



British Sarcoma Group Conference

A Patient's Viewpoint

Shirley Collings

HISTORY

- D.o.b. 1.3.53
- Sept 2003: Full hysterectomy for fibroids, prescribed HRT
- Oct 2003: ULMS diagnosed
- Dec 2003 – Nov 2004: 3 monthly checks but no CT scans
- Nov 2004: Local recurrences & lung mets noted on scan
- April 2005: Local recurrences removed
- Sept/Oct 2005: 3 cycles gem/tax chemo (no response)
- Dec 2005: Royal Marsden (2nd opinion) recommended alternative chemo. Own oncologist decided, due to no further spread, no new disease, to watch & wait & 3 monthly CT scans

Increasing anxiety following discovery, on US www discussion pages, of importance of hormone testing of ULMS tissue and contraindication of HRT; oncologist sceptical

HISTORY

- June 2006: Recurrence tissue finally tested for ER sensitivity – 87% ER positive - PR not tested
- July 2006: Oncologist stopped HRT and prescribed letrozole
- Oct 2006 (i.e. after just **3** months): 10% shrinkage on one met, stability in others, no new mets, no spread
- Jan – Aug 2007: No change
- Aug/Sept 2007: Bilateral thoracotomies for pulmonary metastasectomy at Royal Brompton
- Oct 2007: Post-op x-rays at Brompton show lungs all clear, but
- Jan 2008: One 5 mm lung met remains on CT scan

ER/PR Sensitivity Tests

- Cessation of HRT, if applicable, and treatment with AIs is not relevant to or effective for all ULMS patients
- Percentages of ULMS being hormone receptor positive range from 45%-85%. Figures would be more consistent/accurate if test were routine
- ER/PR tests cost under £20 – a stark contrast to the cost of chemotherapy, surgeries, radiotherapy and other treatments
- NICE quotes the cost to the NHS of letrozole as about £90 a month

ER/PR Sensitivity Tests

- The Royal Marsden has decided that all ULMS patients will be screened for ER/PR receptors
- The East of England region has decided to test all ULMS patients, where appropriate
- Most ULMS patients I have met were not made aware on diagnosis of the availability of the ER/PR sensitivity test, the possible contraindication of HRT and the potential significance of a positive result