

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

ANNUAL REPORT

FOR THE YEAR ENDED

1 OCTOBER 2014

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 2014

The Trustees are pleased to present their report, together with the financial accounts of the charity, for the year ending 1 October 2014. This is the seventh report of **Cancer of Unknown Primary (CUP) Foundation *Jo’s friends*** since it became a 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 benefit for achieving our ultimate goal of seeing the end of CUP by 2020, have been:

- **Introduction of Peer Review Measures.** Hospitals in England that intended to be compliant with the Peer Review Measures for CUP were required to undertake an initial internal validation of their CUP procedures, including their Multi Disciplinary Team (MTD), in CY 2013. The results, available in 2014, showed 130 functioning CUP MDTs. This means that some 130 NHS Trusts in England, with varying degrees of compliance, now have a recognised route for a possible CUP patient without, as tended to happen previously, bouncing the patient around between site specific teams with no particular expertise in CUP. The Peer Review Measures are based on the 2010 NICE Guideline and, whilst there is still much improvement needed, the CUP patient is starting to receive a far higher level of speedy and effective management.
- **Clinical trials.** Recruitment for the CUP-One trial led by Dr Wasan has now reached its target of 572 and has stopped recruiting. 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. A proposal to Cancer Research UK to fund a follow-up study has not been successful; but discussions continue to be held to try and find ways of continuing CUP research that merge with other international trials and leverage the fast-moving technology of molecular profiling.
- **100K Genome Project.** Last year we reported that the Chief Medical Officer’s scientific priority group had selected CUP as one of the clinical areas where the national 100K Genome Project would be focused. Genomics England, the company created by the Secretary of State for Health subsequently to action the project, rowed back on this commitment and we have undertaken some lobbying this year to ensure CUP is not rusticated; lobbying along the lines of ‘need and benefit’ not just ‘ease of sampling’. The formal NHS position at present is that Ovarian, Lung, Prostate, Colorectal, Breast and CLL are ‘approved’ for the project, with CUP, and some other

cancers, on the 'anticipated to be considered' list. We are not in as good a position as anticipated a year ago, but we are still in the running. At best, the project could unlock the secrets of CUP and will, in the future, improve targeted treatment.

- **CUP 2014.** We ran an international seminar on 'The Management, Treatment and Future Perspectives of CUP' in London on 21 & 22 March. Delegates came from Egypt, Germany, Switzerland, Iraq, Italy, Russia, India, USA, Algeria, Armenia, Portugal, Japan, Greece, Australia, Moldova as well as the four countries of the UK. An expert faculty group was chaired by one of the world's leading authorities on CUP: Professor Nicholas Pavlidis of Greece. Drs Wasan and Osborne of our Advisory Board were co-chairs.
- **Sequencing Project.** We contributed the final tranche of funds to Hammersmith Hospital to complete the £55,000 grant for a molecular profiling pilot project that aims to develop more efficient treatment and management of CUP. The project aims to uncover potential biomarkers (predictive and prognostic) of CUP by utilising clinical tissue samples that show hallmarks of CUP metastasis, where no primary site of cancer is identified. Next generation sequencing will be performed on a subset of the samples as a pilot to help understand the disease and detect potentially "drug-able" mutations. A successful pilot will enable further research.
- **Codifying Project.** The research we initiated into how CUP is being codified by registries has now been completed and the data are being analysed. This novel project has the potential to enhance our accurate understanding of the burden of the disease. Accurate measurements are critical to research and patient management. We are working with the University of New South Wales and Public Health England, and others. Our study has exposed the differences in registration and reporting practices for CUP in Australia, England, Wales, Scotland, N. Ireland, and the Republic of Ireland (all registries in each country participated). The data will be used to identify areas of inconsistency and as an evidence base for recommendations that will allow meaningful international comparisons of CUP incidence.

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 our income is a healthy £57,998.93 and that we have spent £44,016.43. The level of income is variable year by year and the last two year's figures have been swelled by sponsorship and fees for CUP 2014. It is unlikely that we will see income remain at this high level in the next year. The funds disbursed in this reporting year have been distributed predominantly to Hammersmith Hospital for the 'Sequencing Project' and for patient experience research to Southampton University (see page 10 *et seq.*). Through the generosity and endeavours of our supporters, coupled with prudent financial management, we have been able to raise our interest-bearing reserves by £30,000 to £164,000.

