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

ANNUAL REPORT

FOR THE YEAR ENDED

1 OCTOBER 2018

Registered Charity Number: 1119380

The Fold, Lower End, Daglingworth, Cirencester GL7 7AH
www.cupfoundjo.org

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

ANNUAL REPORT FOR THE YEAR ENDED 1 OCTOBER 2018

The Trustees are pleased to present their report, together with the financial accounts of the charity, for the year ending 1 October 2018. This is the eleventh 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 (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.

HIGHLIGHTS OF THE YEAR

In 2018 the NHS reached its 70th birthday. Fearing a declining income, an overwhelming majority of doctors opposed the NHS concept in 1948. Seventy years on, the majority of doctors resist changing the underlying principal of a free service at the point of delivery. Described by a former Chancellor of the Exchequer as 'the nearest thing that the British have to a religion', the end result is that governments of all persuasions dare not touch what has become a broken model; broken because the cost of funding medical equipment, coupled with medical advances, and an aging and rising population, create a circle that cannot be squared.

The NHS now and then

	2018	*1948*
UK population:	66.6m.	43m
Life expectancy:	82	65
NHS Budget:	c£144b	c11.4b (in today's money)

Consequently, cancer services are the poor relation of western Europe and much of the developed world. Yet it is widely recognised that Britain has some outstanding cancer scientists and expert cancer physicians. The best 70th birthday present the NHS could receive would be a politically independent commission to re-model this shibboleth and make it fit for its purpose in the 21st century. Instead, the government grants additional funding to the NHS, an extra 3.4% each year until 2023 - announced in the Summer of 2018 – without requiring conditions of improved performance. The Government's commitment is for an extra £20.5 billion per annum. *The King's Fund* has noted that it would require a £43 billion per annum rise to achieve the EU average. It is perhaps unsurprising that the *Wellcome Trust* has concluded that 'the UK appears to perform less well than similar countries on the overall rate at which people die when successful medical care could have saved their lives.'[1]

[1] The NHS' long term cancer plan (next 10 years) is presently being developed. We have contributed our views with regard to diagnosis as follows: 'The NHS seems locked into an old paradigm of 'site specificity' and is way behind the curve, in comparison with other countries, when it comes to operationalising genomic medicine. There is no point investigating patients to identify a 'true' diagnosis linked to an increasingly irrelevant anatomical site. The role of diagnosis is to determine the most appropriate therapy. Science has now given us the capability, in the majority of

At the operational level patients face campaigns to promote early diagnosis but the uncertain symptoms associated with CUP, without a barn door obvious primary site, often mean that a patient is not immediately referred to a consultant. GPs are discouraged from referring patients to secondary care where consultants and imaging equipment are not resourced to meet demand. One encouraging development has been delivered in 2018: the 'one stop shop' pilot in 10 centres in England. GPs can refer patients presenting with 'vague' symptoms including unexplained weight loss, abdominal pain and fatigue to assessment centres, to undergo multiple tests for different cancers. The much- to- be- welcomed initiative aims to ensure a quick diagnosis in those *not* showing 'alarm' signs for a *specific* type of cancer. At last the cancer world is moving away from its rigid focus on anatomical sites as the diagnosis process becomes more sophisticated and the benefits of the molecular revolution start to trickle towards the patient.

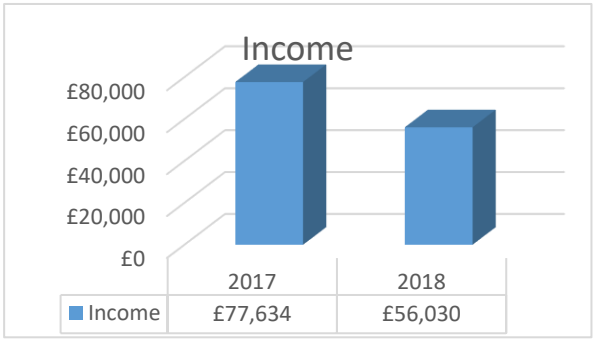
There have been positives and negatives during the year under review:

