



OPA News

FIGHTING OESOPHAGEAL, GASTRIC CANCER & RELATED CONDITIONS

www.opa.org.uk

Summer Issue 2018



Fiona Wade

A P P E A L

Our patron Fiona Wade has designed a wristband to help the OPA raise funds so we can support more patients, families and their carers.

Fiona is an actress, best known for playing the role of Priya Sharma in Emmerdale, amongst many other roles in television dramas. Fiona says, "Early diagnosis is absolutely key in saving lives from this cancer, so join us in the fight against this devastating disease and help us to save lives and also support and reassure every patient who needs our help. Thank you." To donate to the Fiona Wade Appeal please visit our JustGiving page or you can pay via paypal on the OPA website, opa.org.uk/fionawadeappeal.



To purchase a Fiona Wade Appeal wristband call the OPA on 0121 704 9860 to place your order. Wristbands only cost £2 each including postage and packing.

Or email enquiries@opa.org.uk

Light blue in colour with white writing. Soft, flexible and hard-wearing plastic. Nicely presented in a little white ribbon tie bag too!



Our OPA & Fiona Wade event is on Saturday 30th June 2018 at 4:00pm – 8:00pm and to be held at the Guild Hall, 141-142 High Street, Henley in Arden, B95 5BD. For more information read about it on page 7...

Registered charity No. 1062461

Bite-Size Groups update

We can now report the following exciting news!!

Interest in our latest Bite Size Support Groups have been shown in the following areas; Birmingham, Cheltenham, Harrow, Kent, London, Manchester, New Forest, Newcastle, Northumberland, Norfolk & Norwich, North Essex, North Hertfordshire, North Wales, Northampton, Northern Ireland, Peterborough, Powys, Shrewsbury, Southport, Southwark & Lambeth, Stoke, Surrey, West Sussex, Wirral – Liverpool. For further information on any of the groups please contact the OPA office on 0121 704 9860 or email us at enquiries@opa.org.uk.

The OPA will continue this initiative – our aim is to help create bite-size groups, moving away from the larger Hospital Groups for the benefit of those who do not have the time, energy, resource to attend the much larger Groups set up around the country. This is your opportunity to attend smaller more informal groups that you have been asking for! Some great people have expressed an interest in trialling small groups and we have had expressions of interest from many areas that we are currently following up, updates will be provided in due course. Thanks to everyone who has offered their support to the OPA!

If you would like to start a bite-size group, we can help with basic expenses, cost of room, tea, coffee and biscuits. We provide free literature, restaurant cards, leaflets, and access to our helpline and can also arrange to visit your first meeting. For further information please call 0121 704 9860 or email enquiries@opa.org.uk

Benefits of support groups

In a support group, you'll find people with problems similar to yours. Members of a support group typically share personal experiences and offer emotional comfort and moral support. They may also offer practical advice and tips to help you cope with your situation.



Benefits of participating in support groups may include:

- Feeling less lonely, isolated or judged
- Improving your coping skills and sense of adjustment
- Talking openly and honestly about your feelings
- Developing a clearer understanding of what to expect with your situation
- Getting practical advice or information about treatment options

When you join a new support group, you may be nervous about sharing personal issues with people you don't know. So at first, you may benefit from simply listening. Over time, though, contributing your own ideas and experiences can help you get more out of a support group. From experience the OPA was founded on the ethos that help is provided from patients and carers for patients and carers based on their personal journey with oesophageal and gastric cancer and other related conditions. This has helped them to gain confidence and move on and live a meaningful and purposeful life.

