



NEWSLETTER

A Date For Your Diary:

Would you be interested in a meeting entitled: "The Future of Treatment for Oesophageal and Gastric Cancer"?

**THEN COME TO OUR AGM!!
June 21, 2014**

Details on page 8!

**Local Support Group Meetings:
See Page 5**

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Coffee anyone?



Ruth Scott-Beaulieu, daughter of a patient attending the London branch of the OPA, has generously designed a downloadable pack on our website for anyone who wants to raise funds for the OPA by holding a coffee morning.

You can find it on the BRAND NEW "Fundraising" page on our website. Rob and Chris Turner of Nottingham were the first to download and try it. Here is how they got on!

"In February we offered to try out the coffee morning fundraising pack which the OPA had just put online. Rob had had surgery in April 2013 and was almost back to full health, ready to do something to help others affected by oesophageal cancer.

"We started by making a list of all the local shops and stores who might help by donating raffle prizes. We hand delivered letters to them, giving us the chance to answer their questions and to explain how the OPA would benefit from the money raised.

"Prizes and offers of help started to pour in. We were amazed! Almost everyone we asked, friends, family, neighbours, shop-keepers and restaurant managers, all helped out by donating time, money or goods.

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WELCOME to JACQUI

Jacqui Wood has recently joined the OPA as fundraiser. Jacqui, who lives in Warwick, has had many years experience in fundraising for a number of charities.

Following her earlier career in newspapers, she worked for The National Trust in public relations and then fundraising, she set up the fundraising department for Birmingham's St Mary's Hospice and then joined the national Crimestoppers scheme as Head of Marketing and Fundraising.

Returning from London to Warwickshire, Jacqui established fundraising for The Shakespeare Birthplace Trust in Stratford-upon-Avon and has more recently worked as Fundraising Manager for South Warwickshire NHS Foundation Trust.

Jacqui, who has two sons, a daughter and five grandchildren says: 'I am delighted to be working for The OPA at such an exciting time in the charity's development. Having worked to help people with oesophageal cancer for almost thirty years

the OPA is doing a wonderful job and needs help from the public to expand its services to benefit many more people'.



Chairman's Corner

From the News Media.....

An excellent article in the British Journal of General Practice, March 2014, discusses Heartburn, Barrett's Oesophagus and Cancer. It summarised the progress of the Government's 2011 campaign to save 950 lives annually by earlier diagnosis.

The "Be Clear on Cancer" pilot studies in seven regions during 2012 resulted in a 20% increase in oesophageal cancers diagnosed early, the best of the five cancers targeted. No unmanageable demands on endoscopy units were recorded.

As a result, the wider campaign with press and regional TV advertising took place in February 2014 in the North East, where some of the highest rates of oesophageal cancer are recorded. We await the analysis of this campaign with interest.

Meanwhile, from Cambridge comes news that University Researchers have discovered a gene linked to oesophageal cancer that they are confident will lead to new forms of treatment for up to 15% of patients within five years.

Finally, The Daily Mail recently carried an article under the headline

"How a stay in intensive care can leave you as traumatised as going to war".

In it, they told the story of one 61 year old London oesophagectomy patient who woke in critical care believing that he was in Eastern Europe being questioned, and that his wife and son and even the ward itself, were fakes to fool him.

His stay in intensive care was extended by a bout of pneumonia, during which he was given further painkilling and sedating drugs. His delusions continued. He became bound up in stories of suicide and witnessed several, some assisted by doctors, others throwing themselves into canyons. He apparently even told his wife he was going to commit suicide, although he cannot remember this.

He was subsequently diagnosed with borderline post-traumatic stress disorder and depression, from which it took him over a year to recover.

If you have tales to tell of your experiences in, or as a result of, intensive care, and how you dealt with those experiences, please do share them with our fellow members by writing to news@opa.org.uk.



JOHN TALBOT

There is one over-riding message this quarter:

We need more helpers!!

We have so much we want to do as a Committee, but we are down to a seriously insufficient four Trustees. Here are some of the activities and stalled priorities waiting for the right helpers:

Awareness; Raising the profile of the charity within hospitals; New branches; Getting the OPA's existence to more new patients at the point of diagnosis; Patient representation on an ever increasing number of steering group initiatives; Representing the OPA in other cancer charity networks; Website development; Merchandise; Printing; Graphic design; IT; Spokesperson; Fundraising

If you have any time and/or any relevant skills you would like to donate to the OPA, please do contact Head office or me at johntalbot@opa.org.uk.

