

What is CUP?

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.

Patients suffer the double agony of a cancer diagnosis with the added distress of not being able to explain the origin of their cancer.

Why Jo's friends?

The CUP Foundation - 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.

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.

Cancer of Unknown Primary Foundation - Jo's friends is a Registered Charity (No: 1119380)

CUP incidence and further explanation

CUP is one of the 10 most commonly diagnosed cancers and the 4th (2011 data) or 5th (2010 data) commonest cause of cancer mortality (about the same as Prostate cancer). It represents about 3% of cancer incidence affecting some 10,000 people in the UK each year.

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 have lost their unique features in the cancer spread, 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.

Problems with this orphan disease

Many 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 cancer.

There is a lack of research into CUP or even agreed definitions of the disease.

What do 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.

What do the CUP Foundation - Jo's friends do?

Our mission is to Make the Unknown, Known by:

- Providing information & support to CUP patients and their carers.
- Raising awareness of CUP.
- Promoting research that improves diagnosis and treatment leading to the end of CUP.

Some examples of our work

- Jo's friends website – www.cupfoundjo.org – provides essential information for patients and carers. Each month we are accessed by people from 30-40 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.
- Jo's friends was a stakeholder and the Director was a member of the NICE Guideline Development Group and the expert group for Peer Review Measures. The NICE Guideline became extant in 2010 and the Peer Review Measures started to come into effect in 2013.
- Jo's friends joined with Southampton University and others to research the experiences of CUP patients, their carers and treating physicians. The findings show that CUP patients face ambiguity and clinical uncertainty.

- Jo's friends is supporting a 4 year multi-centre, Phase II trial (CUP-One) testing diagnostic approaches and treatment of patients in a project funded by Cancer Research UK.
- In 2009, and again in 2012, Jo's friends brought together CUP experts from around the world for a conference on CUP. In 2014 we are organising a CUP seminar for oncologists from across Europe.
- In December 2013 we handed over the last tranche of a £55,000 grant to fund 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 is now being 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.

For further information and contact see www.cupfoundjo.org