

## Supportive Interventions ICPV Brighton Summer School Fri 4<sup>th</sup> & Sat 5<sup>th</sup> July 2014 Programme

### Friday 4<sup>th</sup> July: Chair – Lesley Turner

Time	Speaker	Subject
1030	Registration	Plus coffee
1100	Lesley Turner	Welcome to event and introductions
1120	<b>Professor Lesley Fallowfield</b> Professor of Psycho-oncology and Director of Sussex Health Outcomes Research and Education in Cancer (SHORE-C)	Patient information leaflets and other decision making tools.  We've got the patient but what about public involvement?
<b>1320</b>	<b>Lunch</b>	
1420	<b>Professor Janet Dunn</b> Professor of Clinical Trials and Head of Cancer Trials Deputy Director WMS Clinical Trials Unit.	Clinical Trial design : what's good and what's poor in supportive intervention trials
<b>1600</b>	<b>Tea</b>	
16.20	Janet Dunn	Workshop – critical appraisal of existing papers – good and bad. Feedback findings to group
1800	End of session	
1930	Dinner	

### Saturday 5th July: Chair – Carolyn Morris

Time	Speaker	Subject
0930	Adrienne Morgan	Good practice – Setting up the NCRI CSG Breast Symptom Management Working Party
0950	Carolyn Morris	Good practice - Follow up after Cancer treatment – a collaborative approach
1010	Hilary Stobart	Good practice - CT Rad – an evolving Consumer Model
<b>1030</b>	<b>Coffee</b>	
1045	<b>Dr Valerie Jenkins</b> Deputy Director, Senior Research Fellow in Sussex Health Outcomes Research and Education in Cancer	“Chemo Brain” - Myth or fact?  Memory and attention tasks.
<b>1215</b>	<b>Lunch</b>	
1300	<b>Dr Richard Simcock</b> Consultant Clinical Oncologist	The challenges of a trial with acupuncture – ARIX – a randomised trial of acupuncture in patients with dry

	and Lead Clinician for Breast Care at Sussex Cancer Centre, Brighton and Sussex University Hospitals NHS Trust.	mouth following treatment of head and neck cancer.. To include a Demonstration of acupuncture.
1430	Rachel Ryves Senior Research Assistant for the GP DAB and MABCan Projects – University of Southampton	Mindfulness and the MABCan Project. To include a demonstration of mindfulness
1530	Tea	
1600	all	Feedback from ICPV members/debrief/next event
1630	End of session	

With grateful thanks to SHORE- C for hosting at the University of Sussex



### **Professor Lesley Fallowfield**

Lesley Fallowfield is Professor of Psycho-oncology at Brighton & Sussex Medical School, University of Sussex where she is Director of the Sussex Health Outcomes Research & Education in Cancer (SHORE-C) group. Professor Fallowfield originally trained as a nurse at Guy's Hospital London but then did a BSc in Experimental Psychology at Sussex. Research for her doctorate in psychophysics was completed at the Universities of Sussex and Cambridge. In 1991 she became the full-time Director of a Psychosocial Oncology Group and was awarded the first European chair in Psycho-oncology from University College London in 1997. Her research interests are wide and include the measurement of quality of life in clinical trials of cancer therapy and the training of communication skills for health care professionals in cancer. She has published over 350 papers, many book chapters and 3 text books. She lectures and runs training workshops throughout the world in psychosocial oncology, quality of life assessment and communication skills. In 2008 she was made a Fellow of the Academy of Medical Sciences. In 2010 she was shortlisted for the British Medical Journal's Lifetime Achievement Award and won the Pfizer/British Oncology Association's Excellence in Oncology, Lifetime Achievement Award. She is currently Chair of the multidisciplinary British Breast Cancer Group. Professor Fallowfield lives in Brighton and has 2 adult children one a Consultant Hepatologist and the other a Paediatric Community Nurse.

### **Professor Janet Dunn**

Professor Janet Dunn is the Deputy Director and Head of Cancer Trials at Warwick Clinical Trials Unit (CTU). She has over 25 years clinical trials experience working as a statistician and now head of cancer trials. She is involved in National Cancer Research Institute breast, upper GI, myeloma, melanoma and head & neck cancer trials. In January 2006 she was appointed as Professor of Clinical Trials at Warwick and was instrumental in establishing cancer trials. Warwick CTU gained full UKCRN registration in 2008 and moved into their new building in 2009 having secured money from Advantage West Midlands Science City and the Wolfson Foundation. Her research interests include the evaluation of prognostic & predictive factors in cancer trials and designing clinical trials to impact on clinical practice. The establishment of the National Cancer Research Network and the continued funding from Cancer Research UK has resulted in the completion of many successful UK academic trials which have challenged and changed clinical practice. She has been successful in attracting NIHR Health Technology Assessment collaborative grants totalling £14 million (£7 million for cancer trials at Warwick). In 2008 Professor Dunn was awarded National Institute of Health Research (NIHR) Senior Investigator status being one of the inaugural cohort of investigators contributing to applied patient centered research including working actively with ICPV.

## **Dr Adrienne Morgan**

Adrienne Morgan was diagnosed with breast cancer in 2005 and secondary breast cancer in 2010. She suffers very badly with hot-flushes and sexual dysfunction caused by an early and sudden menopause induced by chemotherapy and sustained by oestrogen blocking drugs.