Two or three new Trustees, people who have experience of charity Trusteeship, would be VERY WELCOME INDEED!!

As would a new TREASURER.

THANK YOU!

O. P. A.
22 Vulcan House, Vulcan Road,
Solihull
B91 2JY

Telephone:
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9am - 3pm Mon - Fri

Website: www.opa.org.uk
Email: enquiries@opa.org.uk
Registered Charity No 1062461

O.P.A. Trustees:

John Talbot (Chairman)
David Holden
Dr Tony Ingold
Barry Moorefield

Trustee to be appointed:
C Haward Soper

Operations Manager:
Maggie Robinson

Fundraiser:

Jacqui Wood
Medical Support
Team:

Jane Darnton
Richard Steyn FRCS
John Whiting
Laura Nicholson

PATIENT EXPERIENCE

HAWARD SOPER of Leicester

The OPA Committee's Newest Recruit

I was diagnosed with an adenocarcinoma in my oesophagus, Stage 2, Node 1, in Kuala Lumpur on 13th February 2013. I was working for Shell out there at the time. My symptoms were an inability to swallow and some weight loss. My doctor, Ryan Ponnudurai, in the Prince Court Medical Centre, advised me that it had been developing for 2-4 months. I felt generally well but a bit tired.

That week I had a battery of tests, and meetings with a potential surgeon and an oncologist, Dr Azrif Annuar, who took over my treatment. I had looked at the Cancer Research website and read that I had a 50% chance of being dead in a year. Dr Annuar told me to disregard this as my cancer was curable and, even if it wasn't, they would keep me going for a good number of years. At that point I decided to do no more research!

I agreed a treatment plan, including a 50% discount on radiotherapy as the centre was running an offer at the time. On 20th February, I began a course of 23 radiotherapy and 5 chemotherapy sessions. As Dr Annuar notes "cancer doesn't go on holiday".

The surgeon, Dr Yusuf, emphasised the need for me to eat properly and to maintain my weight. I was recommended to go on a high fat high protein diet and I was also recommended a supplement called Prosure.

The other advice I was given was to strive to stay fit. The diet was the easier of the two; lots of cheese, cream, butter and chocolate! But we did walk to and from the hospital every day in 33°C and high humidity. For the first time in my life, perhaps the last, I decided to take all advice and follow it to the letter.

My partner, Celia, made sure that I never missed a meal and that I exercised regularly. This seemed to work and my weight stabilised over time. I was lucky. I had no side effects from the treatment other than a collapse in white

blood cell count late on, but that wasn't enough to defer treatment or a flight home.

The most difficult experience at this stage was telling relatives and friends, always by phone, that I had cancer. The shock and the horror and the upset could be felt on the other side of the world.

Once the treatment had finished I began to put on weight and I flew home in early April to meet Bill Allum of the Royal Marsden, who allowed me to go back to having the odd beer and who advised me to keep on putting on weight; "you'll need it for the operation".



He told me that his worst patients are doctors, lawyers and teachers who turn up with excerpts from The Lancet and cuttings from the internet. "Not me" I told him. "This is so far out of my experience I'm gonna listen and do exactly what I am told".

The operation was carried out by Mr Allum and his team on the 14th May. I woke up on the 19th, my birthday, unable to speak due to a tracheostomy and with people wandering in and out of my room saying happy birthday to a bewildered and smashed patient who thought it was still the 14th.

I have something like an on/off switch which meant that the team could not awaken me slowly. I would wake up suddenly and try to wrench the tubes and lines out of my body and jump out of bed, so they would then put me back under. Celia told them that they could restrain me but apparently this is not allowed.

On the fifth day she persuaded them to allow her to sit by my bedside and talk to me, for around three hours, with the Archers on Radio 4 in accompaniment. She was talking away to me as they raised me from my slumber and this time it worked.

It turned out that I'd had a complete pathological response to the chemo/rad and that the tumour was all gone before the operation. But they don't know that until they haul the bits out.

PATIENT EXPERIENCE

HAWARD SOPER of Leicester, continued from page 3

For a few days I had wonderful hallucinations about , for example, cards which didn't exist but which I could see; about my auntie in the non existent waiting room - I got pretty cross when she wasn't able to get in to see me. There was a Shell petrol station outside my non existent first floor bedroom window and the attendants were allowing anyone who bought V Power to have a look at me. I got cross about this too.

