

Support for Gullet & Stomach Cancer and Related Conditions

NEWSLETTER

Please help the OPA if shopping online



BE CLEAR ON CANCER

NHS England’s Be Clear on Cancer campaign for Oesophago-Gastric Cancers took place in February of this year.

Although no official figures have yet been released early indicators show the campaign to be a complete success with hospitals reporting a significant increase in the number of referrals for endoscopies. One hospital stated they had seen an increase of 49% whilst another reported an increase of 47%.

As of today’s date we are not aware that this campaign will be repeated by NHS England.

With the increasing number of cases of oesophageal and gastric cancers it is vital to continue notifying the public of the “danger signs”.

How you can help.....

Some OPA groups have already held very successful awareness days in their local hospitals, health centres and shopping centres. Head office are able to supply OPA awareness posters and leaflets so why not consider having your own awareness day. It doesn’t have to be at a hospital it could be at your local supermarket (with the managers permission, of course) or a fete etc.

The OPA will continue to lobby the pharmaceutical companies to publish warnings on all “over the counter” anti-acid medications but until they agree why not ask your local pharmacy to place a poster in a prominent position or to place leaflets by their tills.

By keeping the message going we can save lives!!

Local Support Group Meetings: See Page 5

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Ref Lux blowing the whistle on Cancer

Consult your GP if you suffer from

- persistent (every day for three weeks or more) heartburn or indigestion
- food coming back up
- difficulty in swallowing
- pain or discomfort in the throat or back
- a hoarse voice or a cough that will not go away
- unexplained weight loss
- coughing up blood



Chairman's Corner

From the News Media.....

Obese women 40% more likely to get cancer

Obese women have a 40 percent greater risk for developing at least seven different types of cancer, including bowel, post-menopausal breast, gall bladder, womb, kidney, pancreatic, and oesophageal cancer, according to a new Cancer Research UK study.

Is there an environmental link to oesophageal cancer in Tanzania?...

Scientists from the Centre for Environmental Geochemistry are helping health organisations understand why oesophageal cancer is localised within specific areas of the African Rift Valley.

Dr Valerie McCormack from the International Agency for Research on Cancer (part of the World Health Organisation) has studied the high prevalence of oesophageal cancer in the Rift Valley and identified a particularly localised incidence of cases in the Mount Kilimanjaro area of Tanzania. A hypothesis was presented that an environmental factor, such as exposure to potentially harmful elements or organics (e.g. polycyclic aromatic hydrocarbons, PAHs, from wood fires) or deficiency of essential micronutrients (e.g. zinc) that diminishes the body's ability to recover from or buffer an event that may cause cell damage, could be contributing to this.

Smoking, Drinking Combo Raises Odds For Oesophageal Cancer

People who smoke and drink are nearly twice as likely to develop oesophageal cancer as those with only one of those unhealthy habits, a new study indicates.

Previous research has shown that smoking and drinking are risk factors for oesophageal cancer, but this is the first study to show the risk associated with smoking and drinking combined, the investigators said.

The finding, which was based on an analysis of numerous databases, is published in the April 22 issue of The American Journal of Gastroenterology



PROFESSOR BOB MASON

Hi, I am now nearly 6 months into my role as acting Chairman for the OPA and it has been a great experience. I should like to express my thanks to Maggie and all the trustees for their help, advice, encouragement and keeping me on the straight and narrow! I think I now understand my role better.

We are in a very exciting period for the OPA with more groups starting especially in Scotland and the awareness campaign. This is very exciting and we are working both directly with "Ref Lux" as well as with partners such as Action Against Heartburn led by Alan Moss and other like minded groups e.g. BSG. The current publicity especially engendered through parliament with meetings and debates has been very encouraging and we need to carry this forward with the New Parliament in May.

I have so far enjoyed meeting groups in The Royal Marsden and Belfast and have arranged to visit Derby for the AGM, Birmingham, Preston, Brighton, Leeds and Exeter later in the year getting good value from my Senior Citizens Rail Pass.

I hope to meet many of you at the Pearl Celebrations on Thursday 11 June when we can celebrate the work of the OPA "supporting patients by patients" and acknowledge the great debt we all owe David Kirby and Daphne for starting it all up.