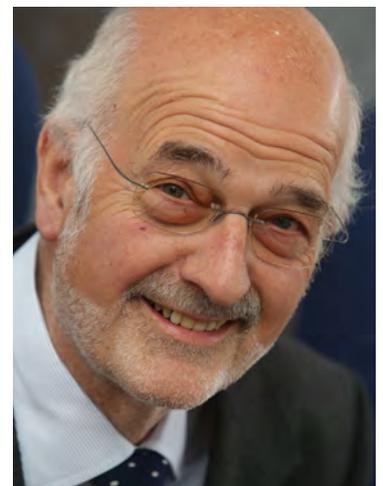
New Trustee John Campolini

I was diagnosed with Oesophageal Cancer over 3 and a half years ago and underwent surgery at St Thomas' under the great care of Bob Mason and James Gossage plus a whole raft of dedicated and wonderful medical staff. By way of background information I come from an Italian immigrant family from a small village in the South of Italy and like lots of Italians in the 1930's who came to the UK my parents made and sold ice cream! I left school and after a number of jobs from a musician to mechanical engineer in the pharmaceutical industry retired after 36 years in the criminal justice system. My Italian heritage is very important to me as are my son, daughter and two granddaughters.

I have belonged to the Knights of St Columba, a Catholic charity, which looks after the less fortunate in our society for over 51 years and am a licensed radio ham (call sign G0CRI). Since being cured of my Cancer, I have, at every opportunity when speaking to groups of people raised the awareness of

reflux and the consequences of ignoring the problem and urging people suffering from reflux to ask to be referred to specialists as soon as possible. Sadly my father died from Oesophageal Cancer over 30 years ago and my 45 year old son is being monitored for the same condition.

My hope is that we support each other in various ways such as meeting up, having discussion groups, inviting specialist speakers to our meetings etc.





New Treasurer/Trustee Paul Drake

Paul is a chartered accountant with extensive experience in the manufacturing and construction sectors. Before retiring in 2015, he held a number of senior positions with the engineering group GKN, including Financial Controller of their factory in Italy and Finance Director of their Asia Pacific region. He has previously served as a trustee of The Shakespeare Hospice, a £2m charity in South Warwickshire, and

BasicNeeds, a £1.5m charity providing mental health services in developing countries.

Paul is lucky. He was tested for various digestive issues in 2017, but found to be free of cancer. He did, however, have to take a long course of proton pump inhibitors to treat oesophagitis, and to have part of his colon removed as a preventative measure.



New Fundraiser – Blair Kessler

I was born and brought up in Birmingham and just never left!

After I left school I started to train as an accountant but my employer and I eventually agreed that this was not for me. It did, however, give me a good basic understanding of accounts which has proved invaluable in my business life. Having given up accountancy, I turned to sales, something which became my passion. Originally trained by American company Lamson Paragon, I spent my career working for different companies, selling and marketing products as varied as professional cleaning equipment, computer supplies and industrial safety products.

In 1994 I was made redundant and found a job as a fundraiser for St Basils, the Birmingham-based charity that works with young people who are either homeless or in danger of homelessness. I thought it would look good on my CV and intended to stay for eighteen months or so. Sixteen years

later I retired from St Basils having been Head of Fundraising for eleven years! I still volunteer for some of their events.

Following my retirement I continued to work with my church, lay preaching around Birmingham and I dabbled in film producing. Then, in 2013, I was diagnosed with oesophageal cancer.

Like many reading this I progressed through chemotherapy, surgery, more chemotherapy and then recovery and rehabilitation. Throughout all this the support that I had from other patients was vital. Their encouragement helped me get through. So when I got a call from the OPA asking would I be interested in coming in for a chat about a fundraising opportunity, I quickly said yes.

For me, fundraising is a great job. We are raising the money that, through the charity, changes lives. I hope that my efforts as part of the team will make sure that the OPA continues to make a difference.



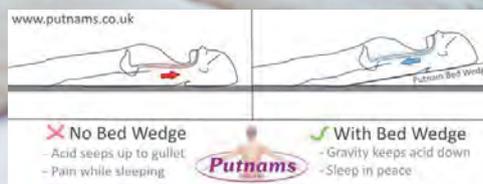
Offer still available!
Over 1000 wedges issued

Bed Wedges

Goodnight Acid Reflux, Hello Sleep! - Bed Wedge special offer from the OPA and Putnams

Thanks to The James Tudor Foundation and the Childwick Trust Foundation we have been able to extend our Bed Wedge offer from the OPA and Putnams.

