

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

ANNUAL REPORT AND ACCOUNTS

FOR THE YEAR ENDED

1 OCTOBER 2022

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 2022

The Trustees are pleased to present their report, together with the financial accounts of the charity, for the year ending 1 October 2022. This is the 15th 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

Daily life has continued to be affected by the peaks and troughs of the CV-19 Pandemic which has continued throughout the year. As the country learns to live with the virus, both cancer treatment and cancer research have picked-up. Oncology departments have worked hard to begin to clear patient backlogs but, inevitably, the Pandemic has taken its toll on the NHS’s capabilities. England’s National Cancer Patient Experience Survey of 2021 (published in July 2022) covers all cancer patients and extracts of key findings illustrate the Pandemic’s impact on the NHS:

... at various points throughout 2021 there were restrictions in place in terms of services available, visiting, access to facilities, hygiene protocols and many more aspects of care ... Respondents often felt support from their GP did not meet their expectations... Concerns included that initial symptoms were not taken seriously resulting in delayed diagnosis; and there was a lack of proactive follow-up by the GP after diagnosis and/or treatment... Communication between hospitals and departments was perceived as problematic by several respondents. This resulted in treatment delays.

The 10 year Cancer Plan (and we have been one of many contributors), which should have been signed-off by the Secretary of State for Health, has been a casualty of the rapid turnover of Government ministers in the Autumn of 2022.

Advances in research

CUP research has resumed at pace and we show more detail on page 11. But, and there always seem to be ‘buts’ where CUP is concerned, there are no significant new major trials in the pipeline. An important trial, CUPISCO, closes in October 2022. We are unlikely to see another trial of the size and scope of Roche’s worldwide trial in the foreseeable future. Hopefully, some initial findings will be available in 2023 including an assessment of the potential of immunotherapy for treating CUP patients.

Advances in CUP are encouraging – never more so than when they originate in the UK. We have given financial support to oncologist Dr Alicia-Marie Conway who has been undertaking PhD research at Manchester under the supervision of Dr. Natalie Cook. She has been focussing on multi-modal blood-based circulating free DNA (cfDNA) profiling in patients with CUP. Patients gain significant benefits if CUP can be diagnosed using a simple blood biopsy rather than a tissue

biopsy. If this can be achieved, then multiple biopsies can also stratify and track mutations of the disease without the stress of invasive tissue biopsies. In the conclusion of her research, she writes:

I have demonstrated the clinical feasibility of using a multi-modal cfDNA profiling approach to predict tissue-of-origin and identify targetable molecular alterations from a single blood draw in patients with CUP. This approach overcomes the challenge of the scarcity of tissue in patients with CUP and could potentially negate the need for a repeat invasive biopsy for molecular profiling.

Dr Cook's CUP researchers, including Dr Conway, at the Christie in Manchester have also made the interesting finding this year, from a retrospective study, that a third of patients with liver-involved CUP (Intrahepatic cholangiocarcinoma) could have been reclassified as bile duct cancer patients. Putting CUP patients on a site specific pathway leads to increased treatment options and a better prognosis.

Mark Stares and colleagues at the Edinburgh Cancer Centre have shown the value of prognostic biomarkers. In a study using the data of 1049 patients they demonstrated that biomarkers of systemic inflammation reliably predict outcomes for CUP patients.

Impact and engagement

Whilst this has been a quiet year for the charity in comparison with pre-Pandemic years we have continued to engage with clinicians and researchers in different ways. The webinar with two experts of our Advisory Board – Drs Greco and Wasan - proved extremely popular (see page 10).

It is always difficult to measure the impact we have, year on year, as a charity amongst our different publics. The website hits are shown on page 9 but this is a very imperfect measure of patient and carer engagement. The Pandemic has changed the nature of sharing knowledge in meetings and conferences but interaction has been made possible through the media of *Zoom* and *Teams*. Much of the work by the Director is spent in engaging with others. Sometimes with patients or their loved ones; sometimes in committees such as the NCRI CUP Group; sometimes at conferences; and sometimes trying to communicate with organisations such as NICE and the NHS to represent CUP patients' interests.

Communicating with organisations such as NICE and the NHS is invariably frustrating as they are not over-responsive. We have tried to engage with NICE to drive their evaluation of whether there should be a review of the 2010 NICE Guideline – we believe it important that there is a full review. There are no signs yet that a review will be considered.