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. (Retired by rotation and re-appointed May 2014)

Kate Fulton Bsc (Hons). (Retired by rotation and re-appointed May 2014)

Philippa McEwan BA (Hons). (Retired by rotation and re-appointed May 2014)

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 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.

Associate Professor Penelope Schofield BSc (Hons) PhD MAPS

Dr Schofield is a behavioural scientist. She is the Director of the Department of Cancer Experiences Research at the Peter MacCallum Cancer Centre, Melbourne, Australia and the lead investigator for the Australian national collaborative cohort CUP study, 'SUPER'.

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 was 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. Particular thanks go also to our auditor, **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 unless it comes from 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 have set the year 2020 as the target to work towards to see the end of CUP: our '2020 vision'.

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 but no Away Day was held in FY 2013/14.

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 2010 using ICD-10 codes C77-80).

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

Year	<i>Incidence</i> (No. of new cases)	<i>Mortality</i> (No. of deaths)
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

diagnosed with CUP and a larger number will die with CUP. The most recent figures (2011) 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
27 people are *diagnosed*, and 30 people *die*, with 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 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.

Table 2: UK CUP Incidence & Mortality 2011 by gender and country				
Data source: NCIN/ CRUK				
CUP incidence 2011				
	England	Scotland	Wales	N. Ireland
Male	3718	293	363	108
Female	4366	341	459	114
CUP mortality 2011				
Male	4211	319	359	104
Female	4898	363	422	136

- 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 and Wales. 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.
- 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 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. This service continues to acquire many new users from around the world and the relevant statistics are shown in Table 3. This year we undertook a complete 'refresh' of the website – the first in 7 years. The refresh involved a new platform and a re-write, or re-positioning, of much of the material (at a cost of £3,996 for the new platform and IT technical expertise). The site is now compatible with phones and tablets and has improved navigation as well as an improved research section. For validation, we asked an oncologist unconnected to the charity to review the site and its information:

I've had a look around the new website and I must say it looks very good, with a good balance of accessible information, but not too much to overwhelm the patient/carer, but plenty of in depth links available. From the medical point of view, it looks comprehensive and accurate. I'm very impressed and will continue to direct my patients, relatives and colleagues to it. Dr Simon Grumett PhD FRCP. Clinical Director Oncology and Clinical Haematology, Consultant & Honorary Senior Lecturer in Medical Oncology, Royal Wolverhampton Hospitals NHS Trust & University of Birmingham.

The new interactive forum for patients and carers has been slow to take off. Changing platforms and a new environment is always challenging and the 'blog' that is compatible with the new site is not particularly user-friendly. We will keep under review and consider a further change during the course of next year. Many patients and carers contact the charity directly for advice as they feel more comfortable with a direct approach.

Table 3: Website Statistics for FY 13/14 (Data from Google Analytics)

	Hits		How reached				Behaviour	
	Visits	First timers	Direct traffic	Referring sites	Search engines	Social media	Time on site (mins)	Page views
Oct	1168	820	399	332	408	28	2.3	2.9
Nov	1153	754	282	389	420	61	2.4	3
Dec	979	580	274	384	304	16	3.2	3.2
Jan	1395	1056	319	672	383	21	2.4	2.9
Feb	1468	940	398	337	686	47	4	6
Mar	1591	1023	426	383	688	94	3.1	5
Apr	869	503	226	146	469	27	3.3	3.5
May	960	575	236	196	503	24	3.5	3.6
Jun	695	433	126	170	393	6	3.4	3.6
Jul	734	474	146	156	420	12	3.3	3.6
Aug	748	440	141	173	415	19	3.3	4
Sep	908	562	168	173	511	56	3	3.2
Tot	12,668	8160						

The total figures for FY 13/14 show 12,668 visits of which 8160 were unique. This is consistent with FY 12/13 where there were 12,684 visits of which 9,334 were unique.

