

Independent Cancer Patients' Voice is a patient advocate group led by patients for patients. By bringing the views and experience of cancer patients, their family and carers, to the cancer research community, we aim to improve outcomes and develop new treatments for every cancer patient.

Independent Cancer Patients' Voice is a charity registered by the Charity Commission for England and Wales (no.1138456) registered office 17 Woodbridge Street, London, EC1R 0LL.

[www.independentcancerpatientsvoice.org.uk](http://www.independentcancerpatientsvoice.org.uk)

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# independent cancer patients' voice



ICPV – a Review

## Continuing the Conversation



Joins us at our fringe meeting at the Britain Against Cancer Conference  
at Westminster Central Hall on 10th December

# bank your tissue... ...invest for future generations

Independent Cancer Patients' Voice is a patient advocate group aware of the value of medical research to public health and the national economy. We believe that medical research in the UK needs a group, whose strategy is led by patients. We bring the opinions, views and experience of cancer patients, their family and carers, to the cancer research community.

Our aim is to improve existing treatments for every cancer patient and develop new treatments by bringing the patients' voice into clinical research.

**Come & join us for a lively discussion about the pros & cons of tissue donation for health research chaired by Baroness Warwick from Human Tissue Authority.**

A presentation by Professor **Charles Swanton** will explain the need for tissue at different stages of cancer development in order to develop better treatments for future cancer patients.

Then an expert panel will answer queries, dispel myths and show the importance of lay involvement.

## Panel

-  **Professor Jo Martin** ..... National Clinical Director of Pathology for NHS England, involved in 100,000 Genome Project
-  **Helen Bulbeck** ..... Director Braintrust UK
-  **Victoria Chico** ..... Lecturer in Law at Sheffield University
-  **Matthew Cooke** ..... Teenage & Young Adult Group

**independent cancer patients' voice**

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# Contents



Welcome

3



Membership

8



Activity and  
Achievements

18



Training

22



Looking to the Future 36

“The importance of truly independent patients’ voices in clinical cancer research is being increasingly recognised. The NCRI and NIHR Cancer research networks, as well as those in Scotland and Wales, have pioneered public engagement in the process of clinical research in cancer, such that the UK is arguably ahead of the rest of the world in this area. However, independence of the patient voices remain as important as independence of thought and freedom from conflicts of interest amongst researchers: and the work done by this small charity is leading the way in this area. There is, in my view, a difference between advocacy and representing patients’ views and experiences, in that the former is often associated with a strength of particular views rather than the breadth of experience, and this charity has worked hard to deliver the latter.

I have worked alongside several of these individuals in the development of a number of breast cancer trials where their input has been significant: they are not ‘token patient representatives’ but active participants in the design of the studies. In addition, I have sat on committees alongside many of the seven founding individuals, and I can personally vouch for their commitment, neutrality and vision.”

**David Cameron**

Professor of Oncology

Edinburgh Cancer Research UK Centre, University of Edinburgh.

# Welcome



**Maggie Wilcox**  
President of ICPV

Welcome to this update on Independent Cancer Patients’ Voice. I think our growth in membership and activity confirms the value of direct and unfiltered patient involvement in cancer research and the ability of lay people to provide an informed and realistic patient perspective to trial design and development. It also underlines the need for funding to provide the education and experience needed for effective patient advocacy.

ICPV started with a few people meeting in a Camden pub, sharing travel costs and discussing how we could make patient engagement in cancer research more effective – and more satisfying. We decided that our primary aim would be to find, educate, mentor and support people who, having been treated for cancer, were interested in participating in the research needed to improve outcomes for future cancer patients.

“ We believe that clinical research is improved by patients being partners with clinicians and healthcare professionals, rather than passive recipients of healthcare.”

Positive feedback has been received from many of the researchers ICPV has collaborated with. Examples of this can be seen throughout this book.

“ Working alongside members of ICPV on trial steering committees has been a major step forward in breast cancer research. Having informed patient participation at each stage of the process from design to recruitment not only speeds up the process of turning a trial idea into a workable design but also brings a welcome new perspective to the whole procedure. ICPV members play a crucial role in ensuring the correct questions are asked and that they are answered in an appropriate and acceptable way.”

