



Caring for the cancer patient & their family

OPA Autumn Newsletter 2020

Responding to the COVID-19 Pandemic

John Taylor - New Chair



I was delighted to be asked to chair the OPA at this time and have enjoyed editing this issue of the newsletter which is dedicated to the impact of the COVID-19 crisis on the services we offer.

The COVID-19 Pandemic has caused serious worries for the Association since the health and survival of some of our members could be compromised if their diagnosis and treatment is delayed, and as a consequence their lives and their quality of life could be severely affected. Research programmes have been temporarily interrupted as researchers' duties needed to

be re-assigned. Nevertheless, we continue to provide telephone support for members but group meetings have had to be cancelled and the Annual General Meeting postponed. We are also aware that sound finances could be threatened as donations may fall as the result of peoples' increasing financial insecurity.

On the other hand, it may also be a time of some opportunity. Particularly noticeable is the significant increase in communicating electronically for one-to-one meetings and for large groups involving people living locally and further afield. There is also the impact of electronic communications on making appointments and holding consultations with G.P.s and specialist nurses, as well as with consultant surgeons and oncologists. It will be surprising if changes in policies and procedures do not result from this situation, and we ourselves are looking to reappraise how we deliver our support to patients and to consider how we may

increase the variety of meetings, their timing in the patients journey and the geographical mix of participants.

I am grateful to Maggie, Drew and my fellow trustees for the insights they offer in this newsletter of the challenges faced by the health service and the research community as a result of the Pandemic and its impact on the charity and the opportunities we see in moving forward.

Currently we have six trustees. John Campolini, Stephen and myself had oesophagectomies in London, Guildford and Leeds respectively. Javed is a consultant surgeon in Manchester, Janusz a leading researcher in oesophago-gastric cancers and Philip is a retired nurse and a carer.

Diagnosis, Surgery and Treatment



Javed Sultan - Trustee

The unprecedented worldwide COVID-19 Pandemic created exceptional pressures on the NHS. At the time of the crisis we had to focus all our efforts on treating patients with immediately life-threatening conditions.

This meant that at that time we had to make the difficult decision to stop investigating and treating patients with non-life-threatening conditions in the interim. We did not know how long this would last as the situation was changing day by day. We fully understood how frustrating this was, and that it left many in pain and discomfort, but during that time we needed all our staff to focus on fighting the crisis. We were fully conscious that this delay would cause great anxiety for those with cancer, but we had to weigh up the risks of treating them in the middle of the first phase of this highly infectious Pandemic versus the risks of delaying their treatment.

We did everything we could to keep essential cancer services

running, but as the crisis worsened, we had to delay diagnoses and treatments.

I am happy to say that we are now in a position to begin to address the waiting lists for diagnostics, surgery, therapies and other treatments, although we have yet to see if, and if so, how a second wave will impact on our efforts. We were very grateful for affected patients', and the general public's understanding of the situation we found ourselves in, and we very much appreciated the support for our colleagues throughout the most alarming phase of the Pandemic.

I also recognise the importance of the work of the Association in supporting patients and their friends and families, and as a trustee I am proud that we are gearing up to meet the increase in demand for our services that we anticipate in response to the impact of the Pandemic.

Research



Janusz Jankowski - Trustee

The COVID-19 Pandemic has had a very big effect on medical research throughout the world. In the UK there has been several specific implications: funding, patient recruitment and clinical staff availability.

In general terms national funding for cancer research has decreased in part due to diminished donations and charities' funds, while resources have understandably been diverted to Covid-19 specific objectives. As a consequence, several world-class studies have found themselves denied funding to the level needed, or have had funding delayed for an as yet unknown period.

We have noted that understandably some patients have been reluctant to take part in trials as they perceived coming into clinical areas to be high risk without realising that in the research areas safety is actually of an exceptionally high standard. Indeed, there is strong evidence to show that patients in clinical trials get better care since they are monitored more carefully and frequently than those in routine care. Unfortunately our research work was also further compromised as clinical staff working in these areas were, for a brief period of 2 months, diverted to other more acute ones, while some other members of staff had been obliged to shield at home.

However, since the peak of the first wave of the COVID-19 Pandemic has passed, we are now in a strong position to push forwards with cancer research again. I would encourage all members and friends to help support cancer research fund-raising. Furthermore, I would hope that OPA members would once more be open to recruitment to clinical trials. In the meantime, we should all adhere to the public health advice about social distancing and wearing face covering to mitigate the acute care burden for their doctors and health care workers.

A new service!