More about Bed Wedges



The OPA has teamed up with Putnam Pillows to provide their standard **Bed Wedge - Acid Reflux** at an affordable price of only £27.98.

Many people with oesophageal disease have to sleep propped up. This can be difficult but some find a wedge pillow helpful. These can be quite expensive.

The OPA is putting £12.50 per pillow towards this partnership. Putnams have, on top of that, agreed to a generous discount. The standard retail price is £57.92, you only pay £27.98 - saving over 48%.

Putnams also offer free delivery or you can pay a little extra for next day delivery.

Both doctors and other practitioners agree a wedge pillow is the best way to relieve the symptoms of Acid Reflux or Gastroesophageal Reflux Disease (GERD) and heartburn by elevating your torso to prevent acid from burning the lining of your oesophagus while you sleep.

The Bed Wedge - Acid Reflux can be used in many ways. Place it under your pillow to sleep in a raised comfortable position which is ideal for sufferers of acid reflux and Oesophagitis. Using a bed wedge whilst asleep to elevate your upper half can severely reduce acid reflux. Just adding extra pillows won't work because they elevate your head, not your upper torso. It's also easier to slip off extra pillows as you sleep.

We are very grateful to Hedley Putnam, Director at Putnam Health Co Ltd and to Putnams for their generous discount and postal service.

To take advantage of this offer

1. Please call or email the OPA first and we will give you a Discount Code. Call us on 0121 704 9860 or email enquiries@opa.org.uk
2. With the Discount Code, call Putnams on 01752 345 678. Email info@putnams.co.uk or visit: www.putnams.co.uk/collections/bed-wedge-pillows/products/bed-wedge

Note, on the website you will be able to enter the Discount Code on the Check Out page.

We are extremely hopeful that this initiative will help many of our members to sleep more comfortably.



International award for Edward Cheong OPA trustee and NNUH surgeon

Mr Edward Cheong (right) pictured with Professor J D Luketich

A consultant surgeon from the Norfolk and Norwich University Hospital has been honoured with a prestigious international award.

Mr Edward Cheong, Consultant Oesophagogastric and Laparoscopic Surgeon, was awarded the inaugural Dr James D Luketich Chairman's International Award for Minimally Invasive Oesophagectomy (MIO) from the University of Pittsburgh Medical Centre (UPMC), USA. Edward is the first British surgeon to be trained under Professor J D Luketich, at UPMC Pittsburgh, an internationally renowned centre for MIO.

The award was presented at an international conference in Pittsburgh where Edward also gave a presentation on developing MIO in the UK, sharing his experience and expertise with peers from across the globe.

Edward is the first individual outside of the United States to receive the award as recognition of being an international leader in MIO and in advancing treatment

for oesophageal cancer. The award has always previously been awarded to a surgeon in the USA who was trained by Professor Luketich or a member of staff at UPMC, which receives referrals for this type of surgery from across the world.

Edward said: "I am very humbled, delighted and also very proud to have been honoured with this award. I've been very fortunate to train with world-leading surgeons in this technique at UPMC, and I am committed to sharing this expertise with colleagues at NNUH and surgeons across Europe. This is the highest recognition one could wish for, and it is a result of continuous diligence and attention to detail from the whole oesophageal and gastric cancer team at NNUH."



Our awareness campaign

Fund raising efforts have included Quiz Nights and invitations to speak at Great Yarmouth Haven Rotary and local Referees Associations. As you can see from the flyer we are organising a football dinner and the main speakers are ex professionals Darren Eadie and Jamie Cureton both of whom I coached when young players at Norwich City Football Club.

The first photo shows our visit to Ormesby Lads F.C. Sammy Morgan coached the young lads one Saturday morning together with Shaun Platten the Chairman of the Norfolk and Suffolk Youth League. We have been visiting NSYL matches most Sundays and Mr Cheong has joined us on a number of occasions raising awareness.



Are you following us?

