



OPA NEWS

Xmas Issue 2015



Fighting Oesophageal and Gastric Cancer & Related Conditions
"Delivered by Patients for Patients"



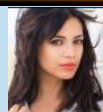
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Registered Charity No. 1062461



Pearl Anniversary

Photography-huwmeredithphotography.co.uk



New Patron Fiona Wade, who stars as Priya Sharma in Emmerdale, has launched our 30th Anniversary Fundraising Appeal. Ten years ago Fiona's father died of oesophageal cancer and she is passionate about raising awareness of the importance of early diagnosis. Fiona made a video to launch the appeal at our 30th Anniversary celebration which was held at The Regency Hotel, Solihull on 11 June. Professor Robert Mason, Chairman of The OPA, spoke at the event which was a successful evening, attended by The Deputy Mayor (previous Mayor) of Solihull Cllr Irene Chamberlain, who made a presentation to David Kirby OBE on his retirement. David will continue his role as Lifetime President of the charity that he founded thirty years ago. The Appeal target is to raise £120,000. Funds raised will help us to expand our network of regional patient support groups; provide wedge (support) pillows, patient videos, confidential database development for communications and future research purposes and creation of training courses, specific to support for oesophageal patients. **Please support our 30th Anniversary Appeal. Anything you do to help will make a difference and help us to reach our target.**

Message from the Chairman & Fundraising Events

Hi, I have certainly enjoyed my first year as Chairman of the OPA. My fellow trustees and Maggie and Jacqui in the office have made life easy for me and led me into the post gently. I have managed to attend several groups-Belfast, Preston, Birmingham, Exeter, Brighton, Royal Marsden as well as the AGM in Derby and the Pearl Anniversary Celebration. I have always been very impressed by the dedication and enthusiasm of everyone I have met and their determination to improve the lot of patients with oesophagogastric cancer. I am also grateful for your understanding of the different direction to which I approach the OPA-not as a patient or carer, but as a clinician. It is well accepted that if you put two surgeons in a room you will have at least three opinions! However much we think we know how it must be to have cancer it is not the same as first hand experience and that is why I am sure the ethos of OPA-"delivering support for patients by patients" must remain central to everything we do.



There are interesting challenges ahead especially with opening support groups in parts of the UK where there is no support we hope to make progress soon in Scotland.

The other challenge concerns awareness of the symptoms that precede cancer. Loraine has done a wonderful job with the REFLUX campaign, which goes from strength to strength and we are fully committed to Action Against Heartburn led by Alan Moss and includes a collaboration of charities. We intend to have a London wide campaign in the New Year to increase awareness and continue to raise the issue from a patient's perspective with those in power.

As retirement approaches at the end of the year I hope to have more time to visit as many groups as I can, as you the individual support groups are the OPA.

Best Wishes and Happy Xmas
Bob Mason

Message from Secretary

Recent publicity surrounding governance and fundraising at a few major charities isn't good for the sector as a whole. The OPA takes governance and the advice of the Charity Commission very seriously. We are guided by the Charity Commission's Hallmarks. In our fundraising we rely entirely on private donations and we do not use aggressive tactics and we do not cold call. We operate in accordance with the standards and policies of the Institute of Fundraising. We do not circulate information provided to us by members; that is held securely by us.

Our activities are guided by a development plan, our members are protected by a data security policy, and we have professionals running our (small) office and fundraising. We are a small charity and we are lucky to have a great Committee with very experienced Trustees. We operate ethically and legally and in the spirit of a small patient to patient charity. We won't let you down!

If you have any questions on this please do not hesitate to get in touch with Haward (haward@opa.org.uk) or Maggie.

Wellington Pub-Birmingham

Wellington Triumphs Again

Our thanks are due to Nigel Barker, Landlord of The Wellington pub, and to the staff and customers who collected £134 for us in the last 6 months. This is on top of the £154 collected in the previous 6 months, and they are still collecting!

