

**Cancer of Unknown Primary (CUP) Foundation – *Jo's friends***

ANNUAL REPORT AND ACCOUNTS

FOR THE YEAR ENDED

**1 OCTOBER 2020**

**Registered Charity Number: 1119380**

The Fold, Lower End, Daglingworth, Cirencester GL7 7AH

**[www.cupfoundjo.org](http://www.cupfoundjo.org)**

# CANCER OF UNKNOWN PRIMARY (CUP) FOUNDATION – JO’S FRIENDS

## ANNUAL REPORT FOR THE YEAR ENDED 1 OCTOBER 2020

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The Trustees are pleased to present their report, together with the financial accounts of the charity, for the year ending 1 October 2020. This is the 13th report of **Cancer of Unknown Primary (CUP) Foundation *Jo’s friends*** since it became a registered charity in May 2007.

The purpose of the report is to explain what the charity sets out to do and how it goes about doing it - showing the main activities and achievements of the year (both qualitative and quantitative) in relation to our charitable objects. We cover also the charity’s governance, funding sources, spending and reserves. In preparing this report the trustees have taken note of the Charity Commission’s guidance on public benefit.

## INTRODUCTION AND HIGHLIGHTS OF THE YEAR

Looking back to 2006, when we began the process of ‘proof of concept’ for a CUP charity, it is possible to create three distinct overarching phases, relating to CUP in the UK, over this time:

Phase I. When Cancer, or more specifically, *Carcinoma* of Unknown Primary (CUP) was something of an ‘inconvenient truth’ within the NHS. Diagnosis and treatment was *ad hoc* and widely recognised by clinicians as ‘sub optimal’. Too many patients were bounced-around different Multi Disciplinary Teams (MDTs) like tennis balls, while they still lived, with no one taking ownership.

Phase II. With the introduction of the NICE Guideline ten years ago CUP became *a diagnosis in its own right*, rather than *a failure of diagnosis*. CUP patients received a treatment pathway, based on evidence, in the same way as any site specific cancer patient. The interest and expertise of oncologists grew with the formation of CUP MDTs, as did research into CUP. ‘MDT tennis’ still happens in a small number of cases but there is no excuse for it.

Phase III. For some NHS patients on CUP trials, treatment is now being based on diagnostic tests which seek to identify the *molecular primary* (not necessarily the same as the anatomical primary) or the *molecular target* to identify the ‘actionable’ genetic mutations that are present in some patients’ tumours. The implication of these approaches for the patient is that by identifying the molecular characteristics of a cancer, targeted rather than empiric treatment - the smart missile rather than the

*It doesn’t matter if you say someone has this or that cancer. In the end it is the mutational spectrum and the molecular features that define a certain individual cancer, and not the organ where the primary has developed.*

Professor Alwin Kraemer, principal investigator for the CUPISCO trial and a speaker at our 2019 international conference quoted in the *New Scientist*.

thousand bomber raid – can follow. Tests can also be performed to predict an individual's likely benefit from specific treatments. The value of immunotherapy treatment in addition to, or instead of, chemotherapy for CUP patients is currently under active investigation. New techniques and treatments that prove beneficial need to be approved as 'standard of care' to benefit patients, but 'chasing the primary' is starting to become an anachronistic approach. Identifying the molecular characteristics of a cancer and treating it with tumour agnostic drugs circumvents the relevance of the primary site. The days of CUP as a classification are drawing slowly to a close.

In 2020 we are in the early stages of what we have cast, above, as Phase III. But for many NHS patients in 2020 personalised, precision, medicine enabled by genomic advances is futuristic. Why? Inevitably cost plays a part, but also because there is a lengthy and tortuous gap between the *bench* (scientific possibilities) and implementation for all patients at the *bedside*. Attendees at our 2019 international conference were encouraged to recognise cancer as *a disease of the genome* rather than *a disease of the anatomy* but practice has yet to recognise this paradigm shift.

At the charity's inception our aspiration was to be 'out of business by 2020 (our 2020 vision). But until genomic medicine in the NHS picks up pace there are still patients with unknown primaries and there remains a role for us to fulfil.

