



Caring for the cancer patient & their family

# OPA Spring Newsletter

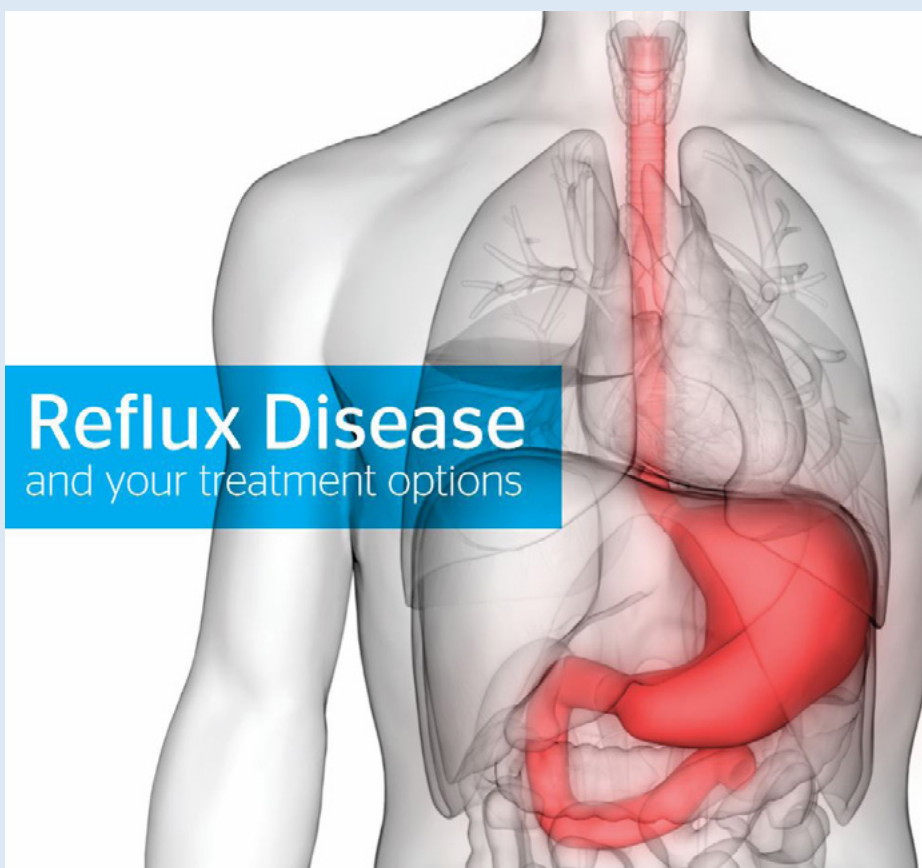
## 2020

### Sometimes Opposites Attract

The OPA was founded 35 years ago, RefluxUK just 2. The OPA was the inspiration of patients who wanted to share their experiences of cancer, to help others. RefluxUK was created by clinicians who wanted to bring their different skills together to help improve the lives of their patients. The OPA provides no clinical services, while this is what RefluxUK does.

But ultimately these differences define the reason why we have decided to come together in partnership, each organisation contributing its respective skills to improve outcomes and quality of life.

In our Mission Statement we are explicit in our goal to increase "awareness and encouraging early diagnosis". Historically the focus of our work has inevitably been for those diagnosed with cancer. But as we all know, most oesophageal cancer in the UK is caused by gastro-oesophageal reflux and associated with Barrett's Oesophagus. While of course only a small proportion



of people with reflux develop cancer, the burden of this disease is enormous. 20% of the adult population experience regular reflux symptoms and for some these can be extremely debilitating; waking every night with acid in the mouth for instance

is truly horrible. Even the most powerful anti-acid medications, Proton Pump Inhibitors such as Omeprazole fail to abolish these symptoms in up to 30% of patients, and yet more often than not these are the only treatment options offered.

But even more importantly, the options for the investigation and management of these patients is often sub-optimal. Too often doctors fail to appreciate the magnitude of the impact of reflux symptoms on people's quality of life and don't refer to specialist centres. Since reflux can be a complex pathology, ideally it should be treated in specialist centres by multi-skilled/disciplinary teams of clinicians, but these are few and far between. And so too often patients do not get comprehensively investigated or get access to the most up to date technologies to diagnose and treat their symptoms. And of course, there is too much ignorance among clinicians as to how to optimally treat reflux. For instance, believe it or not probably no more than 1% of patients who could benefit from

one of the minimally invasive surgical treatments for reflux are given this option. Or, despite recent evidence from the high-quality AsPECT clinical trial that showed a survival benefit in patients with Barrett's treated with high dose PPIs and aspirin, its unusual that patients are offered advice or discussion as to their options. The impact of this lack of evidence-based practice, more often than not born out lack of time in GPs surgeries as well as ignorance of the data, literally will be lost.