She is a PhD medical research scientist with 20 years in academia and industry. After her primary diagnosis and treatment she spent three years as the staff scientist at Children with Leukaemia, and then a year as the secretariat for Cancer52. After her secondary diagnosis she is unable to work, but, through her patient advocacy with the Breast Cancer Campaign Tissue Bank, has recently been able to return to the love of her life - science and laboratory research – with an honorary post at the Barts Cancer Institute.

Adrienne was appointed to the NCRI Breast Clinical Studies Group in 2012. With the support of the group she established a Symptom Management Working Party to address the issues of hot flushes, sexual dysfunction and poor treatment adherence.

Adrienne is a founding member and Chair of Independent Cancer Patients' Voice, a lay member of several Clinical Trial Management and Working Groups, a familiar independent patient voice in Q and A sessions at cancer conferences and with the media. She lives in central London with her husband Chris and is a committed Trekie and Doctor Who fanatic.

## **Carolyn Morris**

Carolyn Morris worked not 100 yards away from this Summer School's setting for many years, latterly as Director of Sussex's Career Development Unit. A psychologist by background, she also spent 10 years working in counselling, working with staff & student clients, alongside her careers work.

Her first diagnosis of cancer in 1999 prompted early retirement, though in truth that was more to do with the side effects of Tamoxifen than with the cancer itself.

Involvements in cancer initially through the UK Breast Cancer Coalition, a patient led advocacy group, many of whose members were founder members of ICPV, and in the then Sussex Cancer Network. Increasingly involved in research, she is a Trustee of ICPV, sits on Research for Patient Benefit SE Coast Committee, leads NCRN's work on the research questions in the National Cancer Patient Survey and is a member of NCRI's Psychosocial Oncology & Survivorship Clinical Studies Group. Carolyn is now on a Phase 2 trial to treat 3<sup>rd</sup> recurrence, diagnosed earlier this year.

## **Hilary Stobart**

Hilary Stobart has worked as a hospital physicist in radiotherapy in the NHS, and for a year in Iceland, followed by 20 years working in IT system administration and management in Cambridge. She was diagnosed with breast cancer in 2009. Looming early retirement and a look from a patient view at what research has achieved in the treatment of breast cancer over the years since she was a hospital physicist, led her to volunteer for her first public and patient involvement role at the NCRI Gynae CSG in 2010. Since then she has also become

involved in the NCRI radiotherapy initiative, CTRad, joined ICPV, trained to take consent as a volunteer at the Nottingham Health Science Biobank, and joined the East Midlands Research and Design Service as a lay reviewer.

### **Dr Valerie Jenkins**

Dr. Valerie Jenkins is the Deputy Director and Senior Research Fellow in Sussex Health Outcomes Research and Education in Cancer (SHORE-C). Val originally trained as a nurse in Wales and worked in Oncology at Velindre Hospital in Cardiff before completing her BSc in Experimental Psychology at the University of Sussex. Her doctorate in neuropsychology was entitled 'Novel Word Association Priming in Amnesic Patients.'

Since joining the SHORE-C (previously Psychosocial Oncology Group) in 1996, Dr. Jenkins has worked extensively on research projects aimed at improving our understanding about doctor/patient communication, especially that around randomised clinical trials. The training materials she developed with colleagues are now being used throughout the UK trials community and in other parts of the world. Her research interests are wide, and include the impact of chemotherapy and aromatase inhibitors on cognition in women with breast cancer; impact of endocrine therapies on cognition and physical strength in men with prostate cancer, the use and effect of complementary therapies including acupuncture and yoga as interventions to alleviate side effects from surgery/treatments, for patients with cancer.

### **Dr Richard Simcock**

Consultant Clinical Oncologist at the Sussex Cancer Centre since 2004 treating breast and head and neck cancers.

Prior to that a Research Fellow at the Sydney Cancer Centre and a Registrar training in London and the South East after a brief flirtation with a career in Palliative Medicine.

Previous Network Lead for Head and Neck and Breast Cancers and current Clinical Lead for Breast Services.

Lead on Survivorship Pilot in Breast Cancer for the NCSI in Sussex.

Chief Investigator of the ARIX study (NCRN / CRUK study of acupuncture in radiation induced xerostomia), and PI of multiple other local studies.

Organiser of British Institute of Radiology's Meeting on 'Current Issues in Breast Radiotherapy' 2013 (and 2015).

Co-Editor of the 'ABC of Cancer Care', a 'primer' on cancer for primary care, students, AHPs and non-specialists.

Married to a GP, and a novice but enthusiastic tweeter (#BreastDocUK).

**Rachel Ryves**

Rachel Ryves completed her Masters in Health Psychology at the University of Southampton in 2012 and has since been working as a Senior Research Assistant with the School of Primary Care and Population Sciences within the Faculty of Medicine at Southampton. She has worked on a wide variety of projects ranging from antibiotic prescribing in general practice, to developing self-management interventions for patients presenting distress symptoms. Her main research interests are the development and promotion of self-management interventions for patients with long-term health conditions, and Rachel hopes to receive funding to start a PhD within this area in the near future; in order to pursue her career as an academic researcher. The biggest research project Rachel has worked on to date involves asking breast cancer patients their understanding and views of an existing mindfulness intervention.