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

ANNUAL REPORT AND ACCOUNTS

FOR THE YEAR ENDED

**1 OCTOBER 2021**

**Registered Charity Number: 1119380**

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

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

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

**ANNUAL REPORT FOR THE YEAR ENDED 1 OCTOBER 2021**

The Trustees are pleased to present their report, together with the financial accounts of the charity, for the year ending 1 October 2021. This is the 14th 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

## The year’s highlights

The year has been dominated by the Coronavirus (or more properly, SARS-CoV-2) Pandemic. Cancer treatment and cancer research have suffered grievously in 2020 and 2021.

Patients, concerned that they might have cancer, have often been unable to access their GPs to initiate investigation. Rapid investigation and treatment are essential for cancer patients. Oncology departments have done their best to maintain their services but at the peaks of the crisis many consultant oncologists and CUP Clinical Nurse Specialists (CNSs) found themselves re-purposed, undertaking emergency duties in Covid wards. For much of 2020, cancer research ground to a halt but it has gradually picked-up in 2021 and Oncology departments have been doing all they can to restore the *status quo ante*. We have joined with other cancer charities in an open, published, letter to encourage the Government to reflect on the Pandemic’s impact on cancer services and promote action.

The Pandemic has encouraged wide recognition that, despite a surprisingly resilient economy, the UK does not have a sufficiently resilient healthcare service for ordinary, let alone extraordinary, times. Even before Covid, cancer services were under considerable strain. The 62-day Cancer Waiting Time target for patients to begin treatment following an urgent GP cancer referral in England has not been met since December 2015. Not only has the target been missed, but it has been in continual decline since 2017, showing a service under increasing pressure.

As Lockdown started to ease in 2021, the NHS has been left with a huge backlog. Estimates of the backlog range between 10 and 13 million cases and, in the judgement of Sir Simon Stevens, in July 2021, the departing head of the NHS, this will take 3 years to clear. Hospital beds are an example of where the NHS is restricted and emergency levels of occupancy during the Pandemic drove extreme measures to avoid overwhelming the service. In 1975 the NHS had 8 beds per 1,000 of the population which has reduced to 1.8 in 2020/21 (alongside Spain, the lowest in Europe).

We have argued before that, despite outstanding doctors, nurses and scientists, the NHS is a broken model long overdue for a sustainable long term fix. Despite the dictum that the NHS is ‘free’ for patients, every taxpayer pays for the service. What is needed is a new funding and payment model perhaps in line with many European countries health care systems: social insurance via hypothecated taxes; or compulsive, progressive, private insurance charges. This topic is far too controversial for political engagement and can only be addressed initially by a Royal Commission.

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 has dropped significantly, we are well cushioned by our reserves and able to continue our work of ‘making the unknown, known’. Events of note in this year (explored further on pages 10 -12) are:

* The start of patient recruitment in June 2021 to a comparative study across tissue and liquid biomarkers for CUP led by Dr Natalie Cook of our Advisory Board: CUP-COMP
* The webinar in April 2021entitled ‘Enhancing Referral and Management of MUO/CUP Patients’. The webinar was led by Dr Sarah Ngan, Consultant in Medical Oncology, Guy’s and St Thomas’ NHS Foundation Trust and member of our Advisory Board. The event was managed by SBK. There were an impressive 259 registrations with 149 attendees on the day.
* The Trustees agreed a grant of £32,390 to researchers at Imperial College, London (to be paid in 2 tranches with the second tranche dependent on the success of the first phase). Working with the Weizmann Institute in Israel, to characterise retrospectively CUP tumour samples in order to understand the intratumoural microbiome and determine if CUP has a distinct microbiome signature.
* The continuation of Roche’s CUPISCO trial at 10 UK sites and the extension of the trial’s end date beyond December 2021.

One sad event to report is that, in November, the Charity’s website was brought down by some malicious person, or persons, unknown who managed to enter the website through a ‘back door’ in order to corrupt it. Resolution Design sprang into action with their website hosting company in the USA. Working night and day it was possible to bring the site back on-line and erode the damage after some three or four days.

There is nothing on our website of any commercial value to whoever attacked it. Resolution Design reported that they have experienced attacks on charity and church websites. All possible precautions have been taken to try and avoid a recurrence from some very sick person or persons.

