independent cancer patients' voice
Registered Charity no.1138456

The Voice Newsletter

Review of Events

Review of Activities

ICPV News

'Quality Advocacy needs Quality Education' presented by Pat Fairbrother at the American Association of Cancer Research Conference, Scientist↔Survivorship Programme, in Philadelphia, April 2015. Pat promoted the VOICE (vision on information, confidence and engagement) science for patient advocates course which has been held for several years at the Barts Cancer Institute. The course is unique, the only course of its type in the UK. More details of the course can be found on page 14, and also www.independentcancerpatientsvoice.org.uk/Voice: Science for Patient Advocates. This year's course will be held once again at Barts on 1-5 September. However, for next year we are considering holding the event in the North of England (venue to be decided) **See Pat's review of the AACR Conference on page 6.**

Welcome to our second newsletter which we hope will be of interest to all ICPV members and also to any other readers.

The response to the first edition of VOICE was very encouraging and meant that we extended readership outside ICPV and in this edition we have contributions from other groups and from researchers. Please note - Isobel Anderson will welcome input for the next edition! Special thanks are due to Isobel for her hard work and patience in collecting content, reminding those of us whose input is overdue and for finding interesting information, events and articles to include for this newsletter

We are also grateful to Dr Adrienne Morgan our Chair, Professor Louise Jones, Professor John Marshall, Dr Richard Grose and the other very special people at Barts Cancer Institute for organising and hosting another VOICE course in September 2015. This is a unique, high level course for experienced patient advocates which adds "hands on" laboratory-based experience to classroom lectures and discussions

I hope you enjoy reading this newsletter and will send feedback as well as suggestions and articles towards content of the next one!

ICPV members take part in national and international conferences by giving presentations about their experiences, engaging in debate with clinicians and researchers, and raising awareness of the work of ICPV. Below are some of the events attended by members during January - June 2015

British Thoracic Oncology Group Conference, Dublin, 28-30 January

EFGCP, Brussels, 28-29 January

World Cancer Day, Surrey, 4 February

Multiple Biopsy Forum, ICR, London, 25 February

Inaugural Cancer52 Patient Engagement Event, London, 3 March

NCRI National Breast Cancer Trials Meeting, London, 5 March

Election 2015: The Guardian Big Health Debate, London, 11 March

BPOS Conference, Leeds, 19 March

Launch of UKCRC Tissue Directory and Co-ordination Centre, London, 24 March

AACR Conference, Survivorship Programme, Philadelphia, USA, 18-22 April

Pharmacogenetics & Stratified Medicine Network, Workshop on Biobanking, Leeds 21 April

Inflammatory Breast Cancer Symposium, Birmingham, 24 April

PPI in Research, Hull, 24 April

Tomorrow's Leaders in Surgical Oncology, London, 11-12 May

ECMC Network, London, 21 May

UK Clinical Trials Conference for Supportive Care in Cancer Research, Sheffield, 3 June

NCIN Cancer Outcomes Conference, Belfast, 8-10 June

NCRI CCB AGM, Nottingham, 17 June

ESO Breast Screening Conference, Dublin, 18-20 June

Breast Screening and Research Conference, Cambridge, 22-23 June

REVIEW OF EVENTS

Attending and Speaking at Conferences

British Thoracic Oncology Group (BTOG) Annual Conference, 28-30 January 2015, Dublin

Tom Haswell of ICPV attended the BTOG conference and made the following observations: "I have to say that it was one of the best conferences I have ever attended. The presentations were excellent and covered all types of treatments and trials for lung cancer and mesothelioma including a tissue biobank based in Cambridge for Mesothelioma. There were also interesting sessions on radiotherapy, including discussions on 4-dimensional computed tomography scanning (4DCTS), and how dose planning is critical in respect of tumour movement. Discussions were held about volumetric modulated arc therapy (VMAT), which is a relatively new type of intensity modulated radiotherapy (IMRT) that was first performed at the Marsden, and also dose-blurring which leads to under-dosing. While it was a thoracic oncology conference, much of the Radiotherapy Training Symposium and various presentations were relevant to other cancer sites.

There was also a Patient and Public Involvement meeting, a small meeting it has to be said. Altogether, there were only three consumers attending the conference who all had the common problem of being advised not to attend pharma-sponsored sessions. As this was, to my knowledge, only the second year that consumers have been invited, I felt it best to acknowledge the advice.

Dave Ardron and I have been trying for the past few years to get consumer invitations to BTOG, although Dave has attended in previous years because of his position as Chair of the Consumer Liaison Group. Hopefully, now that precedent has been set, the door remains open. Overall, an excellent conference."

Tom Haswell, ICPV Member

European Forum for Good Clinical Practice (EFGCP), 28-29 January 2015, Brussels, Belgium

How do we improve health without betraying confidentiality within current and upcoming EU Regulations: what is the cost of maintaining patient confidentiality in health research

Maggie Wilcox attended this major forum which was organised by EFGCP in order to bring together patients, researchers, sponsors, competent authorities and ethics committees to debate the tensions between confidentiality and data access in health research. It provided an opportunity to hear up to date information and opinion from experts involved, views of patient groups, and to consider current solutions. Dr Hugh Davies, Health Research Authority (HRA), EFGCP, UK, opened the forum by highlighting the problems we face today with privacy of our data in this "connected and suspicious world" and the consequent attitudes impacting on research. He felt that it was important to strike a fair balance when legislating for all issues and that consent should be at the centre of proposed data collection for research. Delegates were asked to read a statement (see below) and to complete a short questionnaire asking if they would support the statement or not.

"Major progress in our understanding of the factors underpinning good health is leading us towards developing better treatments. Much of this depends upon use of personal data, such as health records and continuing access will be central to further health career improvements.

On ethical grounds, patients should be able to provide "broad consent" for future use of tissue or data in research without exact definition of the research project, provided the data are anonymous to the research team and the research has been reviewed and approved by a Research Ethics Committee.

"Broad consent" means the details of new research in the future are not precisely specified in the information for research subjects. It is consent that does not define the exact nature of future work but may indicate the areas of interest".

The results of the survey were presented by Kim Champion, Dr Hugh Davies and Dr Beth Thompson. There was a wide survey coverage, which revealed:

- evidence of disagreement within member states
- anonymised data not covered by national legislation
- data protection law often does not recognise broad consent, but it is a popular model in medical research
- some member states allow use of data without consent, but have particular conditions in place

Further notes from the conference can be found at the ICPV Website http//www.independentcancerpatientsvoice.org.uk

World Cancer Day, 4 February 2015, University of Surrey

This public event was organised by the University of Surrey and held at the Surrey Sports Park. World Cancer Day is a worldwide cause celebrated globally. ICPV member, Sophie Gasson, was there on the day and reported as follows: "The joint aim of the event was to serve our community by showing them what there is on offer to support and help them through their illness. There were four main themes: Choosing Healthy Living; Delivering Early Detection; Achieving Treatment for All; and Maximising Quality of Life.

The day included lectures, exercise classes and an exhibition from many local groups and charities showcasing cancer services, treatment and research taking place in Surrey. The Cancer Partnership Research Group (CPRG); Oesophageal Gastric (OG) Cancer Charity; Kent, Surrey and Sussex Cancer Research Network (KSS CRN); and ICPV; all exhibited information. The University and all of the exhibitors promoted the event through social media, posters and word of mouth. The aim was to see as many people through the doors as possible. Attendance was actually disappointingly low with few members of the public coming along. However, it did give exhibitors and health professionals a valuable opportunity to network and share resources."

Sophie Gasson, ICPV Facilitator

Institute of Cancer Research, Multiple Biopsy Forum, 25 February 2015, Chester Beatty Laboratories, London

This important forum was attended by consultant oncologists, clinicians and researchers from the Institute of Cancer Research and Royal Marsden; Patient Advocate Group (PAG); Cancer Partnership Research Group (CPRG); The Patients and Carers Research review Panel based at the Royal Marsden Hospital; and ICPV members: Jacqui Gath, Adrienne Morgan Sophie Gasson, Helen Bulbeck, Mairead MacKenzie, Hilary Stobart, Anna Wallace, Chris Finch and Maggie Wilcox. There is increasing requirement for multiple biopsies within clinical trials and the aim of this forum was to facilitate discussion between the patient advocates and investigators in order to improve future trial design and the understanding of the requirement for multiple biopsies within research. Topics for discussion included requirement for multiple biopsies in current and future trials, acceptability to patients, consent issues, and benefits to future patients. Presentations included:

- Why do we need multiple biopsies?, Professor Mitch Dowsett
- Clinical trials based on minimal residual disease detection in early breast cancer, Professor Nick Turner
- The ctDNA Screening Trial, Professor Nick Turner
- The POETIC-2 Trial, Professor Mitch Dowsett
- PHOENIX Trial, Professor Andrew Tutt
- The plasmaMATCH Trial, Dr Alistair Ring

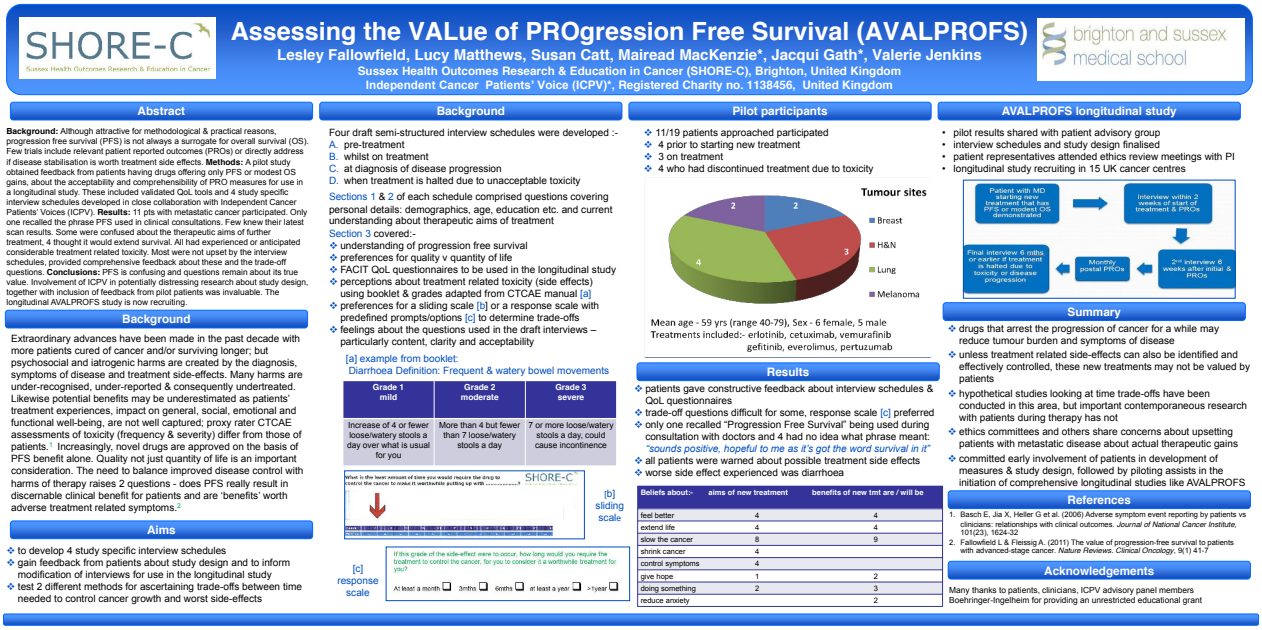
The focus was on breast biopsies and discussions were led by questions and concerns raised from group members. Laura Stevenson, Senior Trials Manager, ICR, kindly offered to share with ICPV members, discussion notes from the meeting, which can be found on ICPV website http://www.independentcancerpatientsvoice.org.uk/ Conference & Meeting Reports

Election 2015: The Guardian Big Health Debate, 11 March 2015, London

ICPV members were invited to attend this debate by the Guardian Healthcare Network and the Association of the British Pharmaceutical Industry (ABPI) during which representatives from the Conservative, Labour and Liberal Democrat parties discussed their plans for the future of the UK's health policy. The meeting began with a welcome from Stephen Whitehead, Chief Executive, ABPI. Delegates included representatives from government, industry and think-tanks, as well as academics, policy experts, healthcare staff and patients.