As a clinician rather than patient or carer I have learned to appreciate the work of the OPA to complement what we do and hope you will have patience with me if my approach is a little different.

Best wishes,
Bob Mason

O.P.A. Trustees:

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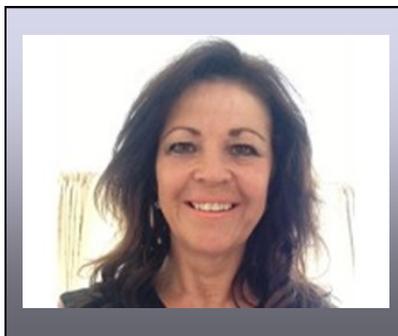
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A DAY IN THE LIFE OF

MAGGIE ROBINSON - OPERATIONS MANAGER, SOLIHULL



We talk to Maggie Robinson, to find out what the daily routine of a Manager of HQ involves.

What are your working hours?

A usual day for me starts around 8.00 am sometimes earlier as I try to have some quiet time and get jobs done before the hustle and bustle of the staff coming in and mainly before the phone starts to ring. I work Monday to Friday and will often be the voice on the phone on weekends and evenings too.

What kind of projects do you work on?

I am currently working on new website project, new database project and I also help towards creating new fundraising initiatives and materials, budgeting, building relationships with the Community and our supporters via MyDonate and Justgiving, to encourage them to raise funds for the Charity. I also offer input into the Newsletter and send out frequent mail shots to keep all of our members, medical profession and supporters up to date with what is happening within the Charity. Organising some of the OPA meetings/AGM and co-ordinating closely with everyone involved is an important part of my role as is working with Pamela Bonshor (our volunteer) to set up OPA micro-sites. I also build on relationships with all of our co-ordinators and medical profession with whom I am in regular contact with. My work involves liaising with the Trustees, Treasurer, Fundraiser, Book-keeper making sure everything is run efficiently. I am pro-active in helping to set up new groups throughout the UK, this year we are seeing more and more new Groups coming on board. I have also part completed the Macmillan Cancer Support course. This involves, communication, counselling, bereavement and cancer treatments etc. I also attend Branch meetings and am hoping to visit more Branches in due course.

As a manager I support the OPA team in their work, either with general advice, or help and advice on projects that are directly linked to the Charity. Overseeing the distribution of our literature to patients, carers, hospitals to ensure that this vital information is sent out promptly.

I have spent the last two years updating virtually everything in the office from setting up new filing systems to inputting my thoughts and ideas into improving the Charity in every way possible.

What does your average day entail?

I know it is a cliché, but no single day is ever the same. My particular role wouldn't be suited for someone who thrives on routine.

One day I might be speaking with our co-ordinators and the next day I may be liaising with the managing director of a major company to go along and accept a cheque on behalf of the OPA. The next day I may be arranging for the Branch pack to be updated or making sure the AGM is on track, the role is very varied. I work continually to maintain relationships with Branches and am also pro-active in encouraging new Branch start-ups as we expand around the UK, Scotland and Northern Ireland.

What are your key tasks?

I manage a small but very busy office and overall responsibility for ensuring that everything at Head Office runs smoothly. I also work very closely with the Treasurer, Book-Keeper and Fundraiser. Taking the phone calls, some happy some sad is a key part of my role, some of which I will refer to our OPA buddies (usually patients) who have an understanding of oesophageal/gastric cancer.

Why did you get into charity work?

I am a real "people" person and I realised I wanted my job to mean something, to contribute to society in a positive way, no matter how small that contribution might be. I love the variety of this role and the hopefully I will be able to visit our Groups this/next year which is one of my objectives. I love what I do!

A DAY IN THE LIFE continued

What skills do you need?

You have to be able to build excellent relationships internally and externally. Enthusiasm, initiative and a “can do” attitude go a long way. Being resilient, staying calm in a crisis are essential. The willingness to lug our books up and down the stairs while keeping a sense of humour is really important.

What are the best and worst things about your job?

