

Report on the European Cancer Congress Amsterdam September 27th – October 1st 2013

For the first time this year the Congress had a series of sessions with an Advocacy and Ethics theme, and invited patient advocates to apply for bursaries. Lesley Turner(Palliative and Supportive Care CSG) and Hilary Stobart(Gynae CSG) were successful in the application process, and with extra support from NCRN, for which we are extremely grateful, we booked our tickets. Maggie Wilcox (Independent Cancer Patients Voice ICPV) was an invited speaker in the Advocacy and Ethics : Best Practice session talking on the subject 'Your biobank needs you', and ICPV had a stand in the Patient Advocacy 'Square', where we displayed material from several UK organisations involved with patient advocacy, including ICPV, NCRN, NCRI, The BrainsTrust and Breast Cancer Campaign.

The Congress

The congress and the venue were enormous, with more than 18,000 participants, and over 3,000 abstracts presented. After a few teething problems at the start, the events, presentations and facilities were well-organised. Some excellent freshly made food and coffee was on offer which provided vital sustenance in the very long walk to some of the meeting rooms. We were also very grateful for the free transport pass for Amsterdam which was included with our registration.

The Patient Advocacy 'Square'

This new innovation to the congress is to be welcomed and it will benefit from this year's experience and feedback from participants. It provided an excellent opportunity to talk to patient advocates from the other organisations that also had stands, but its site was off the beaten track for researchers and other conference participants. Strict Dutch regulations also meant that only 'prescribers' were allowed through the main commercial exhibition area, bookshops and society stands depriving the exhibitors of access from professionals like molecular biologists, as well as patient advocates. Hopefully the petition, protests and suggestions made by various patient groups to the organisers will result in an improved site for the 'Square' at the next congress. Nevertheless we were able to have some interesting and fruitful conversations with different groups working in Europe e.g a small Romanian ovarian cancer charity was interested in the work of the Gynae CSG, and an Italian womens' lung group were interested in how we promote knowledge of trial availability to patients.

The Advocacy and Ethics Sessions

The Advocacy and Ethics sessions kicked off with a mock TV talk show talking about how cancer is treated and researched in the different European Countries. There were guest speakers from Belgium, UK, France, Romania and Germany and it was agreed that more collaboration was necessary.

There were sessions on best practice with a particularly impressive session from Ingrid Kossler (Sweden) who told us about a patient led movement that joined forces with 8 cancer networks to lobby the Government to start an inquiry into cancer treatment in Sweden. This resulted in a National Cancer Strategy being agreed in 2009 and implemented in 2010. The Country now has 6 regional Cancer Centres and funding (70,000 euros) for 40 patients representatives for each cancer type.

There was a session about the social and cultural revolution in cancer care in Italy given by E Iannelli. She told us that due to patient lobbying, Italian Law was changed in 2007 so that cancer patients were given the right to work part time and then to return to full time work if they wanted to. Italian patients are also now considered as disabled after 15 days post diagnosis which means that they are able to get social benefits. The Oncologist fills in a certificate on line which patients find very helpful.

There were further sessions on adolescents and young adults having their own areas in hospitals to network given by a Dutch speaker; the way awareness was raised about rare cancers through the Zebra NET cancer

campaign given by a Bulgarian speaker; and an excellent session by Maggie Wilcox (UK) on “your biobank needs you”.

There were a number of fascinating sessions on Palliative care asking if patients perceive quality of life in the same way as their doctors do. Doctors from Belgium, Switzerland, Ireland and Israel debated the issue and it was agreed that there were not enough clinical trials to provide robust evidence. It was accepted that good palliative care was better than most chemo treatments and would give patients 2 to 3 extra months if given early. It was pointed out that patients should be participants in care not just receivers. 30% of Palliative care patients get chemo in the last month of their life and it was suggested that this might not be the best treatment for patients.

Finally, Lesley Fallowfield (UK) gave a wonderful interactive workshop on dealing with angry patient and families as a care provider. She showed a number of video interviews and asked the audience (mainly medical/surgical) to assess how the doctors had performed. It was fascinating to see how many thought the doctor had done well when clearly the patient had no idea what he was saying!

The Scientific Programme

We were only able to scratch the surface of the rest of the extensive programme, picking subjects that interested us, ranging from Best Abstract papers on the results of a 10 year study on the irradiation of internal mammary and medial supraclavicular nodes, vitamin D status and inflammation in cancer and other diseases, to sessions on aspects of breast cancer, gynaecological cancer, palliative care, and the use of IT to improve patient care. It was good to see real debate going on in some of the sessions between key players in UK and Europe on the direction of trials. There were also a number of sessions conducted as debates on controversial subjects, e.g ‘this house believes that progression free survival is a valid endpoint in drug development’, and ‘this house believes that supra-radical surgery is not the standard of care for advanced ovarian cancer’. The case was put by proposers and seconders on both sides. At one session the speakers used some of the same papers to present both for and against, and the presentations proved very lively.

Learning Points

- The effort towards collaboration in Europe over translational and clinical research projects to ensure progress in surgery/drugs/radiotherapy treatment for people diagnosed with cancer.
- The effect of different health care systems and laws across Europe on their ability to be involved in research and multi-national trials
- Collaboration between health professionals and patients to improve care outcomes is patchy across Europe and collaboration over research is even less evident.
- Some patient groups use innovative ways to make a real difference in cancer care despite regional difficulties and low funding
- European-wide collaborations between patient groups in particular disease areas is growing
- Importance of patient voice in use of data, tissue samples etc

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