British Psychosocial Oncology Society (BPOS) End of Life Care and Practitioner Development and Wellbeing, 19-20 March 2015, Leeds

Mairead MacKenzie and Jacqui Gath attended this conference hosted by Leeds Beckett University. The theme of the conference was 'End of life care and practitioner development and wellbeing' and keynote speakers included Professor Mike Bennett, University of Leeds; Dr Stephen Barclay, University of Cambridge; and Dr Max Henderson, Kings College London. A variety of oral presentations, posters and workshops were included in the programme. 'Acceptance and Commitment Therapy' was facilitated by Dr Nick Hulbert-Williams and there was a panel debate on 'Challenging clinical issues and decisions in end of life care'. Mairead and Jacqui presented the poster on the AVALPROFS study (Assessing the VALue of PROgression Free Survival). Mairead and Jacqui contributed to this 3-year study led by Professor Lesley Fallowfield, Professor of Psycho-Oncology, Director of Sussex Health Outcomes Research and Education in Cancer (SHORE-C). The poster can be viewed at http://www.independentcancerpatientsvoice.org.uk/ICPV Publications



Launch of UK Clinical Research Collaboration (UKCRC) Tissue Directory and Co-ordination Centre, 24 March 2015, held at the Royal Free Hospital, London

This event was held to celebrate the launch of the new UKCRC Tissue Directory and Co-ordination Centre. Speakers included Dr John Fistein, Mrs Anne Carter, Dr Philip Quinlan and Ms Jessica Sims. Maggie Wilcox (lay member of the NCRI Confederation of Cancer Biobanks) and Hilary Stobart (patient member of the Tissue Directory and Coordination Centre's informatics evaluation group), attended the event and Hilary provided a review:

"We were delighted to participate and to hear the progress that is being made towards achieving the aim of increasing quality, visibility and accessibility of the UK's world class specimen and cohort collections for academic and commercial researchers. This is an aim, of course, shared by the patients who have so kindly donated their tissue and samples to the collections.

The various strands of the initiative were outlined by a series of speakers. We heard about setting up the coordination centre and the work on standards, harmonisation and audit from the Director, Anne Carter. Philip Quinlan, Chief Technical Officer, guided us through the work undertaken so far in informatics to begin to provide a robust and scaleable web-based platform to showcase the collections, and to facilitate collaboration amongst researchers. Jessica Sims, Project and Engagement Officer, explained the work taking place to engage stakeholders.

Conference participants ranged from tissue collection holders, biobanks (including commercial), researchers, funders, and patients. Afternoon discussion sessions were focussed around a number of questions such as 'What constitutes a gold standard' , 'Who should undertake audits, what should be audited and how can good practice be shared?', and 'How can the UKCRC Tissue Directory and Coordination Centre help you?'. It is early days for the centre and many more of these discussions are planned as they engage with different stakeholders and develop their resources. Write-ups from all the business of the day can be found on the Centre's website at https://www.biobankinguk.org/resources/. ICPV has registered as a stakeholder so will look forward to being involved in future discussions."

Hilary Stobart, ICPV Member, Member of the Tissue Directory and Co-ordination Centre informatics evaluation group

American Association for Cancer Research (AACR) Annual Meeting, Scientist↔Survivorship Programme, Philadelphia, USA, 18-22 April 2015

Pat Fairbrother was delighted to win a scholarship to attend this premier cancer research meeting in America and to be invited to give a presentation. 30 patient advocates, many of them cancer survivors, took part to learn about cancer science and research so that they could incorporate that knowledge into their advocacy work back home. Advocates were joined by scientific and advocate mentors who guided them through a comprehensive schedule, which included attending special interest sessions and preparing presentations on aspects of cancer medicine. Topics included big data, cancer biomarkers, genome sequencing, cancer complexity, and immunotherapy.

Pat's group elected to attend the immunotherapy lectures and were invited to present their findings at the advocates' celebration dinner on the final evening. The advocates were thrilled to be able to show their posters in the poster sessions in the Exhibition Hall. Pat said: "it was a wonderful opportunity to showcase the advocacies' achievements and for the advocates, mentors and the programme team to become more informed about our fellow advocates' backgrounds. The really big news coming out of this conference was the exciting results in immunotherapy and the fact that, in some cases, patients have had complete responses to this form of therapy, which involves equipping a patient's own T cells with an antibody-like receptor that can target and destroy the cancer. The goal is to increase the number of cancers that respond to immunotherapy. The challenge is to work out how to strengthen the power of the immune response to those not responding. Special thanks to Dr Anna Barker, Director of Scientist↔Survivor Programme, who, along with Administrator Karen Russell Mills, kept us focussed! Finally, advocates and all those working on the programme found the experience to be most rewarding. I personally would like to thank all the organisers who strive to make each year's event a success and, by doing so, help to foster excellent relationships in their communities across the USA and beyond." See Pat's notes on the Conference on the ICPV website http//www.independentcancerpatientsvoice.org.uk/Conference & Meeting Reports

Pat Fairbrother, ICPV Member

Pharmacogenetics & Stratified Medicine Network, Workshop on Biobanking, 21 April 2015, Leeds

Maggie Wilcox, President of ICPV, was invited by Professor Valerie Speirs to present at this meeting which was chaired by Professor Sir Alex Markham, Director of Research and Professor of Medicine, Leeds Institute of Biomedical and Clinical Sciences. Maggie's presentation, which gave a patient's perspective on the importance of biobanking, was very well received, with lots of questions and feedback. In her presentation, Maggie promoted the work of ICPV and other patient and public involvement (PPI) groups and discussed their increasing collaboration with professional colleagues, both local and national, across all disciplines of cancer research, including cancer networks and charities. She highlighted the important role that PPI now plays, such as training for professionals and raising awareness of the need for tissue donation.

As lay member of the Confederation of Cancer Biobanks executive and former member of management board for Breast Cancer Campaign Tissue Bank, Maggie feels strongly about tissue donation and reminded everyone that: *"tissue comes from real people and is not a commodity but has been donated to assist in the development of earlier diagnosis and more effective treatment for future patients."*

Inflammatory Breast Cancer Symposium, 24 April 2015, University of Birmingham

ICPV members, Mairead MacKenzie, Hilary Stobart and Maggie Wilcox, attended a symposium on inflammatory breast cancer (IBC) which is a rare and extremely aggressive form of breast cancer. The symposium, which explored key aspects of diagnosis and management of IBC, was organised by Dr Fedor Berditchevski, University of Birmingham, and kindly sponsored by Breast Cancer Now. Sessions were chaired by Miss Adele Francis, Dr Abeer Shaaban and Professor Valerie Speirs. Speakers included Dr Fedor Berditchevsdki, Dr Daniel Rea, Dr Sarah Vinnicombe, Mr Ramsay Cutress, Professor Andrew Hanby, Dr Vanda Ribeiro, Professor Louise Jones, Dr Massimo Cristofanilli, Dr Steven van Laere and Dr Ellen Copson. A patients' perspective on the diagnosis and management of IBC was presented by Caroline Ballinger UK, and Valerie Fraser USA

According to new guidelines presented at the symposium by the UK IBC Working Group, women with this rare type of breast cancer should be offered less-invasive surgery where appropriate. Dr Fedor Berditchevski, Group Leader at the School of Cancer Sciences, University of Birmingham and UK IBC Working Group academic lead, said: *"We hope the publication of these guidelines will be a trigger, building much-needed momentum for academic and translational research into inflammatory breast cancer in the UK. It's only through the coordinated and concerted efforts of scientists and clinicians from various disciplines in this area that we will be able to better understand the biology of this condition and ultimately save the lives of more women."*

Dr Daniel Rea, Reader and Consultant in Medical Oncology at the School of Cancer Sciences, University of Birmingham and UK IBC Working Group clinical lead, commented: *"These new guidelines represent a real step forward not only for clinicians but, more importantly, for women with inflammatory breast cancer in the UK. Treatment options that specifically target this rare breast cancer do not exist, and we need a concerted research effort to fix that. These new recommendations will allow some inflammatory breast cancer patients to be spared a more invasive mastectomy, and as treatments improve we hope that a breast conservation approach will become increasingly common."*

Quote from Baroness Delyth Morgan, Chief Executive of Breast Cancer Now:

> *"These desperately-needed guidelines will mean a better future for women with inflammatory breast cancer. With up to 1,000 women diagnosed with the disease in the UK each year, many of whom could be spared more gruelling surgery, the needs in this critically under-researched area must be met. Collecting tissue samples from women with IBC into our Tissue Bank will allow researchers around the world to help more women outlive this aggressive disease sooner. These new guidelines represent the fruit of collaborative research that we are very proud to support. We look forward to further work in this area that will give women with inflammatory breast cancer new options."*

New UK guidelines published in the British Journal of Cancer http://www.nature.com/.../journal/vaop/.../full/bjc2015115a.html International guidelines http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3105293/. Inflammatory breast cancer: Time to standardise diagnosis assessment and management, and for the joining of forces to facilitate effective research, Rea et al. British Journal of Cancer 2015 **112**, 1613–1615. doi: 10.1038/bjc.2015.115.

East Yorkshire Clinical Academic Trainees and Doctoral Clinical Fellows, Hull, 24 April 2015

Lesley Turner of ICPV was invited by Professor Miriam Johnson (Professor of Palliative Medicine and Deputy Academic Programme Training Director for the Hull York Medical School) to speak about Patient and Public Involvement in Research: Getting the Added Value. Lesley began the presentation by outlining the three levels of Patient and Public Involvement (PPI) in Research: consultation, collaboration and publicly led involvement. She gave examples of best practice and the pros and cons of each approach. Lesley then went on to discuss why PPI in research is important and presented the knowledge argument, the moral argument, the policy imperative and the consequentialist argument. She discussed the value of research to researchers and to patients, using quotes from other members of ICPV, and explained what she had done as a patient advocate and as a member of ICPV to add value. Lesley ended the lecture with some top tips for researchers working with the public and patients:

- Roles: need to be defined between Patients and the researchers
- Budget: need to pay for expenses and INVOLVE rate of £150 per day.
- Support: offer training and mentoring.
- Respect: allow the patient to voice their opinion. They just might have a valuable point.
- Visibility: to give credit where it is due.
- Language: to write the proposal so that your mother can understand it (at least initially!).

