

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

ANNUAL REPORT

FOR THE YEAR ENDED

1 OCTOBER 2015

Registered Charity Number: 1119380

Registered office:

The Follies, Brightwalton, Newbury, Berks. RG20 7BZ

www.cupfoundjo.org

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

ANNUAL REPORT FOR THE YEAR ENDED 1 OCTOBER 2015

The Trustees are pleased to present their report, together with the financial accounts of the charity, for the year ending 1 October 2015. This is the eighth 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 & 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

The highlights of the year, that have significant potential for achieving our ultimate goal of seeing the end of CUP by 2020 (‘making the unknown known’) and improving patient care in the meantime, have been:

- **CUP-One.** The CRUK - funded trial, led by Dr Wasan, finished recruiting in December 2014 with 624 patients accrued. The significance of the study lies in its quest to validate new diagnostic tools that may identify the primary site simply, rather than impose a barrage of investigations on the CUP patient with little benefit. Analysis of the data is under way.
- **CUP 2015.** Much of the year has been spent preparing for our third triennial international conference: *Improving Patient Management and Outcomes*. On 24 September 140 delegates packed the Seligman Theatre of the Royal College of Physicians to listen to the latest scientific research from around the world, and to discuss the opportunities and challenges of running CUP Multi Disciplinary Teams (MDTs) in England.
- **100K Genome Project.** We reported last year that CUP was on the ‘considered’ list for the 100K Genome Project after an On/Off approach the previous year. The Chief Scientist of the project spoke at CUP 2015 and advised that a small allocation has been made to CUP. He threw down a challenge to the CUP community to propose research and funding to unlock a greater allocation.
- **Patient experience research.** At CUP 2015 we launched the report prepared by Southampton University that we funded on patient experience: *Experiences of Care of Patients with Cancer of Unknown Primary (CUP): Analysis of the 2010, 2011-12 & 2013 Cancer Patient Experience Survey*. Understanding patient experience is vital in helping determine appropriate service models for CUP patients and to monitor performance.
- **New GP referral guideline for suspected cancer.** The National Institute for Health and Care Excellence (NICE) has launched new guidelines for the suspected signs of cancer. This may be a step forward for our patients. It often takes many visits to the GP for those with uncertain cancer symptoms to get a referral and we welcome anything that improves the likelihood of early diagnosis. Only time will tell how transformative the new guideline is for CUP patients in comparison with the previous (2005) version.

- **Peer Review.** The process of Peer Review, where the efficiency of hospital CUP teams (and, of course, site specific cancer sites) is assessed, has been under threat as the NHS strives to save money. It has been agreed that the work is to continue and funding has been allocated to enable this. Peer Review has driven hospitals to be more compliant with the NICE Guideline on CUP and has played an important part in improving CUP patient management in the last few years through Internal Validation (External Validation starts in 2016).
- **New 5 year cancer strategy for the NHS.** An independent task force, led by CRUK, have delivered a proposed strategy with a remit to improve survival rates, quality of life and patient experience. The recommendations include a ‘molecular diagnostics service’ which if implemented could be significant for CUP patients. Time will tell how much, and how effectively, government implement the new cancer strategy recommendations.

Further details expanding the bullet points are given later in the report.

Financial summary. We need sufficient funds to cover our modest operating costs and we aim also to build healthy reserves to fund our conferences and seminars and to make appropriate research grants, which can leverage our objectives. (See page 4 for our objectives.) It should be noted that we are *not* a charity whose focus is specifically to raise funds for medical research. A study of the accounts on page 16 will show that, stripping-out the research grant we made last year, our income and expenditure is broadly similar to FY 2013/14. The major item of expenditure in this financial year was CUP 2015 which took place a week before our year end. Some further costs (e.g. international speaker airfares) will fall into FY 2015/16.

ORGANISATIONAL STRUCTURE, GOVERNANCE AND MANAGEMENT

TRUSTEES

Barry Hamilton B.Soc.Sc. MBA.

(Chairman)

John Symons MBE TD MA MSc MEd PhD. *(Retired by rotation and re-appointed June 2015)*

(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. (*Retired by rotation and re-appointed June 2015*)

Dr Osborne is a Consultant in Medical Oncology at the Dorset Cancer Centre. He has been the Lead Clinician for the development of the NICE Guideline on CUP.

