



# OPA News

Xmas Issue 2016

Fighting Oesophageal, Gastric Cancer & Related Conditions  
Help, advice and support delivered by patients and carers for patients and carers

[www.opa.org.uk](http://www.opa.org.uk)

Registered Charity No. 1062461

## Scotland Update

The OPA has been busy visiting Scotland with the objective of setting up new groups. The OPA presence in Scotland is very sparse and as a consequence we want to create more patient support branches in Glasgow, Edinburgh and Aberdeen as a beginning. We now have OPA buddies based in Scotland for our patient queries and the possibility of new OPA groups especially in Glasgow.

An evening was hosted by Maggie's Centre, Gartnavel, Glasgow & The Oesophageal Patients Association on 26th October which included a presentation by Consultant Surgeon, Grant Fullarton, (who we have now welcomed on board as a Trustee). Hannah Smith (who is only 27 years old) presented a talk reflecting on her personal experience – 'Looking back sprinting for-ward' – her story after life-changing oesophageal surgery. This session was well attended by friends, family and professionals.

The evening was a great success... watch this space!



The Oesophageal  
Patients Association

Caring for the cancer patient and their family



# Message from the Chairman & Fundraising Events



## Message from the Chairman



*Bob Mason*

Hi, It has been another busy and successful year for the OPA. I have managed to visit several groups in the last 12 months including Preston, Lancaster, Peacehaven, Exeter, Leicester, Isle of White, Portsmouth and St Mary's and Guys Hospital in London. In all cases I have been very impressed by the enthusiasm and commitment of the patients and carers plus CNS and other professionals to improve the quality of life for all. We have made great strides in opening up new groups especially in Scotland. Following a presentation to the Scottish Cancer Centres in Edinburgh Maggie and I had a very successful meeting in Glasgow and now have a group starting there. We are very grateful for the support of Maggie's Centres, Macmillan and others in facilitating such improvements.

I should like to give a personal welcome to four new trustees- Phil Coverdale, Hilary Ryan, Philip Wright and Grant Fullerton (oesophago-Gastric Consultant) Glasgow Royal infirmary who will add greatly to the development of the OPA. It goes without saying that we continue to owe much to the enthusiasm and commitment of Maggie and Drew in Birmingham and the energy of Haward, our superb Secretary.

The future looks bright for the OPA and we will continue to develop our role in Support through groups, the website and help line and Awareness through Ref-lux in the next year.

Best wishes for the festive season!

*Bob Mason*

## Hadrian's Wall Walk

A chance meeting with his old school friend, Ian Hinsley, gave Paul McCann the opportunity to walk along Hadrian's Wall from East to West coast. Although it was a personal challenge for Paul, he decided to raise funds for the OPA as his partner Linda had experienced serious oesophageal problems some years ago, at one time being given less than three years to live. She had received support from the OPA during this difficult time.



*Paul McCann*

Thanks to the generosity of Paul's sponsors he raised £530 (plus gift aid) for the OPA.



Thanks to the following who have also raised funds for the OPA:

- Three Peaks Challenge
- Eric Gethin
- Queen Mary's High School
- Family X Runner (Samantha, Jordan, Fenwick, Ellis, Katie, Kayleigh, Heather, Demi & Ryan)
- The Cooper Family
- Alex Stephens – Cardiff Marathon
- The Dave Owens & Frank Goodall Memorial Fund
- Margaret Farrell, Jo Belfield & the Toe Tappers
- Joy Venturi Rose
- The Wellington Pub, Birmingham
- Garden parties, coffee mornings
- Masonic Charitable Trust

Also, thanks to all of our donors and anyone we may have missed who have donated, however large or small!





## Recent News



### Queen Mary's High School



Alf Baker - OPA member & Walsall Branch Coordinator accepting a cheque for £4200.53 which pupils from Queen Mary's High School have raised over the last year from a variety of events. Special thanks to everyone including Laura Butlin, Abbie and family, all teachers and staff. (Nov 2016)

### Thank you to the OPA!

After being diagnosed with oesophageal cancer - I was advised to contact the OPA. It was a very unsettling time for me and my family with lots of questions entering my head each day. The OPA was able to give reassurance about the treatment process and offered practical advice such as putting on weight before my operation. It was good to talk to a friendly voice who had been through the experience and to know I could contact them at any time as my moods changed from confident to total bewilderment, with all the appointments and tests to undergo. After the operation, my wife and I went to an OPA meeting and met lots of patients and carers who had been through the same trauma, some of whom were years on from the situation I currently found myself in. Simple tips on coping with the after effects, such as mints helping with feelings of nausea after meals helped to make life more normal. My wife met other carers and compared meal ideas to enhance our diet along with other practical suggestions. At each meeting a surgeon was a guest speaker and was available to talk to us with specific questions. I feel I was lucky to get a quick diagnosis after my visit to my G.P. and thankful for all the help and support of the OPA.

