

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

ANNUAL REPORT

FOR THE YEAR ENDED

**1 OCTOBER 2016**

**Registered Charity Number: 1119380**

Registered office:

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

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

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

## ANNUAL REPORT FOR THE YEAR ENDED 1 OCTOBER 2016

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The Trustees are pleased to present their report, together with the financial accounts of the charity, for the year ending 1 October 2016. This is the ninth 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:

- **Peer Review.** The process of Peer Review, where the compliance of hospital CUP teams with the measures designed to ensure their effective operation is assessed, has taken place throughout 2016 – this year with external peer review led by the Quality Surveillance Team.
- **CUP-One.** The analysis of the data from the CUP-One trial led by Dr Wasan has continued this year and results are expected in 2017.
- **Grants.** Major grants have been approved by the trustees to support work on immunotherapy treatment for CUP patients and to initiate a Patient Decision Aid for CUP patients.
- **Inclusion of CUP in the 100K Genomes Project.** Genomics England has announced the inclusion of CUP in this innovative project.

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 3 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 13 will show a rise in voluntary income of 74%. Administrative costs remain close to zero ensuring that monies donated to us are available to help achieve our charitable objectives. Expenditure in this financial year includes some conference costs (e.g. international speaker airfares) for CUP 2015 which took place a week before our last financial year end.

## **ORGANISATIONAL STRUCTURE, GOVERNANCE AND MANAGEMENT**

### **TRUSTEES**

**Barry Hamilton** B.Soc.Sc. MBA. (*Retired by rotation and re-appointed May 2015*)  
(*Chairman*)

**John Symons** MBE TD MA MSc MEd PhD.  
(*Director*)

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

**Kate Fulton** BSc (Hons).

**Philippa McEwan** BA (Hons).

### **ADVISORY BOARD**

#### Medical

**Dr F. Anthony Greco** MD.

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

**Dr Richard J. Osborne** MD FRCP.

Dr Osborne works as Senior Staff Specialist in Medical Oncology in the newly established Cancer Care facility at Hervey Bay Hospital, Queensland. Until 2016 he was Consultant in Medical Oncology at the Dorset Cancer Centre. He was the Lead Clinician involved in development of the NICE Guideline for CUP. During his career Dr Osborne has been awarded an ICRF Clinical Research Fellowship, NCI-EORTC Research Fellowship and a Fulbright Senior Scholarship.

**Professor Penelope Schofield** BSc (Hons) PhD MAPS

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

**Dr Maurice L. Slevin** MD FRCP.

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

**Dr Harpreet S. Wasan** MD MBBS PhD FRCP.

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

#### Non Medical

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

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

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

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

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

## **HISTORY**

*Jo's friends* was established in memory of Jo Symons who died with CUP in September 2006 a few days after her 46th birthday. To her family and friends it seemed incomprehensible that, in the 21<sup>st</sup> 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](http://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 as well as 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’; the last Away Day was held in 2015. Quarterly Trustees Meetings were held as normal throughout the year.

## 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

<b>Table 1: UK CUP Incidence &amp; Mortality 2013 (2012)</b>				
<b>by gender and country</b>				
Data source: CRUK @ Jan 2016				
<b>CUP incidence UK – 9,274 persons</b>				
	England	Scotland	Wales	N. Ireland
Male	3636 (3730)	375 (402)	258 (259)	103 (95)
Female	4021 (4235)	460 (463)	306 (311)	115 (125)
<b>CUP mortality UK – 10,406 persons</b>				
Male	4171 (4189)	357 (367)	293 (291)	81 (111)
Female	4612 (4687)	443 (454)	338 (392)	111 (134)

life and at *post mortem*. Incidence is some 3% of cancer diagnoses in the UK; but the actual figure depends on how CUP is defined. **CUP is the 11<sup>th</sup> most frequent cancer diagnosis and the 5<sup>th</sup> commonest cause of cancer death in the UK** (CRUK mortality data for 2013 using ICD-10 codes C77-80). **Every day of the year in the UK about 30 people die, from CUP.**

Encouragingly, **CUP incidence has fallen by over 37% in absolute numbers in the past 20 years, through better diagnosis. Mortality has fallen by 28%.** 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 data are shown in Tables 1 and 2.

