

# CUP Conference

**First Conference of Cancer of the Unknown Primary held at the Royal College of Obs. And Gyn. 27 Sussex Place, Regent's Park, London on 15th October 2009.**

**OVERCOMING THE UNKNOWN: NEW APPROACHES TO THE DIAGNOSIS AND TREATMENT OF CARCINOMAS OF UNKNOWN PRIMARY.**

## Report by ICPV member Jill Bartrop

### INTRODUCTION

This excellent conference was set up by the dedication of a voluntary group "Jo's Friends, Cancer of Unknown Primary (CUP) Foundation." The inspiration came from John Symonds who experienced the pain of his wife Jo having a cancer of unknown primary and the helplessness and fear in such a cancer diagnosis that can result. This group of patients have no clear care pathway for treatment and the professionals have little research evidence to draw on to determine the best practice. Cancer treatment focuses on the primary diagnosis for intervention if this can't be established the treatment has no protocols to draw upon for decision making.

This cancer represents around 3% of all cancers in official statistics but this could be under representative of the whole number. This amounts to 8,000 people in the UK every year!

The CUP foundation's mission is to support and give information to CUP patients and carers through their website and to stimulate change to end CUP ([www.cupfoundjo.org](http://www.cupfoundjo.org)). This group therefore decided to bring together some of the best known professionals from all over the world to share knowledge and experience of working with CUP and to explore ways to develop practice in this challenging area. This inspirational foundation must be congratulated for the hard work, dedication and commitment to make this conference happen. The medical profession should seek to promote such collaboration and to develop a recognised protocol for intervention in this area.

The conference brought together key note speakers from major centres in Great Britain, America, Israel, and The Netherlands. The topics included molecular biology, clinical experiences and psychological implications of CUP. Contributors came from all disciplines and explored ways of developing research to enhance understanding and complimenting existing knowledge. I had the privilege of being able to speak at this event exploring the needs of the patient and to challenge the professionals to develop quality patient centred practice.

Instead of giving a short summary of each contributor I would instead like to share with you some of my impressions.

### The starting point

How do we define the unknown primary? What analysis can we undertake to understand it? Can molecular science such as microarrays identify the tumour type? Is the unknown primary actually a more common known primary that we just haven't the equipment to locate at the moment? Does this primary operate from a small number of rogue cells that then gets bigger only in metastatic sites? Is this one disease pattern that operates by killing the original primary cancer cells as the site of origin once some of the cells have found metastatic sites?

There are definitely more questions than current answers. Does this actually matter? Is the often fruitless search for a primary site a lost opportunity costing precious time as well as the economic implications of countless tests and the psychological distress to the patient? Do we need to treat an unknown primary as just that, unknown and move on to reducing and eliminating the metastatic disease? Is the CUP diagnosis one that we can only determine with post mortem information, if so, does this happen?

It can be seen that this cancer group has major issues for practitioners. Multidisciplinary teams will struggle to come up with a treatment pathway and often the patient has more than one team trying to fit their treatment down a prescribed route which does not necessarily match. Result uncertainty all around.

## **Treatment patterns.**

Without a clear diagnosis the practitioner is left with protocols for their own specialist area of knowledge applying a way forward with little support. In the arena of CUP there appears to be subgroups. There are a number of patients that present with an unknown primary but subsequently through the treatment of the secondary a primary is found. Surgery may confirm a diagnosis at a later stage. The treatment choice may identify similarities with a known cancer such as breast or prostate and they are classified in this group. This then becomes a statistic for the known cancer.

Molecular biology is increasingly uncovering new insights into cancer pathways and at the cutting edge research laboratories are producing tests to help diagnosis. These however are very costly and at the moment are not able to be sensitive enough to be conclusive. The race is on for the definitive test. Rosetta Genomics and bioTheranostics are both research companies in this exciting area.

Pathology colleagues are essential in providing the detailed information from the tissue samples and other predictors to assist in the clinical decision making. This discipline has less funding than other specialisms and with increasing complexities and more challenging testing finds itself under significant pressure. This results in clinicians having to make plans with partial details about the nature of the cancer characteristics as the pathologist tries to make sense with little information.

Clinicians are at the forefront of communication with the patients and planning a treatment pathway. This means trying to stop the metastatic disease from proliferating and involves some level of chemotherapy. The oncologist is left with the decisions. What regime should be considered? What co morbidities does the patient have? Can the chemotherapy reduce the mets. or eliminate them? Will a systemic regime kill the primary even though we can't find it? Should hormone treatment follow any chemotherapy? Is the treatment curative or palliative? What supportive arrangements should be put in place and who has ownership of the cancer journey.

The CUP patient often has a very life limited period and consequently quality of life, symptom control and seamless service are critical for this group. Without a clear protocol and ownership of this group of patients the reality is often a plethora of professionals working in isolation and the patient feeling totally out of control.

## **Living with an unknown primary.**

The start of the journey leads to a diagnosis that shocks to the core. To have a known primary cancer is bad enough but to have an unknown one with a secondary is mind blowing. This seems like an alien invasion, a sense of lurking malevolence stalking the body. Answers are absent and the clinicians appear as helpless as you feel.

You embark on the multiple tests to hunt the primary which involves endless trips to have the body prodded, poked and blood samples by the gallon by a number of specialists. This does little to instil confidence as endless clinicians smile nervously and admit to finding it all a puzzle but now know what it isn't? Whilst this proceeds, the body drops bigger hints of trouble ahead as fear, discomfort and other symptoms manifest themselves.

The way forward needs to be generated and this can be daunting. The extent to which the patients control this process is often determined by the assumptions of the clinician who somehow drew the short straw and has to determine the next step. The information divulged often seems to satisfy neither party who are left to fumble around for a way forward without much evidence to base decisions around.

It is little wonder that seamless service and comprehensive planning fail to be established as everyone involved in this process searches for the way forward. A lot of patients have very limited time to understand what is happening and what choices they have to influence their quality of life as they approach their end of life. The uncertainty and struggle to detect the primary sites mean that valuable time is taken with this costly area of detection at the expense of planning the best care and coming to terms with the time left.

## **Conclusion**

This conference highlighted the importance in managing the patient journey and maximising the expertise of the small group of practitioners and professionals who grapple with this challenging area of medicine. It is essential that research protocols are realistic and practical for successful interventions. Collaboration with other centres of expertise globally, appears central to move forward.

This conference illustrated the significant gaps that exist in our current knowledge and the importance of systematic cooperation and time investment required to meet patient need. It is a tribute to the Cancer of Unknown Primary Foundation, 'Jo's friends' for financing and hosting this conference. The medical community should ensure that they now take this gauntlet on to fund these opportunities for national cooperation to facilitate best practice. The medical community should harness the patient and carer's knowledge and commitment to drive the service provision forward.

My hope for the next 2/3 years are that patients are offered a comprehensive and seamless patient journey which has at its core a named worker whose job is to steer and support the patient and carers as they live with this challenging cancer. My plea is for those with expertise in this field to collaborate to drive improvement. Take your enthusiasm shown from today and generate the changes needed to advance the care for this vulnerable patient group.

Report compiled by Jill Bartrop CUP patient. November 2009.