The nurses and Celia and my many visitors were very patient but I got autonomy back as quickly as I could and began to potter around corridors quite soon and I went home at the end of May.

I travelled back to Kuala Lumpur in early July, back to work, and to recuperate and to travel. In between July and December we went to Bali, Java (twice), Angkor Wat, West Sumatra, Beijing, Perth, Margaret River, Adelaide (for the Third Ashes Test debacle), Borneo, Penang, and Melaka.

By the end of October I was back to normal cardio vascular fitness, and on my return to the UK in December I was beginning to put on weight and muscle and able to eat three meals per day. I am now less concerned about diet regularity and meal size and almost back to normal, but I

do get the occasional stomach cramp, usually minor, but sometimes enough to send me to bed almost in tears. I also experience heavy tiredness just after meals on occasion.

If there is one thing I'd say to fellow patients it's that rigorous attention to keeping and improving cardio vascular fitness before the operation and recovering it afterwards really paid dividends for me. It's hard work but finding the time and the strength to take a brisk walk 30 minute every day is very worthwhile.

I have retired now and I am happy to be able to assist the OPA and share my experience. I shall also be going back to University to study more law. You can find me on Health Unlocked under "Haward".

I've been lucky. I've had great support from my company, my friends and my family. I was diagnosed early enough, the treatment started quickly and I responded well.

We at the OPA Committee are delighted to have Haward on board. For one year post-surgery, he is doing exceptionally well and he is an excellent example to us all with his attitude to exercise and lifestyle.



OPA PRESIDENT, DAVID KIRBY Fundraising in Waitrose

Every branch of Waitrose raises funds for its local charities through their Community Matters scheme. Each month, three local charities are chosen by the branch to be the recipient of a share of £1000.

All shoppers are given a green token and they choose which of the three charities to support by posting their token in the appropriate box. The £1000 is then shared out between the three charities according to how many tokens each received.

The Waitrose store at Hall Green, Birmingham, included the OPA in their April charities. Not only did this raise the magnificent sum of £315, it also gave us a chance to tell more of the public what we do.

We hope that some of our branch members around the country will 'follow our leader' to take up this straightforward method of fundraising. Other supermarkets offer similar schemes.

OPA MERCHANDISE



When ordering, don't forget to state your preference of gold or chrome finish, or shape, where appropriate.

An Introductory Range of OPA Branded Items are now available for purchase. Help support the OPA by buying these products. Not only do the funds help us function, but using these items helps raise the profile of the charity and the work we all do.

Just send us your name and address **and telephone number** with details of what you would like to order, together with your cheque or postal order, to The OPA, 22 Vulcan House, Vulcan Road, Solihull, B91 2JY. All our prices INCLUDE P&P by 2nd Class Royal Mail.



Chrome finish Key Ring Available in rectangle, star or heart shapes.
£5.20 inc P&P



Tie Clip, Chrome or Gold Finish
£4.50 inc P&P



Pin Lapel Badge, in Chrome or Gold Finish
£4.50 inc P&P



A Bright and Really Useful 100% Polyester Tote Bag 39 x 36 cm + Handles.
£5.75 inc P&P



A High Quality Mug, Dishwasher and Microwave Safe
£9.95 inc P&P

SUMMER 2014 MEETING DATES

The highest priority for the OPA is summed up by our slogan "Experienced Patients Helping New Patients" and one of the most successful ways for this to come about is through our local support groups. Anyone who has been touched by oesophageal or gastric cancer or related conditions is warmly welcome at any of these meetings.

These are only some of the forthcoming meetings. Others are planned in Leeds, Liverpool, Manchester and elsewhere. Please check on the OPA website, contact your local organisers or seek information from the OPA on 0121 704 9860. And please verify the meeting details before you attend, in case of last minute changes.

June 7	Frimley and Derby	July 5	Portsmouth	July 30	Preston
June 14	Lincoln	July 9	Brighton	August 21	Nottingham
June 19	Nottingham	July 17	Birmingham	August 27	Preston
June 21	London (inc AGM)	July 17	Nottingham	August 28	Guildford
June 21	Guildford Fun Day	July 25	Royal Marsden, London	August 29	Exeter
June 25	Preston	July 25	Exeter	August 30	Grantham
June 26	Guildford	July 26	Guildford	September 6	Derby

An invitation to all OPA members to help in research to improve the lot of hospital patients.