- Bizarrely, in late 2017, the NCRI removed CUP from its home within the Upper GI clinical studies research group (CSG) without giving it an alternative home. It was in a sub group of this CSG that CUP research proposals were discussed and approved or rejected by peer review to move forward for funding. At the time of writing NCRI have organised the first meeting of a new CUP group which we would like to see formulated as a specific CSG.
- The sun is setting on chasing the anatomical site of the primary and empiric (best guess) chemotherapy. A new dawn is starting to show light on the horizon but the benefits to patients are some way off. The new dawn is the frontier of research focused on finding the *molecular primary* or the *molecular target* (by identifying *actionable genetic mutations* where it is not necessary to know the anatomical primary.) Treatment options may be enhanced with immunotherapy drugs but research is only just starting to see if these drugs will have a beneficial impact. We have made a **research grant of £100,000 this year to Hammersmith Hospital** to help investigate the benefits in the first trial of its kind in the UK.
- The Roche trial called **CUPISCO is starting to rollout in the UK in 8 centres** as well as in 22 other countries worldwide. Roche involved *Jo's friends* in the trial design which has been implemented with extraordinary speed. The trial will test the efficacy of molecular profiling techniques and treatment options that include immunotherapy drugs
- Research in Manchester, is looking at **circulating tumour cells** in relation to CUP. This is potentially very exciting research that may help us to understand CUP biology and improve treatment through liquid, rather than tissue, biopsies.
- During this year we have worked with *SBK events* to run **CUP Multi Disciplinary Team (MDT) training days in Manchester (Oct 17) and Bristol (Jun 18).**
- The director was invited to speak at a meeting of *MEPs Against Cancer* in Brussels in June raising awareness amongst a wider European audience.

cases, and with a high level of confidence, to identify the molecular primary or the molecular target. This is particularly important for Cancer of Unknown Primary but also for all other cancers if you recognise that the, so called, site specific cancers are not simply of one molecular type. The 100K Genomes Project will hopefully deliver some translational benefits in the fullness of time and it is this forward thinking with regard to genomics that the NHS could do well to align with. Why is molecular profiling/gene expression profiling not being used to identify tissues of origin in complex diagnostic cases? It should be, and the health economic arguments opposing it fall away as the price of assays fall and the cost, availability and complexity of traditional diagnostics rise. For the Long Term Plan (LTP): get with the molecular revolution!'

- Those who read the detail of this report will note that **CUP incidence in the UK has shot down from being the 11th commonest cancer to the 15th**. CUP incidence keeps falling, unlike some cancers, and this has to be a validation for improved diagnosis which has developed as a result of the 2010 NICE Guideline. CUP mortality remains stuck at the 5th highest cancer cause of death.
- The Royal College of Pathologists have drafted a 'dataset' (essentially, a guide) to help pathologists when faced with potential CUP cases.

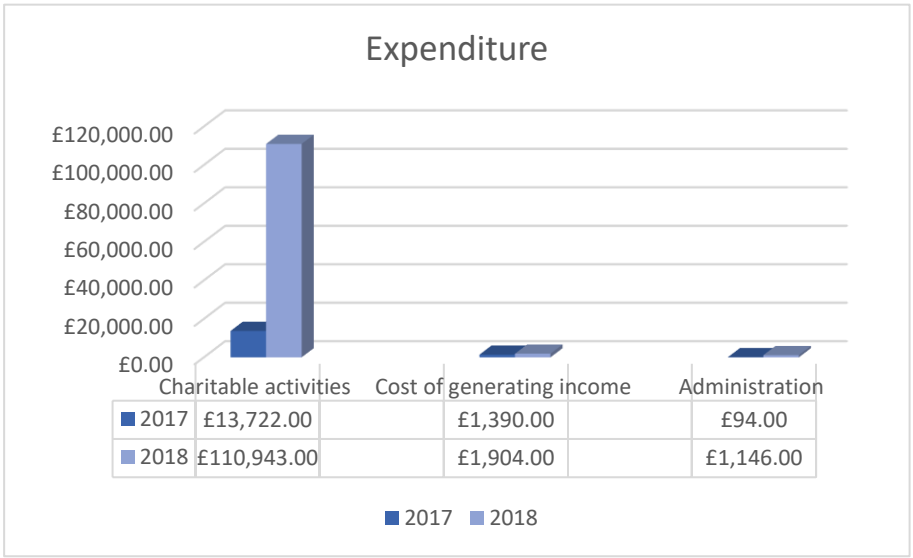
Financial summary. A study of the accounts on page 15 shows a 28% drop in income in 2018. Administrative costs remain low ensuring that monies donated to us are available to help address all our charitable objectives. Our charitable expenditure has risen significantly this year as it has been timely to make a significant research grant to explore immunotherapy treatments for CUP patients. Expenditure in this financial year also includes further funding for the development of a CUP Patient Decision Aid (PDA) as well as funding for CUP MDT seminars.