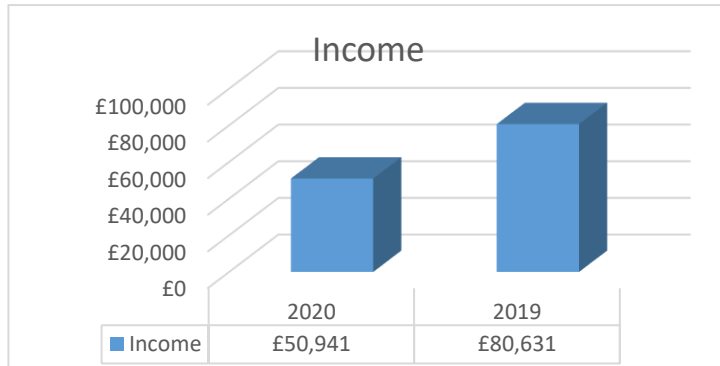
The year's highlights. 2020 has been dominated by the CV-19 pandemic and the NHS's ability to undertake cancer treatment has inevitably suffered. Between March and June cancer research ground to a halt. Both cancer treatment and cancer research re-started gradually in July; but many patients with suspected cancer are not receiving rapid investigation as a result of CV-19 prioritisation. As a charity with no employees and with much of our value to patients and carers enabled by our website, the pandemic has not affected our ability to operate in the way that it has for larger cancer charities.

Disappointing results from the long-running GEFCAPI 04 trial (March 2012 to February 2018) were released early in 2020. The Phase III trial was led by Dr Fizazi in France. 243 CUP patients from 4 EU countries took part in the trial to see if tailored treatment following molecular profiling would improve outcomes. The results *taken overall* showed no significant improvement in outcomes. This does not invalidate the benefits of molecular profiling and some encouragement can be drawn from aspects of the data. Further research is needed reflecting scientific advances since the GEFCAPI 04 protocol was derived almost a decade ago. World-leading CUP authority, Dr Tony Greco, commented on the GEFCAPI trial (Jan 2020): 'I am more optimistic about molecular testing in CUP than ever, particularly since so many previously nonresponsive/poorly treated advanced cancers are becoming more and more treatable/responsive.'

Other events of note in this year (covered on pages 10 and 11) are:

- New centres added for the CUPISCO trial in the UK
- The launch of a comparative study across tissue and liquid biomarkers for CUP: CUP-COMP
- Recruitment opening for the CUPEM trial looking at the potential value of immunotherapy treatment
- A one day workshop in Birmingham for those working in CUP MDTs

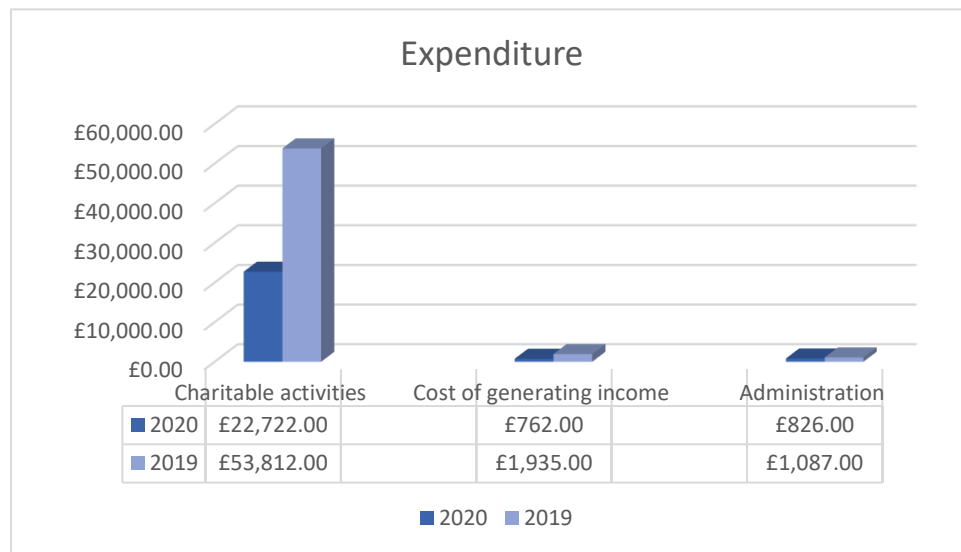
Financial summary. The accounts on page 15 show a 37 % drop in income in 2020. This is unsurprising given the impact of CV-19 on fundraising activities. It is thanks to our generous monthly donors, in particular, that our income is as high as it is. It is likely that we will see a further year of significantly reduced income in 2021. Administrative costs remain



low ensuring that monies donated to us are available to help address our charitable objectives. The main expenditure this year has been £3,000 for a CUP seminar bringing together CUP MDT members from across the UK for a development day in Birmingham in December, and a £16,218 grant to The Christie Hospital, Manchester to help with research into the value of comparative diagnostic approaches to CUP.

- Our income has fallen by 37% in comparison with last year as fundraising activities declined significantly due to CV-19
- We have reduced our costs; but maintained our charitable activities including support for CUP research
- Only 3.4% of our expenditure is spent on administration
- The charity depends entirely on volunteer effort and has no paid staff.