**Miss Adele Francis**

Consultant Breast Surgeon University Hospital, Birmingham

Whilst ICPV now has more than 40 members from across the UK, we do need to increase our membership particularly in the North West and in the devolved nations. The enthusiastic hosting of our study days by academic units helps us to improve our geographic spread and is much appreciated – as is the continued teaching, encouragement and support of our professional colleagues. Our study days have continued and, through the exceptional assistance of the scientists at The Barts Cancer Institute, we have now been able to achieve our aim of a Science for Advocates Course. VOICE is a 5 day residential educational course based on the American Project LEAD training but with the unique addition of lab based experience which is proving very effective.

We are also keen to promote the need for psychosocial research to improve the quality of life during and after treatment – especially for those for whom treatment is not successful. With the increase in long term survival there is a need to collect data and improve the quality of that survival. ICPV is grateful to Professor Fallowfield's team for funding our summer school in Brighton – an enjoyable, interactive and learning experience!

ICPV has continued to collaborate in National and Local Cancer Research. We have had involvement with academic units, charities and other organisations and taken part in stakeholder events with the Health Research Authority (HRA), the Human Tissue Authority (HTA), the National Institute for Health and Care Excellence (NICE), the Association of British Pharmaceutical Industries (ABPI) and the All Party Parliamentary Group (APPG) on Cancer.

Members provide an informed and independent lay perspective in many areas and our challenge now is to grow our membership to meet the requests for involvement. We also need to raise funding to improve our efficiency and communication both with members and with researchers and research organisations. Most members, although interested in other health research, have limited spare time and wish to concentrate their activity to the research which will lead to more effective treatments for future cancer patients.

I am honoured to be president of an organisation which Professor Alastair Thompson recognised at a national meeting as “*The patient group of choice for researchers*” and whose members recognise that interest, education and a sense of humour enables us to enjoy providing an effective VOICE for patient benefit in cancer research.

“ Increasingly regulatory bodies are demanding core support from patient advocacy groups through the research process.

ICPV have been an invaluable help to our translational research program to understand cancer evolution through longitudinal cohort studies such as TRACERx. From trial concept development, through to protocol writing and regulatory submission, ICPV have provided invaluable advice at every step of the process. Their network and attention to detail is unparalleled. Their ability to canvas opinion during protocol development helps us adapt to the needs of patients rapidly, accelerating the approval process and hastening trial recruitment. I look forward to further collaborations with ICPV during the course of TRACERx and other studies we are planning.”

**Professor Charles Swanton**, Chair in Personalised Medicine, UCL Cancer Institute, Consultant Medical Oncologist at UCL Hospitals, Group Leader, Translational Cancer Therapeutics Laboratory, Cancer Research UK London Research Institute

## What we do

ICPV provides researchers, clinical trials units and cancer networks with access to a trained and supported group of patient and carer advocates, thereby offering unique access to patient experience and to the committed, informed, independent and unfiltered patient voice.

ICPV offers training opportunities to cancer patients to improve their clinical knowledge and research awareness and help them communicate on an equal footing with clinicians and researchers.

ICPV engages with clinicians and researchers in a variety of ways including regular study days, which provide training opportunities for patients and clinicians alike. We help design clinical studies and we respond to consultations on cancer care and research, whether strategic consultations or issues around particular trials.

## How we work

Although we are independent of established UK cancer charities we work closely with them. Some of us are members and volunteers of other charities; such involvement is important when we bring our experiences as patients and trained advocates to influence the future of cancer research and evidence based healthcare.

We aim to work within the National Cancer Research Institute (NCRI) Framework with proper monitoring and review of our activity, the impact we have on the research process and the value we add to research outcomes. Most of our members are involved in the design and/or running of at least one clinical trial, usually as a member of a Trial Management Group. We work as advocates at a strategic level with clinicians and clinical researchers in order to improve clinical research and outcomes for all cancer patients.

“The contribution by Independent Cancer Patients’ Voice to the large UK multicentre POSNOC trial has been vital in improving the study design, making sure outcomes important to patients are measured, and making all the study practicalities much clearer.