Research into practice

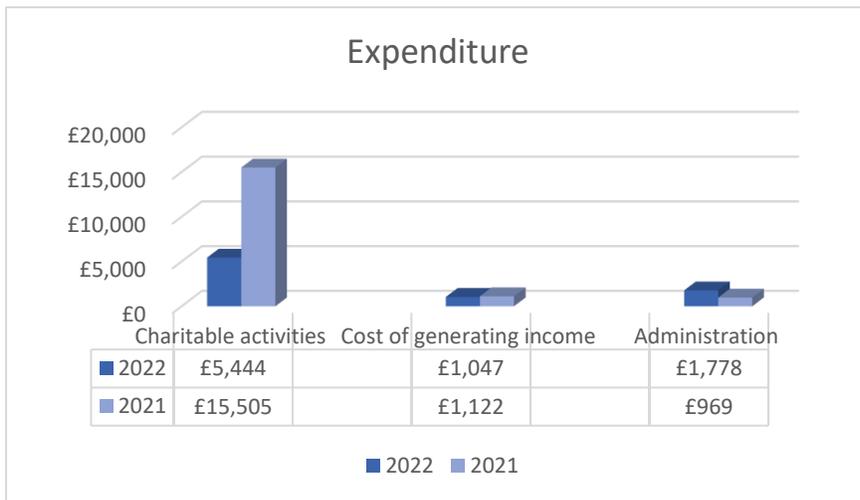
NHS patients in England are starting to benefit from the incredible scientific advances in genomic medicine and the introduction of genetic sequencing of patients and their tissue for certain conditions. We have promoted the use of genomic profiling for CUP patients since the charity's inception. This year we have been engaged with the *NHS National Genomic Medicine Service* in a frustrating exchange to try to ensure that CUP patients have access to Whole Genome Sequencing (WGS). Following considerable confusion, Professor Dame Sue Hill, Chief Scientific Officer for England and SRO for NHS Genomics stepped in, in late September, to advise us that:

CUP WGS in all ages and in upfront testing will be included in the Test Directory in the 31st October 2022 publication as a standalone referral indication (M226.4). Samples in this setting are already being submitted for WGS either via the paediatric cancer route or as M232.1 – solid tumours which have exhausted standard of care testing. As CUP primary tumour site is not identified then SOC has been exhausted and therefore are eligible. We know that samples are being submitted across the country.

In theory, clinicians in England are now able to request whole genome sequencing (WGS) for their CUP patients. This is potentially highly significant but how it works in practice remains to be seen. We are working with the Royal College of Pathologists to ensure that the process is included in their ‘dataset’.

Financial summary

As to finance: 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. Although income is markedly below pre-Pandemic levels, we are well cushioned by our reserves and able to continue our work of ‘making the unknown, known’. We have seen a further drop in income in comparison with 2021 and 2020. This is unsurprising given the negative force of the Pandemic on fundraising activities. (In 2019 income was £80,631 which illustrates the impact of the Pandemic).



Administrative costs remain low ensuring that monies donated to us are available to help address our objectives. The main expenditure this year has been £3,000 for a webinar with Dr Tony Greco being interviewed by Dr Harpreet Wasan.

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. It should be noted that we are *not* a charity whose focus is solely to raise funds for medical research although we remain 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 with a research interest in liquid biomarkers in CUP; Chief Investigator for the CUP-COMP trial; and a Principal Investigator on CUPISCO.

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 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.

Professor Penelope Schofield BSc (Hons) PhD MAPS is Professor of Health Psychology, Swinburne University of Technology. She is also Honorary Principal Research Fellow, Department of Cancer Experiences Research, Peter MacCallum Cancer Centre, Melbourne, Australia, where she is leading the 'SUPER' research on CUP.

Dr Harpreet S. Wasan MD MBBS PhD FRCP is a Consultant and Reader in Medical Oncology at Imperial College London, and the Department of Cancer Medicine, Hammersmith Hospital. Dr Wasan leads the CUP-One trial and has recently instigated the CUPem 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.

Emeritus Board Members

Dr Maurice L. Slevin MD FRCP. Founding Director of The London Oncology Clinic (now Leaders in Oncology Care); co-founder CancerBackup, (now merged with Macmillan Cancer Support).

Dr Richard J. Osborne MD FRCP FRACP. Lead Clinician for the development of the NICE Guideline for CUP.

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 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. We have also a closed FaceBook Group for mutual support.
- 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. We organise conferences and seminars on a regular basis.

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.

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' and in 2021/2 the focus has been on improving clinical knowledge enabled through on-line study steered by the Director.

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 some 2% of cancer diagnoses in the UK (the 15th commonest). It has been estimated by CRUK that 1 in 64 people will be diagnosed with CUP during their lifetime.