CUP is a heterogeneous disease unified by a challenging diagnosis. Usually, the most important step in diagnosis is the biopsy because this allows a general cancer categorisation of carcinoma, sarcoma, lymphoma or melanoma. Most CUP definitions are of metastatic *carcinoma* of unknown primary where (unlike sarcoma, lymphoma and melanoma) further definitions are needed to achieve effective treatment.

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

**Table 2. 20 year UK CUP incidence and mortality** (ICD-10 C77-80). Data from NCIN & CRUK using ONS

Year	Incidence (No. of new cases)	Mortality (No. of deaths)
2013	9,274	10,406
2012	9,620	10,625
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
1993	14,693	14,420

- Improving genetic, pathological and radiological techniques will reduce the incidence of CUP in the future.

## ACTIVITIES, ACHIEVEMENTS AND PERFORMANCE MEASURES (NON FINANCIAL)

### Activities of the last financial year

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

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

Our website is the primary medium for providing 'information' but we offer also leaflets, mainly to hospitals. *Macmillan Cancer Support* produce and distribute an information booklet on CUP which is widely available. We initiated this brochure (with *Cancer Backup* which is now absorbed within *Macmillan*) and contribute to each update. An update has been prepared in 2016.

*Firstly I would like to thank you for this wonderful website, it provided huge support to me & my sisters when our youngest sister was diagnosed with CUP aged just 31, she died 18 months after diagnosis following up to 18 rounds of chemotherapy and weeks of radiotherapy. Your website gave us so much information and at last was somewhere to find others whom were suffering with this horrendous diagnosis. For my sister suffering with CUP she didn't 'belong' to any other groups e.g. breast, ovarian cancer support groups as we didn't know where the cancer originated, which felt like another injustice on top of everything else. I can see the work your foundation is doing in leading the way in providing awareness and research in this area, and I am inspired by the amazing work your organization has accomplished and continues to do. (July 2016)*

Our web-based service continues to acquire many new users from around the world and the relevant statistics are shown in Table 3. 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. The Forum has been subject to many and various 'spam' invasions and this has meant that we have had to re-set it twice. This has inevitably impacted on the critical mass of users that we had achieved some years ago. *Macmillan Cancer Support* has also introduced a CUP forum, supported by their nursing staff, which has made them the 'go to' forum.

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](http://www.cupfoundjo.org). There is no other resource in the world that can rival the information about CUP, its management, treatment and research. 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 donations from users.

**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	1399	1025	304	207	881	7	2.5	2.8
Nov	1459	1023	368	215	812	27	2.2	2.5
Dec	1170	932	236	189	723	12	2.3	2.5
Jan	1462	1146	286	276	881	7	2.39	2.6
Feb	1306	1050	305	94	884	23	3	2.7
Mar	1509	1185	295	327	871	16	1.5	2.1
Apr	1503	1209	324	365	815	9	1.5	2
May	1689	1353	309	498	870	11	1.5	2
Jun	1671	1340	240	476	951	4	1.46	2
Jul	1636	1261	269	425	935	7	1.45	2
Aug	1431	1148	218	362	830	21	1.28	2.1
Sep	2059	1564	340	572	1008	139	1.48	2.3
Tot	18294	14236						

The total figures for FY 14/15 show 18294 visits of which 14236 were new to the site. This is a 19 % increase in total visits, and a 23% increase of first timers, to the site in comparison with FY2014/15. 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.

### ***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. We continue to pursue opportunities to promote knowledge and awareness. On 2 February 2016 the Royal College of Physicians held a ‘teach-in’ for about 150 doctors on Acute Oncology and CUP which was streamed to a wider audience of fellows and members. *Jo’s friends’* Director gave a presentation on CUP epidemiology, diagnosis and patient experience, and Dr Wasan of our Advisory Board spoke to his research in the CUP-One trial.