If we are going to improve quality of life for patients and impact survival in oesophageal cancer we absolutely have to treat reflux better than we currently do. And here RefluxUK and the OPA share a fundamental belief, and that is the people are the best guardians of their own health and wellbeing.

We both focus on empowering people to seek help and advice when they need it by arming them with information and knowledge, from scientific studies but also the experiences of others.

So, this is why OPA and RefluxUK have agreed to partner and work together. Over the coming months we will working together on initiatives to improve an understanding of how reflux is more than just a little heartburn. We'll be doing our best to educate doctors and most of all the public about its association with cancer. And as RefluxUK develops its network of specialist clinicians and centres around the UK we'll also be letting people know that there are lots of new options for treatment and that they simply don't have to live with reflux.



**"Everyone at RefluxUK is absolutely delighted to be working with The OPA. We share a passion to help prevent people developing this horrible disease. Information and patient power are the keys and together we'll be doing absolutely everything we can to get the word out that reflux causes cancer."**

**Nick Boyle - Consultant Surgeon** 

**"As an Oesophageal Cancer survivor that suffered with Reflux for many years. I now know that Proton Pump Inhibitors (PPI) were masking my symptoms of cancer. We are delighted to be working with RefluxUK to increase awareness of the relationship between reflux and this terrible disease and to help improve the quality of life of so many people."**

**Dave Chuter - Chairman**  Caring for the cancer patient & their family



**OK!**  
EXCLUSIVE



## Our Patron Fiona Wade Gets Wed!

OPA Patron, Emmerdale actress Fiona Wade (Priya Sharma) and actor Simon Cotton tied the knot in front of close friends, soap co-stars and family in a gorgeous ceremony after spending six weeks apart a week before their big day.

And, while it may have been raining outside, the feeling at Fiona and Simon's wedding couldn't have been more warm and fuzzy.

The "old-fashioned" couple have plenty to look forward to, including moving in together, as

one of the beliefs of Emmerdale star Fiona's Bahá'í religion is that a couple shouldn't live together until they're married.

So, while the pair couldn't wait to become husband and wife, they are now looking forward to the next exciting chapter in their relationship.

Speaking exclusively to OK! magazine, 40 year old Fiona said: "Simon is on tour until February so we're still deciding where we're going to live and then we'll buy somewhere."

Fiona walked down the aisle on the arm of her mum Tessie. The moment was particularly poignant for the actress as the "daddy's girl" lost her father Colin to oesophageal cancer 14 years ago, and now works closely with the Oesophageal Patients Association (OPA - Charity Number: 1062461).

Read more about the wonderful day here: <https://www.ok.co.uk/celebrity-news/fiona-wade-simon-cotton-wedding-20803284>



# Fundraising?

## Now in stock - New Running Vests and Fundraising pack

We would like to say a huge thank you to everyone who has raised money to ensure we can raise awareness and carry on the fight against Oesophageal and Gastric cancer.

The OPA Fundraising Pack has some great pointers on how to get an event or challenge off the ground and a few branded items, including our new OPA running vests, to get you on your way!

If you would like to raise funds for The OPA, please get in touch today by email at

**charity@opa.org.uk** or take a look on our website **www.opa.org.uk/fundraising** or for a chat call 0121 704 9860.

## Forthcoming Meetings

### 10th March 2020 - Cambridge - 10:30 - 12:00

Maggie's Centre, Addenbrooke's Hospital  
Hills Road, Cambridge, CB2 0QQ

### 16th March 2020 - North Devon - 14:00 - 16:00

The Barnstaple Hotel, Braunton Road  
Barnstaple, Devon, EX31 1LE

### 19th March 2020 - Nottingham - 13:00 - 15:00

Maggies, City Hospital Campus, Gate 3  
Hucknall Road, Nottingham, NG5 1PH

### 19th March 2020 - Lancaster - 14:00 - 16:00

Cancer Care Building, Slynedaes  
Slyne Road, Lancaster, LA2 6ST

### 26th March 2020 - Liverpool - 13:30 - 16:00

Kent Lodge Building, Liverpool Heart & Chest  
Hospital Thomas Drive, Liverpool, L14 3PE