In the afternoon, Lesley and some of the local PPI members facilitated a Dragon's Den looking at a number of current research proposals and provided advice on where the PPI could be improved. The researchers and the Dean of the Medical School were very grateful to Lesley and to ICPV for their support and assistance in making the day such a great success.

Lesley Turner, ICPV Member

The Nuffield Council on Bioethics, Roundtable Discussions with Health Research Authority (HRA), 1 May 2015, London

The National Institute for Health Research, Cancer Research Network (NIHR CRN) kindly invited ICPV members to this event There were lots of interesting talks and discussions and the workshop brought together a small group of clinicians, scientists, regulators, research ethics committees and patient representatives to discuss:

- whether and when sham surgery is appropriate
- understand the concerns of those carrying out and receiving the procedures
- understand the current regulatory framework within which research is carried out and consider whether clarification, guidance or advice is needed.

The meeting began with a short introduction from the Director, followed by 3 presentations bringing in different perspectives on the use of sham surgery: neuroscience, orthopaedic and cardiac. The patients' perspective was presented by patient advocates. This was followed by a summary of current guidance and ethical considerations. The closing discussions and the way forward were chaired by the HRA.

Tomorrow's Leaders: Clinical Trials in Surgical Oncology, 11-12 May 2015, Royal College of Surgeons, London, held by the National Institute of Health Research

Hilary Stobart of ICPV attended and gave the following review of the meeting: "It must be quite daunting to expose one's ideas for discussion and scrutiny by one's colleagues, even for seasoned researchers, so I was very impressed by the confidence with which trainee surgeons presented their research ideas at the Dragon's Den event held as part of this 2-day meeting about clinical trials in surgical oncology. There were some excellent speakers in the main meeting, highlighting, amongst other topics, how to get started and to integrate research into a busy NHS department, quality assurance (with examples from the radiotherapy quality assurance programme), how to secure grants, and how research delivery is managed.

Five breast surgery trainees presented their research ideas for discussion with two senior researchers, myself with the patient perspective, and colleagues. The ideas were wide-ranging from translational to the boundary between primary and secondary care. Apart from the actual comments I could make, Miss Adele Francis (Lead in Breast Cancer Surgery Research, Birmingham) who organised this session, was very keen to introduce trainees to the need to involve patients very early in the research trial design cycle.

There were sessions going on in a number of specialties during the afternoon, including neurosurgery, colorectal, upper GI, head & neck, gynaecology, urology and sarcoma. However, most of these sessions did not have patient involvement. Do look out for this event if it is repeated and volunteer to provide patient involvement if you can. I learnt a lot, and was very encouraged by the new trainees coming through. It was excellent to see the breadth and quality of the ideas proposed, and the enthusiasm and presentation skills of the presenters."

Hilary Stobart, ICPV Member

Experimental Cancer Medicine Centre (ECMC) Network, Annual Meeting, 21 May 2015, London

Experimental Cancer Medicine Centres (ECMC) is a dedicated network for supporting the early stage development of new cancer treatments. The ECMC Initiative is jointly supported by Cancer Research UK and the health departments for England, Scotland, Wales and Northern Ireland.

Four ICPV members participated: Maggie Wilcox, Jacqui Gath,Tom Haswell and Elspeth Banks. The four members had previously attended the inaugural meeting of the ECMC PPI Strategy Group in April, so this was a good opportunity to be brought up to speed with current developments. Elspeth reported on the meeting. "The morning programme included:

- Feedback on the Single Technical Pharmacy Review.
- A personal view of collaborating with industry, presented by Professor Andrew Hughes. He focused on three areas – precision medicine, scientific understanding and patient centricity. Professor Hughes also highlighted the important role played by ICPV in producing a short, comprehensive, and patient-friendly Patient Information Sheet and Consent Form which helped to achieve rapid ethics approval.

- An update by Professor Karen Brown on the work of the UK Therapeutic Cancer Prevention Network, a group chaired jointly by Professor Brown and Professor Dion Morton. This was a useful awareness-raising talk, as I had little prior knowledge of this network. Its work includes the identification and development of therapeutic cancer preventive agents and lifestyle interventions into clinical trials and routine clinical practice. A drug repurposing proposal will see the screening of drugs available to UK/EU market with the aim of testing and repurposing them for a prevention setting.
- Information about the CRUK Accelerator Award in Molecular Pathology
- The recent ECMC Patient Experience Survey which followed the NCPES Patient Experience Survey. Overall, the feedback was extremely positive. Areas to be taken forward include patient awareness of communication with other healthcare professionals - joined-up working - and patient awareness of what research is already happening in hospitals before being invited to participate.

In the afternoon we were offered a selection of parallel sessions. Tom and I attended the 'Adaptive trial design for early phase trials' which was chaired by Thomas Jaki and Lisa Hampson of Lancaster University. By the end of this great interactive session we had been appraised of current opinion about the 3 + 3 design and of the merits of the Bayesian Logistic Regression Model (BLRM). Maggie and Jacqui listened to Alison Pass in the 'Use of IT and social media by health professionals'.

Thanks to ECMC for supporting our participation and in particular to Aoife Regan, Hannah Brown and Elliann Fairbairn who have been extremely active in helping us at both recent events."

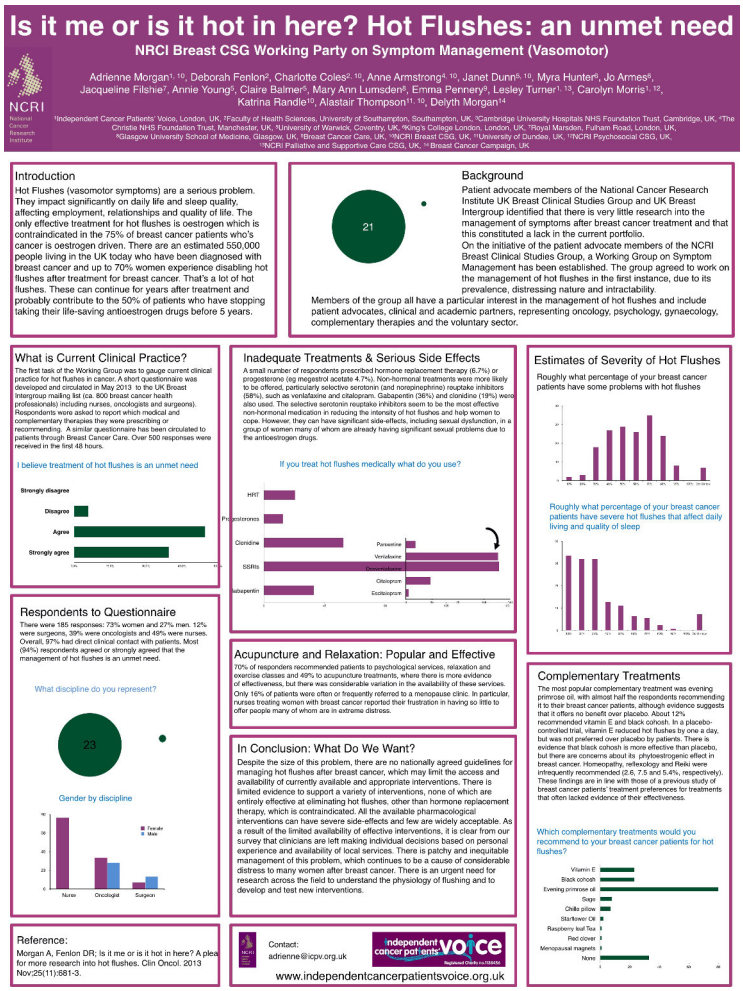
Elspeth Banks, ICPV Member

UK Clinical Trials Conference for Supportive Care in Cancer Research, 3 June 2015, Sheffield

Organised by the NCRI Supportive and Palliative Care Clinical Studies Group

Around 140 people attended the conference which aimed to highlight the work of the Supportive and Palliative Care Clinical Studies Group, and promote research into supportive care. Supportive Care in cancer is the prevention and management of the adverse effects of cancer and its treatment. This includes the management of physical and psychological symptoms and side effects across the continuum of the cancer experience from diagnosis through anticancer treatment to post-treatment care.

Patient Advocate Members of the NCRI Breast Clinical Studies Group identified that there was very little research being carried out into the management of symptoms after breast cancer treatment and that this constituted a gap in the current portfolio. They set up a Working Party on Symptom Management working with the NCRI Supportive and Palliative Care CSG; NCRI Psychosocial CSG; Independent Cancer Patients' Voice; Breast Cancer Campaign (now Breast Cancer Now), Breast Cancer Care, the Universities of Southampton and Warwick; and other organisations. Members of the group all have a particular interest in hot flushes and include patients, oncology, psychology, gynaecology, acupuncture and physiology.



The first task of the working party was to gauge current clinical practice, so a short questionnaire was developed and circulated to Patients and Health Professionals. The finding of this survey formed the basis of a poster entitled *'Is it me* or *is it hot in here? Hot flushes: an unmet need'*. The survey identified that there was an urgent need for research across the field to understand the physiology of flushing and to develop and test new interventions.

The group submitted the poster to the conference committee and the poster was not only accepted, but won first prize against very strong competition. The Conference Committee considered the poster to be a "really readable poster that felt very inclusive and reflected the unmet need of patients". They were awarded a year's subscription to the journal of the Multinational Association of Supportive Care in Cancer.

The NCRI Breast CSG Working Party continues to raise awareness of hot flushes and to promote research in this area.

Lesley Turner, ICPV Member and Member of the Supportive and Palliative Care Clinical Studies Group

NCIN Cancer Outcomes Conference, 'United Against Cancer', 8-10 June 2015, Belfast hosted by the Northern Ireland Cancer Registry

The Conference theme was 'United Against Cancer, Locally, Nationally and Internationally', and was built on the theme of the 2014 conference 'The Power of Information' which highlighted how cancer intelligence is based on high quality data.

Margaret Grayson, ICPV member, who is leader of PPI in Northern Ireland and NCRI and member of the Consumer Forum, gave a brilliant introduction at the beginning of the conference. She emphasised that this is our data and we want it used while recognising the need for regulation in use. See further details on Margaret's talk on ICPV website: http://www.independentcancerpatientsvoice.org.uk/Conference & Meeting Reports

Richard Stephens, Carolyn Morris and Matthew Baker presented, on behalf of the NCRI Consumer Liaison Group, the findings from the National Cancer Patient Survey 2014. Richard Stephens and Chris Carrington, NCIN, held a very effective Dragon's Den about the use of data in research and lay views about current barriers. There is going to be further work on this subject and updates will follow.

