



Since the creation of our charity ICPV it has been one of our main aims to hold a week long science study week for patient advocates. We are therefore very grateful to Barts and sponsors for making this possible.

It was however with some trepidation and excitement that I arrived on the Sunday evening, particularly as I have not had any formal science education – not even at ‘O’ Level standard. Fortunately I knew most of the group I was spending the week with, so that was comforting.

### **Day 1**

We arrived at Barts and had a short time networking and meeting the Barts team who were providing the presentations, teaching experiments, mentoring and generally volunteering to make the week work for us – including a rota of supplying handmade cakes for the coffee break.

The first lecture was a real wake up and quite testing, even though it was titled Basic Biology, fortunately I seemed to keep up but was worried that the week might get more difficult. Morning presentations covered - cell nucleus – DNA – RNA – proteins; mutations in genes; oncogenes and tumour suppressor genes and hallmarks of cancer.

It was then our first afternoon in the lab. Dressed in our lab gowns and glasses we spent the time happily learning to use equipment to move water to specific quantities with a short test at the end.

We were also asked how we would feel about watching later in the week a breast being dissected and diagnosed and whether we would prefer this to be another type of tissue.

Early evening was a memorable presentation by Prof Ian Hart on not believing all you read in the press and then this was followed by a social event.

### **Day 2**

Presentations were relating to signalling messages to cells; how cells grow; how cells die and animals used to study cancer. The second day of presentations helped to endorse the first days and build towards a bigger picture – which is of course the intention.

In the afternoon, back to the lab, taking our own DNA via a swab, isolating and running on a gel. It seemed even more exciting than the previous day and I was very proud that I managed to do it successfully.

### Day 3

Presentations were Breast Cancer – the facts, followed by other presentations relating to different cancers – Leukaemia / Lymphoma, Colon and Pancreatic. All presentations were superb and made the subject very understandable.

Back to lab – every day seems to be more amazing. Today we were working with cancer cells, separating them, treating and then measuring the effects with a biochemical test.

The practical gave a real insight and huge appreciation of the patience and dedication of the scientists who do this work on a daily basis.

In the evening Barts Social Committee arranged a lovely evening giving the chance for delegates to mix socially with other staff from Barts. It was great to be able to do this and talking about what we had learned informally.

### Day 4

Same format as previous day with presentations in the morning including – Biomarkers in cancer; principles of screening including genetic screening; understanding risk and interpreting literature with examples. Again excellent presentations.

We had all agreed to watch the breast being examined in the pathology lab. We were privileged to watch the dissection and examination of a mastectomy breast\*. This was carried out most sensitively and reassuring to all of us who have had breast surgery. By the end of the examination we were all fully aware of the process and were present when an additional tumour was discovered. For the whole day our thoughts were with the poor lady who underwent surgery and treatment. She will never know what a marvellous opportunity she provided us with in addition to the tissue bank donation and future potential science discovery. If possible we would have liked to have sent her a card or flowers but clearly this would not have been appropriate. (*\*the patient had given her consent to the use of her tissue for research but also for teaching*)

We then moved to work again in the lab following through (with much assistance) tissue preparation. Of genuine discovery to me was the limited access to tissue for research. Although I knew about the need for specific tissue I didn't realise for example that there was a need to import tonsil tissue to enable antibodies to be tested.

I had a huge childish pride when my experiments were successful.

In the evening we were invited to dinner with Barts staff.

### Day 5

We spent all of the final day receiving presentations and workshops relating to clinical trials. This was an excellent way to end the week.

### **Summary**

To summarise I started the week with a strong commitment to ICPV including the creation of a week-long patient science week. One of my hopes for the week was to see that it was successful to continue for future years. To date my role within the charity has been mainly relating to governance, fundraising and patient advocacy.

By the end of the week my confidence has been bolstered by the information both from lectures and practical. I believe this will enable me to provide useful input into clinical trials and research matters in the future should I have the opportunity. I also had a far greater grounding of science and understanding of the patience, integrity and dedication of the staff at the Barts Cancer Institute.

I cannot over emphasis how positively and over whelming the welcome and kindness of the staff of the Barts Cancer Institute which made the learning experience simply amazing!