Our financial aim is always to achieve sufficient funds to cover our modest operating costs and to build healthy reserves to fund our conferences and seminars whilst being in a position to make



appropriate research grants. (See page 6 for our objectives.) It should be noted that we are *not* a charity whose focus is solely to raise funds for medical research although we are keen to support clinical research where there is clear potential benefit for CUP patients.

# ORGANISATIONAL STRUCTURE, GOVERNANCE AND MANAGEMENT

## TRUSTEES

**Barry Hamilton** B.Soc.Sc. MBA.  
(*Chairman*)

**John Symons** MBE TD MA MSc MEd PhD.  
(*Director*)

**Rosemary Bates** BA (Hons), PG Dip OCGD.

**Kate Fulton** BSc (Hons).

**Philippa McEwan** BA (Hons).

## ADVISORY BOARD

### Medical

**Dr Natalie Cook** MBChB, MRCP, PhD is a Senior Clinical Lecturer in Experimental Cancer Medicine and Honorary Consultant in Medical Oncology at the University of Manchester and the Christie NHS Foundation Trust. She is the medical lead for the Experimental Cancer Medicine Team at the Christie and a Principal Investigator on the international CUP trial CUPISCO. She has a research interest in liquid biomarkers in CUP.

**Dr F. Anthony Greco** MD is Director of the Sarah Cannon Cancer Center located in Nashville, USA. Dr. Greco's principal professional interest has been clinical cancer research and he specialises in cancers of unknown primary origin, lung cancer and germ cell tumors. He has helped to define the complex group of patients with unknown primary cancer recognizing many subsets of patients requiring specific therapy. He has developed, or helped develop, new and improved therapies for patients with several types of neoplastic diseases, including CUP.

**Dr Sarah Ngan** BMedSci MBBS PhD MRCP is an oncologist specialising in caring for patients with upper gastro-intestinal cancers and Cancer of Unknown Primary (CUP). She is presently the clinical lead for acute oncology and CUP at Guys and St Thomas's (GSTT) and the network CUP lead for the London Cancer Alliance. She chairs a specialist MDM at GSTT for patients with CUP

which is video-linked to units across SE London and is passionate about improving the patient pathway for CUP patients.

**Dr Richard J. Osborne** MD FRCP FRACP, consultant in Medical Oncology Hervey Bay Hospital, Queensland until December 2019 and before that at the Dorset Cancer Centre. He was the Lead Clinician for the development of the NICE Guideline for CUP. During his career Dr Osborne has been awarded an ICRF Clinical Research Fellowship, NCI-EORTC Research Fellowship and a Fulbright Senior Scholarship.

**Professor Penelope Schofield** BSc (Hons) PhD MAPS

Professor Schofield is Professor of Health Psychology, Swinburne University of Technology; and Honorary Principle Research Fellow, Department of Cancer Experiences Research, Peter MacCallum Cancer Centre, Melbourne, Australia, where she is leading the ‘SUPER’ research on CUP.

**Dr Maurice L. Slevin** MD FRCP.

Dr Slevin is Honorary Consultant Medical Oncologist at St Bartholomew’s Hospital and founding Director of The London Oncology Clinic (now Leaders in Oncology Care). In 1985, with Vicky Clement Jones, he established CancerBackup, providing cancer information and support to patients and their families (now merged with Macmillan Cancer Support). He is the author or co-author of 175 peer reviewed publications as well as a number of books and book chapters.

**Dr Harpreet S. Wasan** MD MBBS PhD FRCP.

Dr Wasan is a Consultant and Reader in Medical Oncology at Imperial College London, and the Department of Cancer Medicine, Hammersmith Hospital. Dr Wasan is the Lead Clinician for the CUP-One trial.

#### Non Medical

**Malcolm J. Glenn** – *Communications, Advertising and Marketing*

Malcolm Glenn has been an advertising creative director for more than 30 years, overseeing the development of creative products for clients. He is a lecturer and consultant business adviser for local colleges and the Young Enterprise charity.

**J. Roger Newnham** FCA. – *Finance and Accounting*

Roger Newnham is a recently retired Chartered Accountant with 40 years experience, including considerable involvement with charities as a part of his practice.

Volunteers. We are most grateful for the support of those who volunteer their services for a particular project or, like **Malcolm Glenn**, our graphic designer, **Roger Newnham** with financial advice and **Jill Foulds**, our Conference and Administration Manager, help us throughout the year.

## HISTORY

*Jo's friends* was established in memory of Jo Symons who died with CUP in September 2006 a few days after her 46th birthday. To her family and friends it seemed incomprehensible that, in the 21<sup>st</sup> century, it was not possible to make a diagnosis and that little was being done to promote awareness and research; or to offer information and support to CUP patients and carers. The charity was born in 2007 after 'proof of concept' was established.