After making a plea for help to overcome the current delays and barriers to researcher access to health data, Karen Blakey (Researcher, Rarer Cancers, University of Newcastle) had an overwhelming show of support from all delegates - especially patients. She also announced that there was to be an emergency meeting of the Health Service Data Users Group (HSDUG) in London the following day and CRUK provided details regarding the venue, timing and telephone numbers. Maggie Wilcox, who was attending the NCIN in Belfast that day, was able to input by telephone to support Karen at the HSDUG meeting. She confirmed that Karen had received patient as well as researcher support at the NCIN meeting and mentioned the presentation by Margaret Grayson demanding ethical use of her health data.

National Cancer Research Institute (NCRI) Confederation of Cancer Biobanks (CCB) Annual General Meeting, 17 June 2015, University of Nottingham

ICPV Members and other patient groups were invited to this meeting which was attended by professionals from academia, research and the health care professions.

Talks included a historical overview of the origins and development of the Biobank and Tissue Directory, funding, obtaining of consent and historical regulation of sample collection.

The round table session explored the future of the CCB with regard to funding. The process employed for this was DeBono's six thinking caps. The concluding outcome from this session was that there has been significant work of high value that is too important to lose. As the CCB is incorporated into an overarching organisation of biobanks and tissue directories, the experience gained from the unique development of Cancer Biobanks must be employed to provide benefits in the form of knowledge and lessons, and to aid the further development and expansion of Biobanks for other disease sites.

On the whole, the meeting was both interesting and stimulating and highlighted that there is a need to capture significant amounts of data that will be used in varying amounts by different professionals in order to improve patient care and treatment outcomes. The desire for standards is extremely high and is likely to stimulate significant interest and desire to participate in reviewing and testing. Katrina Randle's notes from the meeting can be found on the ICPV website

http//www.independentcancerpatientsvoice.org.uk/Conference & Meeting Reports

Katrina Randle, ICPV Member

European School of Oncology (ESO) Breast Screening Conference, 18-20 June 2015, Dublin:

Maggie Wilcox presented at this international conference (hosted by Mr James Geraghty, Dublin, and chaired by Professor David Cameron, Edinburgh; Professor Nehmat Houssami, Sydney; and Professor Marco Rosselli Del Turco, Italy). The event focussed on using current knowledge in breast screening and its outcomes to inform future screening practice for breast cancer and its treatment. Evidence on the implementation and the impact of breast cancer screening, its detection and its treatment, were presented, including perspectives on the UK's Marmot report and looking beyond the controversy of over-diagnosis of breast cancer from screening to seek solutions relating to over-treatment in the context of multidisciplinary care. Topics were preoperative diagnosis, borderline lesions, surgical management including sentinel nodes and tumour margins, and radiotherapy and reconstruction. Maggie reported on the conference as follows:

"My remit was a patient perspective following the Marmot report which had reviewed the value of breast screening in England. It was a 3-day conference, with experts from across Europe and further afield and included radiographers, radiologists, pathologists, oncologists and a few surgeons and nurses. I chose to focus on the need for further research which could make screening more effective by picking up smaller tumours earlier, whilst reducing the risk of over-diagnosis/ over treatment (for example, by adding tomosynthesis to mammography and by enabling safe risk stratification for screening). I spoke about the new LORIS trial in low risk DCIS which is one of the most important new trials from a patient perspective. Surgeons have become increasingly aware that some patients with DCIS may be having unnecessary surgery because there is a lack of evidence showing which DCIS can be safely monitored without surgery. Patients with low grade DCIS will have their tumour pathology centrally reviewed and only those confirmed as low risk will be offered participation and then be randomised into surgery or active monitoring.

During this conference, references were made to work by Professor Christiane Kuhl, Aachen, Germany, about the study and routine use of MRI (and fast MRI) instead of mammography with or without Tomosynthesis or Ultrasound. Fast MRI is a much abbreviated MRI test that takes about three minutes but does still require intravenous contrast. Professor Kuhl has recently published a paper entitled *'Abbreviated breast magnetic resonance imaging (MRI): First post-contrast subtracted images and maximum intensity projection - A novel approach to breast cancer screening with MRI'*. Kuhl CK, Schrading S, Strobel K, et al, Journal of Clinical Oncology 32:2304-2310, 2014. jco.ascopubs.org/content/early/2014/06/23/JCO.2013.52.5386.full.pdf+html

I have to confess that I found it very challenging giving a presentation to this large international meeting of professionals interested in breast screening and I was hopeful that UK patients would be invited to present at future meetings. However, the feedback that I received was very positive and reassuring and I have been appointed to the EU Commission on Quality Assurance Scheme Development Group for Breast Cancer."

Maggie Wilcox, President ICPV

Breast Screening and Research Conference, 22-23 June 2015, Robinson College, Cambridge.

A few days after the Dublin Conference, I had a similar remit as a speaker at the Breast Screening and Research Conference at the Robinson College, Cambridge, which was hosted by Dr Sue Barter, Consultant Radiologist, Addenbrookes Hospital, Cambridge. The programme was excellent with world renowned experts in the field of breast imaging presenting a wide range of highly topical issues and the highlights for me were:

- Dr Charlotte Coles' presentation on new approaches in radiotherapy with aim of reduction of risk/harm whilst increasing benefit of radiotherapy. This included new technology, intensity modulated radiotherapy, heart sparing techniques and avoiding radiotherapy in some low risk cancers. Dr Coles values very early lay involvement in her trials and especially the recent input to the design of PRIMETIME by Hilary Stobart and Lesley Turner of ICPV.

- Miss Adele Francis, another early involvement enthusiast, gave a talk about two current breast surgery trials. (see her contribution to the Voice Newsletter on page 20).

- Dr Ros Given-Wilson's presentation on the history of screening and how the service had developed and changed in line with evidence. This was an open and honest account of the success but also the problems and controversies for the breast screening programme. She also mentioned potential changes with increased understanding of risk and availability of new technology.

After hearing about the work of Professor Kuhl at the ESO Conference in Dublin, I was pleased to find that Professor Kuhl was giving the key speech address as well as giving a presentation during the programme.

I also enjoyed the networking and entertainment in Cambridge. I would like to thank Matthew Wallis, not only for the invitation to speak, but for the invitation to help celebrate significant birthdays for Matthew and his wife Sue. Rosita Mandeville, a friend who was visiting me, was also given a warm welcome and will take information about breast screening and PPI in breast cancer research in UK back to both Barbados and to Canada

Maggie Wilcox, President ICPV

REVIEW OF ACTIVITIES

ICPV's fundamental aim is to improve clinical research by providing the patients' perspective. We believe this leads to better recruitment to clinical trials and faster improvements in treatments and outcomes for all cancer patients. ICPV meets its aim by organising study days, collaborating on clinical studies, responding to consultations, and raising awareness and encouraging participation.

Study Days/Courses

Qualitative Research and Research Methods Training Course, University of Warwick 2-3 July 2015

A number of ICPV and Kent, Surrey and Sussex Cancer Partnership Research Group (KSS CPRG) members were privileged to attend a training course for the Mammo-50 study at the University of Warwick, organised for us by Professor Janet Dunn and led by Professor Gillian Hundt and Dr Clara Jorgensen. The course was both an introduction to qualitative research and its methods, and practical work in peer interviewing and facilitating focus groups. It was held at the University of Warwick Conference Centre which provided us with top-class accommodation and hospitality, over the two day course.

We began after lunch on Thursday, meeting in a seminar room in the Warwick Clinical Trials Unit. Professor Hundt and Dr Jorgensen led us through an overview of qualitative methods, learning about the differences between deductive and inductive research, and learning that qualitative research usually takes an inductive approach, ie using findings from the research project to identify implications for theory. Qualitative data comes in the form of words, narratives, interpretations etc. We moved on to gain an understanding of the different types of qualitative methods: ethnography, participant observation, unstructured or semi-structured interviews, focus groups, participatory methods or document analysis. We then discussed some strengths of the qualitative method, such as including unexpected findings and gaining an insider view of the field. Limitations, such as reliability, difficulty in making generalisations, and being time consuming, were also discussed.

After looking in a little more detail at all the methods, we homed in on the qualitative interviews and focus groups which were the most relevant to our involvement. We considered how to decide the membership of groups and who to interview in order to meet one's research goals. We considered random recruitment, snowballing (the practice of using initial participants to recruit others) or the use of pre-existing groups. Also we were asked to consider whether groups should be homogenous (facilitating communication, but may result in groupthink) or heterogenous (inspiring new ideas about topics but more risk of lack of respect for opinions).

Following some discussion about facilitation and moderation skills, we moved on to a talk about research ethics. We noted that ethical issues can be more

pronounced in qualitative research as topics can often be sensitive, there is prolonged contact with researchers, and the subjectivity of the researcher may play a role. A suggested exercise was to consider the ethical issues and how to address them in each stage of one's research project from design, data collection, analysis and dissemination.

The second day of our training began bright and early as we worked on designing a topic guide for semi-structured interviews for the Mammo-50 Study. This is a sort of crib sheet of questions to help a peer interviewer guide the interview through the topic to be discussed. By working on this in advance, it can ensure that all interviewers are working to the same guide, and help the interviewer ensure that they ask open questions. In our case, in groups, we each took a small part of the topic and constructed an initial open question, followed by several follow-on questions. We went on in pairs to practise interviewing using the topic guides we had produced. We did this with varying degrees of success. I think one of the areas we found most difficult was to ensure that we didn't ask leading questions. It was relatively easy to spot when we lapsed into leading questions, but very much more difficult to frame non-leading questions.

Finally the day ended with a practice focus group on cancer followup. Two people were chosen to be facilitator and scribe, and the rest were handed roles to play in the group such as 'refuses to speak' or 'dominant but often off-topic'. We attacked our roles with gusto, making control of the group very hard for the facilitator, but it illustrated the range of people and views that may well be present at a focus group. In contrast, Professor Hundt, one of our course leaders, then acted as facilitator to our group as we discussed our views on follow-up. We could then see how an experienced facilitator might work.

All in all it was an excellent couple of days. We would like to thank Professor Gillian Hundt and Dr Clara Jorgensen for all the hard work in preparing and presenting the course to us, and to thank Professor Janet Dunn and the Mammo-50 team for making it all possible. See Hilary's notes and slide show from the meeting on ICV http://independentcancerpatientsvoice.org.uk/study-days/warwick-july-2015/

Hilary Stobart ICPV Member

Forthcoming Study Day

ICPV VOICE Course, Barts Cancer Institute, Charterhouse Square, London, 1-5 September 2015.

The ICPV course aims to give participants an introduction to basic cancer biology, and will include sessions on what cancer is, how it is caused, how it develops and how it is detected and treated. Course participants will spend time in the research laboratories to help them to build understanding. They will learn about the different types of cancers. Sessions on current understanding, new research technologies and the biology of genetic testing and screening will be included. There will be advice on how to read and interpret scientific papers. The course will give participants increased confidence to become more effectively involved in cancer research as patient advocates and will be led by researchers Professor Louise Jones, Professor John Marshall, Dr Richard Grose and their colleagues at Barts Cancer Institute. Each participant will also be offered a personal tutor/mentor who will offer tailored support and answer any queries about the course content.

