

European Cancer Patients Coalition (ECPC)

Masterclass 2012, Rieti, Italy

The day after the NCIN conference in Birmingham, Maggie Wilcox and I headed for Italy on a 7am flight from Gatwick. We were going to attend the ECPC Masterclass.

This was our first attendance at one of these events, so we had no idea what to expect, except that it was going to be hot!

The two-day meeting was held in Rieti, which is about 100km from Rome. It was a lovely small town in the hills surrounded by forests and villas and the meeting was to be held in a palace, now part of the University.

The event started with an evening social to meet the other delegates. This was held in a restaurant in the geographical centre of Italy. The delegates came from Italy, Romania, Poland, Malta, Denmark, France, Greece, Portugal, Lithuania, Germany, Sweden, UK, USA and Australia.

The Sunday morning started with a very busy agenda, which left little time for speakers to finish and even less time for questions. The talks centred on the European Partnership for Action against Cancer (EPAAC) and the challenges for national cancer plans.

The first session after lunch looked at empowerment for patients and though well chaired it was impossible to get ideas generated from a large group. The discussion centred around a questionnaire that was circulated prior to the meeting asking for comments on doctor patient communication. Results from the survey would be used to feedback to MEPs. To gain the best from this, the session needed to have been split into small groups.

The last session covered personalised medicine and the challenges it faced. No presenters at this session were patient advocates; a paper on the role of patients in bio-banks only mentioned patients as donors.

Monday morning arrived (even hotter) and the first session was on Patients, Professionals, Politicians. This was a lively session, chaired by Gordon McVie, giving case studies from various countries. This was followed by a discussion on the RARECARENet Project (a 3-year European project to build a network of rare cancer patient organisations and identify centres of excellence for the treatment of rarer cancers). We heard the views of patients, industry and case studies from France, UK & Poland.

The day ended with discussions relating to the activities of the various European bodies.

This has been a very quick summary of the two days, but all the presentations will be on the ECPC website in due course (www.ecpc-online.org)

Conclusion

My take-home feeling of the meeting is that I am very glad to be in the UK. Whatever issues we have with the NHS we are very much better off than most of Europe in our level of patient involvement. We know it is far from perfect, but we are years ahead of the majority of Europe.

On the other hand statistics on outcomes give a different picture as we are generally lower than parts of Europe. One reason for this could be that in the UK we often present later to the GP, making our 1year outcomes lower than some countries. I think that once we look at 5yr and over survival the differences are not so apparent.

Gaining a better understanding of how advocacy works in other countries can only help with the work that we do. During the two days I met with some amazing people, widened my knowledge and made some great contacts in other parts of the world.



Mairead MacKenzie, ICPV, June 2012