## OBJECTIVES AND ACTIVITIES

The charity is concerned with the relief of sickness and the preservation and protection of health. Our mission is to *Make the Unknown, Known* by:

- Providing information and support to CUP patients and those who care for them
- Raising awareness of CUP
- Promoting improved diagnosis and treatment
- Undertaking, encouraging or supporting CUP research to achieve the objectives above with the ultimate goal of ending CUP

We seek to achieve these objectives primarily through:

- The website ([www.cupfoundjo.org](http://www.cupfoundjo.org)). This site offers information on CUP, its diagnosis and treatment. *Jo's friends* does not offer medical advice. Exceptionally, we may refer queries to a qualified clinician.
- Activities such as awareness-raising events, journal articles and association with other organisations that can help leverage the charity's objectives.
- Promoting or participating in research – oriented activities and facilitating networks of those working in the area of CUP.

## GOVERNANCE

### ***Governing Document***

Cancer of Unknown Primary (CUP) Foundation – *Jo's friends* is a Charitable Trust governed by its deed dated 27 April 2007. It was registered by the Charity Commission with number 1119380 on 24 May 2007.

### ***Appointment of Trustees and Advisory Board Members***

The founding trustees have been appointed for a mix of 5, 3, and 2 years with an option of re-appointment. Every year the trustees conduct an audit of the organisation's skills set and networks, using a Board Matrix, to identify possible gaps that need to be filled. Advisory Board Members have been appointed on the same basis as Trustees *mutatis mutandis* (with a tenure of 5 years). Trustees and Advisory Board Members are unpaid receiving no remuneration or other benefit from their work with the charity. Trustees and Board members may help the charity with their skills as volunteers. Philippa McEwan, Kate Fulton and Rosemary Bates help with Fundraising, Events and

Supporters; Malcolm Glenn and Roger Newnham provide their professional skills in design and accounting *pro bono*.

**Training and Activity of Trustees**

Trustees and Advisory Board Members are recruited for their specific skills and experience and their enthusiasm for the work of the charity. On appointment, Trustees receive a booklet on the duties and responsibilities of a trustee, published by the Charity Commission. Quarterly Trustees Meetings were held as normal throughout the year. Training for Trustees is conducted through occasional ‘Away days’.

**WHAT IS CANCER OF UNKNOWN PRIMARY (CUP)?**

*‘If you can’t measure it, you can’t improve it.’* Peter Drucker, management guru

CUP is where a patient has been diagnosed as having cancer that has spread but the origin of the cancer cannot be determined in assessment before treatment; and it may remain hidden throughout the patient’s life and at *post mortem*. Incidence is now less than 3% of cancer diagnoses in the UK although the actual figure depends on how CUP is defined. It has been estimated by CRUK that 1 in 64 people will be diagnosed with CUP during their lifetime. CUP represents presently 5% of all UK cancer deaths.

CUP is the 15<sup>th</sup> most frequent cancer diagnosis (unchanged) and the 6<sup>th</sup> (down from 5<sup>th</sup> in our last report) commonest cause of cancer death in the UK (measured by ICD-10 codes C77-80).

<b>Table 1: Latest data on UK CUP Incidence &amp; Mortality (2017) by country</b> Data source: CRUK @ 6 Oct 2020			
<b>CUP incidence UK – 8,341 persons</b>			
England	Scotland	Wales	N. Ireland
6892	786	494	169
<b>CUP mortality UK – 9,156 persons</b>			
7614	806	530	206

Every day of the year in the UK about 20 people are diagnosed, and about 26 people die, from CUP.

However, in the period 2007, when the charity was formed, and 2017 (the latest available data year) **CUP incidence and mortality rates have decreased by about a third (35%) in the UK. CUP, along with stomach cancer, has shown the fastest decrease in incidence in both males and females of all cancer types over this period.**

CUP is a heterogeneous disease unified by a challenging diagnosis. Usually, the most important step in diagnosis is the biopsy because this allows a general cancer categorisation of carcinoma, sarcoma, lymphoma or melanoma. Most CUP definitions are of metastatic *carcinoma* of unknown primary where (unlike sarcoma, lymphoma and melanoma) further definitions are needed to achieve effective treatment.

- Clinical presentations are usually non-specific and often involve metastasis in more than one organ.