This year we needed to spend some funds on a computer upgrade and other requirements to keep our systems secure and compliant with current regulations.

Our strategy is to achieve sufficient funds to cover our modest operating costs and we aim also to build healthy reserves to fund our conferences and seminars and to make appropriate research grants, when appropriate. (See page 5 for our objectives.) It should be noted that we are *not* a charity whose focus is solely to raise funds for medical research.

The charity depends entirely on volunteer effort and has no paid staff.



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 F. Anthony Greco MD.
Dr Greco is Director of the Sarah Cannon Research Institute located in Nashville, USA. Dr. Greco specialises in cancers of unknown primary origin, lung cancer and germ cell tumours.

Dr Richard J. Osborne MD FRCP FRACP.
Dr Osborne works as Senior Staff Specialist in Medical Oncology in the newly established Cancer Care facility at Hervey Bay Hospital, Queensland. Until 2016 he was Consultant in Medical Oncology at the Dorset Cancer Centre. He was the Lead Clinician involved in 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. SUPER is designed to describe the clinical heterogeneity of patients assigned the broad label of CUP, establishing the frequency of genetic mutations in tumours and defining quality of life and psychosocial issues unique to these patients.

Dr Maurice L. Slevin MD FRCP.
Dr Slevin is Honorary Consultant Medical Oncologist at St Bartholomew's Hospital, where he has practiced for 30 years. He is a founding Director of The London Oncology Clinic (now Leaders in Oncology Care).

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 practising 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, and **Jill Foulds**, our Conference and Administration Manager, help us throughout the year. Thanks go also to our external examiner, **Roger Newnham**, for his *pro bono* work.

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 21st 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

It achieves these objectives primarily through:

- The website (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.

Transformational change. The Trustees set originally the year 2020 as the target to work towards to see the end of CUP: our '2020 vision'. It is unlikely that this will be realised although at *CUP 2015* Dr Greco, referring to our strapline, proposed that it was technically already possible to identify 95% of primary sites and that the 'unknown was now known'. Despite considerable progress, *making the unknown, known* remains as relevant a role this year as it was in 2007. But the challenges and opportunities have changed. In the spirit of the philosopher Seneca's dictum, 'luck is what happens when preparation meets opportunity', we need to be prepared to grasp opportunities to continue to effect change for the benefit of CUP patients as the environment shifts.

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 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 'Away days' and an Away Day was last held in June 2017.

WHAT IS CANCER OF UNKNOWN PRIMARY (CUP)?