### 26th March 2020 - Cardiff - 16:00 - 18:00

Maggies Centre, The Chris McGuigan Building  
Velindre Cancer Centre, Velindre Road, CF14 2TQ

### 26th March 2020 - Mid-Cheshire - 19:00 - 21:00

Macmillan Unit, Leighton Hospital  
Middlewich Road, Crewe, Cheshire, CW1 4QJ

### 27th March 2020 - OPA Group - Exeter - 13:00

The Force Centre, Barrack Road  
Exeter, EX2 5DW

### 28th March 2020 - OPA Group - London - 11:00 - 12:30

Tower Hotel, St Katherines Way  
London, E1W 1LD



# RAY CLARK BAND APPEAL

6 ACTS | 1 STAGE | 1 NIGHT OF COMEDY AND MUSIC | FROM THE SHOWS TO ROCK 'N' ROLL  
MR. CHRIS FIELD (FEMALE IMPERSONATOR) • DANIEL DEFOE (MALE VOCALIST - SONGS FROM THE SHOWS) • WILLIAM KNIGHT (COMEDY MAGICIAN) • THE ALCATRAZ SWIM TEAM (ACOUSTIC DUO) • BECKY BROWN (TOP FEMALE VOCALIST) • STAGEFRIGHT (ROCK/POP TRIO)

Charity Concert, Band Appeal, returns for the third time to raise money for The Fiona Wade Appeal and The OPA.

6<sup>th</sup> June 2020 | Tickets £10

Get in touch today  
01405 763652



# Trials & tribulations in oesophageal cancer

*Christopher M. Jones & Tom Crosby, on behalf of the National Cancer Research Institute Upper Gastrointestinal Clinical Studies Oesophagogastric Subgroup*

An important element of the work of The OPA is to assist research by providing a patient's perspective. The National Cancer Research Institute has a specialist subgroup that monitors the progress of current projects. The OPA is represented by a trustee, John Taylor of the Leeds Regional Group.

This article outlines the nature of the work and individual projects will feature in future newsletters.

We have a great deal to learn about oesophageal cancer. In the United Kingdom, the number of patients diagnosed with this disease has grown by 6% over the past two decades and it is now the 14th most common cancer. Sadly, of the approximately 25 patient diagnosed with oesophageal cancer each day only one in 10 will survive for 10 or more years. This is partly due to the late stage at which most cases are diagnosed, with seven in 10 patients already having developed advanced disease before they are told they have cancer. In contrast, when diagnosed early oesophageal cancer is curable and 80% of those diagnosed with early disease survive for more than one year. Nevertheless, a number of patients struggle with side effects from the treatment they receive, both whilst 'on treatment' and in the months and years afterwards.



We need then to ensure we are doing all we can to prevent patients developing oesophageal cancer, to diagnose it early when it does develop, and to find treatments that are both more effective and that result in fewer side effects. Fortunately, a good deal of progress has already been made in this regard. There have for instance been a number of studies focussed on finding new ways to diagnose this disease, and over the last decade the proportion of patients dying from oesophageal cancer has reduced by a tenth. It is anticipated that this improving trend will continue, with rates of death from oesophageal cancer projected to fall by a further 16% between 2014 and 2035.

In order to drive these further improvements, there needs to be more research to understand the 'biology' of oesophageal cancer, and there need to be more trials of strategies to prevent and treat it. One key aspect of these studies will be researching how the different forms of oesophageal cancer affect patients. We know for instance that rather than being one disease, oesophageal cancer in fact develops as one of two main forms. One of these, oesophageal adenocarcinoma (OAC), tends to affect the lower gullet and patients with this disease often first develop a precancerous condition called Barrett's oesophagus. Conversely, cancers affecting the upper part of the gullet are usually cases of oesophageal squamous cell carcinoma (OSCC). A number of research studies in laboratories across the world are focussed on understanding how OAC and OSCC differ from one another, and for example which drugs

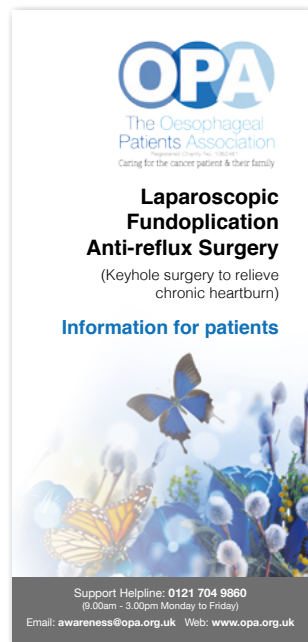


are best for targeting each form. Outside of the laboratory, there are a large number of clinical trials focussed on finding new ways to prevent and treat both forms of this disease.

