

Please help us to help others by raising awareness of CUP or by making a donation towards our work.



You can donate on-line through Just Giving or by Cheque, or by Standing Order.

JustGiving™

Jo's friends has been in existence since May 2007 and has 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, diagnostics and treatment 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 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 website is a fantastic resource.

Dr Maurice Slevin, Medical Oncologist

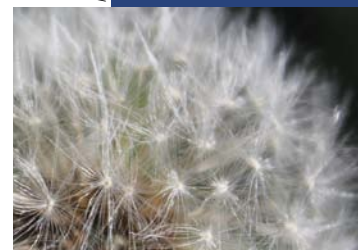
This site provides much needed and accessible help for CUP patients and their loved ones - I'm very, very impressed.

Nicola James, Macmillan
Nurse Consultant

What a brilliant site. It provides a light in the grey world of CUP.

CUP patient (UK)

photo: Resolution Design



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 sufferers 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

cancer of unknown primary foundation 

Providing Information Supporting Research Promoting Change

What is CUP?

cancer of unknown primary foundation 

www.cupfoundjo.org

making the unknown, known

**CUP Foundation
The Fold, Lower End
Daglingworth
Cirencester GL7 7AH**

Registered Charity No: 1119380
03/2017

cancer of unknown primary foundation 



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 represents about 3% of cancer incidence affecting almost 10,000 people in the UK each year. It is the 5th commonest cause of UK cancer deaths.
- Patients suffer the double agony of a cancer diagnosis with the added distress of not being able to explain the origin of their cancer.

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 lymphoma, sarcoma 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 often 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:

(1) Providing Information and Support to CUP patients and their carers.

- Our in-depth website at www.cupfoundjo.org provides essential information for patients and carers.

- Jo's friends has worked with Macmillan Cancer Support to produce a free booklet on CUP for distribution to cancer centres throughout the UK.

(2) Research that improves diagnosis, management and treatment to help today's patients and end the problem of CUP.

- We work with national and international organisations to encourage research, knowledge-sharing and expertise that benefits CUP patients.



- We run international conferences bringing together CUP experts from around the world.

- Jo's friends has committed funds for clinical research and has worked with international partners on patient experience research and epidemiological studies.

(3) Promoting change through:

- Raising awareness of this low profile disease and the unique problems facing CUP patients.

- Supporting the training and validation of hospital CUP Multidisciplinary Teams (MDTs).

- Encouraging the use of scientific advances – molecular profiling of the tumour and the identification of actionable genetic mutations – that support targeted treatments.

- Improved data capture to understand better the CUP patient pathway.

Donations

- I would like to support the work of **CUP Foundation - Jo's friends** by making a donation of £.....
- Please contact me about making a regular payment by Standing Order.

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 Fold, Lower End,
Daglingworth,
Cirencester GL7 7AH**



www.cupfoundjo.org



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making the unknown, known