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 full week of September each year our Awareness Week. In 2016 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 encouraging 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. Awareness is more important than raising funds and much of this is done through FaceBook (FB). This year had a canine sub theme to help promote the week which included photographs of pet dogs with our coloured CUP balloons. This boosted the FB reach to over 1000 and the website received 43% more new visitors than the week before. Shortly ahead of the week, the *Daily Mail* published an article (on 6 Sep 2016) about Karen Lomas’ experiences as a CUP patient. It is helpful when a generous patient, a responsible journalist and an expert CUP oncologist combine to aid the wide readership of the *Mail* in understanding CUP and the suffering faced by patients.

*We as a family are supporting CUP Foundation as this is what took my husband 17 days after getting the official diagnosis. Your slogan ‘making the unknown known’ could not be more true. (Jul 2016)*

### ***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 further without definitive symptoms; but the nature of CUP is that the symptoms are usually non specific.

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 (now re-branded as the Quality Surveillance Team) in October 2012. This means that hospitals treating CUP patients in England from 2013 are audited, or self audited, for compliance with the Measures. In 2013/14, data for internal validation and self- assessment showed 144 hospitals in England putting in returns (up from 130 hospitals the previous year). Compliance was very patchy.

2016 has seen external Peer Review visits of CUP services in hospitals throughout England. The reviews are very thorough and check such things as: the correct composition of the Multi-Disciplinary CUP team and whether the personnel involved have sufficient time in their workloads; the distribution of CUP policy throughout the hospital; the attendance at meetings throughout the year; how well the guidelines and local protocols are working; patient information on CUP; clinical indicators and many other things. The reviews are organised by the Quality Surveillance Team, on behalf of NHS England, and take place over a day. The review team is likely to include an oncologist, a nurse, a manager, a histopathologist and, very importantly, a patient representative.

It is difficult to overstate the value of this external ‘Peer Review’ process in raising the standards of management and treatment of CUP patients throughout England (it only applies to England).

The results, when published, will show how ‘compliant’ each hospital is with the measures. In addition to raising standards nationally, the data will help patients identify top performing CUP teams.

#### Conferences and publications.

SBK Healthcare ran an event on ‘CUP Pathway Development’ on 9 March in Birmingham which *Jo’s friends* supported. This was designed for CUP MDT members from across the country to share experiences of running MUO/CUP teams. A further event is planned for December 2016.

CUP Cancer Nurse Specialist Katy Low gave a presentation at the *Cancer Data and Outcomes Conference 2016* on 14 June in Manchester. The topic, prepared by Katy with John Symons, was: *The impact of the NICE Carcinoma of Unknown Primary (CUP) Guideline in driving service improvements and transforming patient experience.*

*Cancer Australia* published a study in 2016 looking at patient experience: *Comparison of responses to closed questions from patients with a known primary versus unknown primary in the 2013 Cancer Patient Experience Survey (England).* The study team was led by Professor Penny Schofield of our Advisory Board and included *Jo’s friends’* Director.

### ***Undertaking or supporting CUP research***

Patient Decision Aid (PDA). In 2016 the Trustees agreed to fund a research project to devise a Patient Decision Aid (PDA) for patients who have CUP. The purpose of the PDA is to help patients at a difficult time when choosing between therapeutic options. It can be extremely difficult to understand the options and make an informed choice. PDAs can help with this. The research will be led by Dr Paul Perkins, Consultant in Palliative Medicine with Dr David Farrugia, Consultant Medical Oncologist who practice at Gloucestershire Hospitals and *Sue Ryder* Cheltenham. The research process began in Autumn 2016 and *Jo’s friends* is involved.

Inclusion of CUP within the 100K Genomes Project. *Genomics England* has announced that, following internal and external review, the decision has been made to approve the formation of a Cancer of Unknown Primary Clinical Interpretation Partnership (CIP) domain within the 100K Genomes Project. This is an essential step and one that we have been anxiously awaiting since an application was made by Dr Harpreet Wasan following discussions with Prof. Mark Caulfield at our conference in Sep 2015.