In the UK, the National Cancer Research Institute brings together clinicians, scientists, statisticians and lay representatives in 'Clinical Studies Groups' (CSGs) to coordinate the development of these clinical trials. One such CSG - the 'oesophagogastric subgroup' - focusses on coordinating trials for cancers affecting the

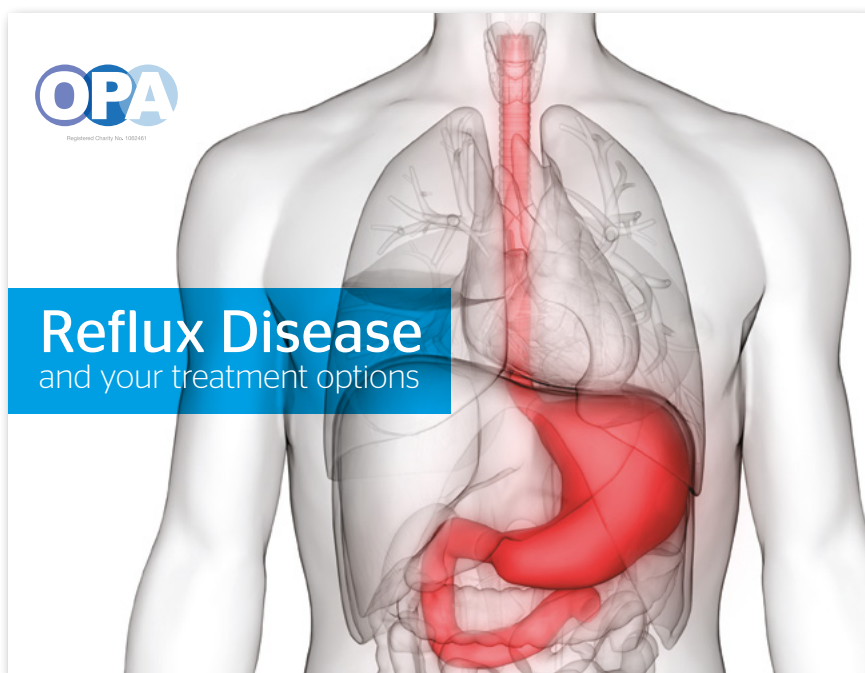
oesophagus and stomach. These include trials relating to disease prevention, such as the BEST3 trial, which is evaluating a new GP-based test for Barrett's oesophagus and OAC in patients with heartburn symptoms. It also includes trials of improved treatments, like the SCOPE2 trial which is analysing the use of higher doses of radiotherapy in both forms of oesophageal cancer. Other trials overseen by the group include the use of new drugs, such as the use of a drug that activates the immune system in the LUD2015-005 study.

In future editions of the OPA newsletter we will tell you more about these and other studies overseen by our group. In doing so, we hope to highlight that whilst we do indeed have much we need to learn about oesophageal cancer, your generosity in taking part in trials means that we are together already doing a great deal to improve the way we prevent, diagnose and treat this disease.



## Our new leaflets and Reflux flipbook are now in stock!

Did you know? There are over 65 Million people in the UK and it is estimated that over 1 in 10 people suffer from Reflux Disease. Reflux disease can have a terrible impact on a patients quality of life affecting many aspects of their everyday functioning. For many people, this can be managed effectively with lifestyle changes and/or medication prescribed by their GP such as omeprazole, lansoprazole and esomeprazole (as well as others). However there are over 2 million people in the UK who do not respond effectively to this treatment and for these people, there are other options they can consider to treat their disease such as a LINX procedure or a fundoplication. More information on these options can be found on our website: [https://www.opa.org.uk/edit/files/20191212\\_patient\\_education\\_booklet\\_resize\\_to\\_a5\\_\\_002\\_.pdf](https://www.opa.org.uk/edit/files/20191212_patient_education_booklet_resize_to_a5__002_.pdf)



# Bed Wedges - Discount for the OPA



The OPA is continuing to put £12.50 per pillow towards this partnership and Putnams have, on top of that, agreed to a generous discount. The new standard retail price is £59.66, so you pay £31.50 – which is still saving over 48%!