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 some 3% of cancer diagnoses in the UK; but the actual figure depends on how CUP is defined. **CUP is the 15th (11th in our 2017 report) most frequent cancer diagnosis and the 5th (unchanged) commonest cause of cancer death in the UK** (CRUK incidence data for 2015 and mortality data for 2016 using ICD-10 codes C77-80). **Every day of the year in the UK about 20 people are diagnosed, and about 30 people *die,* from CUP. Over the last decade, CUP incidence rates have decreased by more than a third (35%) in the UK; but it estimated by CRUK that 1 in 64 people will be diagnosed with CUP during their lifetime.**

Table 1: Latest data on UK CUP Incidence (2015) & Mortality (2016) by country
Data source: CRUK @ May 2018

CUP incidence UK – 8,635 persons			
England	Scotland	Wales	N. Ireland
7070	870	532	163
CUP mortality UK – 9,410 persons			
7825	768	604	213

The latest data are shown in Tables 1 and 2. There has been a welcome dip in incidence since our last report with CUP falling in relative terms to other cancers from 11th to 15th. For most of our existence as a charity it has been within the top 10. Mortality remains as the 5th highest in the UK.

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

Year	*Incidence* (No. of new cases)	*Mortality* (No. of deaths)
2016		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

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 (cancer spread) 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 cancer doctor 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 'fingerprints' to be able to treat it as a site-specific cancer.
- 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 covered). Patient management in England and Wales has improved markedly where there has been an introduction of clinical CUP teams managing and treating patients informed by the Guideline and mandated by Peer Review (England only).
- Improving genetic, pathological and radiological techniques will reduce the incidence of CUP in the future.

ACTIVITIES, ACHIEVEMENTS AND PERFORMANCE MEASURES (NON-FINANCIAL)

Activities of the last financial year
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. The booklet *Understanding CUP,* which *Jo's friends* initiated with *CancerBackup* many years ago, is now in its 4th edition (Sep 2016) as a *Macmillan Cancer Support* publication.

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 perceived qualitative value of the website can be seen

Some recent comments to *Jo's friends*

We lost her less than 4 months later. She was brave and dignified and selfless, and she is the reason we are determined to help you and your wonderful charity spread awareness of CUP. Your charity provided hope when there was none, and answers when we had none. Thank you!

…and I wanted to send you a heartfelt thank you for taking the time to reply and give your opinion on all of our concerns. It means so very much to me and my family, and has helped me personally come to terms with our experience as I have felt truly traumatised by it all and now I feel an air of calm and acceptance. So thank you.

we have lost all trust and confidence in the oncologist hence my desperation in looking and researching any other options that may be available.

…We personally feel that CUP Cancer still is such an unrecognised Cancer and Consultants still don't seem to have enough knowledge or answers available to them so we are forever grateful that the only good advice we received from our consultant apart from leaving the hospital and go make a will was to check out Jo's Friends and we are glad we did.

Why is there not enough research into unknown cancer. Having lost my husband recently [I] still feel angry and frustrated ….

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.

Table 3: Website Statistics for FY 17/18 (Data from Google Analytics)

	Hits		**Acquisition**				**Behaviour**	
	Visits	*First timers*	*Direct traffic*	*Referring sites*	*Search engines*	*Social media*	*Time on site (mins)*	*Page views*
Oct	1054	1004	265	46	744	6	2.01	2.2
Nov	1146	1077	320	35	786	12	1.49	2.2
Dec	948	904	286	36	622	10	1.42	2.1
Jan	1263	1213	367	83	795	25	1.47	2.0
Feb	1255	1189	344	86	830	6	1.36	2.7
Mar	1355	1315	510	36	813	5	2.03	2.1
Apr	1115	1073	374	32	707	6	1.22	1.9
May	1276	1212	403	67	805	16	1.48	3.0
Jun	1304	1245	400	141	763	7	1.26	1.9
Jul	1264	1215	346	89	836	9	2.00	3.3
Aug	1494	1432	379	194	924	10	2.00	3.4
Sep	1591	1527	351	56	1176	22	1.5	3.5
Tot	*15,065*	*14,406*						

The total figures for FY17/18 show 15,065 visits of which 14,406 were new visitors to the site. The overall visits are down by 8% in comparison with the previous year but we have received more new visitors than before. These are very imperfect measures of performance but they do give an indication of the reach of the charity and its significance. Social media is 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 media 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 which is sent by eMail.