Professor Penelope Schofield BSc (Hons) PhD MAPS

Professor Schofield is professor of Health Psychology, Swinburne University of Technology; and Honorary Principle Research Fellow, Department of Cancer Experiences Research, Peter MacCallum Cancer Centre, Melbourne, Australia, where she is leading the ‘SUPER’ research. SUPER is designed to describe the clinical heterogeneity of patients assigned the broad label of CUP, establishing the frequency of genetic mutations in tumours and defining quality of life and psychosocial issues unique to these patients.

Dr Maurice L. Slevin MD FRCP.

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

Dr Harpreet S. Wasan MD MBBS PhD FRCP.

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

Non Medical

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

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

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

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

Volunteers. We are most grateful for the support of those who volunteer their services for a particular project or, like **Malcolm Glenn**, our graphic designer, and **Jill Foulds**, our Conference and Administration Manager, help us throughout the year. Thanks go also to our external examiner, **Roger Newnham**, for his *pro bono* work.

HISTORY

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

OBJECTIVES AND ACTIVITIES

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

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

It achieves these objectives primarily through:

- The website (www.cupfoundjo.org). This site offers information on CUP, its diagnosis and treatment. It also has a moderated interactive area where patients and family members can discuss issues of concern and seek emotional support from ‘comrades in adversity’. *Jo’s friends* does not offer medical advice. Exceptionally we may refer queries to a qualified clinician.
- Activities such as awareness-raising events, journal articles and association with other organisations that can help leverage the charity’s objectives.
- Promoting or participating in research – oriented activities and facilitating networks of those working in the area of CUP.

Transformational change. The Trustees set the year 2020 as the target to work towards to see the end of CUP: our ‘2020 vision’. At *CUP 2015* Dr Greco proposed that it was technically already possible to identify 95% of primary sites and that the ‘unknown was now known’. The challenge remains to bring the science into practice for NHS patients in the UK and for those in less developed countries.

GOVERNANCE

Governing Document

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

Appointment of Trustees and Advisory Board Members

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

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

Training and Activity of Trustees

Trustees and Advisory Board Members are recruited for their specific skills and experience and their enthusiasm for the charity. On appointment, Trustees receive a booklet on the duties and responsibilities of a trustee, published by the Charity Commission. Training for Trustees is conducted through ‘Away days’ and Trustees meetings where topics include learning about cancer issues as well as matters related to the running of the charity. Quarterly Trustees Meetings were held as normal and an Away Day was held in June. The Away Day focused on the strategic options in relation to our 2020 Vision.

The guest speaker was James Luscombe, Digital Director of PanMacmillan who addressed the challenges of engaging people of different age groups with new media. Board effectiveness was also discussed following a review process, and options for brand evolution were discussed.

WHAT IS CANCER OF UNKNOWN PRIMARY (CUP)?

CUP is where a patient has been diagnosed as having cancer 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 3-5% of cancer diagnoses in the UK; but the actual figure depends on how CUP is defined. CUP represents one of the ten most frequent cancer diagnoses and the 5th commonest cause of cancer death in the UK (CRUK mortality data for 2012 using ICD-10 codes C77-80).

CUP is the 5th commonest cause of cancer death in the UK

Encouragingly, CUP incidence has fallen by over 30% (39% in males and 34% in females), in absolute numbers, since the mid 1990s through better diagnosis. The publication of both incidence and mortality figures follows a 2-3 year time lag but, sadly, it is safe to say that in this FY some 9-10,000 people in the UK will be diagnosed with CUP and a larger number will die with CUP. The most recent figures (2012) are shown in Tables 1 & 2. Using this data, simple mathematics illustrates the impact of CUP all too starkly:

Every day of the year in the UK 30 people *die*, from CUP

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

Table 2: UK CUP Incidence & Mortality 2012 (2011) by gender and country
Data source: NCIN/ CRUK

CUP incidence				
	England	Scotland	Wales	N. Ireland
Male	3730 (3718)	402 (293)	259 (363)	95 (108)
Female	4235 (4366)	463 (341)	311 (459)	125 (114)
CUP mortality				
Male	4189 (4211)	367 (319)	291 (359)	111 (104)
Female	4687 (898)	454 (363)	392 (422)	134 (136)

unknown primary where (unlike sarcoma, lymphoma and melanoma) further definitions are needed to achieve effective treatment.