We are working to raise the OPA’s profile to achieve national coverage and that takes a lot of time and effort and there are some groups who want to maintain their independence so keeping a relationship with them isn’t always easy. I am also very conscious of the need to spend funds wisely as I know how hard people work to raise these funds. The charity is back in the black again after a couple of worrying years and I try to make sure that we have the funds we need to do all the things we want to do.

As the OPA Operations Manager, one of the best things about my role is collaborating with others and coming up with new opportunities or creative solutions to problems. I love that my job is varied and that I am empowered to make decisions. I really appreciate the passionate, knowledgeable and lovely people I work alongside. But nothing beats chatting to a patient, carer, or member and hearing how the OPA has helped to radically improve their quality of life.

“What our customers say”

“The Simply Puree meals have been an absolute boon for both my father, who has Alzheimer’s, and my Mother who is his main carer. The meals look ingenious and everyone who sees them is stunned. Not only do the meals look so much more appetising to the person eating them but they alleviate guilty feelings for the carer who doesn’t have to serve up grey mush! A very pleasant attitude on the phone, efficient deliveries and excellent all round service. Looking forward to him having the puddings to try too.”

Many thanks, *David Reynolds.*

“I just wanted to say a big thank you for your range of pureed meals. The care that goes into the look of the meals is amazing and has transformed the portions of food my father is eating. My father is 85 and was recently diagnosed with dysphagia during a hospital admission for pneumonia. He lives with my mother who is also 85 and as a family we were really struggling to get him to eat our own meals which we were blending for him. He now looks forward to meals times, his strength & alertness has improved, as he is getting the nutrition he needs and I feel I have got my dad back.”
Thank you so much, *Tracy Walters.*



Meals that bring dignity back to those with dysphagia



For the full Simply Puree meal range please visit our website and start ordering your meals online today.



www.simplypuree.co.uk



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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.
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A Bright and Really Useful 100% Polyester Tote Bag 39 x 36 cm + Handles.
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A High Quality Mug, Dishwasher and Microwave Safe
£9.95 inc P&P

SUMMER 2015 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.

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.

| | | | | | |
|--------|---------------------------|--------|-----------------------|---------|-----------------------------|
| May 6 | Manchester (Tameside) | May 27 | Preston | June 9 | Manchester (Salford) |
| May 9 | Regional Meeting Exeter | May 28 | Liverpool | June 11 | Lancaster & Morecombe Bay |
| May 10 | Achalasia—London | May 28 | Guildford | June 13 | Portsmouth |
| May 12 | Manchester (Wigan) | May 30 | Grantham | June 20 | Guildford (Charity Fun Day) |
| May 14 | Royal Marsden | June 3 | Manchester (Tameside) | June 21 | Achalasia—London |
| May 14 | Lancaster & Morecombe Bay | June 6 | Derby & AGM | June 24 | Preston |
| May 20 | Manchester (Withenshaw) | June 6 | Frimley | June 25 | Guildford |

EASY FISH PIE



Prep: 45mins
Cook: 30mins



Easy



Serves 4



Ingredients

- 400g skinless white fish fillet
- 400g skinless smoked haddock fillet
- 600ml full-fat milk
- 1 small onion, quartered
- 4 cloves
- 2 bay leaves
- 4 eggs
- small bunch parsley, leaves only, chopped
- 100g butter
- 50g plain flour
- pinch freshly grated nutmeg
- 1kg floury potato, peeled and cut into even-sized chunks
- 50g cheddar, grated

Method

1. Poach the fish. Put the fish in the frying pan and pour over 500ml of the milk. Stud each onion quarter with a clove, then add to the milk, with the bay leaves. Bring the milk just to the boil – you will see a few small bubbles. Reduce the heat and simmer for 8 mins. Lift the fish onto a plate and strain the milk into a jug to cool. Flake the fish into large pieces in the baking dish.

2. Hard-boil the eggs. Bring a small pan of water to a gentle boil, then carefully lower the eggs in with a slotted spoon. Bring the water back to a gentle boil, with just a couple of bubbles rising to the surface. Set the timer for 8 mins, cook, then drain and cool in a bowl of cold water. Peel, slice into quarters and arrange on top of the fish, then scatter over the chopped parsley.