Who is behind this project?

The project is run under the auspices of the James Lind Alliance (JLA) (see below) and the Royal College of Anaesthetists. Dr Tony Ingold, OPA Trustee, (pictured, right) is the OPA representative on the steering group of this project and is hoping that you, as members, will play an active part in this research exercise.



Why does this project exist?

Much of the research that takes place in the UK is run and paid for by large pharmaceutical companies. Whilst their research is often of great value, it is largely aimed at producing new drugs for treatment of diseases. It seldom takes into account the ideas for research that are considered of value directly by patients, carers or clinicians. The JLA has a good track record of attracting funding for such research ideas and projects, and this is where you come in.

What is “anaesthesia and perioperative care”?

We want to improve the quality of care for people coming into hospital and having operations. Apart from the work of the surgeon him/herself, there is a whole team of perioperative professionals—from the anaesthetist to the recovery and ward nurses—who aim to look after the patient’s physical and mental wellbeing during the process.

We are looking for what we should be investigating that might make for a healthier and happier patient. This could involve aspects from start to finish, from the planning for an operation, through to when a patient wakes up from surgery, through to when he or she gets home to finish his or her recovery.

The kind of input we want:

We’re looking for research questions. There are many scientific researchers who look into how hospitals function and how patients are taken care of. What they find from their research can then be fed back to anaesthetists and perioperative care teams and help them improve their procedures, services and care.

By asking patients, clinicians and other perioperative care professionals to complete this survey, we are identifying the most important “unanswered questions” to research. There have been many similar patient-clinician surveys on other medical conditions or environments. To help you, here are some examples of unanswered questions from those different surveys:

- Are breathing exercises helpful in controlling asthma?
- What is the evidence for gargling with aspirin to relieve a sore throat?
- How safe is it for my breast-fed baby if I take antidepressant medication?

We collect all of these short clear questions and sort them into groups to see what people are asking about.

The output:

After the questions have been reviewed, checked to see whether the questions have already been answered or are able to be answered, a top ten ideas are proposed and then put forward for research funding by government and charities, for example. The questionnaire will be put up on the OPA website in the next few months, so we hope you will give us your thoughts and ideas. We will keep you updated with the progress of the project. If you do not have access to a computer but would like to take part, please contact the OPA office on 0121 704 9860.

What is the JLA?

The **James Lind Alliance** is a non-profit making initiative which was established in 2004. It has been established to bring patients, carers and clinicians together, to identify and prioritise the unanswered questions about treatments that they agree are most important. This information will help ensure that those who fund health research are aware of what matters to patients, carers and clinicians.

So, who was James Lind? An 18th century Scottish physician who was responsible for greatly improving the health of the sailors in the British Navy. He is best known for discovering that citrus fruit juices reduced the incidence of scurvy in sailors who were at sea for many months.

Coffee anyone?

Continued from Page 1

“We borrowed garden chairs (we held the event outdoors and luckily the weather was perfect), tables and cups, a large gazebo, and mugs and plates from the local church. We even borrowed a tea urn from our local OPA group to ensure we always had boiling water on tap!

“As the big day arrived we took stock: 29 raffle prizes! We prepared quiz sheets and a darts game – 3 darts in the oesophagus of a figure drawn on the dart board to win (see photo)!

“We had around 70 people attend over four and half hours and it was lovely seeing people all chatting together and making new friends.

“At the end of the day we found we had raised over £600, which FAR exceeded all our expectations. A big “Thank you” to all those who helped out, especially Jillian and Maurice Chatfield, our new friends from our local OPA group, who slaved tirelessly in the kitchen; and those who joined us for coffee, bought raffle tickets or made donations - we couldn't have done it without you!”

Please do let us know (at news@opa.org.uk) how you get on with your coffee mornings. We'd love to hear of any other fundraising events you are involved with, so we can promote them on your behalf. We may also be able to help with materials and literature.



LETTERS COLUMN

We don't appear to have had a readers' letter column in the OPA newsletter before so I wonder if I could start one! A means for us members to pass on our thoughts, suggestions and whatever for discussion and reply?

I am delighted to tell you that I am an 18 year survivor of Oesophageal Cancer and although I owe my life to the skills of the surgeons and nurses I also wanted to be able to tangibly thank the OPA for the massive support I have had over those years.