We are raising the profile of the OPA on social media, so why not get involved, you can follow, comment and share! The more followers we get the higher the OPA's profile and the more patients, carers and their families we can help!



Facebook
opa.org.uk



YouTube
Oesophageal Patients Association



Twitter
opa.org.uk

A message from our Secretary Haward Soper

General Data Protection Regulation (GDPR)

In May this year the General Data Protection Regulation (GDPR) comes into force.

It is a major change in data protection law, intended to transfer control of individual data back to the individual. There are changes that we in the OPA must make but we are in good shape and what we need to do is fine tuning. We take your data protection very seriously. As the Secretary I am responsible for data protection.

For us the GDPR means:

- Our 7600 members and supporters must be able to find out what information we hold on them (through a "subject access request").
- Our members and supporters have a right to have their details deleted.
- In future we will ensure that we obtain explicit consent for all new members and supporters. To contact them with email updates, newsletters etc.

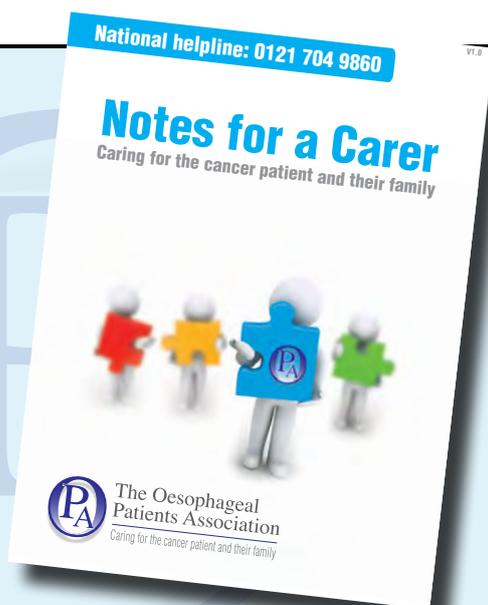
Here is our data protection policy. We have tried to keep it simple but it is a complex area.

Data Protection Policy

Any personal data you supply will be treated strictly in accordance with our Data Protection Policy which requires that:

- All information will be stored securely (both in written and electronic records)
- The data may be used only by the Oesophageal Patients Association for the purpose of providing information
- And services to members and supporters and fundraising from members and supporters.
- Access to data is on a need to know basis.
- None of the data held will be transferred to any external individual or organisation without prior receipt of the individual's or organisation's explicit written consent.
- If at any time you ask us to delete your data we will do so as soon as possible
- You are entitled to know what data we hold on you.

If you would like to have more information about any data we hold on you please send an email to haward@opa.org.uk



Now in stock: Carers book!

The carers book is the perfect book to learn everything about being or becoming a carer.

In this book you can find useful tips about being a carer, what resources are available and all the possibilities for financial support for carers.

All of our booklets are widely distributed free of charge to the NHS Hospitals, Maggie's Centres, Health Care Professionals, Macmillan, patients and carers and their family

Dual Purpose Cards

These dual purpose cards are a must for patients, available in a multitude of languages, this can help when eating out in the UK or abroad, Languages available:

- | | |
|-----------|--------------|
| • English | • Italian |
| • Dutch | • Polish |
| • French | • Portuguese |
| • German | • Spanish |
| • Greek | • Turkish |

We can supply these for you, but if you have booked a holiday, don't leave it too late.



Support group raises £9,000 to open a private room for patients at QA Hospital

"The quiet room is a wonderful addition to the hospital" - Mark Cubbon

The room is on the Upper Gastro Intestinal (GI) Surgery ward on E-level and is a place for clinicians to give information to patients and their family. It has been furnished and decorated thanks to a donation of more than £9,000 by OPA-Splash - the Portsmouth branch of the Oesophageal Cancer Patient's Association (OPA).

Consultant surgeon Simon Toh said the room was an important addition to the surgical floor.

He said: 'OPA-Splash have raised more than £9,000 for a quiet room on our surgical floor so that cancer patients and their carers and family can have a peaceful, calm sanctuary in the midst of a busy hospital.'