The Wellington is located at the top end of Bennett's Hill in Birmingham city centre. It is TripAdvisor number one visitor attraction to Birmingham.

If you are in the city centre, please do call in. You will be sure of a friendly welcome and be amazed by the range of real ales on the bar (see photo above of Maggie receiving the collecting pot from one of the bar team).

If you have a friendly pub landlord, why not ask if he/she will collect for the OPA? If they agree you can get a letter of introduction from the office and they will also send you or the pub a collecting pot.



Maggie Robinson/Wellington Pub

Packington Walk

On Sunday the 25th of October a walk took place in Coleshill, the walk was nine miles long and started & ended in Coleshill. The highlight was walking through Packington Park, which is not generally open to the public. The walk was held by The National Birmingham Exhibitions Lions Club and also accompanied by Mike Ryan who has recently had an operation for oesophageal cancer. The walk was a great turn out and it was nice to see how pleased everyone was after they had completed the nine miles.

Drew Matthews/Mike Ryan



Update

THANK YOU to Mike and Loraine Ruddle-Norfolk & Norwich OPA Group.

I am delighted and honoured to be able to write about the incredible Michael and Loraine Ruddle - I really don't know where they find the energy to do the amazing work they have been doing and we are going to miss them. I have known them since 2008 when we looked after Michael. The relationship with them grew from there and it was very clear that they were passionate about helping cancer patients.



Mike/Sue/Loraine

Their commitment, hard work and sense of duty and giving for any patient, no matter where you are in the country, was second to none. There was a constant and unyielding support for cancer patients before and after surgery and certainly our patients benefitted enormously from them. Michael was the chairman of the Norfolk and Waveney OPA support group who held regular OPA meetings in Norwich to educate and support patients before and after oesophageal and gastric cancer surgery.

Behind every successful man is always a lady, and Loraine was definitely that lady. She was determined, passionate and dynamic, with corporate ideas about expansion and improvements for the OPA. The OPA's oesophageal cancer awareness campaign (Ref Lux campaign) was the brainchild of Loraine's artistic work whilst she was a trustee member of the OPA. Michael and Loraine are moving to Lincolnshire to be nearer family, and we wish them all the very best for the future. We look forward to hearing great news from them.

(Written by Ed Cheong)

Patients' experiences welcomed

Members in Leeds accepted an invitation to share their experiences of the local oesophageal surgical pathway with the surgical team. Patients and carers are shown in the photograph sharing and discussing their observations.



Members were overwhelmingly positive about their experience. Particularly impressive was the speed of progress through the referral and pre-operative stages, accessibility to and the positivity of surgeons, pain relief management and the quality of the teamwork overall. Comments included:

"I was amazed at the speed of which my treatment began after being diagnosed.

"My surgeon gave me and my family such positive thoughts from the outset. I can only describe St James' as 5 star treatment."

"Reassurances about pain management – "it will be uncomfortable but it will not hurt. We can manage pain."

"Feeling safe in the care of a complete team of medical professionals."

"Upper GI nurse was as caring for my carer as for myself."

Members also suggested that there was potential for improvement in terms of the impact on carers of patient confidentiality, the quality of food and nutritional advice, follow up after discharge from hospital and the epidural procedure. Comments included:

"Post op food not related to the operation and the staff had no idea of the requirements at the LGI."

"Epidural came out once back on ward leading to worry and stress."

"Post op – GPs mostly unaware – only one at my practice understood."

Others explained the difficulty they felt in reaching a decision when offered the opportunity to participate in a trial and queried whether it was possible to walk rather than be pushed to the theatre.

The observations were well received by the surgical team and the process was identified as an example of good practice in a recent peer review. The areas of potential improvement are to be explored by the Leeds Branch with local nutritionists, GPs and anaesthetists in the 2016 programme of meetings.