I feel confident that we are asking the right question to improve the health and quality of life of breast cancer patients. ICPV involvement has ensured that the trial information in the patient information leaflet and DVD is easily understood, clear and presented in an unbiased manner. I am glad that their members are part of the POSNOC Trial Management Group and Trial Steering Committee and shall provide a patient and wider public perspective throughout the duration of the trial.”

**Amit Goyal MS, MD, FRCS**

Consultant Oncoplastic Breast Surgeon,  
Honorary Associate Professor,  
Royal Derby Hospital

# Membership

ICPV membership has grown steadily over the past 5 years. There are currently over 40 members from all over the UK, as widespread as Southampton to Glasgow and Belfast.

All of our members are either cancer survivors, or have cared for someone with cancer. Some have had both those experiences, and several have been trial participants. We have a wealth of patient experience and a rich mix of professional expertise, with backgrounds in academia, business law, local government, education, corporate communications, healthcare and science. Because of the nature of our activity and the necessary level of commitment to learn as well as to participate in research, ICPV will not appeal to all cancer patients. We recognise that we are not “representative” – hence our preference for the term “Patient Advocate”

## Trustees



### Pat Fairbrother

Following a diagnosis of breast cancer several years ago Pat became involved in patient advocacy. Working in healthcare, which included a contract as patient involvement facilitator, gave her a unique insight into the need for patients to be involved at the heart of planning services. Pat developed an interest in research after working at a regional and national level with breast cancer charities, and local cancer services. She joined ICPV as a virtual member whilst living in New Zealand where she carried on with voluntary work with national cancer organisations. Since coming back to the UK Pat has become involved in several research projects through ICPV alongside voluntary work in cancer services regionally and nationally. Pat believes research needs the patients' unique perspective and is absolutely essential in order to make the research work.



### Chris Finch

Chris is a carer to his wife, who has advanced breast cancer. By training he is a chartered accountant, and for many years worked as finance director for charities, including, for nearly twenty years, the Biochemical Society. Chris has also been a trustee of charities in the health sector, including Breast Cancer Campaign.

“As an oncologist conducting trials looking for new and better ways to look after women with breast cancer the support of ICPV has been invaluable. The knowledge, interest and support of the group has enabled myself and many colleagues to conduct trials which are not only scientifically robust, but also sensitive to the needs and wishes of women with breast cancer.”

**Dr Alistair Ring**, Chair NCRI Advanced Breast Cancer subgroup



### Linda Larter (MBE)

Linda is married with two sons. A Trustee of Independent Cancer Patient Voice and also sits on the APPG for Cancer Services.

Linda was diagnosed with Breast Cancer in 1998 at the age of 35. Following treatment she became a member of the UK Breast Cancer Coalition and then Breakthrough Breast Cancer following their mergers. Linda was the Chairman of the Campaign and Advocacy Steering Committee at Breakthrough Breast Cancer at the exciting time when Herceptin was agreed for all and the two week referral time introduced.

Linda has worked within local government for 25 years, and has a Fellowship of the Institute of Council Local Management.



### Mairead MacKenzie

Mairead was diagnosed with breast cancer in 2002. She had chemotherapy, followed by a mastectomy with immediate reconstruction, radiotherapy and endocrine therapy. Since her treatment Mairead has developed mild lymphoedema which is now under control and capsular contraction in her reconstruction which has resulted in the need for further surgery. This has prompted Mairead to feel strongly about the issues and potential problems patients face with the long term effects of cancer treatment.

Mairead has been a member of ICPV since 2009 and currently sits on a number of trial management groups. She is a member of the Breast Cancer Campaign Tissue Access Committee, the Breast Cancer Care Research Partnership and the London Cancer Alliance Breast Pathway Group. Mairead still works part-time as a freelance information scientist and enjoys gardening, needlework, reading, walking and travelling.



### Adrienne Morgan

Adrienne was diagnosed with breast cancer in 2005 and secondary breast cancer in 2010. Adrienne is a PhD medical research scientist and worked for 20 years in academia and industry. She now works in the cancer charity sector, having spent three years as the staff scientist at Children with Leukaemia, and then a year as the secretariat for Cancer52 – an umbrella organisation that represents the less common cancers.