Immunotherapy trial. There has been much in the news about the impact of immunotherapy drugs on certain cancer patients. Immunotherapy drugs have been found to be unexpectedly promising in the treatment of late stage lung, pancreas and melanoma patients. Some patients seem to have been ‘cured’, and some have achieved a significant extension of life. This effect was achieved only in cancers where the DNA was ‘hyper mutated’. If hyper mutation is the key, it is difficult to conceive of anything more hyper-mutated than CUP; so a trial to study immunotherapy drugs related to the performance and status of CUP patients in order to predict the likely response of using these drugs could be very interesting. The trustees agreed to commit £100,000 from reserves towards a study that Dr Harpreet Wasan of Hammersmith Hospital is planning to run. Clinical trials are very complex and there are a number of things that need to fall

into place before any trial can start such as agreement from a drug company, peer-review etc. Further funding will be required but our very significant pump-priming contribution will hopefully encourage other major cancer research funders to add their support.

## **FINANCIAL STATEMENTS AND PERFORMANCE**

### ***Statement of Principles and Financial Management Policies Adopted***

It is the policy of the charity to maintain effective financial management systems and programmes, to improve continually financial operations and systems and to identify more efficient methods of operations regarding accounting and financial reporting. In the reporting period there were no contracts from central or local government to deliver services, nor grants from central or local government. The Charity is staffed by volunteers and no payments were made to staff or trustees other than the reimbursement of expenses.

The Financial Statements comply with the requirements of the Statement of Recommended Practice, Accounting and reporting for charities issued by the Charities Commission and are prepared on a *receipts and payments* basis. The Trustees reviewed the Charity's financial controls at their quarterly meeting in Aug 2016.

### ***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 from a variety of sources. Our supporters raise funds and awareness throughout the year. Our annual Awareness Week in September promotes the sale of wristbands and badges and at Christmas time we sell our own cards. The principal sources of funds for the charity lie in memorial gifts and the challenge activities undertaken by our supporters. Significant funds are donated *in memoriam* – usually from funerals in memory of those who have died from CUP. Challenge activities are many and various and this year saw our first officially sponsored runner in the London Marathon. We have received significant corporate and trust donations this year from the following organisations for which we are truly grateful:

Matt's Trust Fund for Cancer  
CSM Sport in memory of Inga Leask  
Poole Hospital

We are very grateful also to Chime Communications for the use of a meeting room for trustees meetings in central London.

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 2016 *Jo's friends* reserves, in its interest-bearing account, stands at £259,000 (a 36% increase on the previous year) with sufficient working capital held 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 items of expenditure relate to CUP 2015 and the £6,102.51 research grant which is the first tranche of payment towards the development of the Patient Decision Aid for 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'. Small items of expenditure included the funding of a CUP Cancer Nurse Specialist's attendance to speak at a conference when her hospital would not provide the funds.

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 16 August 2016.

Approved by the Trustees at their meeting on 22 November 2016 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 2016**

	<b>2016</b>	<b>2015</b>
<b>INCOMING RESOURCES</b>		
Voluntary income	78,157.16	44,895.35
Activities for generating funds	13,404.30	20,971.80
Investment income	884.14	543.44
	<u>92,445.60</u>	<u>66,410.59</u>
<b>RESOURCES EXPENDED</b>		
Costs of generating voluntary income	2,397.81	3,596.70
Cost of charitable activities	4,352.56	2,747.98
Research grant	6,102.51	0.00
Conference costs	3,424.55	16,603.28
Governance costs	0.00	53.40
Postage, stationery & telephone	474.75	547.69
	<u>£16,752.18</u>	<u>£23,549.05</u>
Net receipts	75,693.42	42,861.54
Bank balances at 2nd October 2015	210,906.56	168,045.02
Bank balances at 1st October 2016	<u>£286,599.98</u>	<u>£210,906.56</u>

### **Statement of assets and liabilities at 1<sup>st</sup> October 2016**

Monetary Assets		
Bank balance	26,699.98	46,906.56
Funds with Charities Aid Foundation	£900.00	
COIF Charities Deposit Fund	259,000.00	164,000.00
	<u>£286,599.98</u>	<u>£210,906.56</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 1<sup>st</sup> October 2016 shown on page 13.

**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.  
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