This opportunity is open to patient advocates with a current, active role in cancer research and/or experience, for example, as member of local group, Consumer Liaison Forum, Clinical Studies Group, Trial Management Group, having already attended some courses and wish a further understanding of the science and scientists involved in cancer research. Also, people working in cancer research in NHS or Charities, whose interest and skill would be enhanced by learning about the work carried out by their scientific colleagues, are also invited to participate.

As in previous years, this year's course will be held at Barts Cancer Institute in London. However, in future we are considering holding the course somewhere in the North (venue yet to be decided). Several academic researchers are interested in hosting the event but we are also very aware of the commitment and work involved. Watch this space!

Further information on the course can be found at ICPV website: http://www.independentcancerpatientsvoice.org.uk/Voice: Science for Patient Advocates

Collaboration in Clinical Studies

Article by Dr Adrienne Morgan, Chair ICPV: OPTIMA Trial - Patients' Perspective

OPTIMA is a trial to reduce the number of women who receive chemotherapy

Private Hospital Trust refuses to open trial

Change their minds after pressure from ICPV

Women diagnosed with oestrogen receptor (ER) positive and HER2 negative primary breast cancer whose cancer has spread to their lymph nodes would normally be offered chemotherapy to reduce the risk of relapse – followed by endocrine therapy (tamoxifen or an aromatase inhibitor). However, in recent years, there has been some doubt about the effectiveness of this approach for some patients. OPTIMA uses a test to try and predict who will benefit from chemotherapy sensitivity. Patients are randomised to either standard management (chemo then endocrine therapy) or test-directed treatment. Patients randomised to test-directed treatment will have their tumour tested. Those with a tumour categorised as "high-risk" by the test will be assigned to standard management, whilst those at "low-risk" will be treated with endocrine therapy alone.

This trial is very important as it will reduce the number of women who will have to go through the horrors of chemotherapy unnecessarily.

I am on the Trial Management Group for OPTIMA which has successfully completed a "prelim" phase recruiting 412 patients in 23 months from 35 sites and has now been awarded an NIHR HTA grant for the second phase of the trial – a large scale efficacy trial involving 100-120 UK sites. However, Hinchingbrooke Hospital (managed by Circle Health, a private management company), informed the trials unit in February 2013 that they were not able to take part in the preliminary phase of the study due to being unable to "negotiate an acceptable contract", despite all other 35 sites being able to. The oncologist at Hinchingbrooke was very keen to open the trial, so I wrote to her offering support on the 12th March 2013:

"Hi, I am a patient advocate on the OPTIMA trial management group and I was horrified to hear that your, now privately owned, trust wouldn't agree to the trial being run. At least that was what I understood.

I find this very worrying from a patient's perspective. Your patients will no longer have the choice of entering this important trial and of possibly benefiting from it. And where will it end? What about other trials? What about other privately owned trusts? Where is the patient choice? Where is the democratic control? Sorry. It makes me very cross!!!

If you felt able to, would you mind letting me know the details? I am a member of a patient advocate group (see our web site below). I would like to tell them about this and we would be happy to write to whoever needs writing to....

Dr Adrienne Morgan"

My email was passed on by the oncologist to their R&D Clinical and Innovation Lead, who responded to me:

"Dear Dr Morgan,

Thank you for your email to Dr Cheryl Palmer regarding the OPTIMA trial at Hinchingbrooke. Our R&D Clinical and Innovation Lead has received a copy of it and will respond to you shortly.

Many thanks for taking the time to contact the Trust.

Best wishes

Maxine Glover-Bennett, R&D Co-Ordinator"

I then emailed Maxine Glover-Bennett, R&D Co-Ordinator direct saying:

"I look forward to your response. Independent Cancer Patients' Voice is very concerned about this and would like to hear your side of the story. We believe the OPTIMA trial will lead to significant patient benefit, resulting in providing the evidence to prevent many breast cancer patients being put through gruelling chemotherapy. It is of great concern to us that you have decided not to run the trial."

Although I received no response to my email, in late May 2013 they re-visited their decision and agreed to open to the trial. Which just goes to show that **Patient Power Works** and that it is worth challenging decisions like these.

Interestingly, although at the time (in 2013) Hinchingbrooke was managed by Circle Health (private management company), in February 2015 the management of the hospital was returned to the NHS.

Responding to Consultations

Renewal of the National Contract for PET-CT Services

ICPV Member, Christine Allmark, as lay member of the NHSE PET-CT Clinical Reference Group, was invited to review the bidders' submissions for the renewal of the National Contract for PET-CT services and to make recommendations to NHS England. The process began with presenting the patient/public perspective at the bidders' meeting in May 2015. The contract for 2015-2025 has been awarded to Alliance Medical who expressed appreciation of the patient representative input into the review process. (Details of Alliance Medical can be found on the NHS England website.) Christine has also been invited to join the National Governance Board.

Hepatic Resections for Breast Cancer Liver Metastases Survey by Dr Beatrix Elsberger

As part of a larger study, Dr Beatrix Elsberger, Clinical Lecturer in Surgical Oncology, University of Dundee, would welcome the views of patients with advanced breast cancer regarding surgery (hepatic resections) for secondary tumours in the liver (metastases). The on-line questionnaire, which includes 11 simple questions, will inform the study investigators about treatment/therapy received for various types of breast cancer. The survey is entirely anonymous, confidential and will have no influence on the patient's current or future treatment. The results of the survey will be submitted for presentation/publication.

If you have any questions about this study, please contact Dr Beatrix Elsberger b.elsberger@nhs.net

President's Plea

Requests for input from ICPV has grown so much that we are finding it difficult to provide a prompt and effective response for all researchers. We do try to provide a rapid response when this is needed but it helps when we can be given a realistic time to respond. May I therefore ask that researchers send requests as early as possible in the trial design or development. We are aware that lack of ICPV administrative input means there have been delays in responding, so please feel free to send us reminders whenever necessary to meet your deadlines. Sophie Gasson does a sterling job of the "3 Cs" - collecting, requests, circulating papers and collating comments/responses to return to researchers, and Mairead MacKenzie deals with requests and enquiries via our website.

Members' Activities within Other Research Groups

My role as Independent Cancer Taskforce representative, by Richard Stephens

The independent Cancer Taskforce was formed to deliver a new 5-year cancer strategy for England. It has considered themes in prevention, diagnosis, treatment, the research environment, living with/beyond cancer, end-of-life care, patient empowerment and workforce challenges. Details are at http://www.cancerresearchuk.org/about-us/cancer-taskforce

The Taskforce had over 300 written submissions from individuals and organisations. It held nearly 40 meetings and workshops, and was involved with other events such as the NAEDI Conference.

(Photograph above shows Richard supporting the 'OK to Ask' campaign, as Chair of the National Cancer Research Institute Consumer Liaison Group)

The expertise and knowledge of ICPV Members at several Taskforce events has been useful as individual contributions but, more importantly for me, ICPV members have frequently stimulated other patients and carers to think of wider issues beyond their own personal experiences, and to focus on improving services in future rather than simply identifying problems with services now.

One meeting in particular sticks in my mind, where Carolyn Morris cited reams of figures from NCPES data without notes, and Maggie Wilcox not only debated a viewpoint with Mike Richards but he accepted that she was right.

ICPV members have made positive and important contributions to the work of the Taskforce, which is reflected in the recommendations in the new 5-year Cancer Strategy for England - Achieving World-Class Cancer Outcomes. 2015-2020 http://www.cancerresearchuk.org/about-us/cancer-taskforce

Richard Stephens

Taskforce Representative (and proud member of ICPV)

My transformation into a Patient Advocate and how the Kidney Cancer Support Network evolved, by Rose Woodward

In October 2002 I was diagnosed with kidney cancer. To say my diagnosis and subsequent surgery came as a bolt out of the blue would be an understatement. I was fit, of healthy weight, a non-smoker, occasional wine drinker and enjoying a new life having taken early retirement and moved back to beautiful Cornwall with my husband Ron. Cancer was not on my radar.

Kidney cancer (or to give it it's more formal name - renal cell carcinoma) is a quirky disease. It is usually asymptomatic until it has spread when it is defined as terminal with less than 10% of patients surviving 5 years. When I was diagnosed, open surgery to remove the entire kidney, adrenal gland and primary tumour was the only treatment option and, because surgeons were reluctant to perform metastasectomies, the word "remission" was seldom used. During the course of my 5 year follow-up, I joined an online patient forum but was devastated to find the UK charity I had joined didn't feel able to campaign or offer practical support to help patients trying to access new and clinically effective targeted therapies. It was a desperate time for many patients who knew the drugs were being routinely and successfully prescribed elsewhere in the world but not the UK.

I started to collect evidence via an International Patient Listserv and concentrated on finding ways to make information available in the UK. This was the start of my transformation into what I now know is called a "Patient Advocate". After appealing for in excess of 250 NHS exceptional funding cases, including a full judicial review, we were successful when our three-year campaign was instrumental in causing NICE to re-evaluate the criteria used to appraise "end of life" drugs and NHS funding was finally made available for the kidney cancer drug Sunitinib in 2009.

In 2013 I was diagnosed with cancer again, with invasive DCIS, and therefore more surgery followed. However, this time around, peer support and information were readily available. This made me even more determined to raise the bar for kidney cancer support to the same standard as breast cancer patients.

Empowering patients to take an active role in their care, especially with regard to treatment options and clinical trials, remains our top priority. Nevertheless, we also want to involve patients in the decisions affecting the choice, provision and quality of NHS cancer services. The decision has been taken for the Kidney Cancer Support Network to apply for formal charity status. This next step will secure the future of the Network and will allow us to move forward with our plans to train and support kidney cancer "patient champions" across the UK. These small patient/carer teams will work in collaboration with some of our leading clinicians in the National Cancer Research Institute Renal Cancer Clinical Studies Group, Clinical Research Network Urology and Specialist Leads to encourage a better take-up of renal cancer trials across the UK and provide the resources necessary for every kidney cancer patient to take part in a clinical trial if they wish to.

Rose Woodward, founder of the Kidney Cancer Support Network and ICPV Member

Creating Awareness and Fundraising

ICPV is organising an evening fundraising event at 19.00-23.00 pm on Saturday 15 August at Whiteley Village in Walton-On-Thames, Surrey KT12 4EH.

A 2-course buffet-supper and entertainment from the Guildford branch of the Tenovus Choir will be provided. Adele Francis' son, Michael, who is a chorister in Oxford, will sing a solo for us: *Purcell's 'If Music be the Food of Love'*. It promises to be a fun evening with great entertainment, good food, a tombola and other ways of spending your money! Tickets will cost £25 each with any funds raised to be split between ICPV and the Cancer Partnership Research Group based in Guildford. Tickets can be purchased from Sophie Gasson sophie@icpv.org.uk

A massive thank you to everyone who has signed up to help raise funds for ICPV when they shop on-line. If you have not already done so, please give it a try at http://www.easyfundraising.org.uk/causes/icpv/

ICPV's President, Maggie Wilcox, would really like to hear from you if you have any ideas for fundraising, would be prepared to be involved in fundraising events, know any contacts who would be interested in sponsoring ICPV, or if you have information about grants for which it would be appropriate for ICPV to apply.

