.

Two and a half years ago I started having trouble swallowing bread and chicken, it felt like the food was getting stuck in my food pipe and wouldn't go down for up to a minute each time. Aside from that I was well and healthy - I hadn't smoked for 25 years and I walked and went for 10-mile cycle rides three times a week.

I ignored the struggle to swallow some foods for a couple of months, thinking it was nothing serious, just acid reflux or something like that. Luckily for me, my partner had known someone with oesophageal cancer and he knew this could be a symptom of the disease. He made me go to my GP, and thankfully she took the symptoms seriously too.

I was suddenly put on a fast-tracked pathway where I got the results from every test within two weeks. I believe that process, and my partner's insistence about getting myself checked, saved my life. I was diagnosed with OC in September 2021, had chemo for four months then had an eight-hour operation to remove my oesophagus and the tumour in it. I'd never heard of oesophageal cancer until I was diagnosed with it, but I'd love other people to know it exists.

I've been slowly recovering ever since. It's been a real slog, taking two years to go from six stone to eight, and be able to eat a range of different foods. But I won't ever complain about this because I'm one of the lucky few - two thirds of the people diagnosed with oesophageal cancer find out about it too late to have the operation or anything else that can potentially save their lives.

That's why I am passionate about raising awareness of this cancer - and the potential symptoms everyone needs to get checked out as soon as possible. They are having persistent heartburn or acid reflux, difficulty swallowing food, hiccups that won't go away, unexplained pain in your chest and excessive burping or inability to burp. Suffer with any of these for more than three weeks and you have to get to your GP straight away to ask for a scan.

I'd never heard of oesophageal cancer until I was diagnosed with it, but I'd love other people to know it exists, so they can get treated and survive it instead of having it diagnosed too late.

OPA were the chosen charity for this year's Institute of Travel Management (ITM) Gala Event!

Every year a member of the ITM, the Institute of Travel Management chooses a charity to sponsor, under its program 'ITM cares'. This year, Will Hasler, who had had an oesophagectomy three years ago, nominated the OPA. Trustee Philip Wright attended the banquet that followed the ITM's annual conference to explain the work of the OPA. This year the ITM raised £21,466.90, more than it had ever done for its sponsored charity to date, due, Philip said, to Will's frank and at times witty account of his operation and recovery. Will had previously been an ITM board member for many years, and it was clear how the high regard in which he was held by many of those present at the banquet contributed to the very generous donations that were made that evening.

This year the ITM raised £21,466.90



CITNE





Stacey Preston completed a wing walk!



I chose to complete a wing walk for the OPA charity in memory of my dad, Nick Preston. I chose a wing walk because of the love of planes that me and my dad shared (however this does not mean that i was not extremely nervous lol). We had been to many air shows together along with my mom and sister and watched many wing walks so I wanted to do something different and relevant to raise money for the charity in memory of my dad.

The wing walk itself was absolutely amazing, from start to finish. I was shown a safety briefing to start with, explaining how to get on the aircraft, any hand signals to communicate with the pilot so he could check whether I was okay up there or not. I had a discussion with my pilot beforehand who asked how intense I wanted the wing walk to be and I of course asked for it to be the most adrenaline based flight possible. When actually in the air it was absolutely freezing as it was very windy however I can't believe how safe I felt the whole time, it was so much fun I didn't want to come down. We reached a height of around 400ft and around 150mph.



FACT FILE

Did you know? Over 65 million people in the UK suffer from acid reflux disease, with an estimated 1 in 10 affected.

Did you know?

There are over 6,000 new cases of Gastric Cancer each year.

Did you know?

There are over 9,000 new cases of Oesophageal Cancer each year.

Introducing our new information booklets

We are pleased to announce the release of our latest educational resources designed to provide comprehensive information and support for individuals and families affected by specific health conditions.

Our new booklets, titled **"What is Oesophageal Cancer?", "What is Gastric Cancer?",** and **"Achalasia",** aim to deliver clear and concise information to those seeking to understand these conditions better.









Scan the QR code to visit the OPA shop





Karen Atkinson -Charity walk in aid of Steve

Steve was a 69-year-old Retired Fireman. He was married to Kerry, a retired Policewoman and had one daughter Jess, a Podiatrist in the NHS.