Table 1: Average UK CUP Incidence & Mortality Data source: CRUK @ 02/10/22			
CUP incidence UK (average 2016-2018)– 8,589 persons			
England	Scotland	Wales	N. Ireland
7063	788	541	197
CUP mortality UK (average 2017-2019) – 9,495 persons			
7877	801	589	228

CUP is the 15th most frequent cancer diagnosis and the 6th commonest cause of cancer death in the UK (measured by ICD-10 codes C77-80). Broken down by gender, it is the 4th commonest cause of death for females and 6th for males. Every day of the year in the UK about 20 people are diagnosed, and about 26 people die, from CUP.

However, in the period since the charity was formed in 2007 CUP incidence and mortality rates have decreased by about a third (35%) in the UK. CUP data, kindly provided by CRUK has undergone a change of format making yearly comparison more complicated. The figures from 2006 to 2018 are shown at Table 2.

Table 2. UK CUP incidence and mortality (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	8,589	9,775
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

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 often possible from the biopsy sample which will help determine likely treatment. But in the case of CUP, because the cells have lost their unique features in the cancer spread, identifying the original cancer cells (the target of chemotherapy) is difficult.
- The biology of CUP is not understood, other than that the primary, which may originate in any epithelial cells in the body, spreads unpredictably when very small. The primary

tumour may even disappear after it has spread. This makes it 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'.
- 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.
- 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.

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 offer - 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. Patient Decision Aids which we created with *Sue Ryder* are available for download from our website.

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.

Table 3: Website Statistics for FY 20/21 (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	393	378	268	22	95	12	2.51	1.4
Nov	346	326	194	21	123	15	2.50	1.2
Dec	622	606	187	19	356	70	2.64	1.6
Jan	680	663	231	27	410	15	1.31	1.8
Feb	762	743	264	33	457	19	1.5	1.9
Mar	1147	1130	250	357	532	18	1.3	1.9
Apr	1590	1435	170	884	525	23	1.0	1.9
May	820	794	215	36	564	27	1.48	2
Jun	1094	895	284	362	520	6	1.14	1.8
Jul	1148	916	310	385	433	30	0.52	1.8
Aug	970	942	373	29	540	13	1.46	1.83
Sep	881	855	351	38	495	12	1.44	1.88

Note: 'Acquisition' should logically total 'visits' but it doesn't. It is in the region and serves to give an idea of trends.

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. This has grown to over 150 users in 2021.

Metrics. The figures for this year show a drop in the number of overall visits to our site in comparison with last year: 10,453 compared with 11,685 (whilst it was in the region of 22,000 pre Pandemic.). Website hits are very imperfect measures of performance, and it is difficult to interpret variations, but they give some indications. 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.

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 significant expenditure beyond our current resources. 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 raise awareness, often in conjunction with fundraising and we pursue opportunities to promote knowledge and awareness as they arise.

Awareness Week (AW). We have made the last full week of September each year our 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 social media. As with September 2021, our colleagues *SJK Foundation* (Ireland), and *Missie Tumor Onbekend* (the Netherlands) organised 'World CUP Awareness Week' in September 2022. Webinars this year included contributions from three of our advisory Board members: Dr Natalie Cook, Dr Tony Greco and Professor Penny Schofield.

Promoting improved treatment and the end of CUP

The use of computer-mediated technology has allowed a considerable amount of work to continue during the Pandemic lockdowns of the last three years.

On 21 June we organised a webinar entitled 'Cancer of the Unknown Primary: is the unknown now known' with Dr Tony Greco in conversation with Dr Harpreet Wasan – both members of our Advisory Board. The event was managed by SBK who achieved an impressive 400 registrations. 96% of those who attended on the day rated the event *excellent* or *very good*.

Examples of delegate comments on the Greco – Wasan webinar of 21 June

Clear information, good dialogue between participants, up to date information •Excellent discussion between two specialists in Cancer of Unknown Primary giving some history of CUP, the current knowledge of CUP as well as looking at what the future might hold for these patients. •Exciting •Fascinating and informative •Good clear speakers. •Informative and engaging •Insightful and very well run session •It set the current stage and identified the future ways in which we will determine tumour origin and bespoke SACT for the individual. •It was very informative and really highlighted the complexity of CUP patients and treatments •Nice short chunk to fit into your clinical day •Really good insight into what CUP means, treatment, research and future of CUP. •The format of question and answer was unique and most useful. •Very well presented, informative, thought provoking and discussion was very clear and structured. Thank you and very enjoyable! •Well delivered, organised and informative •Absolutely fantastic thank you •All were clear and concise when talking about this topic which can be extremely complex. Very informative and interesting to hear briefly about the current research that is ongoing •Fantastic all round. •Really engaging, appropriate level of dialogue •Very informative with a wealth of knowledge and experience •Well-constructed - I liked the flow •Brilliant •Cannot believe the hour went so quickly! •Despite short run time, managed to cover a lot of ground, Q&A format worked much better than a lecture would have •Just to thank you for your time and effort in making this webinar, much appreciated •Really great meeting. Thank you.