Members' Recent Publications

The Value of Patient and Public Involvement in Trial Design and Development, Gasson S, Bliss J, Jamal-Hanjani M, Krebs M, Swanton C, Wilcox M. Clinical Oncology. Published Online: 13 July 2015 http://dx.doi.org/10.1016/j.clon.2015.06.020 It should be noted that Mairead MacKenzie of ICPV also contributed to this work. The link to the article http://independentcancerpatientsvoice.org.uk/icpv-publications/members-publications/

Managing fatigue after cancer treatment: development of RESTORE, a web-based resource to support self-management. Foster C, Calman L, Grimmett C, Breckon M, Cotterell P, Yardley L, Joseph J, Hughes S, Jones R, Leonidou C, Armes J, Batehup L, Cornerı J, Fenlon D, Lennan E, Morris C, Neylon A, Ream E, Turner L, and Richardson A Lesley Turner and Carolyn Morris are the lay representatives for this trial which is being led by Dr Claire Foster at the University of Southampton. The aim of the study is to co-create an evidence-based and theoretically informed web-based intervention (RESTORE) designed to enhance self efficacy to live with cancer related fatigue (CRF) following prime cancer treatment. Psycho-Oncology (2015) DOI: 10.1002/pon.3747 Published online in Wiley Online Library wileyonlinelibrary.com www.ncbi.nlm.nih.gov/pubmed/25648410

International Consortium for Health Outcome Measurement (ICHOM), Cambridge, Massachusetts International Set of Minimum Healthcare for Lung Cancer Patients. Tom Haswell was invited to be the patient representative for this Working Group to produce an international set of minimum healthcare outcomes for lung cancer patients. The group was made up of surgeons, oncologists, physicians, radiologists, nurses, charity. It was interesting to hear what was happening in various countries (for example in North and South America, Spain, Holland, Australia). Tom is also named as a co-author on the final manuscript which was published in March 2015. Lung Cancer | ICHOM – International Consortium for Health ...www.ichom.org/medical-conditions/lung-cancer/

Cancer Campaigning Group's: Shifting Gears – Bringing England's Cancer Outcomes In Line With The Best in Europe. (ICPV is a signatory to this report by CCG) The report can be downloaded from their website: www.cancercampaigninggroup.org.uk/ccg-reports/

The AVALPROFS study (Assessing the VALue of PROgression Free Survival)
Poster presented at British Psychosocial Oncology Society (BPOS) Conference 19-20 March 2015, Leeds
Catt S, Jenkins V, Matthews L, MacKenzie M, Gath J, Falllowfield L, Sussex Health Outcomes Research & Education in Cancer (SHORE-C), Brighton & Sussex Medical School, UK. ICPV members, Mairead MacKenzie and Jacqui Gath contributed to this 3-year study led by Professor Lesley Fallowfield. The poster can be viewed at independentcancerpatientsvoice.org.uk/icpv-publications/members-publications/

Biobanking in the 21st Century (due in September 2015)

Professor Valerie Speirs at Leeds gave ICPV members another introduction to publication by asking for a few lines from a lay perspective for her chapter in a new international book on Biobanking in the 21st Century. This developed into a lay chapter which is now with the editors in the USA and is due to be published in September 2015. The text includes information from ICPV members - Helen Bulbeck for Brainstrust, Hilary Stobart on Lay Recruiting in Nottingham, Mairead Mackenzie on Breast Cancer Campaign Tissue Bank, Maggie Wilcox on Confederation of Cancer Biobanks, Margaret Grayson on the education needed for effective lay involvement. Advances in Experimental Medicine and Biology, Springer International Publishing AG, September 2015. ISBN-13: 97833192057786. Edited by Feridoun Karimi-Busheri

Public Guide to Tissue Donation (in progress)

ICPV worked with Dr Bridget Wilkins and her trainee pathologists from Guys & Thomas' to survey patients, members of public and professionals to assess level of knowledge and interest in donating tissue for cancer research. These young pathologists have now produced some good slides which could be used for promoting/discussing tissue donation but our idea of producing a 'Public Guide to Tissue Donation' is still a work in progress.

ICPV Review 2014

ICPV's latest review can be downloaded at www.independentcancerpatientsvoice.org.uk/icpv-publications/

ICPV NEWS

Articles by Professional Colleagues

My Role as Surgical Specialty Lead in Clinical Research for Breast: How Patient Advocates can help, by Miss Adele Francis

The Royal College of Surgeons of England (RCS) is working with partners to develop a nationwide research infrastructure to develop and expand the surgical clinical trials portfolio. Specialty-based trials development are supported by Surgical Specialty Leads (SSL), who have responsibility both for the development of clinical networks to deliver multi-centre studies, as well as ensuring that the studies are relevant to their sub-specialty and their patients.

As the SSL for breast research, I work to develop clinical trials, train surgical investigators and deliver clinical trials. Patient advocates are crucial to make this role a success and there are various ways in which they help.

Patients are needed to be involved in new clinical trial protocol writing groups rather than get involved when a trial is largely already designed. It is clear that this early input is particularly effective in addressing possible recruitment issues. In recognition of this, funders look for patient participation early on and certainly before grant applications are considered. Patient focus groups can also help to inform protocol issues, particularly for trials deemed to be likely to be 'hard to recruit' to. These focus groups are particularly helpful to address issues regarding the likelihood of patients agreeing to be randomised and therefore inform and help the trial statisticians in their calculations.

There are other ways that patients can help SSLs in their task of increasing participation in trials and expanding the surgical trials portfolio: Patients now sit on the Clinical Studies Groups (CSGs) and make an invaluable contribution to these committees by representing patients views. Increasingly patients attend National Meetings and are invited to speak about their participation in clinical trials and interactive sessions such as Dragon's Dens!

The UKCRC Tissue Directory and Co-ordination Centre, by Jessica Sims, Project and Engagement Manager, UKCRC Tissue Directory and Co-ordination Centre, University College London

The UKCRC Tissue Directory and Co-ordination Centre has been set up to support the work of biobanks by improving access to their collections of human tissue samples for research purposes. The Centre has four main work areas which have been designed to support biobanks to maximise the use of their existing and new human tissues sample collections:

- Informatics: making tissue and data collections easier to find and access through a freely accessible online Tissue Directory;
- Harmonisation and Quality: developing standards and consensus on the collection and storage of tissues and data across academia, the NHS and industry so they can be more widely used across projects;
- Stakeholder Engagement: working with people and organisations to promote best practice in sample collection, governance and public engagement; and
- International: connecting the UK with European and other international biobanking initiatives such as BBMRI-ERIC to further increase access to samples and ensure UK systems are compatible with those abroad.

Stakeholder engagement is at the core of the Centre's work as we are convinced engaging with diverse groups of people and organisations interested in biobanking will ensure activities are relevant to the wider community. An example of this engagement is our current survey on the type of information that would be useful in the forthcoming Directory. We would appreciate your input by completing this short survey to help us to structure the work of the Directory over the next six to eighteen months. https://www.biobankinguk.org/informatics-survey/ Notes from the workshops, along with the speakers' presentations at the launch of the UKCRC Tissue Directory and Co-ordination Centre on 24 March 2015, are also available on their website https://www.biobankinguk.org

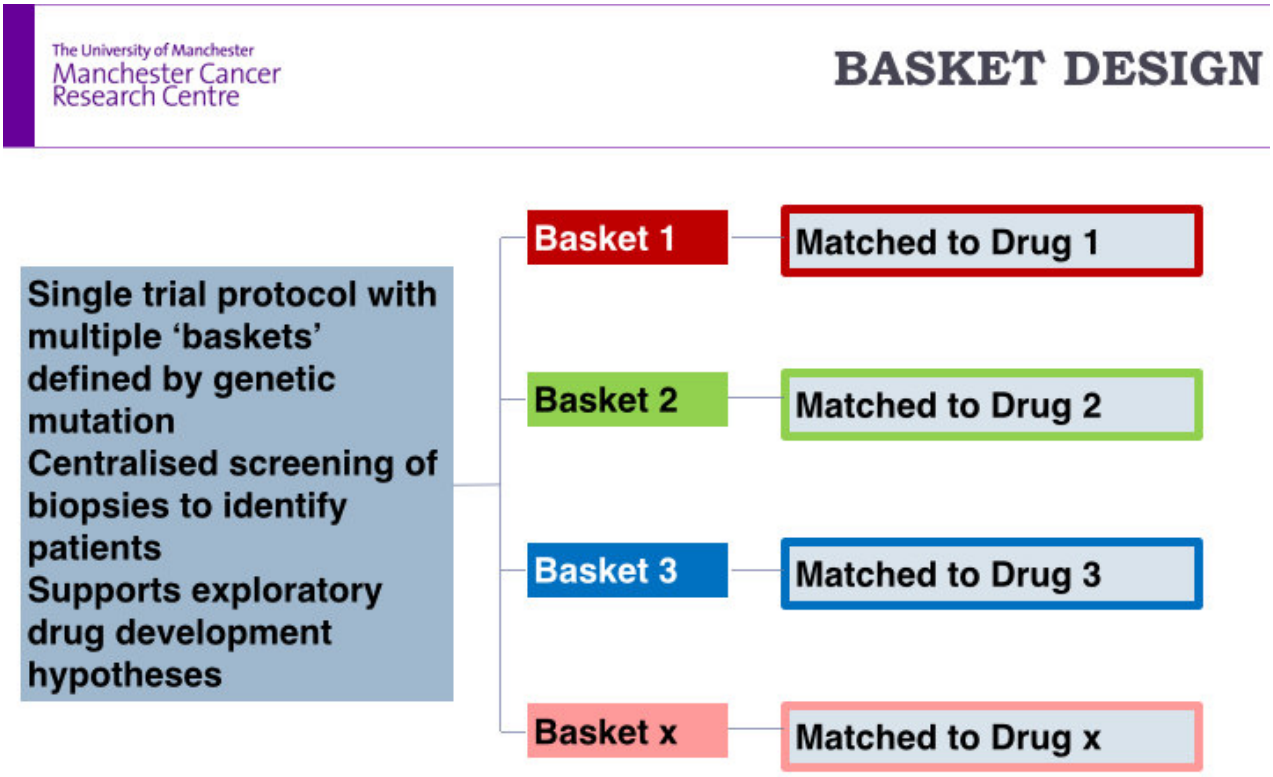
Basket Trials, by Dr Emma Dean, Honorary Consultant in Medical Oncology and Clinical Senior Lecturer, The Christie Cancer Research Centre, Manchester

Maggie Wilcox was in the audience for Dr Dean's presentation at The Christie and was impressed by her explanation of basket trials. Dr Dean has kindly written a short explanation of the basket trials for the benefit of ICPV members who are involved in research:

Basket trials are a novel approach to drug development aiming to deliver the right treatment to the right patient more quickly. These trials enrol patients with a variety of cancer types and a range of specific genetic abnormalities. Treatment is assigned according to a particular genetic abnormality rather than the type of the tumour. The trial tests whether patients with a particular abnormality can benefit from a drug which targets this. For example, BRAF, HER2, EGFR expression all play differing roles in different tumour types – a basket trial can resolve uncertainties of the relevance of each genetic abnormality by assessing response to treatment. The primary aim is to assess the patient's response to treatment.