Our journey started in July 2022, a visit to the Doctors with recurrent heartburn, hiccups and burping resulted in an endoscopy, which revealed a tumour in Steve's oesophagus. This is when Steve was diagnosed with Oesophageal Cancer. The diagnosis came as a shock to us all as a family and with his friends.

He then underwent a series of tests, scans and it was deemed inoperable and had unfortunately metastasised into his Liver and Lungs, and therefore changed the outcome to Palliative management.

He had multiple rounds of chemotherapy, all differing in strength, type, and effectiveness. He received excellent care throughout his Cancer Journey.

One day at work, Jess and Kaz (amazing collegue and friend), decided to go for a walk at lunch, and it was on this walk, that it was discussed and decided that we would organise a charity walk with Colleagues, Friends and Family, to raise money for Oesophageal Cancer.

We reached out to OPA, and dealt with Drew, a very helpful fundraiser, with the charity. We were sent Charity Buckets & T-Shirts to help raise awareness and raise some money for Charity.

It was decided that the Podiatry Department would do a charity walk in October 2023, and this was open to all, including Dogs. Steve really wanted to be there and that was one of his goals.

However, on 8th September 2023, Steve passed away at home with his Wife by his side.

We embarked on the charity walk on October 7th 2023 in memory of Steve, and we successfully completed a 5K walk.

We were extremely humbled by this and everyone's involvement throughout and feel very proud to have such great Family, Friends and Colleagues who made this day such a special day.

We raised £2070 + Gift Aid for the OPA Cancer Charity.



Lisa Månsson – Six the musical

One of our dear colleagues received the heartbreaking news that his mother had been diagnosed with terminal cancer. To lift his spirits, he initiated a fundraising campaign to support the OPA (Fattyfattybumbum collection) in honour of his mother.

Our team members suggested organising a bucket collection after each show to raise awareness and gather donations, knowing that together we could raise more funds than Joel could on his own. Our objective was to continue fundraising for as long as Joel desired. Tragically, his mother passed away after a few weeks.

After collecting donations for 3 weeks following 24 shows, we managed to raise approximately £9800.

OPA Teddy Bears

We believe in the healing power of teddy bears. Our cuddly companions aren't just toys; they're sources of comfort, joy, and resilience.

They provide companionship during lonely nights, courage during tough times, and a listening ear when words fail. Research has shown that the simple act of holding a teddy bear can reduce stress, alleviate anxiety, and promote feelings of security and calmness.

Join us in our mission to spread love, one teddy bear at a time. Together, let's embrace the power of comfort and kindness. Shop now and experience the mental health benefits of cuddling with your very own OPA teddy bear.

OPA Teddy Bears are available online please visit www.opa.org.uk/shop





Sarah Keyworth Cake Sale

When Graham was diagnosed, I was googling information and came across your webpage. I ordered booklets from you which helped immensely but unfortunately we weren't in the position to donate as Graham was on sick pay and I wasn't earning as I was looking after him but I wanted to give something back to you for your amazing work. I set up a Facebook group to try to support others and raise awareness and said to my friend, let's do a bake sale as we are avid bakers.

The local community were amazing and the amount we raised went beyond my expectations. We are planning an even bigger one in July that will be advertised as a banner on our local community board Facebook page so will reach a lot more people.

OPA Helping Research



An online focus group looking at how you would like your child to be treated for gastro-oesophageal reflux disease (GORD)

We are currently working in collaboration with Reckitt Benckiser PLC regarding a funded research study exploring the experiences of parents of infants with symptoms of gastro-oesophageal reflux disease (GORD), or reflux for short.

Study Summary

What: A 60-minute discussion about your preferences for managing your child's symptoms of GORD

Where: Zoom

When: To be decided

Will I be reimbursed: Yes, we are providing £60 as a bank transfer for participation in the research.

Who is this for: The research is being conducted on behalf of Reckitt Benckiser Group plc. Anonymised data (without personally identifiable information) will be shared with the funder.



Why are we conducting this research: We wish to better understand how parents of children with symptoms of heartburn and/or indigestion wish for their children to be managed.

What happens if I agree: You will be contacted (via e-mail) by a member of the research team who will provide you with additional information regarding the study, in the form of a participant information sheet. We will also provide you with a consent form. We will do this ahead of the date and time of the focus group, allowing you time to reconsider your participation if you wish. If you choose to take part the focus group will be conducted via Zoom and audio-recorded for later analysis. All responses will be kept confidential and no personally identifying information will be collected as part of the research study. You maintain the right to withdraw from the focus-group at any time.