- Some further classifications are usually possible from the biopsy sample which will help determine likely treatment. But in the case of CUP, the cells have lost their unique features in the cancer spread. This makes identifying the original cancer cells (the target of chemotherapy) difficult.
- Because CUP may originate in any epithelial cells in the body, and CUP biology is not understood (other than that the primary stays small or disappears yet spreads - metastasises - unpredictably) it is a challenging diagnosis for the oncologist as well as the patient.
- The cancer is likely to be different for every patient, with widely different outcomes. The key diagnostic aim is to gain sufficient evidence of the disease’s genetic ‘fingerprints’ to be able to treat it as a site-specific cancer; or to identify and treat the primary’s molecular profile or ‘actionable mutations’.
- Until the advent of the NICE Guideline in July 2010 there had been no NHS guidance for the treatment and management of CUP patients in England, Wales and N. Ireland (Scotland is not officially covered by the NICE Guideline). Informed by the Guideline and mandated by Peer Review (England only), patient management in England and Wales has improved markedly where there has been an introduction of clinical CUP teams managing and treating patients.
- Improving genomic, pathological and radiological techniques will reduce further the incidence of CUP in the future.

**Table 2. UK CUP incidence and mortality 2006-2016 (ICD-10 C77-80).**  
Data from NCIN/ NCRAS & CRUK distilled from ONS

Year	<i>Incidence</i> (No. of new cases)	<i>Mortality</i> (No. of deaths)
2018	Not yet available	
2016	8,899	9,410
2014	8,930	10,142
2012	9,620	10,625
2010	9,585	10,472
2008	10,752	11,228
2006	11,566	12,267

## ACTIVITIES, ACHIEVEMENTS AND PERFORMANCE MEASURES (NON-FINANCIAL)

We turn now to the year’s activities in relation to each objective.

### *Providing information and support to CUP patients and those who care for them*

Our website is the primary medium for providing information, but we offer also leaflets, mainly to hospitals. Our website explains CUP and the information we provide - particularly on diagnosis, treatment and research - is accessed daily by clinicians, patients and carers throughout the world. There is no other resource that can rival the focused information that we provide. The

*... the information [on the website] is the most comprehensive and timely data regarding CUP in the world. In my view this is an invaluable resource. Thanks for all your dedicated work.*

Dr Tony Greco. Sarah Cannon  
Cancer Center, Nashville, USA.

**Some recent comments sent to *Jo's friends***

Thank you for providing us valuable information as we embark on our CUP journey.

Thanks so much for fighting this cause. You guys are doing a great job please continue to represent the patients and their families with so much passion.

What you are achieving is brilliant.... What amazing 'comfort and a sense of hope' this can ALL bring to those suffering CUP as well as for their relatives & friends, that somebody is committed to doing the work that you are doing.

perceived qualitative value of the website can be seen by looking at the endorsements on the website. In addition, we often receive expressions of thanks and donations from users.

Our web-based service continues to acquire many new users from around the world and the relevant statistics are shown in Table 3.

Those seeking information about CUP may route to us through a search engine (e.g. Google), a referring site (such as *Cancer Research UK* and *Macmillan Cancer Support* who provide a link to *Jo's friends* on their websites) or direct by those who know the charity's URL [www.cupfoundjo.org](http://www.cupfoundjo.org).

In September 2019 we instigated a closed group in FaceBook (FB) to allow *CUP patients and carers* to share experiences. This has grown to over 100 users over the last year.

**Metrics.** The total figures for this year show a drop by half in the number of visits to our site in comparison with last year: 11,685 compared with 22,070. Table 3 shows the dip becoming very apparent in April reflecting the CV-19 impact. Website hits are very imperfect measures of performance but they do give useful indications. A search engine optimisation tool (Yoast) was installed in September to try and improve the number and accuracy of our hits. Social media are becoming increasingly important in terms of accessing the site and for the reach we can achieve on Facebook. Our website is designed to work well on different platforms and increasingly we find that people use portable devices. 50% of access to our website is by tablet or mobile and the same is roughly true for access to our eNews.

**Table 3: Website Statistics for FY 19/20 (Data from Google Analytics)**

	Hits		Acquisition				Behaviour	
	Visits	First timers	Direct traffic	Referring sites	Search engines	Social media & email	Time on site (mins)	Page views
Oct	1660	1603	354	24	1134	156	1.32	1.8
Nov	1541	1487	462	32	1027	34	1.16	1.8
Dec	1184	1148	268	24	864	31	1.42	1.9
Jan	1750	1694	522	76	1144	19	1.14	1.6
Feb	1573	1521	369	64	1121	40	1.30	1.9
Mar	1389	1344	298	179	889	36	1.24	1.7
Apr	419	388	221	48	143	10	1.54	2.2
May	496	479	346	54	91	7	1.09	1.8
Jun	489	472	376	32	74	10	1.47	2.1
Jul	350	344	285	22	38	8	1.33	2.1
Aug	379	373	319	20	32	14	1.12	2.1
Sep	455	436	339	40	60	25	1.50	2.3

## ***Raising awareness of CUP***

Raising awareness of a disease that has had a very low profile helps to stimulate demand for change, and for raising funds. There can be no doubt that awareness of CUP amongst the medical and research communities has risen exponentially since 2007. Since 2010 the disease is now recognised and treated by the NHS in the same way as site-specific cancers, with a clear pathway for management and treatment.

