

CANCER OF UNKNOWN PRIMARY (CUP) FOUNDATION
- Jo's friends -

ANNUAL REPORT
FOR THE YEAR ENDED
1 OCTOBER 2009

Registered Charity Number: 1119380

CANCER OF UNKNOWN PRIMARY (CUP) FOUNDATION – Jo’s friends

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The Trustees are pleased to present their report together with the financial highlights of the charity for the year ending 1 October 2009. This is the second report of the *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 the charitable objects. We cover also the charity’s governance, funding sources, spending and reserves.

It has been an extremely successful year measured by activities and outputs of web hits (up 199%) and awareness-raising. We should note that this is the year of the “credit crunch” and the 09 recession. Charitable donations have been affected throughout the sector. *Jo’s friends* income has suffered significantly and our reserves have been tapped to fund the first international CUP conference which we are organising for 15 October 09.

In preparing this report the trustees have taken note of the Charity Commission’s guidance on public benefit.

ORGANISATIONAL STRUCTURE, GOVERNANCE AND MANAGEMENT

TRUSTEES

Barry Hamilton B.Soc.Sc. MBA.
(*Chairman*)

John Symons TD, MSc, MEd, PhD.
(*Director*)

Rosemary Bates BA (Hons), PG Dip OCGD. (Re-appointed 11 June 09)

Kate Fulton Bsc (Hons). (Re-appointed 11 June 09)

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 Maurice L. Slevin MD FRCP.

Dr Slevin is Honorary Consultant Medical Oncologist at St Bartholomew's Hospital, where he has practiced for 30 years, and he is a founding Director of The London Oncology Clinic.

Dr Harpreet S. Wasan MD MBBS PhD FRCP.

Dr Wasan is a Consultant in Medical Oncology and Honorary Senior Lecturer, Imperial College London, and the Department of Cancer Medicine, Hammersmith Hospital.

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 F.C.A. – 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.

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.

- 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.

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. At the expiry of a Trustee’s tenure it is the charity’s intention to conduct an audit of the organisation’s skills set and networks to identify possible gaps that need to be filled by suitable volunteers. 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.

Training and Activity of Trustees

Trustees and Advisory Board Members are recruited for their specific skills and experience and their enthusiasm for the charity. Training for Trustees is conducted through “Away days” and Trustees meetings where topics covered include cancer and CUP as well as matters related to the running of the charity. Discussion is set against the backdrop of how planned activities will contribute to the Charity’s aim and objectives. On appointment, Trustees receive a booklet on the duties and responsibilities of a trustee, published by the Charity Commission.

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 5% of cancer diagnoses in the UK; but this figure depends on how CUP is defined. 5% of cancer incidence in the UK represents approximately 14,000 people. Taking a universal view, CUP is thought to represent one of the ten most frequent cancers and the fourth commonest cause of cancer death.

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 - metastasizes - unpredictably) it is a challenging diagnosis for the cancer doctor as well as the patient.
- There are few standard treatments, because the cancer is likely to be different for every patient, with widely different outcomes.
- There is presently no NHS Guideline for the treatment and management of CUP patients in England and Wales.
- Improving genetic, pathological and radiological techniques will reduce the incidence of CUP in the future.

ACHIEVEMENTS AND PERFORMANCE MEASURES (NON FINANCIAL)

This review looks at what *Jo's friends* has achieved through the outcomes of its work in the previous 12 months. The review looks at the activities in relation to each Objective (see *Objectives and activities* above) and the benefits that have accrued in relation to those the Charity seeks to benefit.

Some highlights of 2008/09

- Publisher *Pan Macmillan* nominates *Jo's friends* as their charity of the year
- *First Choice Coffee* becomes the first corporate sponsor
- Article by *Jo's friends* Director "Understanding and managing CUP" published in the British Journal of Nursing after peer review (Oct 08)
- 2,500 *Jo's friends* Christmas cards sold
- New York Times article on Molecular Profiling that included an explanation of the formation and work of *Jo's friends* (Mar 09)
- First meeting of the Advisory Board that included Drs Greco, Wasan and Slevin (May 09)
- *Jo's friends* feature on CNN in a lengthy interview with *Jo's friends* Director explaining CUP as part of a programme on difficult diagnoses (May 09)
- Director continues his work as part of NICE's CUP Guideline Development Group
- Researcher appointed for the Patient Experience Research being undertaken with Southampton University
- Booklet on "Understanding Cancer of Unknown Primary" published by *Macmillan Cancerbackup* with input from *Jo's friends*
- *Institute of Cancer Research* publishes 100 faces of Cancer as part of their centenary year. One of the faces and the story behind the photograph is of Jo (June 09)
- Supporters undertake fundraising and awareness raising activities ranging from marathons, cycle rides, garden parties to "busking" in Dorchester Abbey.
- Director joins the Steering Group of Cancer 52
- International CUP experts and corporate sponsors agree to participate in the first international CUP conference on 15 Oct 09.

