

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

ANNUAL REPORT AND ACCOUNTS

FOR THE YEAR ENDED

1 OCTOBER 2019

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 2019

The Trustees are pleased to present their report, together with the financial accounts of the charity, for the year ending 1 October 2019. This is the twelfth 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

It was announced last year that the Government has committed an extra £20.5 billion per annum to the NHS for the next 5 years. *CUP Foundation-Jo’s friends* has participated with other charities to discuss, and seek to influence, the long term plan for the NHS Cancer Programme as part of the increased 5 year funding.

RDCs. We are pleased to see the plan to roll-out Rapid Diagnostic Centres (RDCs) across the country following the 2018 trial as long as RDCs establish a clearly understood linkage with CUP MDT teams to progress a possible CUP patient’s pathway appropriately. Cancer alliances are required to have at least one RDC site accepting patients no later than January 2020. The aim with RDCs is that ‘patients displaying symptoms of cancer can be assessed and diagnosed in as little as a day.’ Existing suspected cancer referral pathways focus on suspicion of tumour-specific disease rather than on diagnosing symptoms. There is currently no dedicated urgent diagnostic pathway for patients who present – often repeatedly - with vague, non-specific, symptoms as CUP patients often do. Consequently, a patient may, to quote the NHS’s *Rapid Diagnostic Centre Vision and 2019/20 Specification*, see their GP multiple times before referral; present more often in an emergency setting; present with late stage cancer (analysis of the National Cancer Diagnosis Audit shows 67% of people with non-specific symptoms are diagnosed at a late stage in comparison to 45% for people with site-specific symptoms); are referred on multiple urgent pathways with resulting inefficiencies in healthcare provision. It is encouraging that the specification for referral to an RDC includes a GP’s ‘gut feeling’ about cancer as well as symptoms such as unexplained weight loss, fatigue, abdominal pain or nausea.

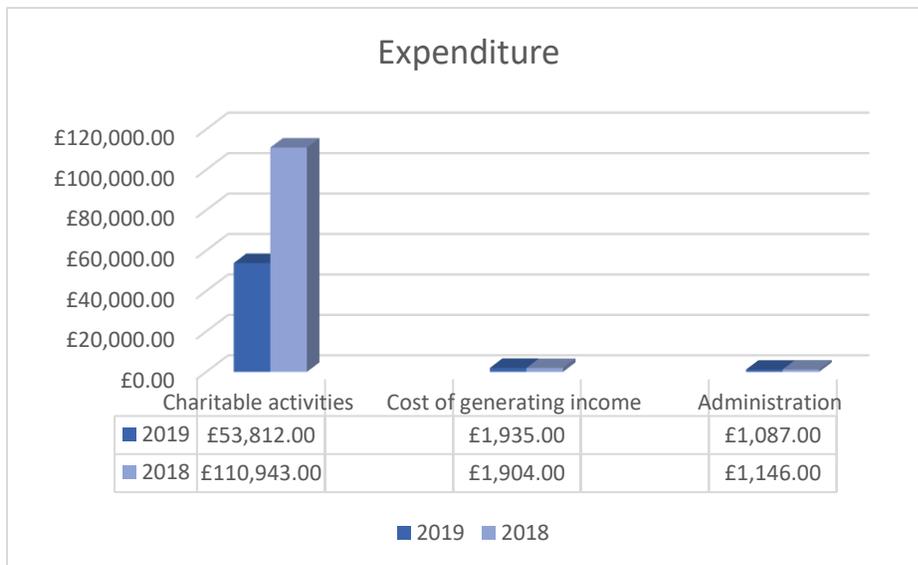
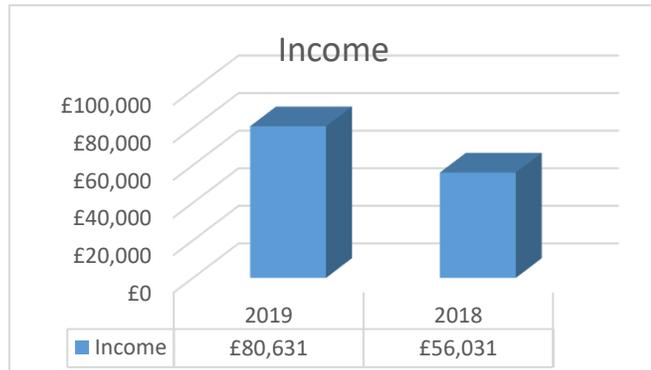
Genomic testing. In the consultation period, and in meetings with the team preparing the plan, we pushed for genomic testing for CUP patients and, at first blush, it is pleasing to see in the long term plan: ‘The offer of genomic testing to all people with cancer for whom there would be clinical benefit, beginning with children and young people, will also increasingly enable more precise diagnosis, and better-targeted and safer treatments’. This would seem to encourage the use of genomic profiling as part of the diagnostic work-up in certain circumstances. Time will

tell whether this is ‘theory in practice’ or empty rhetoric. Early indications in response to questions of NHS England staff have not been encouraging.