In order for a basket trial to be successful, there needs to be strong scientific pairing between the genetic target and the matched therapeutic drug, ie the tumour should be dependent on the genetic target and the drug must be able to selectively inhibit the target in a dominant fashion. Identifying the genetic target requires the testing of samples (biopsies) and there needs to be a sufficient number of drugs available to target the gene. Some patients have several genetic abnormalities in their tumours, and it can be difficult to prioritise and assign treatment. Logistically, basket trials may be challenging to coordinate: identifying rare genetic subtypes requires multi-institutional collaboration, centralised testing of biopsies is required, and there is usually much debate about the most appropriate marker-drug pairing.

However, basket trials can be an efficient way to evaluate many drugs across patient populations, where each "basket" is similar to an expansion cohort but substantially less resource-intensive and requiring fewer patients. Basket trials also give flexibility to add and close arms on an ongoing basis. Although exploratory, basket trials support early drug development by providing a path for patients, particularly those with rare genetic abnormalities, to access novel therapies at an early stage.



Membership

ICPV Board Members

Linda Larter has resigned as Trustee of ICPV and we would like to pay tribute to her work in finding sources of funding for ICPV. Linda has to fit ICPV into the needs of her very demanding work life and her family and we are grateful for her time and expertise. Carolyn, Pat and I have worked with Linda for many years through UK Breast Cancer Coalition and Breakthrough and have found her quiet common sense and business expertise invaluable. The Trustees hope that Linda will continue her membership of ICPV by joining in email discussions, commenting on papers etc, and will be able to join us at some of our workshops and fundraising events.

Elspeth Banks and Tom Haswell have both accepted ICPV's invitation to join their Board of Trustees. This is great news and will certainly help ICPV's plans of expansion north of the border. The new appointments will also benefit ICPV's work with other tumour groups and, in Tom's case, our gender mix! Congratulations to Elspeth and Tom.

Meet our New Members

ICPV has a talented array of new members with stories about their experiences and how they decided to become patient advocates. Here are some of their personal blogs:

Photograph of Mel taken during her chemotherapy period last June (note PICC line on right arm).

Melody McLaren, writer and researcher, was born in Los Angeles and has spent most of her life "travelling in eccentric circles". A graduate of the California Institute of Technology (BS, Independent Studies (biology/psychology), 1977) and Birkbeck College (MSc, Organizational Behaviour 2007), her eclectic career encompasses over 30 years of experience spanning a wide range of fields including research, writing, media relations, sales promotion, web development, social media and corporate responsibility campaigning in the US and Europe. A major turning point arose when she won the 1969 World Hula Hoop Championship, aged 12. When offered the opportunity in 1983 to tour Europe as a media spokesperson for Hula Hoop manufacturer Wham-O, she took a leave of absence from an applied cognitive-psychology PhD programme at UC Berkeley and never looked back. She met ad/marketing specialist Ian McLaren during the European tour in 1984 and they have been together ever since. Melody became an active advocate for Ian following his diagnosis with Parkinson's Disease (2000) and Deep Brain Stimulation surgery (2009) at the National Hospital for Neurology and Neurosurgery, running the London Marathon in 2010 and 2015 to raise money for the National. Following completion of her primary cancer treatment in September 2014, Melody has been eager to join ICPV as it provides an opportunity to re-acquaint herself with cutting-edge immunology research after a hiatus of 40 years as well as to enjoy connecting with other patient advocates. A keen jazz photographer and pianist, she is the co-author of Social Intrapreneurism and All That Jazz: How business innovators are helping to build a more sustainable world (2014 - www.greenleaf-publishing.com/jazz).

Roger Wilson CBE, is well known to most patient advocates and has a wealth of experience and history of working to achieve effective Patient and Public Involvement (PPI) in research. Roger joined the NCRI Sarcoma CSG in the autumn of 2002. He became the consumer rep on the NCRN Operational Steering Group in December 2002. When Derek Stewart stood down as chair of the CLG in 2004, Roger was appointed as the CLG's second chair and a member of the NCRI Board. During this time he also chaired meetings and worked with CECo (the supportive and palliative care research collaborative), NPRI (the National Prevention Research Initiative), UKCRC and UKCRN (which became NIHR CRN CC). During 2007 he was one of the lay members on the Steering Group of the Cancer Reform Strategy. Six weeks after stepping down as chair of the CLG in 2007, he had his lower left leg amputated. He asked at the time that this should not become a precedent. Five months later he was back in action chairing the Active/Advanced workstream of the National Cancer Survivorship Initiative and he was also appointed to the Advisory Board for the National Cancer Director which he attended until 2012.

In 2003 he started Sarcoma UK – initially as a vehicle for developing standardised accurate patient information, working with all the sarcoma MDTs. He made it clear that he felt that Guidelines lay at the heart of the changes that were needed and promptly found himself on the NICE Guideline Development Group for the Sarcoma IOG. When that was finished, he took on developing the British Sarcoma Group's annual conference, which he ran until 2014. He raised the funding for the BSG to develop bone and soft tissue sarcoma clinical guidelines in 2008. In 2009 he was the expert witness for the NICE appraisal of trabectedin, the first new drug for soft tissue sarcoma in 25 years. It was approved. It has not been approved yet in Scotland or the USA. NICE acknowledge that his input swung the balance. In 2010 he worked closely with BCRT (the bone tumour charity) to ensure that the first new drug for osteosarcoma gained NICE approval. In this case NICE had to be forced to re-write its guidance for committees, create a new health economics model, gain Treasury approval for the changes, and then completely re-start the appraisal. The drug is approved in England and Scotland but not in most of Europe or the USA. Sarcoma UK in the meantime had grown and in 2010, having raised sufficient funds to employ permanent staff, the charity moved to London. He stood down from the Trustees not wanting them to feel that he was still in charge. He is Hon President and after 5 years the charity now raises close to £1m a year and has invested over £1m in research. In 2009 he came together with other European sarcoma advocates to create Sarcoma Patients Euronet (SPAEN). He has also worked with EORTC, ECCO and ESMO – one activity being the annual Flims Workshop on Cancer Research Methods for which he was the patient member of faculty for six years until 2012.

The years 2011 to 2013 were dominated by further recurrences, treated with surgery, radiotherapy in 2012 and two thoracotomy metastectomies in 2013. In 2014/5 he has had acute spinal problems and now relies on electric buggies. Despite this he was a member of the NICE Quality Standards for Sarcoma development group in 2014. He was awarded the CBE in the New Year Honours in 2011 and has honorary doctorates from the Universities of Sheffield and Lancaster. He is now 69 and, mobility issues apart, ready for action.

Ann Russell Prior to retirement, Ann was Director of Human Resources with a national charity. Following bowel surgery in 2007, she was invited to take part in the Follow Up after Surgery Trial (FACS) and was randomised into a group which entailed undergoing a CT scan every 6 months for 3 years. Prior to undergoing radical surgery for bladder cancer in 2014, she received 18 months of BCG treatment at 3 monthly intervals and had numerous MRI and CT scans. Since her diagnosis of cancer in 2007, Ann has been heavily involved in patient advocacy and clinical studies groups for cancer research.

Ann is now a member of the NCRN Consumer Liaison Group; previous member of the NCRI Colorectal CSG for 5 years; NCRI Colorectal CSG Surgery sub-group; NCRI Colorectal Adjuvant and Advanced Disease Sub Group; NCRI Primary Care CSG; and NCRN PPI Steering Group. She is also Chair of NCRN Strategic PPI, Advice, Delivery and Evaluation Panel (SPADE) 2012-2014 analysing National Cancer Patient Experience Survey data and developing a mentoring project. In 2012 and 2013 she was the PPI representative for the NCRI's review of CSG annual reports and will be undertaking this role again in 2015. She is increasingly involved in a number of patient advisory groups with regard to clinical trials and studies of various tumour types and offers guidance and advice in reviewing trial protocols and patient information.

She is a consumer representative at the Cambridge Breast Cancer Research Unit and Addenbrooke Hospital where she is a member of the Patients Participation Group (PPG) involved in developing a Cancer Patient Charter and representing patients in various clinical departmental meetings. Her PPI involvement includes the East of England Clinical Senate; East of England Citizens' Senate; East of England Cancer PPI Group and the Anglia Cancer Network Colorectal NSSG. Ann is co-author for the manuscript entitled *'A Systematic Review and In-depth Analysis of Outcome Reporting in Colorectal Cancer Surgery at Bristol University'*. She is also co-author of *CHALLENGE UK* (the UK arm of a Canadian trial on Colon Health and Lifelong Exercise trial).

Survey of ICPV Membership

You may remember that earlier this year Mairead MacKenzie asked ICPV members to fill in a short Survey Monkey. This is to help us identify where our members are from and what they feel they have to offer ICPV. Most members have kindly participated in the survey but a few have yet to complete the form. It doesn't take long to complete and is important to help us utilize our members skills efficiently. https://www.surveymonkey.com/r/ICPVMembershipSurvey I know that you are all busy people and if you find that you no longer have time to be part of ICPV, please inform Mairead so that she can remove your name from the membership list. We hope very much that you will remain part of the ICPV group.

Awards/Achievements

Adrienne Morgan, Carolyn Morris and Lesley Turner, on behalf of the NCRI Breast CSG Working Party on Symptom Management, won first prize for their poster entitled ***'Is it me or is it hot in here?: Hot Flushes: an unmet need'***, at the UK Clinical Trials Conference for Supportive Care in Cancer Research, which was held on 3 June 2015 in Sheffield. The poster won first prize against very strong competition and the Conference Committee considered the poster to be a "really readable poster that felt very inclusive and reflected the unmet need of patients". The group were awarded a year's subscription to the journal of the Multinational Association of Supportive Care in Cancer. Congratulations to the group.

Adrienne Morgan

Carolyn Morris

Lesley Turner

Maggie Wilcox has been appointed to the EU Commission, Quality Assurance Scheme Development Group for Breast Cancer. This group will agree on the general quality requirements and make use of the evidence provided by the guidelines for the quality requirements specific for breast cancer care. The group includes professionals actively working in breast cancer screening and diagnosis, and also individual citizens or patients who are users of breast cancer screening and diagnosis services (such as patients diagnosed of breast cancer), their family members and their carers. Congratulations Maggie on achieving this significant appointment.

Pat Fairbrother has been invited to join the National Cancer Research Institute, Clinical Studies Group for Skin Cancer as a patient representative. Pat's membership to this group will help to keep ICPV up to date with the latest developments in skin cancer. Well done Pat!