## Financial summary

The accounts on page 16 show a drop in income for 2021 in comparison with 2020. (In 2019 income was £80,631 which shows the impact of the Pandemic). This is unsurprising given the negative force of the Pandemic on fundraising activities.

Fundraising activities began to pick up in the late Spring of 2021 and it is thanks to our generous monthly donors, in particular, that our income is as high as it is.

Administrative costs remain low ensuring that monies donated to us are available to help address our objectives. The main expenditure this year has been £2,994 for a virtual CUP seminar, and a £9,890 initial grant to Imperial College, London to begin research exploring intratumoural microbiome signatures in CUP.

Our financial aim is always to achieve sufficient funds to cover our modest operating costs and to build healthy reserves to fund our conferences and seminars whilst being in a position to make appropriate research grants. (See page 5 for our objectives.) It should be noted that we are *not* a charity whose focus is solely to raise funds for medical research although we are keen to support clinical research where there is clear potential benefit for CUP patients.

**ORGANISATIONAL STRUCTURE, GOVERNANCE AND MANAGEMENT**

**TRUSTEES**

**Barry Hamilton** B.Soc.Sc. MBA.

*(Chairman)*

**John Symons** MBE TD MA MSc MEd PhD.

(*Director)*

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

**Kate Fulton** BSc (Hons).

**Philippa McEwan** BA (Hons).

**ADVISORY BOARD**

Medical

**Dr Natalie Cook** MBChB, MRCP, PhDis 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](http://www.cupfoundjo.org)). This site offers information on CUP, its diagnosis and treatment. *Jo’s friends* does not offer medical advice. Exceptionally, we may refer queries to a qualified clinician. 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*isa 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 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.

|  |  |  |  |
| --- | --- | --- | --- |
| **Table 1: Average UK CUP Incidence & Mortality** Data source: CRUK @ 01/10/21 | | | |
| **CUP incidence UK (average 2016-2018)– 8,589 persons** | | | |
| England | Scotland | Wales | N. Ireland |
| 7063 | 788 | 541 | 197 |
| **CUP mortality UK (2018) – 9,775 persons** | | | |
| 8106 | 816 | 607 | 206 |

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 2-3% of cancer diagnoses in the UK although the actual figure depends on how CUP is defined. It has been estimated by CRUK that 1 in 64 people will be diagnosed with CUP during their lifetime.

CUP is the 15th most frequent cancer diagnosis (unchanged) and the 6th (down from 5th in our last report) commonest cause of cancer death in the UK (measured by ICD-10 codes C77-80). 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, along with stomach cancer, has shown the fastest decrease in incidence in both males and females of all cancer types over this period.

CUP is a heterogeneous disease unified by a challenging diagnosis. Usually, the most important step in diagnosis is the [biopsy](http://www.cupfoundjo.org/diagnosis_and_treatment/hospital_diagnosis.html) because this allows a general cancer categorisation of carcinoma, sarcoma, lymphoma or melanoma. Most CUP definitions are of metastatic [*carcinoma*](http://www.cupfoundjo.org/research_and_resources/dictionaryofterms.html) 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](http://www.cupfoundjo.org/diagnosis_and_treatment/classifications.html) 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](http://www.cupfoundjo.org/research_and_resources/dictionaryofterms.html) 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’.

|  |  |  |
| --- | --- | --- |
| **Table 2. UK CUP incidence and mortality** (ICD-10 C77-80).  Data from NCIN/ NCRAS & CRUK distilled from ONS | | |
| Year | *Incidence*  (No. of new cases) | *Mortality*  (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 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 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.

**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](http://www.cupfoundjo.org). In September 2019 we instigated a closed group in FaceBook (FB) to allow *CUP patients and carers* to share experiences. This has grown to over 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.

**57% of patients diagnosed with CUP in the UK (9% of all cancer cases) present as an emergency**

NCIN Routes to Diagnosis study, 2014.

***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.

**Awareness Week Webinars**

CUP Initiatives & research in Australia

Prof. Linda Mileshkin,

Prof. Richard Tothill,

Prof. Penelope Schofield

CUP initiatives & research in the UK

Dr. Natalie Cook,

Dr Kai-Keen Shiu,

Dr. Alicia-Marie Conway,

Dr. Mark Stares,

Dr Mark Lythgoe

Update on the CUPISCO trial

Prof. Chantal Pauli,

Prof. Alwin Kramer,

Dr. Tilmann Bochtler,

Maria Pouyiourou

Innovative diagnostics for CUP

Dr. Phil Febbo,

Piarella Peralta,

Edwin Cuppen,

Léon van Kempen

CUP initiatives & research in the Netherlands

Warnyta Minnaard,

Caroline Loef,

Fatameh Kazemzadeh

Karlijn Hermans,

Dr. Petur Snaebjornsson

CUP research: the Future?