We have to acknowledge that awareness amongst the general public, other than those families and friends touched by a CUP diagnosis, remains very low. But to achieve a rapid and dramatic shift would require vast

expenditure. Our website raises awareness of CUP particularly amongst patients and carers. Wider general public awareness, particularly local awareness, is achieved through supporters undertaking events. We are very grateful to all those who

**57% of patients diagnosed with CUP in the UK (9% of all cancer cases) present as an emergency** (NCIN Routes to Diagnosis study, 2014).

CUP patients presenting as an emergency have the lowest survival of all the routes to diagnosis. This means that it is important for those who have possible cancer symptoms to visit their GP without delay. The problem is that GPs are unwilling to refer further without definitive symptoms; but the nature of CUP is that the symptoms are usually non-specific.

raise awareness, often in conjunction with fundraising and we pursue opportunities to promote knowledge and awareness as they arise.

Awareness Week. We have made the last full week of September each year our Awareness Week (AW). We regard raising awareness as equal to, if not more important than, raising funds. Much of general public awareness raising is done by our supporters through the medium of FaceBook (FB). FB offers a powerful and rapid way of reaching people.

## ***Promoting improved treatment and the end of CUP***

On 3 December 2019 in Birmingham we worked with SBK to design a day's workshop for those working in CUP MDTs. Topics included: exploring prognostic factors in patients with CUP/MUO, a clinical update on the CUPISCO trial, genomic profiling and circulating tumour cells, working collaboratively with radiology services and with acute medicine to improve referral processes for CUP patients, the practicalities of recruiting GPs to refer and request diagnostics for CUP.

The booklet *Understanding Cancer of Unknown Primary* which *Jo's friends* initiated with *CancerBackup* many years ago, and continue to help with reviewing, is now in its 5<sup>th</sup> edition as a *Macmillan Cancer Support* publication.

For years we have been battling to see the full report of the 2016 external peer review of CUP services in England made available. Although it has still not received clearance to be placed on the NHS website, we have been given permission by the Quality Surveillance Team to put the

unexpurgated version on our website – which we are pleased to do! This challenging saga of delay and obscurity has been quite extraordinary and worthy of a *Yes Minister* script.

NCRI. For many years CUP was covered within a sub group of the Upper GI Clinical Studies Group (CSG) of the National Cancer Research Institute. It is really important that CUP is recognised within NCRI to stimulate research and peer review. Towards the end of 2017 NCRI reviewed the positioning of CUP and it was removed from its home within the hepatobiliary sub group. After an interval, a CUP working party was established by NCRI which met throughout 2019 under the chairmanship of Dr Natalie Cook of the Manchester Institute. This provisional arrangement has been replaced in 2020 with a permanent MUO/CUP sub-group of the cross-cutting Living With and Beyond Cancer Group. *CUP Foundation – Jo's friends* is represented on the group which has met on Zoom during the pandemic.

### ***Undertaking or supporting CUP research***

Clinical and translational research where *CUP Foundation – Jo's friends* has contributed financial support or has been actively involved.

- **CUP-One.** This major study has suffered from issues with commercial partners and data analysis problems in recent years which has delayed the findings. At the time of writing it is anticipated that final results should be available to the research team in the Autumn of 2020.
- **CUPEM.** The immunotherapy trial – CUPEM – led by Dr Wasan to investigate the benefits of immunotherapy treatment started recruiting patients in three London centres this year only to be halted by Coronavirus. The research re-started in July 2020. The first phase took patients when first line chemotherapy treatment had failed. Initial data has proved encouraging and in the next phase immunotherapy treatment will be allowed as first line treatment for patients who have not received chemotherapy.
- **CUPISCO.** The *Roche* trial (some 87 sites in 23 countries including 9 centres in the UK) has been handicapped by the Coronavirus pandemic. In the UK, the trial re-started in late August. The trial consists of 3 cycles of chemo induction followed by randomization of responders to either molecularly guided therapy or an additional 3 cycles of chemo.
- **Circulating Tumour Cell research.** In previous years we have made research grants towards this exciting project at the CRUK Manchester Institute and the research continues to investigate the viability of liquid biopsies in relation to CUP, and to characterise CUP tumours molecularly in order to gain greater understanding of their biology and behaviour.
- **CUP-COMP.** This is a comparative study across tissue and liquid biomarkers for CUP led by Dr Natalie Cook of The Christie NHS Foundation Trust. Examining genetic changes in CUP tumours alongside blood based biomarkers could help reveal the origins of the tumour and predict responses to existing or new treatments. Dr Cook has formed a collaboration that spans Academia, the NHS (7 UK hospitals), and large and small industrial enterprises in order to compare genetic assays in the diagnosis and treatment stratification in CUP. This work has been funded by Innovate UK and will recruit 150 patients from across the UK. We have made a modest grant to enable a CUP specific molecular tumour board that was unfunded in the Innovate grant.