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:

Thank you for creating such a brilliant website!

Thank you ... I really do appreciate your massive part in part in helping us to come to understand and not be afraid of questioning the illness and treatments. You and this site are really what I have used as a support measure, the best educational tools possible and this knowledge has helped me to adjust to a level of calm acceptance of CUP, more so than any other form of educational literature or professionals involved in my care. So a real heartfelt thank you.

My daughter found your website upon many a Google search when John was diagnosed and found your support invaluable.

I have only recently found your website which is very informative & only wish I had found it sooner.....This year has been the most horrendous & traumatic experience that I could only have dreamt about in my worst nightmares. We were given very little information on the condition & I feel very let down by both the oncologist and our local GP. There is very little information available It is very much the "unspoken" cancer....

I've never run for charity but when I was asked to join the team I knew I must raise money for Jo's friends as I got so much support 4 years ago when I was caring for my mum who died of CUP.

The website is an excellent resource a 'beacon of light' for me. Thank you for all your efforts.

We should not be complacent. It is estimated that as many as 2/3 of patients dying from CUP do not get post- assessment treatment (NCRI, HB subgroup). It is difficult to offer definitive numbers, but research by CRUK and NCIN in 2014 shows the problem of cancer deaths linked to lower levels of income – put simplistically, the gap between rich and poor is particularly marked in some cancers including CUP. The study shows that Lung cancer is the most statistically significant cancer in terms of the 'deprivation gap' in England between 2006-2010. CUP follows in second place with 1,600 'excess cases'. NCIN data, published in January 2014, show that more than half (57%) of newly diagnosed cases of CUP in England between 2006 and 2010 presented as an emergency compared to 23% for all cancers.

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 awareness, particularly local awareness, is raised through supporters undertaking events and grasping opportunities. One of our key supporters, Gordon Williams, has been active with his MP and with Andrew Burnham MP, Shadow Secretary of State for Health in raising awareness of CUP this year. A number of Parliamentary Questions (PQs) which we prepared were asked in June 2014 by Luciana Berger MP, shadow minister for Public Health. It is always useful to make influential MPs aware and to raise CUP in Parliament. The answers prepared by civil servants in the DoH have been predictable, but not illuminating.

We are very grateful to all those who raise awareness, often in conjunction with fundraising, and often by someone who has been affected CUP. We have some tireless awareness-raisers who undertake events year after year such as Paul Barker and Gordon Williams and his family.

Each edition of our eNews contains examples. To take one: a schools poetry competition was held in Cambridge on 2 April organised by The Stephen Perse Foundation with prizes presented by Sir Andrew Motion. It was held in memory of Megan Young - school alumna, poet and equine vet - who died of CUP at the age of 32 in 2010. Trustee Philippa McEwan spoke about CUP and the work of the charity at the event.

Sadly, it can sometimes take the death of a well-known person to raise awareness in a particular community. For example, Carlo Paganini was well known to many race-goers as a staff member of Ascot Racecourse. He died recently from CUP but not before he was honoured by the racing fraternity. A horse named after him 'What About Carlo' ran in the opening race on Derby Day at Epsom in the Summer of 2014. Carlo was given the honour of presenting the prize for the first race in front of 80,000 people with HM The Queen watching.

Awareness Week. We have made the last week of September our Awareness Week. In 2014 we have 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. In 2014 these activities have included the 'ice bucket' challenge and local media slots such as one on Radio Essex by a CUP specialist nurse. The formula allows considerable funds to be raised by generous people paying more than the RRP for badges and band of £1 each. As one supporter, who raised £1,000 wrote: "Through my yoga club I have been raising money for various charities for the past seven years...I would like to thank you for the CUP badges, wristbands and collection box. This made my job of raising money for charity the easiest and quickest method I have experienced so far." Another supporter demonstrates the value of the *10 X More* campaign in a letter: "My 17 year old son came home from college and told me that a boy on his course had asked what the wee badge was for (he had it pinned to his sweatshirt). He explained and the boy was interested as, like most people, he had never heard of CUP. So it just shows it can work in spreading knowledge."