In the UK a number of cancer charities exist to support, undertake research or maintain advocacy on behalf of most of, what are often referred to as, the *lesser* or *rarer* cancers. These cancers account for some 52% of cancer deaths (the big 4 cancers accounting for 48%) and 46% of

incidence. It is worth noting that where no CUP charity existed, *Jo's friends* is filling a gap and is valued by oncologists, patients and carers. Testimonials on the website bear witness to this claim. Others, notably in the USA, are considering setting up similar organisations based on the *Jo's friends* model.

Some of the charity's activities allow measurable results whilst it is more difficult to judge other activities aimed at longer term strategic benefit. It is easiest to offer some measures in relation to the objective of *Providing information and support to CUP patients and those who care for them* because the primary vehicle for achieving this is the website.

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

The website. Table 1, below, shows a growth in "hits" in comparison with the previous year. The "absolute unique" hits indicate someone accessing the site for the first time. In the previous reporting period "visits" moved from about 100 to about 400 per month. In the period under review visits have maintained or exceeded this baseline with the exception of a slight dip in January and December. Spikes have been caused by particular events and it would be unwise to expect a long term trend that exceeded 400-500 visits month. Equally encouraging is the access from people in different countries which, in the period under review, has shown considerable growth indicating the increasing global awareness of our message.

Table 1: Website Statistics (Data from Google Analytics)

	Hits				How reached			Visitors from # countries
	Visits	Absolute unique	Average page views	Av time on site (mins)	Direct traffic %	Referring sites %	Search engines %	
Oct 2007	116	46	4.3	3.2	67	30	3	5
Nov	125	73	4.2	3	56	20	24	8
Dec	103	62	4.9	3.1	62	10	28	7
Jan	124	83	4.8	2.2	50	18	31	7
Feb	227	138	6.1	4.2	61	21	17	11
Mar	192	139	4.7	3.4	59	15	26	17
Apr	274	179	4.6	3.4	55	20	24	16
May	138	121	4.1	2.2	30	40	30	9
Jun	396	229	6.8	6.5	46	21	33	13
Jul	413	230	4.8	4.51	37	24	38	14
Aug	345	206	4.4	5.03	38	31	31	14
Sep	418	281	3.4	3.0	45	27	28	19
Oct 2008	411	280	4.3	3.34	39	22	39	20
Nov	475	327	4.3	4.08	52	16	32	21
Dec	333	229	5	4.36	43	16	41	18
Jan	359	224	4.8	4.38	39	24	37	19
Feb	444	263	5.4	4.47	20	39	41	23
Mar	1303	936	4.5	3.49	22	59	19	41
Apr	555	347	3.9	3.38	25	45	30	22
May	839	622	3.5	2.57	18	61	21	45
Jun	1254	961	3.3	2.38	44	40	15	67
Jul	748	555	4	3.38	37	32	30	26
Aug	816	613	3.6	3.15	43	36	21	28
Sep	1054	781	3.8	2.57	37	30	33	33

Note: Traffic was boosted by an article in the New York Times in March 09 and by a CNN feature in May 09. Advertising for the Conference is likely to account for the spikes in June and September.

Those seeking information about CUP may route through a search engine (e.g. Google), a referring site (such as Cancer Research UK, Macmillan Cancer Care 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 website where examples of endorsements from patients, carers, and medical professionals are captured on various pages. We show some examples of patients and carers comments in Table 2 below.

Booklet. *Jo's friends* has worked with Macmillan Cancerbackup (part of Macmillan Cancer Support since 2008) to produce a 72 page free booklet on CUP for distribution nationwide to cancer centres, and cancer patients who request it. *Understanding Cancer of Unknown Primary* includes *Jo's friends* web address for further information.

