

"...promoting research that improves diagnosis"

"...helping people to cope"

what is CUP?

*"making the unknown,
known"*



Cancer of
Unknown Primary
(CUP) Foundation

“...a challenge that we intend to win”

CANCER OF UNKNOWN PRIMARY (CUP)

is hidden cancer. The term is applied when a patient is diagnosed as having cancer which has spread, but its origin cannot be identified.

This makes treatment, which is based on the profile of the primary cancer, extremely difficult.

Jo's friends was established in memory of Jo Symons who died of 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 primary diagnosis and that little was being done to promote awareness and research; or to offer information and support to CUP patients and their carers.

WHO HAS HEARD OF CUP?

- **CUP is one of the 10 most commonly diagnosed cancers and the 4th commonest cause of cancer mortality.** It represents about 5% of cancer incidence affecting some 14,000 people in the UK each year.
- **Patients suffer the double agony of a cancer diagnosis** with the added distress of not being able to explain the origin of their cancer.



Cancer of Unknown Primary (CUP) Foundation

WHAT IS CUP?

- **CUP biology is not understood** other than that the primary cancer stays small or disappears, yet the cancer spreads unpredictably, often to more than one organ.
- **Most CUP definitions are of carcinoma of unknown primary** where (unlike sarcoma, lymphoma and melanoma) further distinctions are needed to achieve effective treatment.
- **Because the cancer cells lose their unique features** as the cancer spreads, identifying the original cancer cells (the target of chemotherapy) is difficult.
- **The primary cancer may remain hidden during treatment** (and at post mortem). This makes CUP a challenging diagnosis for both doctor and patient.
- **There are few standard treatments**, because the cancer is likely to be different for every patient, with widely different outcomes. Some of those who have a provisional CUP diagnosis may be treated successfully. Life expectancy of those with confirmed CUP rarely extends beyond 8 months. For some, it is a matter of weeks.

CUP IS AN “ORPHAN” DISEASE

- **Doctors lack understanding of the disease** and patients presenting with CUP do not have the medical and other benefits available to those with site-specific cancers.
- **CUP patients need:**
 - rapid identification with early and appropriate specialist involvement
 - efficient arrangements to manage the initial diagnostic investigations without delay
 - support and information about CUP
 - early involvement of specialist palliative care.
- **There is a lack of research into CUP** or even agreed definitions of the disease.



WHAT DO WE DO?

Our mission is to **Make the Unknown, Known** by:

Providing information & support to CUP patients and their carers

- Our website – www.cupfoundjo.org – provides essential information for patients and carers. Each month we are accessed by people from 20-40 countries. The site includes a moderated area for people affected by CUP to interact.
- **Jo's friends** has worked with Macmillan Cancer Support to produce a free booklet on CUP for distribution to cancer centres throughout the UK.

Raising awareness of CUP

- Raising awareness of a disease that has a very low profile is the precursor of stimulating demand for change and the funds for research. We have published articles in medical magazines, and have been the subject of features in the *New York Times* and on *CNN*.

Promoting research that improves diagnosis and treatment leading to the end of CUP

- In 2010 NICE published the first guideline for the management and treatment of CUP. **Jo's friends** was a stakeholder and the Director was a member of the Guideline Development Group.
- We have joined with Southampton University and others to research the experiences of CUP patients, their carers and treating physicians.
- **Jo's friends** is a stakeholder in a 3 year multi-centre, Phase II trial (CUP-One) testing diagnostic approaches and treatment of patients in a project funded by Cancer Research UK.
- We ran the first international conference ever held on CUP in 2009 bringing together experts from around the world. The second conference takes place in April 2012.



DONATIONS

- I would like to support the work of **Jo's friends** by making a donation of £.....
- Please contact me about making a regular payment by Standing Order or with information on leaving money to **Jo's friends** in my will.

TITLE INITIALS NAME

ADDRESS

..... POSTCODE

EMAIL

I enclose: Cheque CAF Voucher
(Made payable to *CUP Foundation – Jo's friends*)

Please treat all donations I make from the date of this declaration, until I notify you otherwise, to **Cancer of Unknown Primary Foundation – Jo's friends** as Gift Aid donations. I am a UK taxpayer and pay an amount of income tax and/or capital gains tax each year at least equal to the tax that can be reclaimed on my donation(s).

Please sign to allow us to recover Gift Aid from HMRC.

Signature Date

All donations will be acknowledged.
Please return this form to:

CUP Foundation
The Follies
Brightwalton
NEWBURY
RG20 7BZ
UK

PLEASE HELP US TO HELP OTHERS

by raising awareness
of CUP or by making
a donation towards
our work.

You can donate online
through **Just Giving**
(see our website for the link)
or by cheque, or Standing Order.



Cancer of
Unknown Primary
(CUP) Foundation

Jo's friends has been in existence
since May 2007 and has quickly
filled the gap that existed for patient
information and support.

The charity acts also as an advocate
for those affected by this unknown
disease.

WHAT DO WE NEED FUNDS FOR?

- **Research** – to help us undertake, commission, and stimulate research into CUP e.g. the epidemiology and biology of CUP, as well as to continue “*patient experience*” research.
- **Reaching out and raising awareness** – to make people realise that there is still a hidden cancer that is killing thousands every year because there is insufficient demand for action. We need also to raise awareness amongst medical charities and medical professionals (*who may see only one or two cases of CUP in a lifetime's practice*).

ENDORSEMENTS

“The Foundation has been instrumental in bringing together experts from across the world and encouraging the development of research to improve the outcomes of patients with CUP.”

Dr Andrew Fowell,
Macmillan Consultant in Palliative Medicine

“This site provides much needed and accessible help for CUP patients and their loved ones - I'm very, very impressed.”

Nicola James
Macmillan Nurse Consultant

“This website is a fantastic resource.”

Dr Maurice Slevin, Medical Oncologist

“A valuable patient support organisation that advocates much needed research and change for this neglected group.”

Prof Orest Mulka (former GP)

www.cupfoundjo.org

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.”*

“If you have CUP you are given less support than other cancer suffers as you do not slip into a definite category.”

“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 to friends and some doctors but this website has helped me realize that the world needs to know about us.”

To learn more about the work of the Cancer of Unknown Primary Foundation – *Jo’s friends*, or to contact us by email, please visit:

www.cupfoundjo.org

Our annual report is available online – see **www.cupfoundjo.org** then “research and resources/archive”.

**CUP Foundation
The Follies
Brightwalton
NEWBURY
RG20 7BZ
UK**



Registered Charity No: 1119380
03/2011

Cancer of
Unknown Primary
(CUP) Foundation

www.cupfoundjo.org