Promoting improved treatment and the end of CUP

The one year survival rate for CUP patients in England (NCIN Routes to Diagnosis study, 2014) is 16%. This is very low in comparison to most other cancer types. CUP patients presenting as an emergency have the lowest survival of all the routes to diagnosis, whereas CUP patients presenting through the GP have significantly better survival. The age of patients also impacts survival. About 40% of CUP patients diagnosed in England are aged 80 years and over. These facts encourage the need for better treatment. Early diagnosis of cancer is critical, as is rapid and intelligent assessment.

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' to see whether they are 'compliant' with the 'measures'. This year has been the first for self assessment and 130 hospitals provided a return. This is most encouraging and a very significant step forward for CUP patients of the future in England. Hospitals treating CUP patients that are deemed non compliant with the Measures in the future, through external validation starting in 2014, will be named publicly.

CUP 2014. Our international seminar on 'The Management, Treatment and Future Perspectives of CUP' took place in London on 21 & 22 March. Delegates came from Egypt, Germany, Switzerland, Iraq, Italy, Russia, India, USA, Algeria, Armenia, Portugal, Japan, Greece, Australia, Moldova as well as the four countries of the UK. An expert faculty group was chaired by one of the world's leading authorities on CUP: Professor Nicholas Pavlidis of Greece. The epidemiology, pathology and biology of CUP were discussed before there were sessions on diagnostic challenges, treatment options, national guidelines and molecular profiling. A moving contributor to the session on 'caring for CUP patients' was Jon Lacey who had lost his young, pregnant, wife to CUP. The event was judged to be a very valuable opportunity for learning and exchanges by the oncologists, nurses and researchers that attended. (100% of delegates viewed the seminar as 'useful' or 'extremely useful', rating the speakers collectively as 'very good' or 'excellent').

Undertaking or supporting CUP research

Patient Experience Research with Southampton University. In this FY we have 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. This new study should help us challenge the lingering aura of nihilism surrounding CUP and go further than our preliminary in-house study last year which showed:

- CUP patients responses to be generally more negative than the national 'all cancers'. Using the DoH's benchmark of less than or equal to 70% as being 'less positive' there are 23 'less positives' for CUP versus 16 for 'all cancers'.

- Information and support, confidence and trust, and effective communication by doctors and nurses in relation to CUP patients are perceived to be significantly lower than the national 'all'.

A paper entitled "Uncertainty and anxiety in the Cancer of Unknown Primary patient journey: a multi-perspective qualitative study", (Foster R, Wagland R, Symons J, Davis C, Boyland L, Foster C, Addington-Hall J & Richards A.) was published in November 13 in *BMJ Supportive & Palliative Care*. This reflects our previous 3 year research project looking at CUP patient experience.

Codifying project. It is fundamental to research spend, awareness-raising and treatment that we have an accurate understanding of CUP incidence and mortality in the UK. It is the intelligence on which our battle plan depends but we know the present data to be inconsistent and not fully representative. In simple terms, much of the data comes from Cancer Registries to ONS and is 'manipulated' into meaningful intelligence by CRUK and NCIN.

As previously reported, we have initiated a research project to understand how CUP is registered in the different nations of the UK compared with the Republic of Ireland and Australia. Our proposal has been embraced by colleagues in the Prince of Wales Clinical School, University of New South Wales *and the* Statistical Information Department of Cancer Research UK. Together, we have formed a research team from representatives of cancer registries, NCIN, Public Health England. This is a novel project that has been embraced by those responsible for cancer registration in the United Kingdom (eight regional registration branches in England, the Welsh Cancer Intelligence and Surveillance Unit, and the Scottish and Northern Irish Cancer Registries; n=11) and the cancer registries of Australia (n=8) as well as the cancer registration service of the Republic of Ireland. The data will be used to identify areas of inconsistency and as an evidence base for recommendations that will allow meaningful comparisons of CUP incidence between jurisdictions and to inform future international practice/guidelines and research.