Dr Manel Esteller,

Dr Faisal Mahmood,

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

Wider general public awareness, particularly local awareness, is achieved through supporters undertaking events.We are very grateful to all those who 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.

In September 2021 we joined forces with other CUP charities for a ‘World CUP Awareness Week: *SJK Foundation* (Ireland), and *Missie Tumor Onbekend* (the Netherlands). Each day there was a live webinar with expert international speakers. The technical support came from Ireland and was made possible by sponsorship from *Roche* and *Illumina*. Whilst patients and carers were welcome to attend, the sessions effectively enabled a sharing of research initiatives amongst researchers. In the absence of face to face conferences in the last year this proved a valuable opportunity.

***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 2020/21. For example:

# On 15 Jan 2021 our friends in the SJK Foundation in Dublin organised a global symposium and the Director addressed the topic ‘What next for CUP?’

# The Director was on the panel for an NCRI webinar on 6 May 2021 ‘Cancers of unknown primary – challenges and opportunities’.

* On 29 Apr 2021 we organised a webinar entitled ‘Enhancing Referral and Management of MUO/CUP Patients’. The webinar was led by Dr Sarah Ngan, Consultant in Medical Oncology, Guy’s and St Thomas’ NHS Foundation Trust and member of our Advisory Board. The event was managed by SBK who achieved an impressive 259 registrations with 149 attendees on the day.

**Delegate comments on** *Enhancing Referral and Management of MUO/CUP Patients*

• Extremely informative many thanks • Great speakers. Informative session. • Helpful summary of recent advances and also to have an idea of MUO/ CUP service in other regions • I do not have much experience in CUP however I really enjoyed the talk and it was easy to follow. • Informative, up to date and very useful • Informative, interesting, engaging • Interesting and informative • Interesting subject. • Interesting to hear other hospitals perspective on this • Really informative, excellent speakers • The ability to listen/attend webinars remotely is a fantastic development • Very good and informative • Very good insight into the various work that is going in towards better diagnosis and better treatment option for CUP/MUO patients • Very informative • Very informative • Very informative background and challenges of CUP MUO service • very interesting - the work up for a MUO patient and the development of an MUO/CUP MDT • Very useful and practically applicable to CUP services • well organised, easy access would have liked a longer session• Excellent overview of what is changing. • Excellent overview of what the current issues are in CUP, and challenges faced • Great support from CUP foundation to support webinars like this as so difficult to get to study days otherwise • Really good, made things easy to understand thank you. Very informative • Very good • Wealth of knowledge in CUP information • well presented, clear information.

***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 2021.
* **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 will be extended to 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**In previous years we have made research grants towards this exciting project at the CRUK Manchester Institute and the research continues to investigate the viability of liquid biopsies in relation to CUP, and to characterise CUP tumours molecularly in order to gain greater understanding of their biology and behaviour.
* **CUP-COMP**. This is a comparative study across tissue and liquid biomarkers for CUP led by Dr Natalie Cook of The Christie NHS Foundation Trust. 150 patients from across the UK will be recruited and recruitment began in June 2021 at 7 UK centres. 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 characterising 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.

**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 July 2021.

***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, CCAM Asia Ltd, Ribble Packaging* and *PayPal Giving Fund.*

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 2021 the charity’s reserves, in its interest-bearing account, stand at £335,000 (with sufficient working capital held in the current account). The charity has no other financial investments. Cash flow and reserves are monitored by the Director and reviewed at each quarterly Trustees meeting. All funds in this financial year are unrestricted. In considering the reserves policy the Trustees have taken a number of factors into consideration. The Charity was financed initially by a gift from the founding Director which met the start-up costs. The Charity has since raised sufficient funds each year to meet its low operating costs and has built reserves to (a) allow operational flexibility, and (b) to build a ‘war chest’ in order to be in a position to fund, or contribute to, research and associated projects that meet our charitable objectives. (Clinical research involves multi million pound investments but smaller amounts that could have a significant impact on partly funded projects are actively considered by the Trustees).