My first "prompt" was the flyer we all received in a recent newsletter and I pledged a small monthly amount by standing order. But I decided that I could do more, so, after discussion with my wife, I decided that I was in a position to make the OPA a beneficiary of my estate in my Will to ensure that the organisation can continue to do such wonderful work after I am no longer around.

There are many charities chasing our money these days, but anyone who has visited an OPA meeting knows how dedicated the organisers are. I understand the OPA operates on a shoestring and I believe that if we can help in even a small way it will help it thrive.

Of course most of us have to save for a "rainy day" whilst we are alive, but I would encourage anyone who has had as positive an experience from the OPA as I have to consider making the OPA a beneficiary in your Will.

Your views are always welcome—write to news@opa.org.uk

And finally consider this...apart from it being a living legacy it might also save you money as any bequests to a charity are exempt from Inheritance Tax on your estate!!!

DF Nottingham.

In the last Newsletter, you asked for any comments on the experience of needing stretches after an oesophagectomy.

I had my operation in October 1994 and needed several stretches over the following months, indeed the narrowing was an ongoing problem. It was two or even three years before I felt confident eating.

If I was eating out I would locate the nearest "ladies" to my table so that should food stick I could beat a hasty retreat and clear the problem.

I was always treated promptly and sympathetically at Heartlands when the tightening occurred and over the years confidence builds up and later you can relax in the knowledge that if you don't panic the spasm can pass on its own.

Never be afraid to ask for help if you are worried.

Sylvia Peach.

USEFUL INFORMATION AVAILABLE FROM THE OPA

There are three booklets created and published by the Association for the benefit of members:

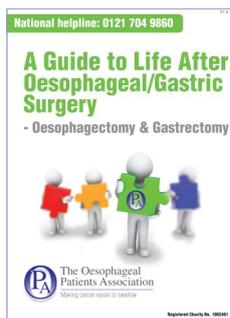
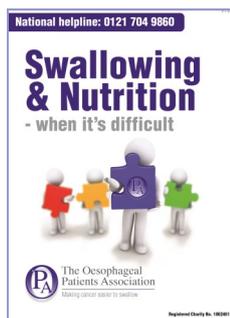
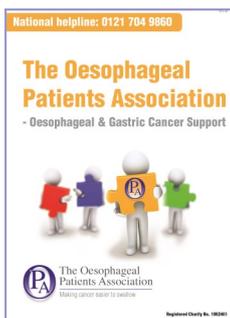
- The Oesophageal Patients Association (who we are and what we do).
- Swallowing - Nutrition When It's Difficult
- A Guide to Life after Oesophageal/Gastric Surgery.

We also have factsheets on advice for relaxation and sleeping and we can provide Restaurant and Toilet cards for use in most European countries.

Please call the helpline on 0121 704 9860 or email enquiries@opa.org.uk

Other Information is also available from:-

www.macmillan.org.uk & www.corecharity.org.uk



OPA ANNUAL GENERAL MEETING

Looking Forward to the Next 10 Years in Oesophago-Gastric Cancer Treatment

Prof Hanna, Prof Mason, Prof Mughal

Saturday 21 June 2014

10.30am – 1.00pm (Doors open: 10am)

followed by a buffet lunch and the

NATIONAL AGM

2.00pm – 2.30pm

**The Friends Meeting House,
173-177 Euston Road,
London NW1 2BJ
(opposite Euston station)**

ALL WELCOME

You can now donate to the OPA using your mobile phone. We will get 100% of the donation. Simply text OPAS14 and then after a space add the amount of the donation, figures only. So, for example, to donate £10 you text **opas14 10** - it's that easy. Send your text to 70070 and Vodafone JustTextGiving take care of it. Don't forget to GiftAid if they ask! THANK YOU!

✂-----

Donation Form

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

Date of donation..... (Please make cheques payable to OPA and complete your details below)

I confirm I have paid or will pay an amount of Income Tax and/or Capital Gains Tax for the current tax year (6 April to 5 April) that is at least equal to the amount of tax that all the charities that I donate to will reclaim on my gifts for the current tax year. I understand that other taxes such as VAT and Council Tax do not qualify. I understand the charity will reclaim 25p of tax on every £1 that I have given.

NAME:.....

ADDRESS:.....

POST CODE:

TELEPHONE NUMBER:.....

EMAIL ADDRESS:

Oesophageal Patients Association, 22 Vulcan House, Vulcan Road, Solihull, West Midlands B91 2JY.