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

Table 1. UK CUP incidence and mortality 1996-2012 (ICD-10 C77-80).
Data from NCIN & CRUK based on ONS stats

Year	Incidence (No. of new cases)	Mortality (No. of deaths)
2012	9,620	10,625
2011	9,762	10,812
2010	9,585	10,472
2008	10,752	11,228
2006	11,566	12,267
2004	12,640	13,288
2002	13,428	14,058
2000	14,013	14,559
1998	14,972	15,259
1996	15,838	15,024

ACTIVITIES, ACHIEVEMENTS AND PERFORMANCE MEASURES (NON FINANCIAL)

Activities of the last financial year

We turn now to the last year's activities in relation to each Objective.

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

In terms of providing 'information', our website is the primary vehicle although we provide also leaflets, mainly to hospitals. Our web-based service continues to acquire many new users from around the world and the relevant statistics are shown in Table 3. Last year we undertook a complete 'refresh' of the website – the first in 7 years – and this has been very well received. The site is now compatible with phones and tablets and has improved navigation. Taking March to

May 2015 as an example, 65% of all hits were made from a desktop; 23% from a mobile; and 12% by a tablet. 53% of all hits were from the UK. Of all hits, 54% were made by women; only 5.5% of all hits were from people aged 65 and over (the highest age groups for CUP incidence).

The interactive forum for patients and carers has not been very active but many patients and carers continue to contact the charity directly for advice.

Table 3: Website Statistics for FY 14/15 (Data from Google Analytics)

	Hits		Acquisition				Behaviour	
	Visits	First timers	Direct traffic	Referring sites	Search engines	Social media	Time on site (mins)	Page views
Oct	995	691	236	218	486	55	3.4	3.5
Nov	820	594	176	166	471	6	3	2.6
Dec	765	558	172	174	411	7	3	3.3
Jan	934	657	189	223	491	31	3.2	3.2
Feb	1244	873	321	271	565	87	3.1	3
Mar	1314	998	255	364	667	28	2.3	2.6
Apr	1293	1028	211	324	644	114	2.2	3
May	1712	1344	381	640	678	13	2.1	2.4
Jun	1847	1486	278	864	696	8	1.5	2.3
Jul	1679	1281	403	406	765	105	2.3	2.6
Aug	1203	933	244	303	637	18	2.3	3.3
Sep	1631	1096	351	295	935	50	3	4.6
Tot:	15437	11539						

The total figures for FY 14/15 show 15,437 visits of which 11539 were new to the site. This is 22% increase in total visits, and a 41% increase of first timers, to the site in comparison with FY2013/14. Social media is becoming increasingly important both in terms of accessing the site and on Facebook where ‘likes’ exceeded 500 for the first time in 2015. These are very imperfect measures of performance but they do give an indication of the increasing reach of the charity and its significance.

Those seeking information about CUP may route 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. The 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 rewarding or concerning comments from users, such as these examples from the last year:

I just want to say thank you for helping my friend when she needed something other than a friend.

My wife and I used to read this website ... There is such little info available about CUP. So thank you so much for doing a great job about educating others. I've been practicing medicine since my early 20's and I had never heard of it [CUP].

I just wanted to email to say what a fantastic website this is. My mum was also called Jo (Joanne) and died of CUP with brain mets aged 49 4 years ago now. I really struggled at the time with the unknown and wish I had known about this website. I'm a nurse and since all this I have gone into

oncology and now work as an acute oncology specialist nurse I hope to recommend the site to our CUP patients.

...when the oncology team could not locate the source of Paul's cancer, it was through information on [this] site that we were able to at least find others in the same position and, further, to find access to information on the newer science around Molecular/Gene Profiling. In our case, tragically, Paul's cancer was left undiagnosed and untreated for a number of months and then because of the lack of information as to its origin, underwent a very harsh regime of standard 'domestos-type' chemo... It was only late on in the scheme of things that we paid privately for a molecular test to be done which gave a 96% chance that the cancer was of 'renal' origin. Sadly by this time Paul had very little time left ... We lost Paul less than 7 months after learning that he had a tumour in his pelvic area It's been a very painful and hard road this past 2 and a half years but I feel grateful for the fact that the CUP Foundation's site was there and able to help us feel 'less alone in the storm'.