'We often have to give difficult news about their condition there and it allows patients space and time to come to terms with their condition in a safe and confidential environment.' Phil Coverdale, branch co-ordinator for OPA-Splash, said it was great to see the room finally open for use after two years of asking. He added it was already showing its benefits and was being used by other patients, not just those of the Upper GI ward.

'In the past, there hasn't really been a place for patients and their families to be told sensitive news so the room is about giving them dignity,' Phil said.

'It gives them somewhere to be away from the bustle of the hospital where they can be together.'



'Most of the money came from one person but we have also had members doing sponsored walks and raising money at our quarterly meetings'. 'There is enough cash left to maintain the room for the next three years.' Phil added: 'It was fantastic to have the chief executive open the room, it shows how much it is valued.' Mr Cubbon welcomed the room and thanked OPA-Splash for their generosity. He said: 'The quiet room is a wonderful addition to the hospital and I'm delighted that patients, their families and carers will now be able to make use of it.'

'Patients affected by cancer tell us that having a quiet place to reflect is so important and I would like to thank the OPA for making it a reality, as without their tireless fundraising it wouldn't have been possible.'

"Phil Coverdale – OPA Co-ordinator – 01730 261 775"

Dressed to Kill Cancer



Come along and meet Fiona Wade at this event!

OPA Fashion Show

Dressed to Kill Cancer, is an upcoming fashion show that will be attended by our patron Fiona Wade from TV's Emmerdale.

This event is for everyone that wants to come and support the OPA in our battle against Oesophageal and Gastric Cancer.

At this event there will be a fashion show that is being sponsored by The Henley House and Studio 34, Music and songs provided by Marty Elliot.

There will also be a bar with drinks.

This event will be on Saturday June 30th in the beautiful Henley-in-Arden Guildhall and tickets will be £20 each.

It will start at 4pm and will last until 8pm.

At 5pm there will be a wine reception.

For tickets call : 0121 704 9860

*Saturday, June 30th from 4pm until 8pm
Guild Hall, 141-142 High Street, Henley-in-Arden, B95 5BD*

Come and support the OPA!

AGM Details / Forthcoming Meetings

21st April 2018 - Birmingham - 10:00 for 10:30

Macdonald Burlington Hotel, Burlington Arcade, 126 New Street, Birmingham, B2 4JQ

21st April 2018 - Lincoln - 10:30

Wragby Town Hall, Louth Road, Wragby, Market Rasen, Lincolnshire, LN8 5PH

27th April 2018 - Exeter - 13:00

The Force Centre, Exeter, EX2 5DW

28th April 2018 - Norfolk & Norwich - 10:30

Benjamin Gooch Room, Norfolk and Norwich University Hospital, Coleny Lane, Norwich, NR3 7UY.

AGM Meeting - 5th May 2018 - London - 10:00 for 10:30

Guy's Hospital, The Robens Suite, Great Maze Pond, London, SE1 9RT

12th May 2018 - Exeter - 10:00

The Kenn Centre, Kennford, Exeter, EX6 7UE

17th May 2018 - Nottingham - 13:00 for 15:00

Maggie's Centre, City Hospital Campus, Gate 3, Hucknall Road, Nottingham, NG5 1PH

25th May 2018 - Exeter - 13:00

The Force Centre, Exeter, EX2 5DW

2nd June 2018 - Derby - 09:45 / 12:00

Hilton Village Hall, Peacroft Lane Hill, Derby, DE65 5GH

Christmas Cards

These cards are available all year!
Get in touch with us to place your order.

These cards are produced by the OPA at no profit, due to popular demand, to help make a difference to those touched by this devastating disease.

We welcome your generosity in giving what you can as a donation, so we can continue to provide help and support for Patients, carers and their families.



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.

Please treat as gift aid

For online donations – Account number: 02301636 Sort Code: 40-42-12

NAME:

ADDRESS:

POST CODE:..... TELEPHONE NUMBER:.....



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The Oesophageal Patients Association