Raising awareness of CUP

Raising awareness of a disease that has had a very low profile is a precursor of stimulating 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. The disease is now recognised and treated by the NHS in the same way as site-specific cancers. No longer is CUP a failure of diagnosis: it is a diagnosis in its own right, 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 is a vehicle for raising awareness of CUP particularly amongst patients and carers. Wider general public awareness, particularly local awareness, is raised through supporters undertaking events. We are very grateful to all those who raise awareness, often in conjunction with fundraising. We will continue to pursue opportunities to promote knowledge and awareness.

Awareness Week. We have made the last full week of September each year our Awareness Week. In 2018 we repeated the '10 X More' campaign, begun in 2013, asking supporters to *make 10 times more people aware of CUP*. This is done by selling lapel badges and wristbands and encouraging individual activities. The formula allows funds to be raised by generous people paying more than the RRP for badges and band of £1 each. Awareness is more important than raising funds and much of this is done through FaceBook (FB).

Promoting improved treatment and the end of CUP

Pathology. Pathology is critical to an accurate diagnosis of cancer – and for getting the best possible clues to aid treatment from the tissue of a patient where a site-specific diagnosis remains elusive. There are very few pathologists with expertise in CUP so it is good news – if not overdue news –that The Royal College of Pathologists have drafted a 'dataset' (essentially, a guide) to help pathologists through this difficult area. This could well have an impact on driving down CUP incidence. *Jo's friends* was consulted in the preparation of the draft. The dataset is now extant and available to view on our website.

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.

Patient Decision Aid (PDA). Our patient experience research shows that patients with CUP face uncertainty regarding their diagnosis and are unprepared for what to expect regarding diagnostic investigations. To meet this need we are funding, and contributing to, the development of a PDA specifically for patients who have CUP. The purpose of the PDA is to help patients to understand their disease and to make informed choices between therapeutic options and supportive care. The work is being led by Dr Paul Perkins, Consultant in Palliative Medicine and Dr David Farrugia, Consultant Medical Oncologist (who practice at *Gloucestershire Hospitals* and *Sue Ryder* Cheltenham). It is hoped that the PDA, co-branded with *Sue Ryder*, will be available in late 2018 or early 2019.

Conferences. With input from *Jo's friends, SBK Healthcare* ran development days in Manchester on 17 October and in Bristol on 18 June for clinicians working in CUP MDTs to develop their knowledge and share best practice.

Undertaking or supporting CUP research

Clinical and translational research.

- **CUP-One**. The long-awaited clinical results (the ECX chemotherapy regimen) of CUP-One are expected with the publication of a paper in preparation in November 2018. They are expected to show a higher than average one year plus survival rate. The transformational aspects (the use of a molecular profiling diagnostic assay) is subject to delay caused by the collapse of a commercial partner.
- **Immunotherapy research.** We have made a research grant of £100,000 this year to Hammersmith Hospital to help investigate the benefits of immunotherapy treatment and, as part of that, to try and identify a protein profile to predict for immune stimulation. This is the first trial of its kind in the UK. The trial should start to accrue patients in Jan 2019 in 3 London sites. The target is for 70-80 patients. The first 20 will have already received chemotherapy and the next 54 will not have had chemotherapy.
- **CUPISCO.** The planned Roche trial reported in last year's report, now named CUPISCO, has gained momentum[2]. It has started recruiting in some of the 87 sites in the 23 countries of the trial. 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. There are 8 centres in the UK with recruitment in the UK starting in Autumn 2018.
- **The 100K Genomes Project**. Blood and tissue collections from contributing CUP patients continues at all the 100K Genomes Project centres throughout 2018. The target for CUP is to collect 250 genomes. Dr Harpreet Wasan is the GECIP CUP lead.