## FINANCIAL STATEMENTS AND PERFORMANCE

### *Statement of Principles and Financial Management Policies Adopted*

It is the policy of the charity to maintain effective financial management systems and programmes, to continually improve financial operations and systems and to identify more efficient methods of operations regarding accounting and financial reporting. In the reporting period there were no contracts from central or local government to deliver services, nor grants from central or local government. The Charity is staffed by volunteers and no payments were made to staff or trustees other than the reimbursement of expenses.

The Financial Statements comply with the requirements of the Statement of Recommended Practice, Accounting and reporting for charities issued by the Charities Commission and are prepared on a *receipts and payments* basis. The Trustees reviewed the Charity's financial controls at their quarterly meeting in August 2020.

### *Financial and Risk Management*

The trustees maintain effective financial management to ensure successful implementation of activities and assure appropriate expenditure for projects in line with the organisation's objectives. The Trustees keep under review the finances of the charity, including cash flow and reserves, at the quarterly trustees meeting and monitor the activities of the charity in relation to the charitable objects. Watchful of the Charity's reputation, *ante omnia*, the trustees are minded to take all steps to ensure that the reputation is protected through appropriate activities whilst recognising that some risk is necessary to achieve its mission. The charity has a risk management matrix which is reviewed annually by the trustees; or more often if circumstances change.

### *Fundraising Objectives and Principal Sources of Funds*

*CUP Foundation - Jo's friends* aims to secure the funding it needs to achieve its objectives from a variety of sources. Our supporters raise funds and awareness throughout the year. Our annual Awareness Week in September provides a particular annual focus. We have wristbands and badges available for purchase at a nominal cost throughout the year and at Christmas we sell our own cards. The principal sources of funds for the charity lie in memorial gifts and the challenge activities undertaken by our supporters. Significant funds are donated *in memoriam* – usually from funerals in memory of those who have died from CUP. Challenge activities are many and varied with marathons being particularly popular.

We have received also corporate and trust donations this year from the following organisations for which we are truly grateful: *Geometric Manufacturing Ltd, Dolby Developments, CCAM Asia Ltd, and PayPal Giving Fund.*

In the light of bad press in 2015 about charity fundraising, and the consequent amendment to the Charities Act, it is worth recording that the charity does not partake in unsolicited cold-calling, face-to-face or door step fundraising, either directly or through partnership with any external fundraising agencies. We do not undertake street collections. The charity seeks to engage supporters in our work and maintain, through an e-newsletter, a transparent reporting and communications system to ensure that donors are well informed of the successes and challenges

being faced by the charity which they are supporting. In short, we respect the rights, dignities and privacy of our supporters and beneficiaries and make ourselves accountable.

### ***Reserves and Investments Policy***

For the year ended 1 October 2020 the charity's reserves, in its interest-bearing account, stand at £335,000 (with sufficient working capital held in the current account). The charity has no other financial investments. Cash flow and reserves are monitored by the Director and reviewed at each quarterly Trustees meeting. All funds in this financial year are unrestricted. In considering the reserves policy the Trustees have taken a number of factors into consideration. The Charity was financed initially by a gift from the founding Director which met the start-up costs. The Charity has since raised sufficient funds each year to meet its low operating costs and has built reserves to (a) allow operational flexibility, and (b) to build a 'war chest' in order to be in a position to fund, or contribute to, research and associated projects that meet our charitable objectives. (Clinical research involves multi million pound investments but smaller amounts that could have a significant impact on partly funded projects are actively considered by the Trustees).

Whilst *CUP Foundation - Jo's friends* is not unique in the small charity sector, it is unusual in that it is run without salaries, office expenses etc. whilst achieving considerable impact. The Risk Matrix, which is reviewed annually, recognises the significant risk to the charity in the event of the Director's long term incapacity.

The Trustees are resolved to

- (a) maintain reserves that permit the Charity to be sustained in the event of the voluntary Director's incapacity, and
- (b) to only disburse meaningful amounts that contribute to the Charity's objectives that represent value for money.