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](mailto:enquiries@opa.org.uk)

2. With the Discount Code, call Putnams on 01752 345 678, email [info@putnams.co.uk](mailto:info@putnams.co.uk) or visit <https://www.putnams.co.uk/collections/bed-wedge-pillows/products/bed-wedge>

OFFER STILL AVAILABLE

## Publication of National Oesophago-Gastric Cancer Audit 2019



The National Oesophago-Gastric Cancer Audit (NOGCA) was established to evaluate the quality of care received by patients with oesophago-gastric (OG) cancer in England and Wales.

It collects prospective data on adult patients diagnosed in England and Wales with invasive epithelial cancer of the oesophagus, gastro-oesophageal junction (GOJ) or stomach, and patients diagnosed with high grade dysplasia (HGD) of the oesophagus. This report describes the care received by patients diagnosed between April 2016 and March 2018 and their outcomes.

All 134 NHS acute trusts in England and the 6 local health boards in Wales participated in the 2016-18 audit period.

The 2019 Patient Report is available to download as a pdf at [https://www.opa.org.uk/publication-of-the-national-oesophago-gastric-cancer-audits-2018-patient-report.html?fbclid=IwAR3A6ViAE4E-ef aD2Tz5fTgL2BJfBGB9QXiN7cVTPV186PQ\\_O9S4Qy\\_QYUM](https://www.opa.org.uk/publication-of-the-national-oesophago-gastric-cancer-audits-2018-patient-report.html?fbclid=IwAR3A6ViAE4E-ef aD2Tz5fTgL2BJfBGB9QXiN7cVTPV186PQ_O9S4Qy_QYUM).



## Ormskirk FC U11's - Jack Hook

The OPA were delighted to help the Ormskirk FC U11's purchase a new football kit. Jack Hook, their manager, tells us they were very excited to wear and play in it.



# Fiona Wade on Catchphrase



## Did you miss our Patron Fiona Wade on Celebrity Catchphrase, Saturday 4th January 2020?

Stephen Mulhern hosts a celebrity special of the classic game show, with James Jordan, Fiona Wade and Louis Walsh all trying to 'say what they see' for charity. Fiona raised a grand sum of £8,200 for The OPA! Check out the episode here <https://www.opa.org.uk/news/our-patron-on-celebrity-catchphrase.html>





# Oesophageal Cancer. Leanne's Story:



My father, David Roberts, was the strongest person I've ever known. He was diagnosed with oesophageal cancer in November 2012, just a few months after his oldest brother Bobby died from the same awful cancer aged 76. His mum also died of oesophageal cancer in 1971 age 61 years.

He wasn't able to have the tumour removed due to previous circulation issues so started his chemotherapy & radiotherapy treatments on his 65th Birthday (5th December 2012). He took it like a champ and went in with a positive attitude and a smile on his face. Mr Harvard, his specialist in the Royal Glamorgan hospital said that people with his attitude usually do well.

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## We had him for almost 7 years after the original diagnosis

The treatment didn't work as they'd hoped so he had to go in for surgery. He had the Ivor Lewis operation in October 2013 (where they take away a large amount of the oesophagus and bring stomach further up to connect them) in the Heath Hospital Cardiff, this was performed by Mr Harvard and Mr Lewis.

The operation went well and he was smiling and chatting in recovery afterwards.

Unfortunately due to his circulation issues the join became necrotic later that night so they had to bring his stomach back down, staple it shut and put in a feeding tube. Then he had a hole in his neck where the end of his oesophagus was with a colostomy bag that would catch anything he swallowed. He was on life support for almost 9 weeks and this was an extremely hard time for all the family. We were called in to say goodbye a few times but he was never one to give up without a fight. He came through it and the first thing he asked was how his dog Benji was!

Having the bag and feeding tube was quite hard for my dad to adjust to as he was a bit conscious of people seeing the bag but did however manage to keep his positive attitude.