She has worked informally as a patient advocate with Breakthrough and Breast Cancer Campaign since her diagnosis. Most recently she has been involved with Campaign's new Tissue Bank initiative. She is a lay member of several Clinical Trial Management and Working Groups and a familiar independent patient voice in Q and A sessions at cancer research conferences.



### Carolyn Morris

Carolyn's first diagnosis of cancer in 1999 prompted early retirement, from her work as Director of Sussex University's Career Development Unit – though in truth that was more to do with the side effects of Tamoxifen than with the cancer itself.

Her involvements in cancer were initially through the UK Breast Cancer Coalition, a patient led advocacy group, many of whose members later went on to become founder members of ICPV, and in the then Sussex Cancer Network. Increasingly involved in research, she is a Trustee of ICPV, sits on Research for Patient Benefit SE Coast Committee, leads NCRN's work on the research questions in the National Cancer Patient Experience Survey and is a member of NCRI's Psychosocial Oncology & Survivorship Clinical Studies Group. She is a member of a number of trial steering groups in Psychosocial & Palliative Care and the radiotherapy trial FASTForward. She is now on a Phase 2 trial to treat 3rd recurrence, diagnosed earlier in 2014.

A link with her earlier roles as a counsellor and careers psychologist is her work on a number of evaluations of user involvement and advocacy – interviewing & report writing for, inter alia, Macmillan Cancer Support, the UK Clinical Research Collaboration, and a user-led study looking at the personal impact on advocates of our involvement.



### Maggie Wilcox

Maggie trained in general nursing and midwifery before training to become a Health Visitor.

Maggie was diagnosed with breast cancer in 1997 and treated with surgery and radiotherapy. This was followed by a mastectomy a year later because of post-radiotherapy problems and, after 10 years endocrine therapy, no further treatment and – so far, so good.

As a lay member of the NCRI Breast Clinical Study Group, Maggie's involvement became more specific to cancer research and the ethical use of data and tissue. Maggie was involved in the development of Breast Cancer Campaign Tissue Bank and is a member of the executive of CCB and Stakeholder & Fee Group for the Human Tissue Authority (HTA). Maggie's interests include spending time with family and friends, trying to play golf, keeping fit (and relaxing!) at her David Lloyd Club and travelling. Maggie volunteers at a local arts centre and a member of the National Association of Decorative & Fine Arts Societies (NADFAS) and a wine-tasting group.

*"I have really enjoyed the opportunity of working together to provide a patient perspective and improve the understanding of the professional community in cancer research. The ICPV has been a highlight and inspiration and I feel a real privilege to have been a founding member of this dynamic group. I know that in your capable hands and with the boundless energy and devotion you all show that the group will continue to be seen as a leading force for good. I wish each of you success in all your endeavours and that health and happiness goes with you all."*

**Jill Bartrop**  
Founder Member of ICPV

# Thank You

The nature of ICPV membership means that we have to say farewell to people as Trustees or as Members through loss of life or because secondary disease creates different priorities – as does increasing age! We also lose the valuable input of those whose priorities change due to professional or family changes and sometimes members need to close the door on cancer related activities and resume “normal living”!

## Daphne Havercroft

Founding member of ICPV after she & Maggie had met with a member of the Cancer Action Team. The discussions at this meeting underlined the need for an independent, patient led group who could add a direct, informed and unfiltered patient view to cancer research in the UK. Daphne is an experienced project manager and added the necessary realistic framework to our aspirations in the early days.

Daphne and Maggie had both undertaken Project LEAD education provided for breast cancer advocates in the USA and decided this type of course should be available in the UK where we have excellent researchers and the NHS provides an ideal framework for patient involvement in cancer research. Together with Jill, they were members of the Breast Clinical Study Group whose professional members encouraged the formation of ICPV and gave invaluable assistance in our development of education for cancer patient advocates. ICPV study days started at Leeds at the invitation of Professor Hanby with a one day education event led by Prof Speirs and this progressed to our pilot 5day science course run at Barts & the London in 2013 led by Professor Jones and Professor Marshall.