On the Website



Adventure Challenges

If you like taking part in exciting challenges and are planning to get fit again after Christmas, perhaps you, your family, friends or work colleagues would like to take part in an adventure challenge next year, such as the London to Paris Bike ride. You can choose from a wide range of UK and overseas challenges and raise funds for us at the same time. There is a really exciting variety of challenges you can take part in but they are very popular and you need to book early.

Christmas shopping

How about doing your Christmas shopping online through 'Easy Fundraising'. When you register and buy online through Easy Fundraising, then a donation from your purchase will be made by the retailer directly to the charity. It really is that easy! For full details see the Easy Fundraising page on our website, under the heading 'Shop and Give'. There are more details and links on all the above on our website, as well as information on a variety of ways in which you can make a huge difference. Please support our 30th anniversary appeal and help us to expand the work of the OPA to assist many more oesophageal and gastric cancer patients. Your help will be hugely valued. Thank you!

Thinking about booking Holidays after Christmas, why not make your booking through Easy Fundraising?



Fundraising nowadays is increasingly challenging and we would like to say a big "thank you" to those of you who are doing so much to support the work of the OPA through making donations and organising or taking part in events. You are making a difference- THANK YOU!

Ref Lux - blowing the whistle on Cancer

Consult your GP if you suffer from

- Persistent (every day for three weeks or more) heart burn 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



About Oesophageal Cancer

There are over 8000 new cases of oesophageal cancer in the UK each year. It is the sixth most common cause of cancer death.

There are two main types of oesophageal cancer:

Adenocarcinoma - about 70% of UK oesophageal cancer cases, and on the increase. It is associated with Barrett's Oesophagus and the effects of stomach acid on the lining of the oesophagus. So anything that increases acid reflux, like obesity, can be a factor. It tends to occur around the junction of the oesophagus and stomach.

Squamous cell carcinoma comprises about 30% of the oesophageal cancer cases in the UK. It tends to be higher up towards the throat. This sort of cancer is associated with high levels of tobacco and alcohol intake. If caught early enough, it can sometimes be successfully treated by chemo-radiotherapy and surgery.

In an ideal world the OPA would be pushing the early diagnosis message for all the causes/symptoms of all oesophago-gastric cancers. We have decided, for now, to concentrate all our resources on the one message that will save most lives in the short term: do not ignore persistent heartburn.

There could be tens or hundreds of thousands of people out there with undiagnosed Barretts Oesophagus. Up to 10% of them WILL go on to develop adenocarcinoma. The surest way to reach people who run this risk is to get those with persistent heartburn to see their GP. Many of those patients will be sent for an endoscopy which will diagnose Barretts, if present, leading to treatment and regular ongoing monitoring, both of which WILL save the lives of significant numbers of those patients.

If you are interested in attending or organising an 'Awareness Day' please contact us for more information enquiries@opa.org.uk

OPA Merchandise

An Introductory Range of Ref-Lux/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.



Ref-Lux Awareness T-Shirts
£5.99 inc P&P



Ref-Lux Badge
£2.00 inc P&P



Reflux Awareness Pens
£1.50 inc P&P



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 Fin-
ish
£4.50 inc P&P

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



Coffee Morning

Why do we organise anything outdoors in this country"?! was our comment as we put up a marquee in our garden in the pouring rain on the evening of 24th July.

Derek had had surgery for oesophageal cancer in February 2014 and following the success of a coffee morning held by two other members of our OPA group last year, we decided that we would like to do the same, to say thank you to the OPA for the support given to Derek and to help others affected by oesophageal cancer.

So we began collecting prizes for a tombola, I knitted, sewed and made cards as well as making jam & marmalade.

We borrowed tables, chairs, cups & saucers and urn. Delicious cakes were made & brought by family, friends and OPA members so we were all set.

Fortunately the morning of July 25th dawned bright and dry.

Soon there were lots of people buying from the stalls and the garden was full of those enjoying coffee and cream teas. It was lovely to see everyone chatting together and making new friends.