*Roy Swain*



### Into the Dragons Den

On 22 September last, an intrepid group set out from the Queen Elizabeth Hospital Birmingham, prepared to enter the Dragons Den. The group comprised Olga Tucker, Upper GI consultant surgeon (now at Heartlands Hospital), physiotherapists Jonathan Weblin and Dave McWilliams plus me, Tony Ingold from the OPA as Patient Representative. The Dragons Den in question was not the one with Alan Sugar, instead it was at the AUGIS (Association of Upper GI Surgeons) conference in Leeds. The dragons consisted of 3 upper GI consultant surgeons and 3 university professors. There were four groups of "contestants", each of them presenting a presentation of up to 8 minutes on a research proposal. These contestants were selected from a larger group who had put their proposals forward for a chance to present to the Dragons. Following each presentation, the groups were questioned for 3 minutes by the Dragons then 3 minutes of audience (Surgeons and other health professionals) on their presentation. Our presentation was on preconditioning and post operation conditioning of patients who were undergoing Oesophagectomy or Gastrectomy, to try to ensure they were in the best possible condition to undergo surgery, then to recover to a good level of fitness afterwards. At the end of the presentations, the proposals were voted on by the audience, then separately the Dragons picked their winner. We were delighted to find that the audience voted ours the top proposal, with over 50% of the total vote. A little later the Dragons came back from their deliberations and they unanimously voted our proposal top! Needless to say we celebrated our success that evening.

Tony Ingold. October 2016



# New Trustees



## Phil Coverdale

Having graduated from Keele University with a Joint BA in Economics and Law, Phil worked for Lloyds Bank for 30 years in a variety of roles up to and including Senior Management. He describes his Banking career as being a “Jack of all trades but master of none”! He then spent 5 years as a School Business Manager before retiring in 2008. In late 2012 he was diagnosed with oesophageal cancer and spent 2013 on the familiar path of chemotherapy followed by an Ivor-Lewis operation in April. Just for good measure – and to round the year off in style – he had a kidney removed in December! So much for 2013! In collaboration with the Upper GI staff at Portsmouth’s Queen Alexandra hospital Phil helped to set up the OPA Branch for the Portsmouth and South Hampshire area (OPA-SPLASH) and acts as the Branch Coordinator for this very successful group. His passion now is to set up and drive forward the OPA strategy on Creating Awareness of this type of cancer. His other interests include playing golf, supporting Hull City (well someone’s got to!) walking, and acting as a School Governor.



## Hilary Ryan

Hilary is three years post oesophagectomy, and having returned to full time work afterwards, now feels it is time to retire and take things a little easier. She firmly believes in the benefit of the support that OPA members can offer to each other to complement the support offered by the medical teams. Born in Bristol she has spent all her adult life in Wales and has earned her Welsh passport! Having three grown up children, three grandchildren and two grand-dogs keeps her busy along with walking, cooking and gardening. Hilary has recently joined the very active South Wales branch of OPA. Hilary has a finance background, having worked in the both public and private sectors, with jobs as diverse as internal audit at a health authority to costing Harvey’s sheries. The last 28 years have been spent working for housing associations, specialising in scheme appraisal and funding, whilst the last six years she has been Chief Executive of a housing association that houses vulnerable people, specialising in those with learning disabilities, and Veterans. She is experienced in governance, working with voluntary boards and preparing and reviewing accounts.



## Philip Wright

Philip Wright is a carer. M.A. (Cantab.), Dip.N.(King’s College, London) 1972-92 worked in art museums and galleries as a curator, researcher, writer and lecturer, and continuing occasional researching and writing up till the present. 1993-2015 trained, and then worked as a ward nurse until 2010, and then worked in the community until retiring last year. I have studied, lived or worked in France, Spain, Italy, Germany, the UAE, Saudi Arabia and the USA, and speak French, German, Spanish and some Italian.



## Grant Fullerton

Grant Fullerton is a Oesophago-Gastric Consultant Surgeon in Glasgow Royal Infirmary with major interests in management of malignant and complex benign upper GI disease. In his role at University of Glasgow he is an Associate Professor of Clinical Surgery with extensive research interest in benign and malignant upper GI disease. Grant’s particular interest is in the field of Barretts oesophagus including its role in cancer development and treatment with Radiofrequency Ablation.