Daphne is still a valued member of ICPV but full time employment and her local campaigning work led to resignation as a Trustee in 2012.

## Jill Bartrop

We understood but very much regretted Jill's resignation from all cancer patient advocacy in 2013 – including her role as a Trustee of ICPV. Jill was a founder member of ICPV who was involved in advocacy for many years and her knowledge and experience about CUP and patients with other disadvantages or disabilities was particularly appreciated by ICPV and by other groups including the Breast Clinical Study Group. Jill's straightforward and common sense approach cut through the jargon and acronyms to assess problems effectively in order to find solutions and her priority was always to increase patient benefit. We will miss her humour and dry comments as well as her integrity, experience and care for others.

We wish Jill and Alan a very happy and much deserved retirement with lots of interesting travel.

## Hilary Blackburn

Unfortunately for ICPV, 2013 was also the year when Hilary was unable to continue giving her time and expertise due the increasing needs of both family and business. Hilary had experience as a patient advocate working at Board level with NCRI but also at grassroots level in her local cancer research partnership group. As a young survivor of triple negative breast cancer Hilary is a keen supporter of much needed research in this area of less common breast cancer. ICPV will miss her friendship and support as well as her organisational and promotional expertise but recognise that, having beaten the odds not only to survive this cancer but to have become mother to two lovely children, Hilary's family must now take priority.

## Vonny Tarapore

Vonny was one of our early members who joined us after experience in her local cancer research group. She had been treated for breast cancer and was keen to learn more about the biology of breast cancer so as to better understand the rationale of trials on which she was asked to comment. She undertook the Project LEAD International course held in Buenos Aires by the National Breast Cancer Coalition and kept in touch with other “PL Grads” to exchange information and news about new research in their countries. Vonny worked in banking and was unable to continue in patient advocacy due to pressures of work, family needs and some health problems. Her gentle, quiet and perceptive contributions to ICPV are much missed and we would welcome her back whenever this becomes possible.

# In Memory

**Alka Welinska**, one of our founder members, has died from breast cancer. Maggie Wilcox remembers her:

Alka was a very bright and lively young lady and a founder member of ICPV. Her full-time professional work and busy social life meant that she was a virtual member but she contributed to discussions online and in one to one conversations. She had a particular interest in HER2 positive breast cancer problems of living with advanced breast cancer. Alka was keen to promote discussion about research in secondary breast cancer and improving quality of life and felt that there was a need to find better ways of approaching these patients to increase participation in studies. She acknowledged that raising the subject was often uncomfortable for professional and family carers as well as for patients themselves and felt it would be much easier if research was a routine part of cancer treatment prior to a secondary diagnosis.

Alka continued working fulltime through many courses of treatment and managed to continue to self-manage her care but also to enjoy social activities with her many friends until the six months following her last surgery. She lost her hair several times so she welcomed meeting Trevor Sorbie and strongly endorsed his work in training stylists to provide attractive wigs for patients with hair loss. When appearing on television to talk about the need for research to provide better, more targeted treatments Alka also emphasised the need to follow this with proper access to those treatments for any patient likely to benefit.

Alka did not ask for help in managing her care until she experienced problems organising her potential need for residential care. This demonstrates the need for provision of appropriate 24hour support for younger terminally ill patients who live alone and need assistance with personal care and daily living activities. Her parents, brother and his wife all live in Australia and it took Alka and her sister-in-law, almost 4 of her 6 month prognosis to overcome Australian bureaucracy in order for her to spend her last weeks there – cared for by her family. However Alka had been given a visa for only a month so asked for help to explore the options for care should she have had to return home to the UK. Hospices in the UK usually only offer short term in-patient care and Alka’s experience demonstrated the problems related to the longer term care needs for those young patients who need assistance with self care and for whom nursing homes are inappropriate.