Undertaking or supporting CUP research

Shown below are updates on 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.
- **CUPem.** This is a three year Phase II trial looking at the potential benefits of immunotherapy treatment at, initially, three London centres. The trial, led by Dr Wasan, investigates whether giving *Pembrolizumab* to patients with CUP (recruitment target of 77 patients) works better than giving standard chemotherapy. The initial cohort target – for patients who have already received chemotherapy – was reached in November 2020 and recruitment to the second cohort - those who have not received chemotherapy - has continued through 2022.
- **CUPISCO.** The *Roche* trial (some 87 sites in 23 countries including 10 centres in the UK) has been handicapped by the Coronavirus pandemic. In the UK, the trial re-started in late August and recruitment was extended to Autumn 2022. 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.** PhD research by Dr Conway at the Manchester Biomedical Research Centre, for which we have contributed funds, has concluded this year. The research was focused on multi-modal blood-based circulating free DNA (cfDNA) profiling in patients with CUP. By her research Dr Conway has demonstrated the clinical feasibility of using a multi-modal cfDNA profiling approach to predict tissue-of-origin and identify targetable molecular alterations from a single blood draw in patients with CUP. This approach overcomes the challenge of the scarcity of tissue in patients with CUP and could potentially negate the need for repeat biopsies.
- **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. 150 patients from across the UK are being recruited and recruitment began in June 2021 at 7 UK centres and will end in Spring 2023. 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.
- **Intratumoural Microbiome in CUP.** In 2021 we made a research grant to Imperial College, London to analyse the Intratumoural Microbiome in CUP and exploring diagnostic and biomarker utility. The researchers are collaborating with the Weizmann Institute to characterise the tumour specific bacteria present in an expanded range of different cancer types. By correlating the microbiome signature with therapy outcomes, it is hoped to identify the effect that intratumoural bacteria may have on therapy efficacy as well as identifying whether CUP has a distinct intratumoural signature. To date, insufficient tumour samples have been acquired and the research will continue into 2023.

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 2022.

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. The trustees are minded to take all steps necessary to ensure that the Charity's 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. We have received also corporate and trust donations this year from the following organisations for which we are truly grateful: *Dolby Developments Ltd, Coupland Cardiff Asset Management, Morton Charitable Trust, and Ribble Packaging.*

In the light of bad press in 2015 about charity fundraising techniques, 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 doorstep 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 2022 the charity's reserves in total stand at £370,000 (with £133,000 invested in the COIF Charities Global Equity Income Fund and £237,000 in the COIF Charities Deposit Fund). 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 disburse only meaningful amounts that contribute to the Charity's objectives and 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 paid SBK £3,000 to manage the webinar with Dr Tony Greco
- We continue to spend money on maintaining and enhancing our website which is our primary 'route to market'.

Administrative 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. 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 kindly agreed to continue as the Independent Examiner and he was formally re-appointed at the August 2022 Trustees meeting.

Approved by the Trustees at their meeting on 14 November 2022 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 2022

	2022	2021
	£	£
INCOMING RESOURCES		
Voluntary income	26,846.16	36,689.52
Activities for generating funds	2,055.15	6,489.26
Investment income	1,149.34	41.25
	<u>30,050.65</u>	<u>43,220.03</u>
RESOURCES EXPENDED		
Costs of generating voluntary income	1,047.11	1,122.86
Cost of charitable activities	2,443.85	2,620.29
Research grants		
Imperial College	0.00	9,890.00
Conference costs	3,000.00	2,994.00
Governance costs	904.64	220.15
Computer costs, printing and stationery	873.30	749.43
	<u>8,268.90</u>	<u>17,596.73</u>
Net receipts	21,781.75	25,623.30
Bank balances and investments at 2 October 2021	367,116.67	341,493.37
Bank balances and investments at 1 October 2022	<u>£388,898.42</u>	<u>£367,116.67</u>
Statement of assets and liabilities at 1 October 2022		
Monetary assets		
Bank balance	18,898.42	32,116.67
COIF Charities Deposit Fund	237,000.00	335,000.00
COIF Charities Global Equity Income Fund	133,000.00	
Net assets	<u>£388,898.42</u>	<u>£367,116.67</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 2022 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