Raising awareness of CUP

The website is also a vehicle for *Raising awareness of CUP*. Raising awareness of CUP and awareness of *Jo's friends* are inextricably linked. The site explains CUP, what we are doing, and what we want others to do. There are 3 distinct publics: the medical profession, patients and carers and the public at large. Raising awareness of a disease that has a very low profile is seen as the precursor of stimulating demand for change and the funds for research.

Table 2. Examples of what patients say

Soon after my diagnosis my daughter contacted you and you were kind and gave her hope.

Am so glad to have found this site!!!! Since diagnosis I have felt like I'm on a raft in the middle of the ocean and no one knows I'm there or can rescue me.... I started to cry at the thought that I found people who have experienced the frustration of dealing with this illness and can understand my frustration.

Your site is so great. I have a hard road ahead but feel calmer now that I've started a targeted chemo treatment. I fully understand the importance of your website and help.

At first I was tired of answering the questions about CUP ... but this website has helped me realize that the world needs to know about us.

It has really helped me to lose that sense of fear and dread, and I feel much more positive and in control.

This afternoon, I forwarded to 50 of my friends and relatives a link to your story at CNN. To this day, a lot of them have not fully understood what type of cancer my mum had.

One of the things I so like about this site is the various information you get from people sharing their experiences.

Thank you for creating such a site! It's helped me in just the few moments I visited.

Through meetings with members of the medical profession, other cancer charities, conference attendance, journal articles, advertising and Membership of Cancer 52 – an umbrella organisation for those charities concerned with rarer cancers – *Jo's friends* has drawn attention to itself in order to raise the profile of CUP. An article written by the Director about CUP,

Understanding and managing cancer of unknown primary, was published in the October edition of the British Journal of Nursing.

Promoting improved treatment and the end of CUP

NICE Guideline. *Promoting improved treatment and the end of CUP* is in part a function of awareness to stimulate demand for this to happen. In 2008 the NHS, through NICE, initiated the process of developing a Guideline for the management and treatment of CUP in England and Wales. *Jo's friends* is a Stakeholder in this exercise and the Director is an *ad hominem* member of the Guideline Development Group. Once in place in July 2010, the Guideline is likely to have a significant impact on regularising the present *ad hoc* treatment of CUP with rigorous, evidence-based, assessment of best practice.

Transformational change. The Trustees have set the year 2020 as the target to work for to see the end of CUP.

Undertaking or supporting CUP research

Patient Experience Research. *Jo's friends* has joined with Southampton University and palliative care experts to undertake research into understanding CUP patients, family members and medical staffs' perceptions of treatment. Funding has been forthcoming from *Dimbleby Cancer Care*. In 2009 a researcher has been hired to work on the project at Southampton University. The Director of *Jo's friends* is a member of the project group directing the research. The detailed research proposal is due to proceed to ethics approval in the Autumn of 2009. This work falls also within the objective of *Undertaking or supporting CUP research* but it should be noted that medical research of any sort is extremely expensive. The research mentioned above is costed at some £80,000.

CUP-One trial. Clinical research is significantly more expensive and *Jo's friends* can only hope to stimulate clinical research and offer support where appropriate. To that end, *Jo's friends* have become Stakeholders in a 3 year multi-centre, Phase II trial (CUP-One) testing diagnostics and treatment of patients in a project funded by Cancer Research UK. *Jo's friends* activity to date in relation to the trial has been to review the trial protocol from the patient-carer perspective as it progresses through various regulatory committees. The Director meets with the lead clinician of the trial on a regular – usually every 2 months- basis to review activities.

More details of all our activities are shown on the website www.cupfoundjo.org.

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 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 the charitable objects. As the Charity establishes its reputation 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 and Fundraising Objectives

Jo's friends aim to secure the funding it needs to achieve its objectives through a core group of Supporters who raise funds and awareness. Funds and awareness are raised through a *Jo's friends* Christmas card. Advertisements are placed in appropriate magazines e.g. the Law Society Gazette.