# Full ICPV Membership List:

- |                          |                   |
|--------------------------|-------------------|
| Christine Allmark        | Tom Haswell       |
| Isobel Anderson          | Daphne Havercroft |
| James Ashton             | Megan Hill        |
| Elsbeth Banks            | Linda Larter      |
| Elizabeth Benns          | Mairead MacKenzie |
| Julia Black              | April Matthews    |
| Samantha Brace-McConnell | Jean McGregor     |
| Melanie Brooks           | Carolyn Morris    |
| Helen Bulbeck            | Adrienne Morgan   |
| Dave Chuter              | Annette Rauf      |
| Alero Dabor              | Peter Rainey      |
| Joanna Dugher            | Emma Shanks       |
| Jim Elliott              | Simpi Sikhosana   |
| Hilary Essen             | Richard Stephens  |
| Pat Fairbrother          | Derek Stewart     |
| Helen Ferns              | Hilary Stobart    |
| Chris Finch              | Lesley Turner     |
| Sophie Gasson            | Alison Walker     |
| Jacqui Gath              | Maggie Wilcox     |
| Margaret Grayson         | Rose Woodward     |
|                          | Julia Wright      |

## New Members

ICPV is always looking for new members and welcomes interest from people who have been treated for, or affected, by cancer. It is advisable for prospective members to gain advocacy experience eg with a local group before considering joining ICPV. Members should also:

- Demonstrate an interest in cancer and research
- Want to help make a difference in the research community in collaboration with professional researchers
- Provide an advocate patient/carer perspective as part of a team
- Demonstrate an ability to give time to the group and its activities
- Have a willingness to attend study days and meetings and develop understanding of cancer and research
- Be able to take part in online discussion group
- Be a good listener and contribute effectively in a variety of settings
- Show enthusiasm and possibly a sense of humour
- Be able to work within own health limits
- Be able to respect others and observe confidentiality
- Share knowledge gained and endeavour to raise public awareness of value of research
- Be willing to represent ICPV on local and national groups to ensure transfer of information both ways

Full details of membership criteria and the recruitment process can be found on the ICPV website [www.independentcancerpatientsvoice.org.uk](http://www.independentcancerpatientsvoice.org.uk)

“It has never been more important to engage patients in the development of new cancer treatments. As we move into the stratified medicine era, the complexity of treatment options will increase and we must ensure that the questions (and answers) remain relevant to the patients we are treating.”

**Prof. Dion Morton**  
Colorectal Surgery Consultant

ICPV is planning to introduce new levels of membership to enrich the group and enable interested people to support the group on many levels. A supporter level of membership is being considered to allow corporate membership to either support ICPV financially or help raise the profile of the group.

### ICPV members can expect to benefit from the following:

- **ICPV website – [www.independentcancerpatientsvoice.org.uk](http://www.independentcancerpatientsvoice.org.uk)**  
This is regularly updated with two-way information, enabling members to share their experiences and supply information to clinicians
- Quality education and training opportunities together with peer support and mentoring
- The hosting of meetings between patients, clinicians and researchers
- The provision of other means of communication including a Google discussion group (this is a closed group for members only)
- Recognition from researchers who value the input of ICPV in their research projects
- Opportunities to take part in UK and International conferences – presenting as well as attending
- Facebook page for open comments and members activities  
<https://www.facebook.com/Independentcancerpatientsvoice>
- New Twitter feed @icpvtweets

“I have worked with several members of the Independent Cancer Patients Voice on a range of issues related to prevention and treatment of breast cancer. I have found them very knowledgeable and helpful to us in planning and conducting our clinical trials. It is very important to have views from patients on a range of questions related to this work. I have found that they are extremely helpful and give us advice that is based on personal experience and highly relevant to the needs of patients in our trials. I look forward to continuing to work with them on new projects.”