The survey data have now been collected but the analysis will take some time. A first pass of the data shows many inconsistencies. For example: the overarching coding system, i.e. whether registries use ICDO3 or ICD10 for recording cancers differs between countries, making national and international comparisons difficult; in England and Wales, the NICE CUP guideline identifies different stages in the diagnostic pathway but these distinctions cannot be made in registries on the basis of diagnostic codes; there are differing interpretations and/or systems for recording the primary diagnosis - this is particularly problematic for CUP as some registries record metastatic behaviours as the primary diagnosis whereas others do not, and multiple metastatic sites are recorded to a single code not allowing outcome analysis by number of metastases and/or analysis by metastatic site; registry practices vary with regards to whether 'ill-defined' primaries are included as part of the CUP profile.

A paper on the project was presented at the 2014 NCIN Cancer outcomes conference (The Challenges of Coding Cancer of Unknown Primary (CUP) – A Survey of Current Practices in the UK, Ireland and Australia. Claire Vajdic, Claudia Oehler, Nicola Cooper, John Symons.) Further presentations and a publication are planned.

CUP-One trial. As reported previously, *Jo's friends* is a Stakeholder in a multi-centre, Phase II trial (CUP-One) testing diagnostics and treatment of patients in a project funded by Cancer Research UK and led by Dr Wasan (Consultant & Reader in Medical Oncology Department of Cancer Medicine, Hammersmith Hospital). Overall, this study should allow a more logical framework to be derived, both clinically and biologically, as to how highly metastatic cancers may be efficiently and economically investigated and managed in the future. The trial may help also in the future with selecting the best chemotherapy for patients with CUP. Recruitment for the CUP-One trial has now reached its revised target of 572 and has stopped recruiting. A proposal to Cancer Research UK to fund a follow-up study, CUP-Two, has not been successful; but discussions continue to be held to try and find ways of continuing CUP research that merges with other international trials and leverages the fast-moving technology of molecular profiling. A proposal to extend the collection of tissue begun in CUP-One, and add blood samples, has been put forward to the Clinical Trials Awards and Advisory Committee (CTAAC) by Dr Wasan. This modest proposal, if accepted will allow the data bank to be extended for future trials and links made to the 100K Genome Project if required.

Sequencing project. This year, with £15,000, we have completed funding the £55,000 grant to Hammersmith Hospital for a molecular profiling pilot project that aims to develop more efficient treatment and management of CUP. The project aims to uncover potential biomarkers (predictive and prognostic) of CUP by utilising clinical tissue samples, accrued at the Hammersmith Hospital, that show hallmarks of CUP metastasis, where no primary site of cancer is identified. Next generation sequencing will be performed on a subset of the samples as a pilot that will help us to understand the disease and detect potentially “drug-able” mutations. A successful pilot will enable further research. The processes that need to be undertaken to extract DNA and RNA to the accuracy levels required for triplicate testing are themselves part of the trial. It is anticipated that there will be a reportable output in Q1 of 2015.

Publications by members of our Board. Our new website has an increased focus on research resources. Amongst the growing number of publications about CUP this reporting year are contributions by members of our Board:

2014. Cancer of Unknown Primary (CUP). Richard Osborne's chapter in *Problem Solving in Acute Oncology*. Young A, Clark PI, Selby P, editors. 1st ed. Oxford: Clinical Publishing.

2014. Hainsworth JD, Greco FA. Gene expression profiling in patients with carcinoma of unknown primary site: from translational research to standard of care. *Virchows Arch*. 2014 Apr; 464(4):393-402.

2014. The Challenges of Coding Cancer of Unknown Primary (CUP) – A Survey of Current Practices in the UK, Ireland and Australia. Vajdic C, Oehler C, Cooper N, Symons J. *NCIN Cancer Outcomes Conference*, 9 & 10 June, Birmingham.

2013. Richardson A, Wagland R, Foster R, Symons J, Davis C, Boyland L, Foster C, Addington-Hall J. Uncertainty and anxiety in the cancer of unknown primary patient journey: a multiperspective qualitative study. *BMJ Supportive & Palliative Care*. Nov.

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. The new electronic system for Gift Aid reporting has added a further administrative burden on the charity, albeit making matters easier for HMRC.