Of matters where we have a more direct influence, there have been a number of events and activities during the year under review, explained later in the report, that have potentially profound impact for CUP patients:

- CUP 2019 – our international conference held in May
- CUPEM– the launch of an immunotherapy trial for CUP to which we have contributed significant funding
- CUPISCO - The accrual of patients on this international trial, instigated and funded by *Roche*, which is testing the efficacy of molecular profiling techniques and treatment options that include immunotherapy drugs
- CUP Patient Decision Aids (PDAs) – the launch of the output of our joint venture with *Sue Ryder*
- Circulating Tumour Cell (CTC) research on CUP patients to which we have made a research grant.

Financial summary. The accounts on page 15 show a 44% increase in income in 2019. Administrative costs remain low ensuring that monies donated to us are available to help address all our charitable objectives. Expenditure in this financial year includes further funding for the development of a CUP Patient Decision Aid (PDA) and a research grant towards Circulating Tumour Cell (CTC) research.



Our financial aim is to achieve sufficient funds to cover our modest operating costs and to build healthy reserves to fund our conferences and seminars and to make appropriate research grants. (See page 4 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 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, 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 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

We seek to achieve 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

Much has changed since the charity was founded in 2007. Thirteen years ago, patients were receiving sub optimal care. Patients and carers were not receiving (any) information about CUP in the way that they did for a site specific cancer presentation; too many oncologists took a nihilistic approach to CUP and treatment was *ad hoc*. There were no CUP CNSs. Very few medical professionals showed interest in CUP; there were no meetings or obvious platforms to develop or share knowledge on CUP amongst medical professionals and, apart from CUP-One (findings awaited), there was no UK CUP research. National epidemiological data did not show CUP as an entity and it was not recognised by doctors or epidemiologists as a syndrome with one common name.

Looking back from the perspective of 2019 there has been a sea change in the UK. The game-changer has been the NICE Guideline of 2010: effectively treating CUP in the same way as site specific presentations with a clear pathway (although not officially applicable to Scotland it has been adopted into practice). These were reinforced 3 years later by Peer Review Measures.

The landscape for CUP patients has changed beyond all recognition compared with 10 years ago... the CUP Foundation has been behind the vast majority of these steps.
Dr Richard Osborne, 29 July 2019.

At our conference, *CUP 2015*, Dr Greco, referring to our strapline, proposed that it was technically possible to identify 95% of primary sites and that the ‘unknown was now known’ through advances in genomic science. At *CUP 2019* we focused on the issues associated with identifying the molecular primary and/or the molecular target (in the latter case identifying actionable genetic mutations where it is not necessary to know the anatomical primary.).

Whilst science, in this ‘golden age of cancer research’ and ‘precision medicine’, is moving fast a significant gap is opening-up between what is scientifically possible and actual patient benefit. We are encouraged to glimpse the tantalising sunlit uplands of personalised, or precision, medicine but rhetoric is outpacing reality. As TS Eliot put it: ‘between the idea and the reality falls the shadow’. The challenge today is to see the relevant scientific advances for CUP become mainstream.

When the charity started, our aspiration was to be ‘out of business’ by 2020 (our 2020 vision). It is apparent that this aspiration will not be met and the trustees have begun a strategic review to look at the positioning of the charity beyond 2020. The challenges for 2020 reflect the gap – or TS Eliot’s ‘shadow’ between ideas and reality, manifest in a number of obvious dilemmas and uncertainties:

- We don't yet know what impact immunotherapy treatment may have on CUP. For some highly mutated (metastatic) cancer types it has had a Lazarus effect for reasons that are not yet understood.
- Even if the primary is known (though a combination of genomic profiling and standard immunohistochemistry), does that change the outcome for a patient with metastatic cancer? Quite possibly *Yes* for a patient in a favourable group, but probably *No* for the majority as the disease has progressed and mutated (although life expectancy may be increased by a few months with better-targeted treatment).
- For most cancers early diagnosis is key. Can an earlier diagnosis be achieved for CUP patients? Probably not because it is by definition a metastatic disease at presentation.
- There are some very exciting, potentially transformative, scientific advances that may benefit CUP patients such as: the ability to track mutations through liquid, rather than tissue, biopsies and 'tumour agnostic drugs'. These are at the 'bench stage' but will evidence validate their use for CUP patients at the 'bedside'?
- An important diagnostic issue for CUP is whether the way forward is to identify the *molecular primary* (not necessarily the same as the anatomical primary which is increasingly becoming an anachronistic approach) or the *molecular target* - using next generation sequencing (NGS) or by identifying 'actionable mutations'. Judging from *CUP 2019*, the CUP community is divided at present.