Principal Sources of Funds

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* seek to engage supporters in our work and maintain, through newsletters and eMail updates, 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. In 2008/09 the Trustees have sought to move occasional donors to commit to Standing Orders but with little success. *Jo's friends* is particularly grateful to *Pan Macmillan* who appointed *Jo's friends* as their Charity of the Year. This has brought in much appreciated funds through book sales and office cake days undertaken by the employees. Additionally, *Nature Publishing Group*, part of *Macmillan Publishers* has given valuable free advertising to the Conference in some of their cancer journals.

Reserves and Investments Policy

For the year ended 1 October 2009 *Jo's friends* has £31,000 in a reserve account. All reserves are unrestricted. In considering the reserves policy, the Trustees have identified the need to accumulate cash reserves to allow operational flexibility and any potential downturn in donor funds. It is recognised that it will be difficult to sustain the initial levels of giving associated with the start-up of *Jo's friends*. It is also too early in the charity's existence to determine spending trends. The reserves are monitored at each quarterly Trustees meeting.

How Expenditure has supported the Charity's Key Objectives

In the year under review major expenditure has been on the Conference. Corporate sponsorship has been achieved to ameliorate the cost of the conference which is budgeted at £32,000. For all commercial undertakings we seek, where possible, to achieve "charity rates" to reduce expenditure. We have been fortunate that significant design work has been undertaken by *Malcolm Glenn Marketing* pro bono. Corporate Sponsor *First Choice Coffee* has also contributed work on a major fundraising brochure pro bono.

Admin costs. There have been costs for travel by the Director. However, it should be noted that the costs are artificially low as the charity is run from the volunteer Director's house and no charge is made presently for rent, heat, light, car travel etc. 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.

Future Plans

Jo's friends future plans will be guided by a mixture of opportunism and planned activities. Opportunism, in the sense of opportunities that can raise the profile of CUP, 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. The Trustees have referred to the guidance contained in the Charity Commission's general guidance on public benefit when considering future plans.

Conference. The main event of the calendar year is the first international conference on CUP to be held in London on 15 October 09. The conference will impact on all *Jo's friends* charitable objectives for the benefit of patients and those who care for them. The current account bank balance at year end reflects sponsorship money received specifically for meeting conference expenditure.

It is likely that the *Jo's friends* office will move in the next reporting year.

Financial Adviser

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 2008.

Approved by the Trustees at their meeting on 18 November 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 2009

	2009	2008
INCOMING RESOURCES		
Voluntary income	6,773.79	46,094.46
Activities for generating funds	23,859.76	3,463.70
Investment income	964.48	253.02
	<u>31,598.03</u>	<u>49,811.18</u>
RESOURCES EXPENDED		
Costs of generating voluntary income	1,807.90	2,122.66
Cost of charitable activities	9,697.80	15,527.18
Governance costs	338.40	512.70
Postage & stationery	411.78	343.66
	<u>12,255.88</u>	<u>18,506.20</u>
Net receipts	19,342.15	31,304.98
Bank & cash balances at 2nd October 2008	31,304.98	0
Bank & cash balances at 2nd October 2009	<u>£50,647.13</u>	<u>£31,304.98</u>

Statement of assets and liabilities at 1st October 2009

MONETARY ASSETS		
Bank balance	19,647.13	4,894.10
COIF Charities Deposit Fund	31,000.00	26,500.00
Cash in hand		46.39
	<u>50,647.13</u>	<u>31,440.49</u>
Amounts paid by Dr J Symons to be reimbursed	0.00	(135.51)
	<u>£50,647.13</u>	<u>£31,304.98</u>

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

I report on the Receipts and Payments Account and the Statement of Assets and Liabilities of the Trust for the year ended 1st October 2009.

Respective responsibilities of the trustees and the examiner

The Charity's trustees consider that an audit is not required for this year (under section 43(2) of the Charities Act 1993 (the Act), as amended by s.28 of the Charities Act 2006) and that an independent examination is needed.

It is my responsibility to:

- examine the accounts (under section 43 of the Act, as amended),
- to follow the procedures laid down in the General Directions given by the Charity Commission (under section 43(7)(b) of the Act, as amended), 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 I do not express an audit opinion on the accounts.

Independent examiner's statement

In the course of my examination, no matter has come to my attention which gives me reasonable cause to believe that in, any material respect, the trustees have not met the requirements to ensure that:

proper accounting records are kept (in accordance with section 41 of the Act); and accounts are prepared which agree with the accounting records and comply with the accounting requirements of the Act; or 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