Once he'd got his strength back and was doing well he went up to St Thomas in London to have another big operation in January 2015. Mr Gossage performed an operation (Supercharged Jejunal Interposition) where he would rebuild him a new oesophagus using his lower intestine. This meant my father could slowly start to eat again which was fantastic! He kept in touch regularly with London and visited them around 3 times per year to see the plastic surgeon and Mr Gossage to dilate the structure to ensure he could keep swallowing.

Our local GP would send students to the house to see his notes and examine him then ask him questions about his experience and what it was like living with his new anatomy.

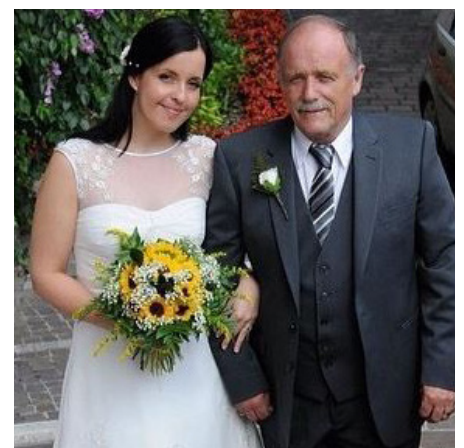
The doctors, nurses, specialists, surgeons and so many others were fantastic when caring for my father and we feel so lucky we had him for almost 7 years after the original diagnosis. He met his newest grandchildren, travelled to some lovely places and celebrated his 50th wedding anniversary with my mum.

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## He was never one to give up without a fight

He sadly passed away on Saturday August the 31st with causes of death on his certificate being ischaemic leg and oesophageal cancer.

Even at the very end he was still fighting to stay with us. His passing has left us all devastated but so very proud of how he faced this awful disease and never gave up.



# Thank you to our Supporters and Fundraisers

Ray Clark

Helen Ripley

Wellington Pub

Robert Williamson

Emily Covall

Nicola Nolan

Michelle King

Maureen Brown

Nigel Adams

Louise Henley

Fran Jackson

Jennie Jamieson

Zoe Johnson

Marie Larkin

John Connolly

Julie Brace

Pippa Graham

Harry Jackson

Tanya Brittain

Max Taylor & Friends

Joan Bardsley

# For Standing Order Donations

## By bank transfer

Recipient bank: HSBC Bank,  
34 Poplar Road, Solihull, B91 3AF  
Sort Code: 40 - 42 - 12  
Account Number: 51354973

## To make an online donation visit:

<https://www.opa.org.uk/donations.html>

### By regular Standing Order payment –

Sort Code: 40-42-12

Account Number: 51354973

I wish to make regular donations to the Oesophageal Patients Association of (tick appropriate box)

£2  £5  £10  £25  £100,

or other amount:

Please state amount in words:

every (tick appropriate box)  Week  Month  Year starting on \_\_\_/\_\_\_/\_\_\_ until further notice.

### Your bank details

To: (insert name and address of your bank) \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Sort Code: \_\_\_\_-\_\_\_\_-\_\_\_\_

Account Number: \_\_\_\_\_

## Boost your donation by 25p of Gift Aid for every £1 you donate

Gift Aid is reclaimed by the charity from the tax you pay for the current tax year. Your address is needed to identify you as a current UK taxpayer.

### In order to Gift Aid your donation you must tick the box below:

I want to Gift Aid my donation of £\_\_\_\_\_ and any donations I make in the future or have made in the past 4 years to the OPA.

I am a UK taxpayer and understand that if I pay less income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay.

### Your Details

Title: (Mr/Mrs/Dr etc.) \_\_\_\_\_ Name: \_\_\_\_\_

Address: \_\_\_\_\_  
\_\_\_\_\_

Tel: \_\_\_\_\_ Email: \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_/\_\_\_/\_\_\_

## Any other Donations

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

Title: (Mr/Mrs/Dr etc.) \_\_\_\_\_ Name: \_\_\_\_\_

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Signature: \_\_\_\_\_ Date: \_\_\_/\_\_\_/\_\_\_

For online donations – Account number: 51354973 Sort Code: 40-42-12

Please send this form to: Fundraising Dept. The OPA, 6 & 7 Umberslade Business Centre, Pound House Lane, Hockley Heath, Solihull B94 5DF. Or email to: [enquiries@opa.org.uk](mailto:enquiries@opa.org.uk)

For further information please contact The OPA on 0121 704 9860 or email [charity@opa.org.uk](mailto:charity@opa.org.uk)

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