# Useful information



## Radar Key

The National Key Scheme, sometimes known as the RADAR Scheme, was developed because some public toilets designed for disabled people had to be locked to prevent damage and misuse. This has been countered by their being locked separately from other toilets. The NKS aims to provide disabled key holders with independent access to the toilets provided for them and increase the likelihood of the facilities being in a useable state. If accessible toilets for disabled people do have to be locked, providers are asked to join the NKS, which involves fitting standard locks to their toilets and making keys available to disabled people. Over 400 local authorities in all parts of the country have now adopted the scheme. In addition to public conveniences, toilets for disabled people provided by a wide range of other public, voluntary and commercial organisations have been fitted with the NKS lock. So it can now be found in shopping centres, country parks, railway and bus stations, bars, motorway service areas and sports venues. Around 7000 toilets are now fitted with the lock and can be found from Shetland to Jersey and Derry to Dover.



Within the scheme RADAR:

- supplies NKS keys to disabled people who cannot, or have difficulty, getting one locally,
- maintains a list of toilets fitted with the NKS lock and
- provides general information about the scheme to individuals and providers.

RADAR does not advocate the general fitting of locks to all toilets for disabled people but does urge that the NKS is used where a lock is required.

## Region List for Radar Key

Price: £3.50

A list is available of NKS toilets in your area in return for a donation of £3.50 with every purchase of the key, the regions available are:

Greater London	West Midlands	Highlands and Islands
South East England	North West England	North Wales
Southern England	Yorkshire	Mid and West Wales
West Country	North East England	South Wales
Devon and Cornwall	South East Scotland	Northern Ireland
Eastern England	South West Scotland	Channel Islands
East Midlands	East Scotland	Isle of Man

For more information please visit <https://crm.disabilityrightsuk.org/region-list-radar-key>





# Awareness



Special thanks to:  
 Robert Lee-bird (Essex Group),  
 John Taylor (Leeds Group), Sam  
 King (Walsall), Tony Ingold  
 (Birmingham) and all Health Care  
 professionals who have supported  
 the Ref-Lux awareness campaign on  
 behalf of the OPA

The OPA held an awareness day in Touch-wood Shopping Centre, Solihull, West Midlands on 15th June 2016 to raise aware-ness of persistent (every day for three weeks or more) heartburn or indigestion. The day was a great success. Watch the video on YouTube and here are some photos

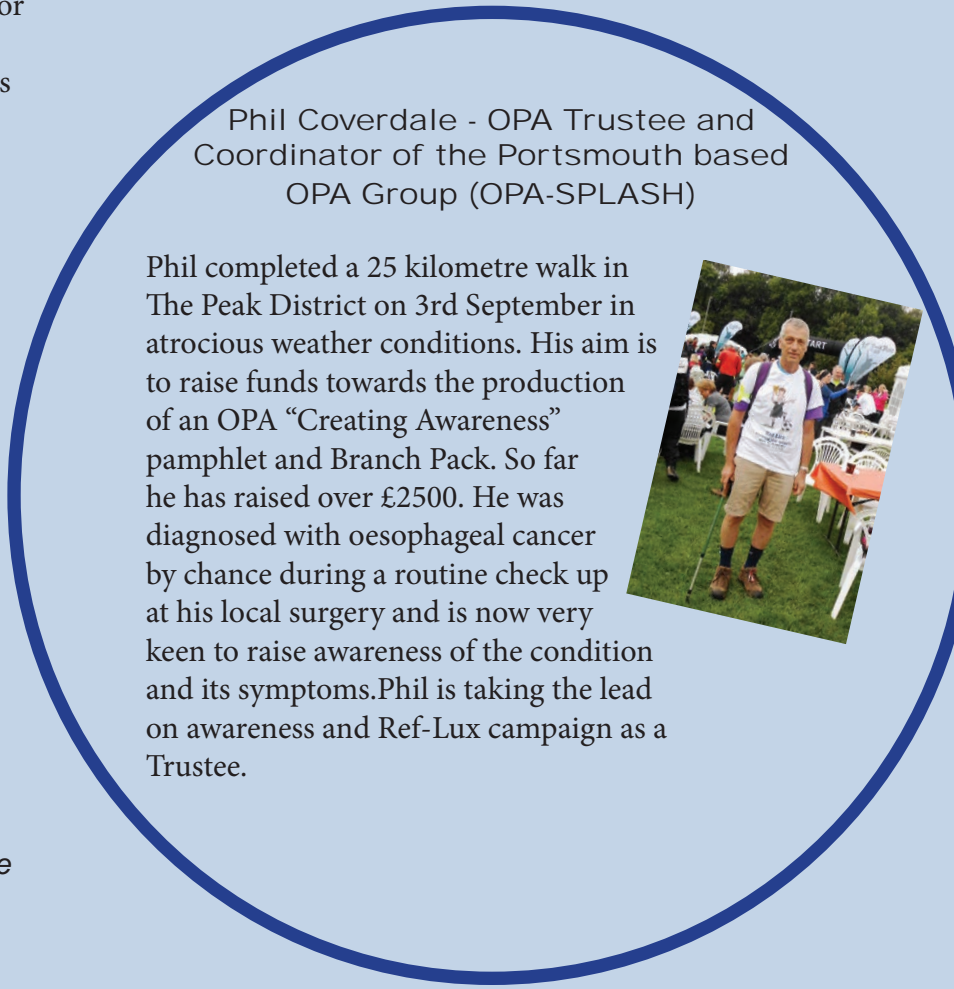
<https://www.youtube.com/watch?v=GcOj8CB5-OY>



The event was supported by our Trustees and volunteers from the Birmingham Group.