Maggie Robinson and Drew Matthews - Head Office



Maggie Robinson



Drew Matthews

We continue to seek to alleviate the concerns of members with our advisory services through the free virtual live chat of TawkTo, and with link ups with other members, OPA Groups, mentors or buddies and with the information posted on our expanded website.

We are also pleased that collaboration with RefluxUK has strengthened our campaign to raise awareness about this condition and to support those affected in taking immediate steps to alleviate it, and also to seek specialist treatment where needed.

During these stressful and uncertain times, it can be reassuring to find you have the support and insights of fellow OPA members and of local clinical specialists with which to cope with the dramatic challenges you face. The OPA aims to create a safe space for patients, carers and their families to talk, to explore and to understand the "new normal" during these trying times.

We are now able to offer a one-to-one meeting with a patient buddy via Zoom. Our patient buddies are provided with a personal meeting



ID by Zoom and this is then used as a weblink that we will send out from Head Office. The patient can then initiate or join a meeting using the weblink.

Join a Meeting



Joining a meeting - <https://support.zoom.us/hc/en-us/articles/201362193-Joining-a-meeting>

How Do I Host A Video Meeting? - <https://support.zoom.us/hc/en-us/articles/201362613-How-Do-I-Host-A-Video-Meeting->

Scheduling meetings - <https://support.zoom.us/hc/en-us/articles/201362413-Scheduling-meetings>

Take a break in your day to provide self-care, to gain helpful tools and to connect with others.

If you are interested in using Zoom, please see the tutorials on the bottom of our website - www.opa.org.uk or you can download the instructions here - <https://www.opa.org.uk/downloads.html>

We are also considering ways to extend virtual support for patients, carers and families through

- **Themed meetings on specific subjects**
- **Meeting individually with a buddy or a virtual drop in of up to six participants**
- **Regional meetings**

If you wish to take part please write to me at maggierobinson@opa.org.uk or to The OPA, 6 & 7 Umberslade Business Centre, Pound House Lane, Hockley Heath, Solihull, B94 5DF and I will make the necessary arrangements.

*Please bear in mind if you are worried about zoom end to end encryption then you may prefer to speak via telephone



The AGM



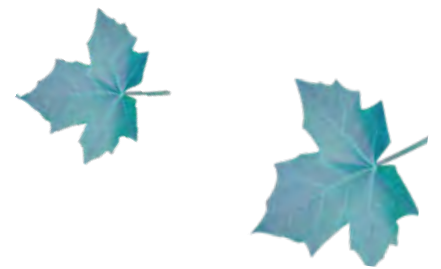
Philip Wright - Acting Secretary

The trustees met on 4 July to prepare for an AGM at which the Annual Report and Accounts were to be presented, and the Chairman, Secretary, Treasurer and Trustees appointed for the following year.

The AGM was due to be held before 7 September at the latest. However, the trustees thought they needed to take into account the effects of the current Pandemic, the Government's advice for people to minimize contact and travel, and the risk of another spike in infection and of renewed lockdown, all of which considerations militated against holding a physical, as opposed to a virtual or Zoom AGM.

However, they foresaw a problem in the organization and expense of delivering an AGM with voting entirely by mail, or alternatively accommodating a fair representation of the OPA's 6300 members in a Zoom meeting. The trustees decided to consult the Charity Commission for their advice on postponing

an AGM in these circumstances, and the Commission saw no objection, if decisions were seen to be taken in the interests of good governance and with transparency. The trustees have therefore decided to postpone the AGM until early next year. In the meantime, as David Chuter stepped down as Chairman, the trustees asked John Taylor to take on the role until the next AGM can be held.



Finance

Stephen Brinkworth - Treasurer

In 2019 the OPA was fortunate enough to be able to show a slight increase from grants and donations. This was due to the efforts of our Patron, Fiona Wade, through her Just Giving page, and her participation in the TV game show 'Catchphrase', and to the very successful fundraising

Golf Tournament organised by one of our patients.

There had also been an initial rise in donations in response to the expanding services provided to our members by Maggie and Drew at Head Office, to our relaunched website incorporating our new collaboration with Reflux UK, and to the work of our trustees.