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)?

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 (measured by ICD-10 codes C77-80). Every day of the year in the UK up to 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 has been estimated by CRUK that 1 in 64 people will be diagnosed with CUP during their lifetime.

Table 1: Latest data on UK CUP Incidence & Mortality (2016) by country
Data source: CRUK @ Jul 2019

CUP incidence UK – 8,899 persons			
England	Scotland	Wales	N. Ireland
7342	786	574	196
CUP mortality UK – 9,410 persons			
7825	768	604	213

The latest data are shown in Tables 1 and 2. There has been a slight rise in incidence since our last report.

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.

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)
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

- 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 ‘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 genetic, pathological and radiological techniques will reduce further 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 Cancer of Unknown Primary* which *Jo’s friends* initiated with *CancerBackup* many years ago, and continue to help with reviewing, is now in its 5th edition (June 2019) 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 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.

Some recent comments to *Jo’s friends*

Jo's Friends is a wonderful Charity - Without them my family would never have understood this truly awful form of cancer. I have personally seen first hand the tremendous work they do. I attended a number of the seminars they organise to better inform all those working with CUP sufferers, keeping them up to date with the latest CUP research & trials, often sponsored by Jo's Friends

The only information we found, we researched ourselves, and it came from your website. Thank you for all your help, advice and support over the past few years. I shall continue to promote awareness and fundraise.

From diagnosis until the end it was 6 weeks- cup is terrible and there is hardly any info about it so I'd just like to say thank you for your blog and I enjoy the email updates. I hope we can put an end to cup (and all cancer) for good!

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.

In September 2019 we instigated a closed group in FaceBook (FB) to allow *CUP patients and carers* to share experiences. For some years we have been without an interactive forum as our very successful one, which had been in existence since the charity started, was destroyed by spamming machines. FB offers more security. The return of an interactive forum has been welcomed and 50 people joined the group within 48 hours of its launch.



Table 3: Website Statistics for FY 18/19 (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	1918	1847	311	88	1515	9	1.23	3.9
Nov	2011	1911	528	119	1366	21	1.51	4.8
Dec	2292	2203	849	90	1271	92	1.18	4.4
Jan	2460	2363	441	60	1692	290	1.31	1.9
Feb	2503	2384	500	75	1844	108	1.24	1.8
Mar	2274	2152	475	64	1644	105	1.30	1.8
Apr	2036	1931	401	72	1502	86	1.18	1.8
May	2004	1874	323	88	1493	118	1.42	2.1
Jun	1233	1161	279	44	903	18	1.40	1.9
Jul	1134	1083	238	55	838	13	1.39	2.0
Aug	1024	979	213	88	708	23	1.39	2.0
Sep	1181	1127	225	74	819	76	1.46	2.2

The total figures for FY18/19 show a 45% year on year increase in visitors but this will be in large part due to the conference. Taking the year as a whole the most popular pages of our website are those covering Diagnosis. These are very imperfect measures of performance but they do give an indication of the reach of the charity and its significance. 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 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.

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.

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.

Awareness Week. We have made the last full week of September each year our Awareness Week (AW). We regard raising awareness as equal, if not more, important as 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 and in 2019 some 2,500 people were reached with our AW message in a matter of hours.

Promoting improved treatment and the end of CUP

CUP 2019. We held the 4th in our series of international conferences on Friday 3 May at the Royal College of Physicians in London: *Cancer of Unknown Primary in the Era of Precision Medicine*. We had a full house with 135 delegates and speakers. Our international expert speakers were all very highly rated and it was recognised as an extremely useful day by the CUP community. The programme was grouped under the headings of: *current optimal tissue diagnostics for CUP; current clinical and translational trials; optimal management; and focus on the future*. For the first time as part of the programme we held a session of debates on contentious issues around CUP which proved very successful. It is worth noting that we are the only organisation in the world that holds, or has ever held, conferences devoted to CUP.