A big thank you to everyone who came and for the support we had in putting on the event. Derek & Carolyn Smith



'A Day in the Life of a Coordinator' or 'Go With The Flow as and when'

By Ron, Branch Leader, South Coast OPA.

I thought perhaps a bit of history about my involvement as coordinator for the OPA South Coast Branch might help to build up a picture of 'a day in the life of...'

I didn't go looking for the job nor was I head hunted it just kind of happened, mostly because no one else wanted it. I was at a meeting of the group a year or so ago when our illustrious leader, Verena the founder of our group, asked if anyone was interested in the job because she had to leave for personal reasons. Verena was well liked as our leader and there was a stunned silence amongst the dozen or so attendees with no response to the request.

Clearly the group had to continue, I stayed behind, had a chat with Verena and indicated that I would make myself available. Soon after I collected the list of patients, ex patients and carers (about 50 individuals), equipment, bags of handouts, the bank details etc., Also I had the continued support of Mick, Sheila and Betty, the raffle organisers, Steve our events organiser, Graham a co signatory and our stalwart regular supporters.

Just a tip, you do need to have a sense of commitment because of arranging meeting dates etc., but you don't need to have any previous experiences or passion for the job in order to get it. You just dive into the deep end!!!! However, once you come into closer contact with the wonderful brave and courageous people with whom you are privileged to share an indescribable sense of mutual understanding and friendship, you suddenly become very passionate about the OPA so be

Well now, down to the nitty gritty, what you really want to know. Obviously it isn't really all done in one day but there are specific tasks such as managing one's own time and priorities, sending out meeting notices, arranging venues and dates, begging for an outside guest/speaker, dreaming up an agenda, alerting everyone just prior to the meeting, getting to the venue early on the day to make sure the room is secured with everything set up by the raffle team and that refreshments are organised and hoping that the outside speaker will turn up and that we could fill the two hours to the satisfaction of all the attendees.

There is of course time given to answering telephone enquiries and the many email exchanges that are par for the course.

I dutifully started sending out meeting invites to everyone on the list, about 50, but I found that we were getting only about 10 to 20 members attending the meetings with just a few replies of apology.

I became concerned about those who did not reply and wrote to all non attendees. I had a couple of replies from relatives of deceased members, unfortunately we are not always informed in those cases. I also had a reply from a member who said that he had attended a meeting a few years ago but found that he was not particularly welcomed and felt solitary. I was most grateful for his comments because it opened my eyes for the need to change my approach.

When I first started, I had modelled the meeting on the same pattern as that prior to my takeover. I found it quite hard going, although I had attended several meetings over the past couple of years I only knew a few by name despite name badges being worn, although I had started a signing in book and I had no idea of who had attended previous meetings. Some of the original members who attended regularly knew each other and would meet up for lunch prior to the meeting.

Thus, with some lessons learnt, it came to pass that OPA South Coast has evolved into a mutual patient/carer debating group with prominence given to newly diagnosed patients and those who have recently undergone surgery, chemotherapy or some form of radiation therapy with mentoring by more experienced survivors who have successfully recovered or are recovering from similar experiences. We remain open to continued evolution and to new ideas.

Many thanks to the lovely Maggie for her kind support!

Recipes

These recipes have been donated by **Karyn Booth** who is a freelance food stylist, Home Economist and Cookery Writer. Her work mainly involves creating food for film, television commercials, magazines and food packaging. She is passionate about making food look appetizing and delicious.

Increasing the calorie contents of existing meals and snacks

Fortify milk by mixing 4 heaped tablespoons of dried milk powder to 1 pint of milk. Mix a little milk into the powder to make a paste, gradually add the remaining milk until the powder has blended into the milk.