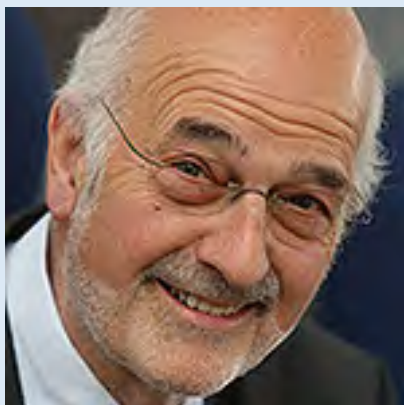
Those trustees are aware of the risk to maintaining levels of fundraising that many charities are experiencing due to the current pandemic. In the first half of this year the OPA appears to have been fortunate in maintaining its level of funds raised and thus also its reserves, which can protect its work for the year ahead, in the event of any further unforeseen circumstances. This has been due to the continuing generosity of both regular and

occasional donors, in response to the increase in information services and support which our hard working staff, and the expanded website, are able to provide.

However, due to the Covid-19 pandemic, donations have been hit in 2020, since lockdown started.

Donations are down by £10k for the first 7 months in 2020, compared with the same period in 2019. This, we believe, is due to the delay in Probate being granted, and the restrictions in funerals, which has seen a significant reduction of "in memory of" donations. The increasing visits to our site, and requests for our free publications continue to broaden users' awareness of our reliance on their generosity.





Trusteeship

John Campolini - Vice Chair


The OPA's constitution requires trustees to meet at least twice a year, and of course to hold an Annual General Meeting at which officers are appointed for the following year.

Not surprisingly, since lockdown the trustees have been meeting more frequently, to address matters which the lockdown has brought to the fore, and we are keen to increase the number and range of experience that new trustees can bring to our deliberations. At present the majority of our trustees have had this cancer and are survivors, but this is not a prerequisite for becoming a trustee. Ensuring the good governance of the charity, the effective delivery of services to our members, and the pro-active raising of awareness in the wider community of the causes of, and the available treatments for this diseases are our principal aims and responsibilities.

We are seeking up to three new trustees and are particularly interested in receiving applications from those with Company Secretarial skills and others with expertise in communications and digital marketing. We also wish to widen the diversity of our membership in terms of gender and ethnicity.

If you wish to join us please write to me at johncampolini@gmail.com outlining your experiences and of how you have become interested in oesophago-gastric cancer. I will be pleased to respond.

Connect with us

 **Like us on Facebook**
[@opa.org](#)

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[@opacancercharity](#)

 **Tweet us on Twitter**
[@OPA_UK](#)

 **View our videos on You Tube**
The Oesophageal Patients Association
- Cancer Charity



Fiona Wade - Patron

The last few months have been an incredibly challenging time for so many people. It is hard to imagine how much harder it must be for those facing diagnosis and treatment for oesophageal and gastric cancers at this time.

As the waiting lists caused by the impact of the pandemic are addressed there will be an even greater call on the OPA to support many distressed people. At this difficult and disruptive time please remember the invaluable work of this Charity and continue to support it with your donations.

Leave A Gift In Your Will

"Some years ago I lost my father to oesophageal cancer. He was such an amazing person, the best father I could ever wish for and it was so sad and shocking when he was diagnosed. I had never heard of this type of cancer before and I always feel to this day that if we had been more aware of oesophageal cancer or reflux disease then for sure earlier diagnosis would have made a huge difference and maybe saved his life.

Early diagnosis by spreading awareness is absolutely key in saving lives from this cancer, so please help us to carry on doing all we can to make people more aware and help us to save lives and to support and reassure every patient who needs our help. Thank you."

"Your legacy will help to save lives. Please remember The OPA in your Will and help us to continue our fight against oesophageal and gastric cancer."

Your Legacy

You can support The OPA by making a gift in your Will; one of the most effective ways to help ensure that our fight against oesophageal and gastric cancers continues our mission to save the lives of future generations.

The OPA has supported thousands of patients since it started over thirty years ago. By remembering The Oesophageal Patients Association (OPA) in your Will you can help us continue and to save the lives of future generations of family and friends.

Your legacy will help to fight oesophageal and gastric cancers and support patients, carers and families to cope with this devastating disease. The OPA supports people with life threatening cancers and works to save lives through raising awareness and early diagnosis. However, people of all ages should be made aware regular heartburn or indigestion could be early symptoms of oesophageal or gastric cancers which can be dealt with through a straightforward procedure long before developing into cancer.

<https://www.opa.org.uk/leave-a-gift-in-your-will.html>



Please will you help us?

By bank transfer

Recipient bank: HSBC Bank,
34 Poplar Road, Solihull, B91 3AF
Sort Code: 40 - 42 - 12
Account Number: 02301636

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: 51354981

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: _____

Address: _____

Tel: _____ Email: _____

Signature: _____ Date: ___ / ___ / ___

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

For further information please contact The OPA on 0121 704 9860 or email charity@opa.org.uk

Registered Charity No 1062461