Please read this document which explains the project in further detail- https:// opa.org.uk/wp-content/ uploads/2024/06/PIL-FOCUS-GROUP-PARENTS_v2.pdf



If you wish to be involved in the online focus group, email simon@visfo.health





DATE FOR YOUR DIARY Next London Meeting

Mark your calendars for **Saturday 17th August 2024**, from 12:00 pm to 2:30 pm. We'll be gathering at the C P Hart Newnham Terrace, Hercules Road, London SE1 7DR



This meeting invite will be sent out via email, so please make sure we have your current email address by completing and returning the form on page below or by subscribing online at www.opa.org.uk

3



Updating our records

At OPA, we're dedicated to maintaining accurate records of our valued supporters like you. To ensure that we can stay connected and keep you informed about our latest initiatives, events, and impact stories, we kindly ask for your assistance in updating your contact information.

Please take a moment to provide us with your current email address below. By doing so, you'll help us keep our systems up-to-date and continue to deliver meaningful updates directly to your inbox.

Name:
Email Address:
Postal Address:

Rest assured, your email address will be kept confidential and will only be used for communication purposes related to OPA Cancer Charity.

Paula Dale Running a bus route

I am raising funds for OPA after a friend/ work colleague (bus driver) passed away from oesophageal cancer. He was a team player & a valued union representative.

So I approached the family of Pat & asked to run in his memory, his favourite bus route for a charity!! The charity they chose was OPA & his favourite bus route was our 73A route. It was a challenging route as there was 5 big hills in it. The route was Liskeard-St Keyne-Duloe-Sandplace-East Looe-Polperro then the same in reverse. Pat's son (Justin) ran back with me from Looe to Liskeard!! My bestie (Carol) was support crew carrying my energy food & drinks! Pats family supported me all the way & have been fab throughout even though they only lost Pat in the last 9 months!!



Acid Reflux Campaign

In November 2023, we launched our **fourth** successful Acid Reflux Awareness Week, timed to coincide with Thanksgiving in the USA and recognised globally. This condition can greatly impact a patient's quality of life, influencing various aspects of daily life. While lifestyle changes and medications such as omeprazole and lansoprazole, often prescribed by GPs, can effectively manage symptoms for many, over 2 million people in the UK do not respond adequately to these treatments. For them, exploring alternative options is crucial.

Our campaign focused on three key messages:

Get Educated

Reflux involves more than just heartburn. We aimed to raise awareness about the diverse symptoms associated with the condition.

Get Evaluated

For patients for whom lifestyle changes aren't enough, we emphasised the importance of undergoing tests to accurately assess the extent of their condition, facilitating personalised treatment plans.



Scan the QR code to visit the OPA shop to order the booklets.



Get Treated

We aimed to empower patients with knowledge about the array of treatment options available, enabling informed discussions with their GPs or Reflux Centres.

Our Patron, Fiona Wade, strongly supports the charity with awareness videos and endorses our campaign in memory of her father, who passed away from oesophageal cancer.

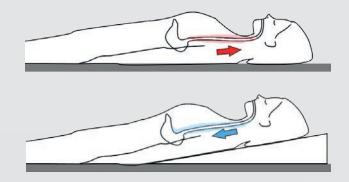
We eagerly anticipate this year's Acid Reflux Awareness Week, aiming to build upon the successes and insights gained in 2023.



Goodnight Acid Reflux, Hello Sleep!

Both doctors and the practitioners agree a wedge pillow can help to relieve the symptoms of Acid Reflux (also called Gastro-Oesophageal Reflux Disease, or GORD) and heartburn by elevating your torso to prevent acid from burning the lining of your oesophagus while you sleep. Using a bed wedge to elevate your upper half can severely reduce acid reflux. Just adding extra pillows won't work because they elevate your head, not your upper torso.

This triangular bed pillow gently tilts your torso reducing acidic discomfort during the night.



Order your bed wedge by visiting: www.putnams.co.uk/collections/ bed-wedge-pillows or call 01752 345678



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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)		
Your bank details To: (insert name and address of your bank)		
Sort Code:	Account Number:	
	Gift Aid for every £1 you donate e current tax year. Your address is needed to indentify you as a	
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		
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The OPA on **0121 704 9860**



Charity Number 1194327