I just wanted to say thank you for providing this website. My mother [posted] after she was diagnosed with CUP in Sept 2011. It was so nice to be able to go back & read what she posted. She unfortunately lost her battle to CUP on June 11, 2013. The autopsy found that she had pancreatic cancer. I know this website was a source of comfort during her battle with the unknown, and I am forever grateful that she found y'all.

Our Nursing team monitors CUP patients as soon as they are admitted to hospital and have found your leaflets extremely helpful and reader-friendly for patients.

...It has been my experience to date that if your Oncologist does not understand 'Cups' you are at a great disadvantage and have to fight your corner very hard. Luckily for me I am strong enough to do this, but not all patients are..... Thanks for all your great work and for creating such an informative and supportive website.

As an oncologist treating numerous patients with the diagnosis of CUP and as a lead clinician of CUP MDT and CUP network group, I greatly value the work of Jo's friends for this group of patients and your personal effort in setting up the CUP meetings. I am also very impressed by the Jo's friends website which is a very useful resource for patients, carers and health professionals.

Raising awareness of CUP

Raising awareness of a disease that has had a very low profile is a precursor of stimulating demand for change, particularly through research, and for raising funds. The website is a vehicle for raising awareness of CUP particularly amongst patients and carers. Our website explains CUP, what we are doing, and what we want others to do. Wider general public awareness, particularly local awareness, is raised through supporters undertaking events and grasping opportunities. We are very grateful to all those who raise awareness, often in conjunction with fundraising, and often by someone who has been affected CUP.

There can be little doubt that awareness of CUP amongst the medical and research communities has risen exponentially in recent years. Awareness amongst the general public remains low but to achieve a rapid and dramatic shift would require vast expenditure. We continue to take small steps through our supporters, mostly in local communities where a person has been affected by CUP.

Awareness Week. We have made the last week of September our Awareness Week. In 2015 we repeated the '10 X More' campaign, begun in 2013, of asking supporters to *make 10 times more people aware of CUP*. This is done by selling lapel badges and wristbands and other individual activities. The formula allows considerable funds to be raised by generous people paying more than the RRP for badges and band of £1 each. The most significant event of Awareness Week in 2015 was our conference, *CUP 2015*, on 24 September.

Promoting improved treatment and the end of CUP

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 without definitive symptoms and the nature of CUP is that the symptoms are usually very non specific. In 2015 the National Institute for Health and Care Excellence (NICE) launched new guidelines for the suspected signs of cancer. The new Guideline takes a 'symptoms approach' but remains very focused on site specificity. We welcome anything that improves the likelihood of early diagnosis. Only time will tell how transformative the new guideline is for CUP patients in comparison with the previous (2005) version.

Peer Review Measures for CUP. The Peer Review Measures for CUP, based on the NICE Guideline of July 2010, were launched by the National Cancer Action Team on 24 October 2012. This means that hospitals treating CUP patients in England from 2013 are audited or self audited for compliance with the Measures. The latest, 2013/14, data for internal validation and self-assessment show 144 hospitals in England putting in returns (up from 130 hospitals the previous year). Compliance is very patchy. The PHE Quality Surveillance team (previously Peer Review Programme) show that, by Network, London and Wessex are 100% compliant with the South West being less than 10% compliant and other networks ranging in-between. Looking at individual hospitals there are few that are 100% compliant and some that have not initiated a CUP team at all. Only 30% of the country has a lead CUP clinician and core team in place. Eight 'Immediate risks' were reported and 41 'Serious concerns' (from no functional MDT to lack of: cover, robust pathways, good practice).

Conferences.

It is encouraging that other organisations are now including CUP in conferences and seminars. The Royal Society of Medicine included a session as part of a seminar on Acute Oncology in January 2015, and the Christie Hospital in Manchester have included it as a future seminar topic. The largest annual UK oncology conference – the Oncology Forum – included a lengthy session on CUP in June 2015 (and *Jo's friends* Director was one of the invited speakers).