3. Make the sauce. Melt half the butter in a pan, stir in the flour and cook for 1 min over moderate heat. Take off the heat, pour in a little of the cold poaching milk, then stir until blended. Continue to add the milk gradually, mixing well until you have a smooth sauce. Return to the heat, bring to the boil and cook for 5 mins, stirring continually, until it coats the back of a spoon. Remove from the heat, season with salt, pepper and nutmeg, then pour over the fish.

4. Assemble and bake. Heat oven to 200C/fan 180C/gas 6. Boil the potatoes for 20 mins. Drain, season and mash with the remaining butter and milk. Use to top the pie, starting at the edge of the dish and working your way in – push the mash right to the edges to seal. Fluff the top with a fork, sprinkle with cheese, then bake for 30 mins.

Suitable for freezing without the eggs

*****STOP PRESS*****

Fiona Wade & Sammy Morgan join OPA as patrons

Fiona Wade, actress, is best known for playing Priya Sharma in Emmerdale and Anya Vicenze in the American drama 24 Seven. Fiona is very keen to help promote awareness and we all look forward to working with her.

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If you are a fan of football then Sammy Morgan requires no introduction. Sammy is a former Northern Ireland international striker with 18 caps to his credit. He began his footballing career in Norfolk before playing professionally with Port Vale, Aston Villa, Brighton and Cambridge accumulating 46 goals in 215 games.

LETTERS COLUMN

Across the "Pond"

I just got my first newsletter from the O.P.A.

Interesting to read how this disease effects people. Mine was a bit different from most as mine was a ruptured Oesophagus.

It started in September 2006 with dinner out with my family and imbibing on a lot of alcohol at home later. I then decided to have a snack of cashew nuts. I can't have chewed them properly as a piece of cashew half nicked a bit of my Oesophagus. I knew about half an hour later that something wasn't right. It's funny how the body can let you know when something is up. I said to my wife I don't feel well, and I don't think it's good. I then asked her to call me an ambulance.

I was lucky in that I was diagnosed quickly and a surgeon wasn't far away.

Dr Ross Roberts was preparing to operate as my family were told my outcome was not good, actually survival was minimal. My family were all called in and I said my last good byes. I said to my doctor as they put me under, "I'm not going anywhere, let's get this out of the way".

I think from what I was told I was under the knife for 5 hours, then recovery got a bit aggressive so they put me in a coma for 5 days.

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

I then came around and spent 10 days in hospital. I was cut from top of breastbone to navel and from my back to my front on my left side. They opened me up and removed cashew pieces that were in my body cavity and put me back together.

A few months off and then life got pretty much back to normal. I suffered from nerve pain where scarring was but my doctor put me on 1 pill of *gabapentin* a day to relieve the pain.

I'm one of the lucky ones I believe and enjoy my family every day.

Russell
Christchurch.
New Zealand

Gabapentin

Gabapentin (Gabba-pen-tin) is a medicine which is used in peripheral neuropathic pain, partial epilepsy and secondarily generalised partial epilepsy. Gabapentin is not suitable for everyone and some people should never use it. Other people should only use it with special care .

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

Professor Bob Mason

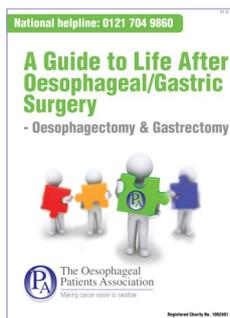
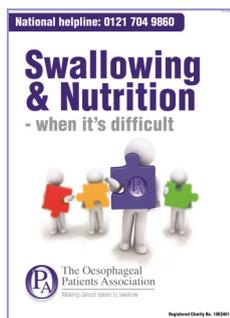
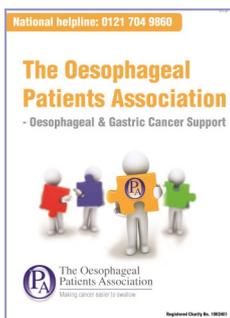
Saturday 6 June 2015

10.15am—14.15pm

ALL WELCOME

Hilton Village Hall Derby

Buffet Lunch



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!

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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.

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EMAIL ADDRESS:

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