### ***How Expenditure has supported the Charity's Key Objectives***

Mindful of the generosity of our donors and fundraisers, and the heavy cost of research, the trustees are reluctant to make any significant research grants that will not be of the highest value in 'making the unknown, known.' In this FY we have made grants to: the Christie NHS Trust of £16,218 in relation to research into diagnostic approaches to CUP; and we spent £3,000 to enable the SBK-organised training event in Birmingham (see the section: Promoting improved treatment and the end of CUP).

We continue to spend money on maintaining and enhancing our website which is our primary 'route to market'.

Administration costs. The Trustees take the view that sound administration is a vital foundation of an effective organisation. Whilst administrative expenses will always be kept as low as possible, this should not be to the detriment of achieving the Charity's objectives. There have been travel costs for the Director. However, it should be noted that the overall administrative costs are artificially low as the charity is run from the volunteer Director's house and no charge is made presently for rent, heat, telephone, light, etc.

### ***Future Plans***

The Trustees have referred to the guidance contained in the Charity Commission's general guidance on public benefit when considering future plans. *CUP Foundation - Jo's friends* will seek to influence through planned activities where it is possible but the reality is likely to be a mixture

of planned activities and opportunism. Opportunism in the sense of making the most of circumstantial opportunities outside the charity's control as they arise. As Shakespeare has Brutus say: 'We must take the current when it serves or lose our ventures'.

***Independent Examiner***

Roger Newnham FCA was re-appointed as the Independent Examiner at the August 2020 Trustees meeting.

Approved by the Trustees at their (Zoom) meeting on 17 November 2020 and signed on their behalf by:

Barry Hamilton  
Chairman

John Symons  
Director

**CANCER OF UNKNOWN PRIMARY FOUNDATION – JO’S FRIENDS**  
**Receipts & Payments Account for the year ended 1st October 2020**

	<b>2020</b>	<b>2019</b>
	£	£
<b>INCOMING RESOURCES</b>		
Voluntary income	33,272.49	52,790.67
Activities for generating funds	16,394.51	26,029.72
Investment income	1,274.34	1,810.84
	<u>50,941.34</u>	<u>80,631.23</u>
<b>RESOURCES EXPENDED</b>		
Costs of generating voluntary income	762.30	1,934.70
Cost of charitable activities	3,383.86	3,134.94
Research grants		
The Christie NHS	16,218.00	
Sue Ryder		5,352.51
Manchester Institute		27,950.00
Conference costs	3,120.00	17,374.46
Governance costs	418.19	495.28
Computer costs, printing and stationery	408.03	592.07
	<u>24,310.38</u>	<u>56,833.96</u>
Net receipts	26,630.96	23,797.27
Bank balances at 2 October 2019	314,862.41	291,065.14
Bank balances at 1 October 2020	<u>£341,493.37</u>	<u>£314,862.41</u>
<b>Statement of assets and liabilities at 1 October 2020</b>		
Monetary assets		
Bank balance	6,493.37	14,862.41
COIF Charities Deposit Fund	335,000.00	300,000.00
Net assets	<u>£341,493.37</u>	<u>£314,862.41</u>



**INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF  
THE CANCER OF UNKNOWN PRIMARY (CUP) FOUNDATION – JO'S FRIENDS  
Charity number 1119380**

I report on the Receipts and Payments Account and the Statement of Assets and Liabilities of the Trust for the year ended 1<sup>st</sup> October 2020 shown on page 15.

**Respective responsibilities of the trustees and the examiner**

The charity's trustees are responsible for the preparation of the accounts.

The charity's trustees consider that an audit is not required for this year under section 144(2) of the Charities Act 2011 and that an independent examination is needed.

It is my responsibility to:

- examine the accounts under section 145 of the 2011 Act,
- to follow the procedures laid down in the general Directions given by the Charity Commission (under section 145(5)(b) of the 2011 Act, and
- to state whether particular matters have come to my attention.

**Basis of independent examiner's report**

My examination was carried out in accordance with General Directions given by the Charity Commission. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts, and seeking explanations from the trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit, and consequently no opinion is given as to whether the accounts present a "true and fair" view and the report is limited to those matters set out in the statement below.

**Independent examiner's statement**

In connection with my examination, no matter has come to my attention

1. which gives me reasonable cause to believe that in, any material respect, the requirements:
  - to keep proper accounting records in accordance with section 130 of the 2011 Act; and
  - to prepare accounts which accord with the accounting records and comply with the accounting requirements of the 2011 Act have not been met; or
2. to which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.

J.R. Newnham F.C.A.  
Lawn Cottage, Portsmouth Road,  
Milford, Surrey.  
GU8 5HZ