Voice Your Opinions

NICE has updated and redesigned its guidelines to support GPs to recognise the signs and symptoms of 37 different cancers and refer people for the right tests faster. The update, which is the first for 10 years, includes new guidelines for brain and CNS tumours. The new guidelines are:

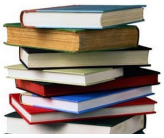
Adults: Consider an urgent direct access MRI scan of the brain (or CT scan if MRI is contraindicated) (to be performed within 2 weeks) to assess for brain or central nervous system cancer in adults with progressive, sub-acute loss of central neurological function. [new 2015]

Children and Young People: Consider a very urgent referral (for an appointment within 48 hours) for suspected brain or central nervous system cancer in children and young people with newly abnormal cerebellar or other central neurological function. [new 2015]

ICPV Member, Helen Bulbeck's response, as Director of Services and Policy for Brainstrust, to these updates:

Read full story http://www.brainstrust.org.uk/ News

Recommended Reading



5-year Cancer Strategy for England - Achieving World-Class Cancer Outcomes. 2015-2020
http://www.cancerresearchuk.org/about-us/cancer-taskforce

My Role as Independent Chair of the Cancer Strategy Task Force, by Harpal Kumar, Chief Executive of Cancer Research UK and Head of the NHS Cancer Taskforce. CRUK science blog, 11 January 2015
http://scienceblog.cancerresearchuk.org/2015/01/11/my-role-as-independent-chair-of-the-cancer-strategy-taskforce/?utm_source=twitterfeed&utm_medium=twitter&utm_campaign=Feed%3A+cancerresearchuk%2FSHhE+%28Cancer+Research+UK+-+Science+Update%29

Keeping The Customer Satisfied - It's OK to Ask - Is Taking Part In Research Associated With Better Experience of Care? Findings from the 2013 National Cancer Patient Experience Survey

Morris C, West R, Stephens R, Baker M, Pavitt S, Brannan R, Blaveri E, Poole K, Inns K, Fisher S, Hanson J, Race R.
http://www.crn.nihr.ac.uk/wp-content/uploads/cancer/sites/7/Keeping-the-Customer-Satisfied-1.pdf

Realising Genomics in Clinical Practice. Public Health Genomics (PHG) Foundation press release about this report.
http://www.phgfoundation.org/file/16426. http://www.nature.com/gim/journal/v16/n12/pdf/gim201460a.pdf

Risk Determination and Prevention of Breast Cancer, Anthony Howell et al http://breast-cancer-research.com/content/16/5/446

Inquiry into the Impact of Physical Activity and Diet on Health, Commons Select Committee, 15 March 2015
Can be found on the UK Parliament website: www.parliament.uk/healthcom

The PHE Strategy for Research, Development & Innovation, by Public Health England (PHE) the home of the National Cancer Intelligence Network (NCIN). https://www.gov.uk/government/consultations/doing-supporting-and-using-public-health-research

Long-term Follow-up in Cancer Prevention Trials (It Ain't Over 'Til Its Over) by Jack Cuzick
Cancer Prevention Research, Perspective on Vogel et al. Can be found on the AACR website www.aacrjournals.org

Radical Therapies that could Beat My Brain Tumour, by Stuart Farrimond New Scientist, health, volume 225, issue 3003, 10 January 2015 http://www.newscientist.com/article/mg22530034.000-radical-therapies-that-could-beat-my-brain-tumour.html#.VLpCXWSsXIb

Clinical Trial Designs for Rare Diseases: Studies developed and discussed by the International Rare Cancers Initiative, by Jan Bogaerts et al. European Journal of Cancer. February 2015, Volume 51, Issue 3, Pages 271–281.
DOI 10.1016/j.ejca.2014.10.027 http://bit.ly/172QovL

Defeating Cancer, the 'evil genius' by Fergus Walsh, Medical Correspondent, BBC News, Health.
http://www.bbc.co.uk/news/health-31365272?fb_ref=Default

An evaluation of the process and impact of patient and public involvement in the advisory groups of the UK Clinical Research Collaboration, by TwoCan Associates,
http://www.twocanassociates.co.uk/perch/resources/files/MHRN_CaseStudiesAugust_2013(1).pdf
http://www.twocanassociates.co.uk/perch/resources/files/2384_PPI+_Evaluation_Report%20(4).pdf

Taking Stock by INVOLVE Co-ordinating Centre, Report 2015 www.invo.org.uk/news

Citizen Space. Few items on consultation that may be of interest https://aggregator.citizenspace.com

CRUK Cancer Taskforce: Statement of Intent http://www.cancerresearchuk.org/about-us/cancer-taskforce

Evaluating Holistic Needs Assessment in Outpatient Cancer Care - a randomised controlled trial: the study protocol, Austyn Snowden et al BMJ Open 2015;5:e006840 doi:10.1136/bmjopen-2014-006840. http//:bmjopen.bmj.com/content/5/5/e006840.full

Walking the Line between Quick Access and Evidence by Francesco Pignatti Cancer World Journal, March - April 2015. www.cancerworld.org/pdf/6991-pagina-4-10-CoverStory/Article Archive, issue 65/ **www.cancerworld.org/pdf/6991-pagina-4-10-Cover-Story/Article-Archive/Cover=Story/issue-65/**

World Health Organisation calls for increased transparency in medical research, 14 April 2015 Statement can be viewed in WHO website www.who.int/mediacentre/news/Notes for the Media. Also in Science Journal, The Verge and Reuters

ECMC Research Nurse Network Group patient experience survey. Results can be found on the ECMC website: http://www.ecmcnetwork.org.uk/news/announcement/patient-experience-ecmcs

Human Tissue Authority (HTA) Annual Review 2014-2015: Supporting Change, Progress and Innovation https://www.hta.gov.uk/sites/default/files/HTA_Annual_Review_2015_web.pdf

Investors in Pharma Companies Call for Clinical Trial Transparency See story in AllTrials website www.alltrials.net/ Latest News. Also in Financial Times, The Economist and Wall Street Journal .

Epigenetics Articles http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2579375/ http://news.sciencemag.org/biology/2014/07/moms-environment-during-pregnancy-can-affect-her-grandchildren http://www.ncbi.nlm.nih.gov/pubmed/23103179

Breast Cancer Hope as Hormone Shown to Slow Tumour Growth http://www.theguardian.com/science/2015/jul/08/breast-cancer-hope-as-hormone-progesterone-shown-to-slow-tumour-growth

Cheap Drugs Cut Breast Cancer Deaths by 18%, by James Gallagher, Health and Science Reporter, 24 July 2015 ICPV member Adrienne Morgan appeared on BBC News on 24 July promoting this research and the need to get this drug used. Find out what happens now http://bit.ly/1SEoGqk NICE Guidelines for the Use of Bisphosphonates for Various Tumour Types https://www.nice.org.uk/Search?q=+Bisphosphonates This is something that the charity sector has been looking at for some time – we need to keep campaigning http://breastcancernow.org/get-involved/campaign-with-us/unlock-drugs

Value in Cancer Care Interesting new guide from ASCO - http://www.asco.org/practice-research/value-cancer-care

Taking Part in Clinical Trials by Simon Rodwell, 17 June 2015 https://youtu.be/sTR52WaboxQ

Surgery doesn't help women with breast cancer, by Katherine Hobson, 3 June 2015 http://www.npr.org/sections/health-shots/2015/06/03/411698622/surgery-doesnt-help-women-with-early-stage-breast-carcinoma

Scottish Palliative Care Guidelines http://www.palliativecareguidelines.scot.nhs.uk

Biobanking from the Patient Perspective by Derick Mitchell et al Research Involvement and Engagement (2015) 1:4 DOI 10.1186/s40900-015-0001-z www.researchinvolvement.com/content/1/1/4

Data Saves Lives, European Data in Health Research Alliance campaign datasaveslives.eu

Abbreviated breast magnetic resonance imaging (MRI): First post-contrast subtracted images and maximum intensity projection - A novel approach to breast cancer screening with MRI, Kuhl CK, Schrading S, Strobel K, et al, Journal of Clinical Oncology 32:2304-2310, 2014. jco.ascopubs.org/content/early/2014/06/23/JCO.2013.52.5386.full.pdf+html

Is it worth doing? Measuring the impact of patient and public involvement in research, by Kristina Staley of TwoCan Associates Research Involvement. The electronic version of this article is the complete one and can be found online at: http://www.researchinvolvement.com/content/1/1/6

Another Personal Genetics Company is Sharing Client Data, by Katie M Palmer WIRED http://www.wired.com/2015/07/another-personal-genetics-company-selling-client-data/

HRA Year in Review – How our work benefits the lives of patients http://www.hra.nhs.uk/about-the-hra/our=publications/year-review/

Painting a Richer Picture - DNA Methylation and Breast Cancer Risk, by Breast Cancer Now-funded researcher Dr James Flanagan, Imperial College London, and Prof Paolo Vineis, Imperial and the Human Genetics Foundation in Torino, Italy. The research compared the DNA from women involved in four individual studies, including Breast Cancer Now's Generations Study. Breast Cancer Now http://bit.ly/1KOLvWo

Thank you to those who kindly contributed to the second edition of the Voice Newsletter. In order to keep the momentum going and to help raise the profile of ICPV with further issues of this very well received Newsletter, we would appreciate your continued input. We would be particularly interested to receive:

- A short summary of conferences/meetings attended
- Your involvement in Clinical Trials
- Activities within other research groups
- Professional colleagues contributions to the newsletter
- Members' recent publications, as author or co-author
- Your opinions about issues you feel strongly about
- Fundraising activities
- Members' personal achievements or news of interest
- Details of forthcoming events

We thank you in advance. Contributions for the newsletter to be sent to Isobel Anderson i.m.anderson@me.com

Dates for Diary

- ICPV fundraising event, 19.00 - 23.00 on Saturday 15 August at Whiteley Village in Walton-On-Thames, Surrey Kt12 4EH. The event includes 2-course buffet supper and entertainment from the Guildford branch of the Tenovus Choir. Good food, easy parking, great entertainment, tombola and other ways of spending money! Tickets are £25 each with any funds raised to be split between ICPV and the Cancer Partnership Research Group based in Guildford. Contact Sophie Gasson, sophie@icpv.org.uk
- ICPV VOICE Course, Barts, London, 1-5 September 2015
- Unknown Primary Cancer Conference London, 24 September 2015
- ESMO European Cancer Conference, Brussels, Belgium, 25-29 September 2015
- Teenage and Young Adults Cancer Conference: Genes, genetics and TYA cancer ... from the science to the MDT', College Court Conference Centre, Leicester, 28-29 September 2015 To find out more and to register: www.tyac.org.uk/conference
- BACR Conference, Gateshead, 7-9 October 2015. Mairead MacKenzie will be speaking and also ICPV will be presenting a poster
- Europa Donna Conference, European Breast Cancer Advocacy, Time for Action on Equal Access, 17-18 October 2015
- International Society for Quality of Life Research Conference Vancouver, Canada, 21-24 October 2015
- NCRI Cancer Conference, Liverpool, 1-4 November 2015
- BASO Conference, Royal Society of Medicine, London, 1-3 November 2015. Maggie Wilcox, Rose Woodward and Mired MacKenzie have been invited to speak at this important surgical oncology conference

More detailed information about ICPV membership, activities and achievements can be found on the website http//www.independentcancerpatientsvoice.org.uk