

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

ANNUAL REPORT
FOR THE YEAR ENDED
1 OCTOBER 2008

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 2008. This is the first 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 aims to do and how it goes about it - showing the main activities & achievements (both qualitative and quantitative) in relation to the objects; as well as noting its governance; charitable objects; funding sources; spending and reserves.

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.

Kate Fulton Bsc (Hons).

Philippa McEwan BA (Hons).

ADVISORY BOARD

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.

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 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 treatment and the end of CUP
- Undertaking or supporting CUP research

It achieves these objectives primarily through:

- The website (www.cupfoundjo.org). This 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 events, journal articles and association with other organisations that can help leverage the charity’s objectives.

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, who are, at the time of this report, three distinguished oncologists have been appointed on the same basis as Trustees *mutatis mutandis* (with a tenure of 5 years). Trustees and Advisory Board Members are unpaid.

TRAINING 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 a wide variety of topics are covered in relation to cancer and CUP as well as the running of the charity. 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, Wales and Northern Ireland.
- Improving genetic, pathological and radiological techniques will reduce the incidence of CUP in the future.

ACHIEVEMENTS AND PERFORMANCE MEASURES (NON FINANCIAL)

In the UK charities exist to support 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 already valued by oncologists, patients and carers.

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. Table 1, below, shows a steady growth in "hits".

Those seeking information about CUP may route through a search engine (e.g. Google), a referring site (such as Cancer Research UK, CancerBackup, Macmillan Cancer Care who all provide a link to *Jo's friends* on their website) or direct by those who know the charity's URL (www.cupfoundjo.org). The growth in the "search engines" category, and the number of countries that visitors are accessing the site from, is likely to be a function of web advertising (Google ads) and a wide range of key words and phrases related to CUP that trigger a hit on the site for those searching. We would expect the relative numbers from referring sites to diminish, and the numbers for direct traffic and search engines to increase, as *Jo's friends* become better known in the UK and worldwide.

The qualitative value of the website can be seen by looking at the website where endorsements from patients, carers, and medical professionals are shown on various pages.

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 %	
Sep 2007	34	11	4	4.5	82	15	3	2
Oct	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
<i>CY tot</i>	<i>378</i>	<i>192</i>						
Jan 2008	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
<i>CYTD</i>	<i>2,527</i>	<i>1,606</i>						

In addition to the web environment, *Jo's friends* has been working with CancerBackup (which became part of Macmillan Cancer Support in 2008) to produce a new hard copy information sheet on CUP for distribution to cancer centres nationwide. This document will include *Jo's friends* web address for further information.

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 includes a section of what the CUP problem is, what we are doing about it, 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. 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 themselves in order to raise the profile of CUP. An article written by the Director about CUP has been published in Nursing Times.

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 have initiated the process of developing a Guideline for the management and treatment of CUP in England, Wales and N. Ireland. *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 the Summer of 2010, the Guideline is likely to have a significant impact on regularising the present *ad hoc* CUP treatment based on rigorous, evidence-based, assessment of best practice.

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

In a separate undertaking *Jo's friends* has joined with Southampton University, palliative care experts and other medical researchers to undertake research into understanding the patients, family members and medical staffs' perceptions of treatment. In this reporting year funding has been sought and granted by Dimpleby Cancer Care and the project is funded from 1 October 2008. Whilst separate, it is intended that the findings of this 3 year project will inform the NICE Guidelines in relation to patient-carer aspects. 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. 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.

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

FINANCIAL STATEMENTS AND PERFORMANCE

STATEMENT OF PRINCIPLES AND FINANCIAL MANAGEMENT POLICIES ADOPTED IN THE PERIOD

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 ensure 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 purpose. 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. Fund-raising activities in the period under review include: gift fair, corporate days (dress down, cake days etc.) concert, garden party, marathon running and cycling. Funds and awareness have also been raised through a *Jo's friends* Christmas card.

Advertisements are placed in appropriate magazines e.g. the Law Society Gazette, to raise awareness and seek legacies.

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 the Trustees have sought to move occasional donors to commit to Standing Orders.

We are most grateful to individuals and organisations who have given money to *Jo's friends*. We have been fortunate to secure donations from the Sandra Charitable Trust and the Straton Thornhill Trust; and we are delighted that publishers Pan Macmillan have appointed *Jo's friends* as their charity of the year for 08/09.

Gift Aid allows a substantial increase to many donations. In the course of the year we have opened an account with the web company *JustGiving*, which allows money to be donated on-line, This has proved a useful source of fundraising. Finally, it should be noted that Founders donations have distorted the income for the year and it will be challenging to achieve as much income in the following year.

RESERVES AND INVESTMENTS POLICY

For the year ended 1 October 2008 *Jo's friends* has £26,500 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 Trustees meeting.

HOW EXPENDITURE HAS SUPPORTED THE CHARITY'S KEY OBJECTIVES

The majority of the expenditure in the first year has related to establishing the website, and its technical support and, to a lesser extent, designing and printing materials to publicise the charity. We seek where possible to achieve "charity rates" to reduce expenditure wherever possible. We have been fortunate that significant design work has been undertaken by Malcolm Glenn Marketing *pro bono*.

Admin costs. There have been costs for Away Days and travel by the Director to London, plus insurance cover for public events, for example. However, it should be noted that the costs are artificially low as the charity is run out of the volunteer Director's house and no charge is made presently for rent, heat, light, etc. The Trustees take the view that sound administration is a vital foundation of a sound organisation and that 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 major target is a CUP conference to be held in London in either 2009 or 2010. The keynote speaker and chairman have been "signed-up" but the timing is dependent on the speaker's availability to travel from the USA to London. Significant funds will be needed to finance the setting-up of the conference. It is likely that the conference will impact on all *Jo's friends* charitable objectives for the benefit of patients and those who care for them.

FINANCIAL ADVISER

A resolution proposing the appointment of Roger Newnham FCA as the Independent Examiner to the Charity was approved by the Trustees at their meeting on 15 August 2008.

Approved by the Trustees at their meeting on 21 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 period 10th May 2007 to 1st October 2008**

INCOMING RESOURCES

Voluntary income	46,094.46
Activities for generating funds	3,463.70
Investment income	253.02
	<u>49,811.18</u>

RESOURCES EXPENDED

Costs of generating voluntary income	2,122.66
Cost of charitable activities	15,527.18
Governance costs	512.70
Postage & stationery	<u>343.66</u>
	<u>18,506.20</u>
Net receipts	<u>£31,304.98</u>

Statement of assets and liabilities at 1st October 2008

Monetary Assets

Bank balance	4,894.10
COIF Charities Deposit Fund	26,500.00
Cash in hand	<u>46.39</u>
	31,440.49
Amounts paid by Dr J Symons to be reimbursed	<u>(135.51)</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 2008.

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.
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