On 24 Sep 2015 we held our third triennial international conference: *Improving Patient Management and Outcomes*. We filled the Seligman theatre at the Royal College of Physicians with 140 delegates. The majority were from the UK but we had also representation from America, Australia, and a number of European countries. Very encouragingly, nearly half the delegates were CUP Cancer Nurse Specialists (CNSs). CUP CNSs' are highly valued by patients and have been introduced following the NICE Guideline in July 2010. The majority of the delegates were oncologists.

In comparison with CUP 2009 and CUP 2012 the mood of CUP 2015 was very up-beat. Chairman Dr Tony Greco from the USA identified that it should be technically possible to diagnose the primary site in 95% of CUP patients through molecular profiling and immunohistochemistry. (The adoption of scientific advances moves slowly however, particularly in the UK. What is possible and what happens are very different things.). For patients in England it was clear that the 2010 NICE Guideline was having a significant impact on improved service delivery and that Peer Review would drive further improvements for the CUP patient.

The day was well received by the audience. Feedback forms showed that 93% regarded the day as either *useful or extremely useful*; the content of the programme overall was viewed as *excellent or very good* by 90% of respondents; and the speakers overall were considered by 93% of respondents to be *very good or excellent*.

Dr Greco – the world-leading authority on CUP – summarised after the event: *‘I found the meeting to be state of the art and expect changes eventually for the better for most CUP patients.’* We have received many, many other positive comments – some remarking on the new mood of optimism amongst the CUP community – a few of which are shown below:

- ..an inspiring and stimulating day...[the] CUP team left enthused to keep improving the care for our CUP patients
- The programme was well planned and the speakers excellent.
- ..the mood of confidence, feeling valued, and feeling validated was palpable, and a great sign for the future.
- ..a terrific conference. You can be very proud of your achievements in CUP not only in the UK but beyond.
- You’ve done a brilliant job at mobilising the front line community to improve care options for patients.
- Thank you once again for everything you have done for the CUP community. It is recognised and greatly appreciated.
- Congratulations on an amazing conference.
- The progress made since 2009 has been inspiring!
- I thoroughly enjoyed the day and left feeling that progress is finally being made.

Undertaking or supporting CUP research

Patient Experience Research with Southampton University. In the last FY we made a grant of £10,573 for a study to mine the qualitative comments of CUP patients who contributed to the national Cancer Patient Experience Surveys. The Cancer Patient Experience Survey conducted by the DoH offers us an insight into cancer patients’ experiences from which we can argue authoritatively for change. Some key findings of the report *Exploration and analysis of free-text comments from respondents with Cancer of Unknown Primary (CUP) to the 2010, 2011-12 & 2013 Cancer Patient Experience Survey (CPES) England* are shown below:

- **Inadequate communication within and between NHS agencies reduced coordination of care.** Analysis of coded data found a high level of poor experiences of communication between different health sectors (e.g. primary and secondary), different providers (e.g. trusts), and between different hospital departments and health professionals within the same trust. Patients with advanced cancer and cancer of unknown primary will often have treatment across a number of clinical teams and multi-disciplinary teams (MDTs), and if they do not communicate well with one another patients will experience care that is not seamless. Coordination could be particularly poor between different hospital trusts and between secondary and primary care, with frequent reports by patients that their GPs were unaware of their cancer treatment.
- **Clinical teams working in ‘silos’.** Due to the problems respondents experienced with regards a lack of intra-agency communication, and the comments of a number of respondents about clinicians treating ‘only a part of their bodies’ and not ‘the whole person’, there was a perception that they were not concerned with a holistic view of the patient as a person. Again, this is of particular concern for patients with CUP who will frequently be transferred between clinical teams and MDTs.
- **Poor intra-agency communication can lead to delays in investigations and treatments or else duplication of tests.** Many comments described delays occurring when their care was referred to other clinical teams and investigation reports were often misfiled, lost, or were not available at outpatient clinic appointments. Such lack of coordination appeared to lead to delays to treatment and created greater anxiety for patients.
- **Poor intra-agency communication could lead to a lack of continuity of care.** Continuity of care involves management and relational continuity. However, in addition to clinical teams reportedly working in silos and information not being passed between clinical teams, respondents often also reflected on the large number of health professionals they came into contact with and the concern that no-one appeared to have overall responsibility for their care, which caused further anxiety.
- **Poor communication between health professionals and clinical teams could lead to patients receiving conflicting information.** Some clinicians were unaware of investigations for which their colleagues in other teams had referred respondents, and consequently a few respondents reported receiving conflicting information from different health professionals, thus undermining confidence in their care.
- **The importance of access to a clinical nurse specialist (CNS) was emphasised.** Many respondents described their experiences with clinical nurse specialists (CNSs), and these comments were overwhelmingly positive. Many described the importance of a CNS as a point of contact who provided information and explanations in terms they could understand, and were very important in helping patients have trust in their care. Almost all negative comments concerning CNSs related to a lack of access to one, and often this was blamed upon economic constraints and cost cuts.
- **The importance of the manner in which health professionals interact with patients and their families.** Respondents frequently described the manner in which health professionals interacted with them, whether they conveyed a caring and attentive attitude that put patients at ease and generated confidence in their care, or whether they did not. Many patients reported positive experiences where they were treated as a ‘person’ or ‘a human being’ rather than ‘a set of symptoms’.