**Jack Cuzick**, Director, Wolfson Institute of Preventive Medicine,  
Queen Mary University of London

# Activity and Achievements

ICPV activity has grown and developed since the group was founded. Some of the Research Studies & Clinical Trials with ICPV involvement are listed below:



### Other Studies with ICPV Involvement:

- |            |                           |                               |
|------------|---------------------------|-------------------------------|
| ANCHOR     | HeartSpare                | REMoDL-B                      |
| ARISTACRAT | HOLySTIC                  | SMART (Macmillan)             |
| AVALPROFS  | IMAGINT(EU)               | STAMPEDE                      |
| AWOS       | INTERGRATE (EU Pall Care) | SURECAN                       |
| COSTA-TRUC | IPET                      | TOMMY                         |
| CREW       | POSNOC                    | TRACTOR                       |
| EPAN       | PRIMETIME                 | Vacuum Biopsy Study           |
| FOCUS 4    | PROMIS                    | Vaginal dryness/atrophy study |
| GUIDE-care | RCAHT                     |                               |

Most ICPV involvement is as members of Trial Management Groups. For some of the trials listed, ICPV members are involved as a Co-Investigator or as a member of Trial Steering or Working Group.

**ICPV also has collaboration or involvement with the following:**

- ASCO Guidelines Group for Treatment of Metastatic Breast Cancer
- Association of Breast Surgeons (ABS)
- Association of British Pharmaceutical Industries (ABPI) Patient Forum
- Brainstrust
- Breast Cancer Campaign Tissue Bank (BCCTB)
- Breast Cancer Care Service User Research Panel and Research Committee
- Cancer 52
- Cancer Partnership Research Groups (CPRG's) in Kent, Surrey and Sussex, North Trent and Derbyshire
- Cancer Peer Review
- Christie NHS Foundation Trust, Manchester
- CRUK Clinical Trials Awards and Advisory Committee (CTAAC)
- Electronic Transmission Prescriptions Programme
- Glasgow Bio-repository and Beatson Cancer Centre CTU and Institute
- Health Research Authority (HRA): advising on PPI strategy, attending workshops and stakeholder meetings. ICPV took part in a joint presentation with INVOLVE to the HRA Board to demonstrate the value of Patient and Public Involvement and Engagement
- Health Technology Assessment panels
- Human Tissue Authority (HTA): ICPV contributed to the Academy Medical Science Review of Arms Length Bodies. HTA is advising ICPV in the writing of a Lay Guide to Tissue Donation
- Institute of Cancer Research, London
- London Alliance: Breast steering group
- London Cancer UCL Partners: – ICPV advised on effective PPI, joined interview panel for Research Director. ICPV member is Non-Executive Director on Board
- Marmot Panel on breast screening
- Medical Research Council (MRC): Trial Protocols Review Committee and CTU PPI Steering group

- MD Anderson, Texas, link with Patient Research Advocacy Network
- National Awareness and Early Diagnosis Initiative (NAEDI)
- National Cancer Intelligence Network (NCIN): Lay members of the following Site Specific Groups – Head and Neck, Brain and CNS, Sarcoma, Psychosocial Oncology and Survivorship, Haematology, Primary Care, Skin and Lung. Also the NCIN Scientific Reference Group, Biomarkers and Imaging Clinical Studies Group and the National Lung Cancer Clinical Audit Reference Group
- National Cancer Research Institute (NCRI): Lay members of the Palliative and Supportive Care (think this unnecessary? Site Specific Group.) Also the Advanced Disease and translational Sub-Groups of the Breast CSG, NCRI HUB, Confederation of Cancer Biobanks (CCB), the Consumer Liaison Group (CLG), Breast Intergroup, Portfolio Working Group, Psychosocial Oncology & Survivorship CSG, Service Development and Evaluation sub-group and Breast CSG working group on Symptom Management
- National Collaborating Centre for Cancer
- National Prostate Cancer Risk Awareness Advisory Group
- NHS England PET-CT Clinical Reference Group
- NICE Diagnostics Assessment Committee for Skin
- Northern Ireland Cancer Trials Exec, Network Steering Group and Cancer Registry
- Rare Cancer Foundation (RCF)
- Regional Ethics Committees (REC)
- Research for Patient Benefit (RfPB): Regional committees
- Sloane Project
- Stakeholder status with National Institute for Clinical Excellence (NICE) and the All Party Parliamentary Group (APPG) on Cancer
- Surrey Cancer Research Institute (SCRI) – launched July 2014
- Wellcome, NCIN and UKBiobank Conference: Session Chair
- West Midlands Collaborative of Surgeons
- Working group for new screening info – bowel, breast and cervical cancer

# Training

ICPV is passionate about education and development for its members and organises regular educational events. Over the past few years these have included one day workshops as well as several longer events at locations including Glasgow, Leeds, Cardiff, Birmingham, Brighton and London.