Patient experience research. Providing accurate and helpful information and preparing patients with CUP for their treatment trajectory is especially difficult– we know well from empirical and anecdotal data that confusion and anxiety are amplified for the CUP patient because of the uncertainty surrounding the disease. With Southampton University and the Peter MacCallum Cancer Centre in Australia we have been carrying out various studies over recent years to try and understand the experiences of CUP patients and their families. The latest study, part funded by CUP Foundation (£1,620) and Cancer Australia, has compared CUP patients with patients who have site-specific metastatic cancers (colorectal, breast, head and neck, kidney/adrenal, prostate, pancreas, and upper and lower gastrointestinal). The data source for this study is the national Cancer Patient Experience Survey (CPES) which is an England-wide programme of research about cancer patients' experiences of care while undergoing treatment. The findings from this research have been published as:

> 'Differences in experiences of care between patients diagnosed with metastatic cancer of known and unknown primaries: mixed-method findings from the 2013 cancer patient experience survey in England'. Wagland, R; Bracher, M; Drosdowsky, A; Richardson, A; Symons, J; Mileshkin, L; Schofield, P. *BMJ Open* Volume 7, Issue 9. 2017

[2] We were involved in the trial design meeting in March 2017 and the Director attended, and presented, at a Roche meeting in Amsterdam in November 2017.

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 improve continually 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 2018.

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 promotes the sale of wristbands and badges and at Christmas time 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: *The Lilleybrook Ward Fund, Software AG (UK) Ltd, Leeds Day.* We are very grateful also to *Chime Communications* for the use of a meeting room for Trustees meetings in central London in 2017.

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 2018 the charity's reserves, in its interest-bearing account, stand at £285,000 (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. In the event that the Charity was required to appoint a salaried Director with associated support and offices, the annual running costs would be likely to rise from negligible to an estimated 20% of income. Consequently, 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 a significant research grant of £100,000 to Hammersmith Hospital towards an immunotherapy trial.

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

We have continued to work with SBK on delivering MDT training and development days. Whilst the profit and loss for these events normally fall to SBK, in 2018 we were particularly keen to run an event outside the normal geographic range of SBK. We contributed £3,000 to run an event in Bristol. Small items of expenditure have included the funding of a CUP Cancer Nurse Specialist's attendance at a CUP conference, £478.80, when her hospital would not provide the funds. (Money for this purpose was passed to us by Dr Richard Osborne when he left the Dorset Cancer Centre for Australia. The funds had been donated to him by grateful patients.) We plan to run our next international conference 'CUP 2019' in May 2019 and have paid a deposit for the RCP venue.

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 costs for some train travel by 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, car travel etc.

General Data Protection Regulation -GDPR. This year we have spent some time and money to ensure that we are compliant with the new regulation. This required a small sum of money to *Resolution* - £270 - who run our website to effect the necessary changes.

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

A resolution proposing the re-appointment of Roger Newnham FCA as the Independent Examiner to the Charity was approved by the Trustees at their meeting on 17 August 2018.

Approved by the Trustees at their meeting on 20 November 2018 and signed on their behalf by:

Barry Hamilton	John Symons
Chairman	Director

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

Receipts & Payments Account for the year ended 1st October 2018

	2018	2017
	£	£
INCOMING RESOURCES		
Voluntary income	47,537.80	71,523.31
Activities for generating funds	7,723.42	5,224.04
Investment income	769.43	886.78
	56,030.65	77,634.13
RESOURCES EXPENDED		
Costs of generating voluntary income	1,904.13	1,390.05
Cost of charitable activities	6,562.89	6,000.11
Research grants	100,000.00	7,722.51
Conference costs	4,380.00	0
Governance costs	201.65	19.30
Computer costs, printing and stationery	944.06	74.92
	113,992.73	15,206.89
Net receipts	(57,962.08)	62,427.24
Bank balances at 2nd October 2017	349,027.22	286,599.98
Bank balances at 1st October 2018	£291,065.14	£349,027.22

Statement of assets and liabilities at 1st October 2018

Monetary Assets		
Bank balance	6,065.14	29,027.22
COIF Charities Deposit Fund	285,000.00	320,000.00
	£291,065.14	£349,027.22

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 1st October 2018 shown on page 16.

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