We have received very many comments on CUP 2019 many commenting on the 'excellent scientific content'. The examples below give a flavour:

- What a fantastic conference! Well attended, brilliant speakers and it was great to see everyone so enthused by CUP.
- I think it was a great success.... From my perspective, it was a tour de force! It was so nice to meet with others active in the field...
- It was really a wonderful day and it has filled us all with lots of enthusiasm that things are moving forward in the world of CUP research.

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 have funded and contributed to, the development of a series of PDAs specifically for patients who have CUP. The purpose of the PDA document is to help patients to understand their disease and to make informed choices between therapeutic options and supportive care. *The CUP Foundation – Sue Ryder* PDA document was launched in 2019 and is available from our website. Initial reaction has been very favourable. We are awaiting feedback from patients, carers, oncologists and nurses before creating a hard copy. In this financial year we have paid £5352.51 to Sue Ryder.

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. 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 and has met throughout 2019 under the chairmanship of Dr Natalie Cook of the Manchester Institute. This has been a provisional arrangement to be replaced in the Autumn of 2019 with a permanent MUO/CUP working group as part of an NCRI cross cutting group that will include also acute care, end of life care and methodology. *CUP Foundation – Jo’s friends* is represented on the group.

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.** The long-awaited clinical results (the ECX chemotherapy regimen) of CUP-One 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 failure of a commercial partner.
- **CUPEM. Immunotherapy research.** The immunotherapy trial – CUPEM – led by Dr Wasan has recruited its first patients at Hammersmith Hospital. There are two other planned sites in London: the Royal Marsden and Guy’s and St Thomas’. It is possible additional sites may come on stream at a later date. *CUP Foundation-Jo’s friends* has contributed significant funding towards this trial with a research grant of £100,000 in 2018 that aims 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. The target is for 70-80 patients.
- **CUPISCO.** The *Roche* trial (some 87 sites in 23 countries) continues to gain momentum. 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. The trial started with 8 centres in the UK and this is now being expanded. Recruitment in the UK began in Autumn 2018. Meeting the strict criteria of the trial protocol means that there is a high attrition rate of some 40-50% of patients and only about 100 patients were accepted onto the trial by June 2019.

- **Circulating Tumour Cell research.** We have made a research grant of £27,950 this year to the Manchester Institute who are investigating the viability of liquid biopsies in relation to CUP. The grant is to characterise CUP tumours molecularly to gain greater understanding of their biology and behaviour.

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 2019.

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 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: *Dolby Developments, Barrett Developments, PayPal Giving Fund, Cee Jay Project Management.*

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 2019 the charity's reserves, in its interest-bearing account, stand at £300,000 (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: CRUK Manchester Institute of £27,950 for research into circulating tumour cells; £5352.51 to Sue Ryder for R&D in relation to Patient Decision Aids; and we have used £7,107.26 in this FY to run CUP 2019 – our international conference (This is the net figure. Overall expenditure of £17,374.46 being offset by £10,267.20 conference fees collected and later refunded by SBK. Some costs fell into the previous FY and the actual cost of putting on CUP 2019 was in the region of £12,000).

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 kindly agreed (16 May 2019) to the trustees invitation to continue his role with the charity as the Independent Examiner.

Approved by the Trustees at their meeting on 19 November 2019 and signed on their behalf by:

Barry Hamilton
Chairman

John Symons
Director

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

Receipts & Payments Account for the year ended 1st October 2019

	2019	2018
	£	£
INCOMING RESOURCES		
Voluntary income	52,790.67	47,537.80
Activities for generating funds	26,029.72	7,723.42
Investment income	1810.84	769.43
	<u>80,631.23</u>	<u>56,030.65</u>
RESOURCES EXPENDED		
Costs of generating voluntary income	1,934.70	1,904.13
Cost of charitable activities	3,134.94	6,562.89
Research grants	33,302.51	100,000.00
Conference costs	17,374.46	4,380.00
Governance costs	495.28	201.65
Computer costs, printing and stationery	592.07	944.06
	<u>56,833.96</u>	<u>113,992.73</u>
Net receipts	23,797.27	(57,962.08)
Bank balances at 2nd October 2018	291,065.14	349,027.22
Bank balances at 1st October 2019	<u>£314,862.41</u>	<u>£291,065.14</u>

Statement of assets and liabilities at 1st October 2019

Monetary Assets

Bank balance	14,862.41	6,065.14
COIF Charities Deposit Fund	300,000.00	285,000.00
	<u>£314,862.41</u>	<u>£291,065.14</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 1st October 2019 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