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 a *Jo's friends* Christmas card. 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. Here are a few of many examples:

- Gordon Williams, in addition to other fundraising activities, gave £910.05 - the money he didn't spend in his 'Dry Demi-year'. He has secured articles in local press. Gordon's daughter Michelle Darracott braved the water to do the Henley Bridge to Bridge Swim (a length of 14K) in memory of her Mother. To date she has raised more than £8,200 for *Jo's friends* and is planning to take on a new challenge, a half Iron Man.
- CUP patient Paul Barker continued his fundraising and awareness raising of CUP by holding his second golf day on and raised £1474. In total he has raised over £10,000 for our work.
- Ray Collins organised Wantage Health & Wellbeing Day which included a stand on CUP and monies raised from the day.
- To help launch Serco25 a prize draw was held for Serco people across the world, with 25 winners receiving £1000 to donate to a charity of their choice. One of the winners was Alison Rooker (who works at the National Physical Laboratory) who chose to donate her

money to *Jo's friends*. Alison's best friend lost a relative to CUP and she felt the donation would make a real difference to our charity.

- Friends and family of Michael Curtis, who died of CUP in 2013, gathered for a coffee morning in his memory on May 10th at the Luggar Pub in Fowey. Over £1000 was raised for CUP Foundation. Angela Collings and her daughter Hayley subsequently undertook a tandem sky dive during Awareness Week nearly doubling the original donation.

We have received significant grants this year from the *Orr Mackintosh Foundation* and *The Lindsay Foundation*. We receive also occasional donations from a range of associations, and fellowships. For all this support we are truly grateful.

It is the Trustees policy to access a range of sources of short and long term funding without becoming over-reliant on any individual donor. *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 in the charity which they are supporting.

Reserves and Investments Policy

For the year ended 1 October 2014 *Jo's friends* has increased its reserves in its interest-bearing account to £164,000. It 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

In this financial year the largest items of expenditure relate to the part payment of the award of the research grant to Dr Wasan of Hammersmith Hospital (£15,000) and the research grant of £10,573 to Southampton University for patient experience research. Our seminar – CUP 2014 – was largely funded by sponsors and resulted in a surplus. 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'. The 'refresh' of the website was achieved for £3,996.

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 communications and travel by the Director. (Travel by the Director for NHS work – NICE, NCAT, TVCN and the NCRI - is met by the NHS). 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* future plans will continue to be guided by a mixture of opportunism and planned activities. Opportunism, in the sense of opportunities that can benefit CUP patients, is necessary to respond to circumstances outside the charity's control in relation to cancer and CUP. *Jo's friends* will seek also to influence through planned activities where it is possible.

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 21 August 2014.

Approved by the Trustees at their meeting on 18 November 2014 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 2014**

	2014	2013
INCOMING RESOURCES		
Voluntary income	30,421.95	55,920.39
Activities for generating funds	27,045.83	11,007.32
Investment income	531.15	906.76
	<u>£57,998.93</u>	<u>£67,834.47</u>
RESOURCES EXPENDED		
Costs of generating voluntary income	3,125.43	6,287.42
Cost of charitable activities	5,810.69	8,586.74
Research grant(s)	25,573.00	20,000.00
Conference costs	9,055.50	2,178.00
Governance costs	0	106.03
Postage, stationery & telephone	451.81	250.82
	<u>£44,016.43</u>	<u>£37,409.01</u>
Net receipts	13,982.50	30,425.46
Bank balances at 2nd October 2013	154,062.52	123,637.06
Bank balances at 1st October 2014	<u>£168,045.02</u>	<u>£154,062.52</u>
Statement of assets and liabilities at 1st October 2014		
Monetary Assets		
Bank balance	4,045.02	20,062.52
COIF Charities Deposit Fund	164,000.00	134,000.00
	<u>£168,045.02</u>	<u>£154,062.52</u>

**INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF
THE CANCER OF UNKNOWN PRIMARY (CUP) FOUNDATION – JO'S FRIENDS
Charity number 1119380**

I report on the Receipts and Payments Account and the Statement of Assets and Liabilities of the Trust for the year ended 1st October 2014 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