



Christmas 2014

Dear Jo's friends Supporter,

Through the umbrella bodies that we belong to, we are trying to influence the manifestos of the major political parties ahead of the 2015 General Election. The NHS is likely to be the crunch issue. Last year I said that it was too early to tell the impact of the NHS reorganisation brought in by Andrew Lansley and enabled in the *2012 Health and Social Care Act*. It is much clearer now. The changes are impacting negatively on cancer services. The removal of the National Cancer Action Team, the downgrading of the Cancer Tsar post, the removal of dedicated regional cancer networks are examples where important structural gains made in the early years of the present Government are being eroded. The Peer Review process, that has pushed many trusts into forming CUP teams, is presently under threat. Specialist knowledge and 'joined-up' thinking are being lost in an attempt to make financial savings. All this at a time when the UK has lower 5-year survival rates than the EU average; and UK and Ireland have the lowest cancer survival rate for people in their 70s and 80s than anywhere in Europe (CUP affects mostly older people). Ask searching questions of those who seek your vote!

Research by CRUK shows that 46% of all cancer cases are diagnosed at a late stage making them harder to deal with. Some good news is that NICE is working on new GP referral guidelines for the suspected signs of cancer which are due to be published in May 2015. The draft guideline – presently out for consultation with stakeholders such as *Jo's friends* - sets out the possible symptoms linked to cancer, and provides recommendations on how these should be tested and referred, including advice on timescales. Importantly for us, recommendations for GPs on how to avoid missing cancers in those presenting with symptoms are also set out.

For CUP patients, the most significant thing that they need is a knowledgeable and skilled oncologist. A diagnostically- skilled physician who is abreast of the latest research is to be prized. To that end, we ran a two day international seminar in London this year to develop the CUP knowledge and understanding of oncologists. Reports of the event and all our activities throughout the year can be found in our annual report and accounts which are available on the website.

Thank you for your continuing work and support

With Best Wishes for Christmas and the New Year

John

Making the unknown, known - Some highlights of the past year

The highlights of the year, that have significant potential benefit for achieving our ultimate goal of seeing the end of CUP by 2020, have been:

- **Introduction of Peer Review Measures.** The results, available in 2014, showed 130 functioning CUP MDTs. This means that some 130 NHS Trusts in England, with varying degrees of compliance, now have a recognised route for a possible CUP patient without, as tended to happen previously, bouncing the patient around between site specific teams with no particular expertise in CUP. The Peer Review Measures are based on the 2010 NICE Guideline and, whilst there is still much improvement needed, the CUP patient is starting to receive a far higher level of speedy and effective management.
- **Clinical trials.** Recruitment for the CUP-One trial led by Dr Wasan has now reached its target and has stopped recruiting. The significance of the study lies in its quest to validate new diagnostic tools that may identify the primary site simply, rather than impose a barrage of investigations on the CUP patient with little benefit. Discussions continue to be held to try and find ways of continuing CUP research that merge with other international trials and leverage the fast-moving technology of molecular profiling.
- **100K Genome Project.** Last year we reported that the Chief Medical Officer's scientific priority group had selected CUP as one of the clinical areas where the national 100K Genome Project would be focused. Genomics England, the company created by the Secretary of State for Health to action the project, rowed back on this commitment and we have undertaken some lobbying this year to ensure CUP is not rusticated; lobbying along the lines of 'need and benefit' not just 'ease of sampling'. The formal NHS position at present is that Ovarian, Lung, Prostate, Colorectal, Breast and CLL are 'approved' for the project, with CUP, and some other cancers, on the 'anticipated to be considered' list.
- **CUP 2014.** We ran an international seminar on 'The Management, Treatment and Future Perspectives of CUP' in London on 21 & 22 March. Delegates came from Egypt, Germany, Switzerland, Iraq, Italy, Russia, India, USA, Algeria, Armenia, Portugal, Japan, Greece, Australia, Moldova as well as the four countries of the UK. An expert faculty group was chaired by one of the world's leading authorities on CUP: Professor Nicholas Pavlidis of Greece. Drs Wasan and Osborne of our Advisory Board were co-chairs.
- **Sequencing Project.** We contributed the final tranche of funds to Hammersmith Hospital to complete the £55,000 grant for 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 that show hallmarks of CUP metastasis, where no primary site of cancer is identified. Next generation sequencing will be performed on a subset of the samples as a pilot to help understand the disease and detect potentially "drug-able" mutations. A successful pilot will enable further research.
- **Codifying Project.** The research we initiated into how CUP is being codified by registries has now been completed and the data are being analysed. This novel project has the potential to enhance our accurate understanding of the burden of the disease. Accurate measurements are critical to research and patient management. We are working with the University of New South Wales and Public Health England, and others. Our study has exposed the differences in registration and reporting practices for CUP in Australia, England, Wales, Scotland, N. Ireland, and the Republic of Ireland (all registries in each country participated). The data will be used to identify areas of inconsistency and as an evidence base for recommendations that will allow meaningful international comparisons of CUP incidence.