

"ICPV is a group of people from a broad background who have in common the experience of being diagnosed and treated for cancer. With this experience they provide an important and constructive contribution in many settings, on the clarity and relevance of written information, on the acceptability or otherwise of clinical studies, on the need for better information and improved understanding in different situations. ICPV alert the medical profession to the patient perspective and as such provide a critical contribution to the improvement of medical research and patient care."

**Louise Jones Professor of Pathology, Institute of Cancer, Barts and the London Medical School**



"ICPV make new research clinically relevant to the people who count - the patients"

**Jacqui Stringer**  
Clinical Lead for Supportive Care Services, The Christie NHS Foundation Trust

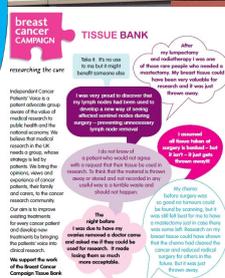
Full details of ICPV's work are in our Yearbook 1: Opening The Conversation  
A record of achievement 2009-2011  
[www.independentcancerpatientsvoice.org.uk](http://www.independentcancerpatientsvoice.org.uk)

### Breast Cancer Campaign Tissue Bank

ICPV members have been involved from the beginning. ICPV suggested that the groups collecting tissue should work together, which led to the formation of a larger tissue bank. ICPV initiated significant changes to the Tissue Access policy: no application can go out to review unless the lay summary is understandable to the patient advocates who are also now able to discuss the application before making a decision. ICPV has produced a patient-to-patient leaflet about the importance of tissue banking, research and consent, which is being used by the tissue bank staff when consenting patients.



ICPV members have voiced the patient perspective at over 20 national and international research conferences in the last 12 months



### POETIC

The clinical view suggested that mentioning a trial at the time of diagnosis would exacerbate an already stressful experience. Our ICPV member argued that not mentioning the trial was denying patient choice and that as long the issue was approached in a sensitive way, most patients would be happy to consider participating in a trial.

Feedback from patients later in the POETIC trial confirmed her view and that patients generally welcome being approached to donate tissue and to consider trial entry. The trial recruited ahead of expectations.



### TACT trial – consent to use of tissue

ICPV members joined with the research team and others to convince the ethics committee that the biological studies should be treated as an amendment and not as a new study, so that renewed consent would not be required.



"ICPV meetings have provided a productive interplay between biomedical researchers and active patients and participants in research"

**Dr Norma Morris,**  
Research Fellow, Dept of Science & Technology Studies, UCL

"ICPV members have been invaluable in helping us to understand how we should design the next generation of trials"

**Professor Peter Barrett-Lee**  
Consultant Clinical Oncologist and Interim Medical Director  
Academic Breast Unit  
Velindre Cancer Centre  
Cardiff

"ICPV continues to improve clinical trial information and processes, including 'bureaucracy busting' for tissue collection and consent"

**Professor Janet Dunn,**  
Deputy Director of Warwick Clinical Trials Unit, Head of Cancer Trials, University of Warwick

### BISMARCK zoledronic acid in metastatic bone disease.

Prompted by an ICPV member's concerns, the steering committee agreed that patients should be advised to have their teeth examined and to have any necessary treatment done before their cancer treatment.

"ICPV's advice was crucial in influencing decisions made both by funding bodies and ethical committees"

**Professor Ian Smith**  
Consultant Medical Oncologist, Professor of Cancer Medicine, The Royal Marsden and the Institute of Cancer Research

ICPV members have so far co-authored 5 research publications