- **The manner in which participants were informed of their diagnosis by health professionals could have significant impact upon their emotional and psychological wellbeing.** The manner in which health professionals informed patients of their diagnosis featured strongly in the data, and is a theme that is closely related to the emotional needs of patients. Respondents who provided positive comments describing the way they were informed reported being treated respectfully and courteously, with some form of hope being conveyed by health professionals. Poor experiences of being informed of their diagnosis included being emotionally unprepared, being told too abruptly and brusquely, often on crowded wards, by doctors surrounded by colleagues, with only a simple drawn curtain to protect their privacy.
- **The importance of hope.** Part of being treated as a human being by staff involved reassurance of hope in the future. Hope was important for patients even though their prognosis was poor, and could take the form of assurance that they would be able to enjoy a period with some quality of life.
- **The need for patient preparation.** The need to be prepared for the effects of cancer and its treatment was a latent theme that ran through many coded semantic themes. Preparation primarily meant being provided with information concerning the possible treatment side effects that might affect them and advice about self-management strategies that would address these problems.
- **The prevalence of delays by GPs in referring participants for investigations or specialist consultations.** Comments often indicated months and sometimes years of presentation to GP services with cancer symptoms before diagnosis and/or referral. Delays for investigations, secondary referral and treatment were often reportedly caused through ‘misdiagnosis’, with GPs either treating patients symptomatically or relating symptoms to a health problem other than cancer. Comments suggested that many instances of delayed diagnosis could have been prevented had GPs more often taken the concerns of their patients seriously. Many participants with a diagnosis of CUP indicated their belief that their treatment options and prognosis might have been improved had their symptoms been recognised by GPs earlier.
- **Unmet emotional needs:** Outstanding psychological needs primarily concerned fears around diagnosis, treatment options and side-effects, prognosis and uncertainty about the future. Some respondents gave positive comments relating to support services or reflected a desire for more information on support services. However, the majority of comments indicated that staff could most effectively meet participants’ emotional needs in the main phases of the cancer journey with improved communication skills and sensitivity from staff. In many cases emotional needs were related to the importance of staff conveying a sense of hope, however limited a participant’s life expectancy. While emotional problems were described throughout the patient journey, problems were most frequently reported to be acute once active treatment had been completed.

Whilst, perhaps, many of these findings might apply to a study of site specific cancers, the nature of CUP is such that it amplifies patient concerns. The lengthy and comprehensive report can be accessed in full from the Research section of our website.

FINANCIAL STATEMENTS AND PERFORMANCE

Statement of Principles and Financial Management Policies Adopted

It is the policy of the charity to maintain effective financial management systems and programmes, to improve continually financial operations and systems and to identify more efficient methods of operations regarding accounting and financial reporting. In the reporting period there were no contracts from central or local government to deliver services, nor grants from central or local government. The Charity is staffed by volunteers and no payments were made to staff or trustees other than the reimbursement of expenses. The Trustees reviewed the Charity's financial controls at their quarterly meeting in June 2015. On the recommendation of Roger Newnham, an 'anxiety receiver' was appointed to allow anyone with concerns to raise them other than through the management line of Director and Chairman.

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.