Whilst *CUP Foundation - Jo’s friends* is not unique in the small charity sector, it is unusual in that it is run without salaries, office expenses etc. whilst achieving considerable impact. The Risk Matrix, which is reviewed annually, recognises the significant risk to the charity in the event of the Director’s long term incapacity. The Trustees are resolved to (a) maintain reserves that permit the Charity to be sustained in the event of the voluntary Director’s incapacity, and (b) to disburse only 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 made a payment to Imperial College, London of £9,890 (as part of an overall grant of £32,390) to research the intratumoural microbiome in CUP.
* We paid SBK £2,994 to organise the webinar ‘Enhancing Referral and Management of MUO/CUP Patients’ for those working in the UK’s CUP teams.
* 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 July 2021 Trustees meeting.

Approved by the Trustees at their meeting on 18 November 2021 and signed on their behalf by:

Barry Hamilton John Symons

Chairman Director

|  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | | **CANCER OF UNKNOWN PRIMARY FOUNDATION – JO’S FRIENDS** | | | | | | | |
| **Receipts & Payments Account for the year ended 1st October 2021** | | | | | | | |  |  |
|  |  | |  |  |  |  |  | **2021** | **2020** |
|  |  | |  |  |  |  |  |  | £ |
| **INCOMING RESOURCES** | | | |  |  |  |  |  |  |
|  |  | |  |  |  |  |  |  |  |
| Voluntary income | | |  |  |  |  |  | 36,689.52 | 33,272.49 |
|  |  | |  |  |  |  |  |  |  |
| Activities for generating funds | | | | | |  |  | 6,489.26 | 16,394.51 |
|  |  | |  |  |  |  |  |  |  |
| Investment income | | |  |  |  |  |  | 41.25 | 1,274.34 |
|  |  | |  |  |  |  |  | 43,220.03 | 50,941.34 |
| **RESOURCES EXPENDED** | | | |  |  |  |  |  |  |
|  |  | |  |  |  |  |  |  |  |
| Costs of generating voluntary income | | | | |  |  |  | 1,122.86 | 762.30 |
|  |  | |  |  |  |  |  |  |  |
| Cost of charitable activities | | | |  |  |  |  | 2,620.29 | 3,383.86 |
| Research grants | | | | | |  |  |  |  |
|  | The Christie NHS | | |  |  |  |  |  | 16,218.00 |
|  | Imperial College | | |  |  |  |  | 9,890.00 |  |
|  | | |  |  |  |  |  |  |  |
| Conference costs | | |  |  |  |  |  | 2,994.00 | 3,120.00 |
|  |  | |  |  |  |  |  |  |  |
| Governance costs | | |  |  |  |  |  | 220.15 | 418.19 |
|  |  | |  |  |  |  |  |  |  |
| Computer costs, printing and stationery | | | | |  |  |  | 749.43 | 408.03 |
|  |  | |  |  |  |  |  |  |  |
|  |  | |  |  |  |  |  | 17,596.73 | 24,310.38 |
|  |  | |  |  |  |  |  |  |  |
| Net receipts | | |  |  |  |  |  | 25,623.30 | 26,630.96 |
|  |  | |  |  |  |  |  |  |  |
| Bank balances at 2 October 2020 | | | | |  |  |  | 341,493.37 | 314,862.41 |
|  |  | |  |  |  |  |  |  |  |
| Bank balances at 1 October 2021 | | | | |  |  |  | £367,116.67 | £341,493.37 |
|  |  | |  |  |  |  |  |  |  |
| **Statement of assets and liabilities at 1 October 2021** | | | | | | |  |  |  |
|  |  | |  |  |  |  |  |  |  |
| Monetary assets | | |  |  |  |  |  |  |  |
|  |  | |  |  |  |  |  |  |  |
| Bank balance | | |  |  |  |  |  | 32,116.67 | 6,493.37 |
| COIF Charities Deposit Fund | | | |  |  |  |  | 335,000.00 | 335,000.00 |
|  |  | |  |  |  |  |  |  |  |
| Net assets | | |  |  |  |  |  | £367,116.67 | £341,493.37 |

**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 2021 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:

1. examine the accounts under section 145 of the 2011 Act,
2. 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
3. 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:

1. to keep proper accounting records in accordance with section 130 of the 2011 Act; and
2. 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