Left to right June Woodhall, Les Woodhall, Drew Matthews, Tony Ingold (Trustee), Maggie Robinson, Rick & Jane Martin



Phil Coverdale - OPA Trustee and Coordinator of the Portsmouth based OPA Group (OPA-SPLASH)

Phil completed a 25 kilometre walk in The Peak District on 3rd September in atrocious weather conditions. His aim is to raise funds towards the production of an OPA "Creating Awareness" pamphlet and Branch Pack. So far he has raised over £2500. He was diagnosed with oesophageal cancer by chance during a routine check up at his local surgery and is now very keen to raise awareness of the condition and its symptoms. Phil is taking the lead on awareness and Ref-Lux campaign as a Trustee.



**Giving cancer the yellow card**



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## *A day in the life of a carer*

The sound of John taking his morning tablets as quietly as he can has become my new alarm call. It is a good sound as it means he wasn't up in the night. Nearly a year has passed since his surgery, so this is becoming the norm but every now and then – for whatever reason – something upsets his system and he pays the price in the wee small hours.

I have been asked by the chairman of the support group to write about being a carer. I find that word has so many connotations and doesn't really sit comfortably with me. The word 'carer' conjures up someone being pushed around in a wheelchair like Matt Lucas and David Walliams in "Little Britain", not my husband and me. Don't all wives (or husbands) 'care' anyway? I just see myself as having to do more than before, that is all. So, John gets up and cooks his very small breakfast and I leave him to it. This is partly because he was never at his best in the morning and now he is even worse! It is also because I think it is good for his morale to be able to do things for himself. That is my excuse ... the fact that I get a lie-in is a carer's perk, it's a well-known fact. After he has eaten, John always needs to sit quietly for a while as his insides deal with the latest intake, so once he has retired to the living room, I have my breakfast in peace. Then, it is off to the supermarket to do a food shop. John used to like coming with me but he tires far more quickly these days, so I suggest he saves his energy for something more interesting than going up and down the aisles at Morrison's looking for things on the list we have made. We like lists. In the supermarket, I am irritated by the assumption that everyone is trying to lose weight; so many items are described as 'low fat' as if that is a Good Thing (actually, they are usually low in fat but high in sugar!). He has lost over a stone, which is totally normal and neither he nor his consultant are concerned but as winter approaches, I would like him to carry a few more pounds if possible. Our kitchen cupboards are now bulging with a range of desserts and goodies that he has tried and liked but then his tastes have changed.



*John & June Metcalfe*

I shall keep trying, though; pain au chocolat, anyone? When I return home, I am pleased to see he is working in the garden. The fresh air and exercise will do him good. However, after an hour or so, I start to worry that he is overdoing it and neither of us knows whether or not that is true. There is such a fine line between caring and fussing! We will only find out when he wakes up tomorrow morning. They call it learning the hard way. After years working in IT, much of John's time is spent on his computer. We have been told that his body needs a good two years to get over all that has been done to it, so I see this as a good way of letting the healing process take place. All the time that he is sitting quietly working on the competitions for his photographic club or on the schedule for the chess club he captains, his body is getting on with recovering. Evenings are spent pretty well in the same way as they have always been with a few minor tweaks. This evening, he has choir practice so I remind him to take a cheese sandwich with him to eat mid-session - the new regime of eating little and often has to be observed. Then it is bedtime and a case of propping himself up with extra pillows while I hope that the next sound I hear will be him taking his tablets in the morning, at the start of another day's healing.

*June Metcalfe*





# Merry Christmas!



## Winner of OPA student scarf competition with Heriot Watt University announced!

Haward Soper, OPA Secretary, and Celia were invited to the Heriot Watt campus in Galashiels where Angela Cassidy and Jane Robertson of the School of Textiles showed the eight entries for the scarf competition over lunch. These were of a very high standard. Students had researched the condition, one had spoken to patients and the students had considered the scarf from multiple viewpoints. Haward was very taken aback at the thought and effort that had gone into scarf designs. They all included periwinkle as a colour and it wasn't possible to exclude any particular scarf at first glance. The final winner was eventually chosen and is Jolene Guthrie (pictured right) who wins a prize of £250. The runner-up and other participants all win a prize too.



Jolene Guthrie

A formal presentation will follow and the plan is to put the winning scarf into production, so watch this space!



### 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