- Add olive oil and melted butter to pasta.
- Serve peanut butter or jam on toast.
- Add milk powder and butter to mashed potatoes.
- Use fortified whole milk to prepare soups and hot cereals.
- Top porridge with thick and creamy yogurt, honey and fruit.
- Smoothies made with frozen fruit, fortified whole milk or yogurt and honey with a scoop of ice cream.
- Flavour whole milk with flavoured syrups.
- French toast.
- Crackers topped with cream cheese and sliced apple or pate, cheese and chutney or salmon mousse (whizz tinned salmon with cream cheese).
- Butter hot toast, top with baked beans and grated cheddar cheese.
- Use fortified whole milk to make nourishing drinks such as milky coffee, Horlicks, hot chocolate, Ovaltine and cocoa.
- Use hot milk to make instant soup.
- Fruit compote or tinned fruit with yogurt and honey.
- Milky desserts (fortified milk) – bread and butter pudding, apple crumble etc.
- Add butter, margarine, cream, grated cheese, olive oil, mayonnaise and fortified milk to potatoes and vegetables. (E.g. Champ – poach scallions in fortified milk, mash boiled potatoes add the scallions, milk, grated cheddar, butter and mix well).
- Use fortified milk to make sauces e.g. cauliflower cheese, macaroni cheese.



Lamb Curry

Preparation time: 5 minutes, Cooking time: 10 minutes, serves 4

Ingredients

- ½ large onion, chopped
- A little olive oil for frying
- 1 clove of garlic, crushed
- 3 level teaspoons of Madras curry powder
- 400ml coconut milk
- ½ lamb stock cube
- 2 heaped teaspoons of tomato puree
- 1 teaspoon mango chutney
- 1 small handful of coriander leaves, chopped
- 1 small handful of fresh mint leaves, chopped
- 4 spring onions, chopped
- 600g lean lamb leg steak, thinly sliced

To Serve

- Cooked basmati rice
- Tandoori Nan bread

Method

Heat the olive oil into a large pan and fry onion until soft. Add the garlic, curry powder, coconut milk with the crumbled ½ stock cube, tomato puree and mango chutney. Let the sauce come to the boil, then reduce the temperature and let it simmer for 5 minutes until it thickens, keep stirring. Add the chopped herbs and spring onions. Finally drop the thinly sliced pieces of lamb into the hot sauce and continue to simmer for 2 – 3 minutes until the meat cooks – changes



Leeks, bacon and potato soup

Preparation time: 10 minutes, cooking time: 30 minutes, serves 4

Ingredients

- 50g butter, cut into cubes
- 1 tablespoon olive oil
- 2 large leeks, washed, trimmed and finely sliced
- 1 large onion, peeled and chopped
- 250g smoked back bacon, finely chopped
- 2 large potatoes (750g) peeled and cut into small dice
- 1 litre chicken stock made from bouillon or stock cubes
- 200ml full fat milk
- 50g milk powder blended to a paste with 75ml of milk
- Salt and black pepper

Method

Trim, cut the leeks long ways and make sure they are thoroughly washed to remove all the trapped dirt between the layers of leek, slice finely. Gently melt the butter in a heavy based saucepan. Add leeks and onions, season with pepper. Cover and let the vegetables sweat over a very low heat for about 15 minutes. Add the bacon pieces and fry for 2 minutes. Add the diced potato, chicken stock, milk and blended powder. Stir well. When the soup reaches a gentle simmer, cover and cook gently for a further 10 minutes. Use a hand blender to blend the soup to a smooth consistency before serving.





Leeds Region were delighted to assist Harrogate District Hospital in a campaign to raise awareness of the symptoms of oesophageal cancer in September.



The Leeds group was very grateful for the valuable support of the Norfolk group in designing the roller blind, cardboard cut out figure and accompanying literature.

Over one thousand leaflets were given out at the hospital and local pharmacies and GP surgeries. A copy of the associated press release is available on the Leeds microsite.



OPA AGM

Hosted by Birmingham

Old Joint Stock

4 Temple Row West, Birmingham B2 5NY

**Saturday 25th
June 2016**

10:30 am – 16:00 pm

A buffet lunch will be provided

All Welcome!

**Welcome aboard
Drew Matthews our
new administrator at
Head Office.**



✂

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.