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

Jo's friends aims to secure the funding it needs to achieve its objectives through a variety of sources. A small core group of Supporters raise funds and awareness and support the sales of cards, wristbands and badges. As the charity has become better known funds are increasingly raised by donations received *in memoriam* from funerals in memory of those who have died from CUP. The principal sources of funds lie in the challenge activities undertaken by our supporters many of whom do so in memory of a friend or loved one.

We have received a significant grant this year from the *Sandra Charitable Trust*. We receive also occasional donations from a range of associations, and fellowships. For all this support we are truly grateful.

In the light of bad press in 2015 about charity fundraising, and the consequent amendment to the Charities Act, it is worth recording that: *Jo's friends* does not partake in unsolicited cold-calling, face-to-face or door step fundraising, either directly or through partnership with any external fundraising agencies. *Jo's friends* seeks to engage supporters in our work and maintain, through an electronic 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 2014 *Jo's friends* reserves, in its interest-bearing account, remains unchanged at £164,000. Some £47,000 is available in the current account at year end. Because of the timing of CUP 2015, and to facilitate rapid payments, this unusually high amount was retained in the current account. The surplus will be transferred early in FY 2015/16 leaving only sufficient working capital in the current account. The charity has no other financial investments. Cash flow and reserves are monitored 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 *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 visited by the Trustees annually, recognises the significant risk to the Charity in the event of the Director's long term incapacity. In the event that the Charity was required to appoint a salaried Director with associated support and offices, the annual running costs would be likely to rise from negligible to an estimated 20% of income. Consequently, the Trustees are resolved to (a) maintain reserves that permit the Charity to be sustained in the event of the voluntary Director's incapacity, and (b) to only disburse meaningful amounts that contribute to the Charity's objectives that represent value for money.

How Expenditure has supported the Charity's Key Objectives

The major item of expenditure has been CUP 2015, as described. Whereas our seminar – CUP 2014 – was largely funded by sponsors and resulted in a surplus, the trustees took the view that CUP 2015 would be self-funded to avoid the difficulties of meeting sponsor demands. This event brought together the international clinical-scientific CUP community as well as UK oncologists and nurses. It is the only international CUP conference held in the world and probably, ahead of any other activity, contributes the most to 'the end of CUP'. 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'. 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 costs for some train travel by the Director. However, it should be noted that the overall administrative costs are artificially low as the charity is run from the volunteer Director's house and no charge is made presently for rent, heat, telephone, light, car travel etc.

Future Plans

The Trustees have referred to the guidance contained in the Charity Commission’s general guidance on public benefit when considering future plans. *Jo’s friends* will seek to influence through planned activities where it is possible but the reality is likely to be a mixture of planned activities and opportunism. Opportunism in the sense of making the most of circumstantial opportunities outside the charity’s control as they arise. As Shakespeare has Brutus say: ‘We must take the current when it serves, or lose our ventures’.

Independent Examiner

A resolution proposing the re-appointment of Roger Newnham FCA as the Independent Examiner to the Charity was approved by the Trustees at their meeting on 17 August 2015.

Approved by the Trustees at their meeting on 19 November 2015 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 2015

	2015	2014
INCOMING RESOURCES		
Voluntary income	44,895.35	30,421.95
Activities for generating funds	20,971.80	27,045.83
Investment income	543.44	531.15
	<hr/>	<hr/>
	66,410.59	57,998.93
RESOURCES EXPENDED		
Costs of generating voluntary income	3,596.70	3,125.43
Cost of charitable activities	2,747.98	5,810.69
Research grant	0.00	25,573.00
Conference costs	16,603.28	9,055.50
Governance costs	53.40	0.00
Postage & stationery & telephone	547.69	451.81
	<hr/>	<hr/>
	23,549.05	44,016.43
Net receipts	42,861.54	13,982.50
Bank balances at 2nd October 2014	168,045.02	154,062.52
	<hr/>	<hr/>
Bank balances at 1st October 2015	210,906.56	168,045.02
Statement of assets and liabilities at 1st October 2015		
Monetary Assets		
Bank balance	46,906.56	4,045.02
COIF Charities Deposit Fund	164,000.00	164,000.00
	<hr/>	<hr/>
	210,906.56	168,045.02

**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 2015 shown on page 16.

Respective responsibilities of the trustees and the examiner

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

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

It is my responsibility to:

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

Basis of independent examiner's report

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

Independent examiner's statement

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

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

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