## Brighton Workshops 2012 and 2014:

Professor Lesley Fallowfield and her team kindly funded and hosted ICPV in Sept 2012 for a 2 day workshop on psychosocial and quality of life issues in cancer and kindly repeated this in July 2014. Some feedback from one of the attendees of the 2014 workshop follows:

Re Lesley Fallowfield: "Her final thoughts were that cancer and its treatment has become complicated, that many words and phrases are meaningless, counter-intuitive or ambiguous and that we need to ensure patients are in receipt of appropriate, accessible information in order to make informed choices."

Re a presentation from some of the ICPV members: "Adrienne, Carolyn and Hilary presented a trio of patient-led themes and we all benefited from hearing about their networking, broad experiences and excellent practice. This was an important inclusion because not all of us are aware of colleagues' involvement and contribution in key areas of research and development. I was struck by their enthusiasm, work output, their commitment to making a difference and the obvious respect in which they are held by others."

## Radiotherapy Workshop, October 2012:

70 delegates were able to attend this workshop due to a kind offer from Tim Cooper, previously Radiotherapy Lead at the National Cancer Action Team, Charlotte Coles and Peter Kirkbride, to organise and provide the venue and speakers. This enabled ICPV to open the workshop to other interested lay people including members of CTRad. It was an extremely interesting and informative event which underlined the huge advances in this important treatment which have resulted from UK radiotherapy trials.

## Glasgow Neuro-Oncology Course – May 2013:



**Helen Bulbeck writes:** This course was a joint venture with the charity *brainstrust* and ran over 2 days based at the Beatson Institute. It was made possible by a grant from Macmillan. The programme covered what is brain cancer and why it is so intransigent to treat, as well as the patient's pathway and treatment options available. Brain cancer is not like any other cancer diagnosis, as patients and their carers often face progressive neurological disease and loss of identity. Clinicians gave excellent presentations on the current developments in treating this catastrophic diagnosis and how treatments are becoming personalised.



**Vision On Information, Confidence & Engagement**

In 2013 ICPV achieved one of its primary goals – a week's intensive biology education for its members. This had been a goal since ICPV was founded because several members had benefited previously from Project Lead training provided in America. Through the hard work, expertise and enthusiasm of the scientists at Barts Cancer Institute we were able to hold our pilot 'science for advocates' course – VOICE – 'Vision on Information, Confidence and Engagement' in 2013. With the laboratory-based content this course is unique and especially valuable for patient advocates in cancer research. 'A study week taking patient advocates from bedside to bench' – leading to translational patients!

"The session where we discussed how chemotherapy agents work in relation to the cell cycle was the best teaching experience I think I've had – moving, informative and productive."

**Dr Richard Grose**  
Barts Cancer Institute

The second VOICE course was held in September 2014 again at Barts Cancer Institute. The course aims to give participants a basic understanding of cancer biology and an introduction to research terminology and practice. This is a residential course held over 5 days and is the only one of its kind held in the UK. The students attend lectures in the morning and consolidate their learning with practical sessions in the teaching laboratories each afternoon. Some feedback from this year's students:

It comes up in support groups all the time; what happens to your tissue? Now I can talk about it with authority and encourage more people to get involved in research.

It gives me more confidence to interact with the scientific community

ICPV continues to be grateful to academic centres and researchers around the UK who have hosted the group with enthusiasm and looks forward to continuing to expand this collaboration.

ICPV plans to repeat the VOICE course and we are receiving expressions of interest from researchers keen to support this project.

“Following ICPV input into a research proposal by Jamilla Hussain, including presentation of the proposal at the Consumer Liaison Group’s Dragon’s Den session at the 2012 NCRI Cancer Conference, Jamilla was recommended for PhD funding by the NIHR. Professor Miriam J Johnson wrote to ICPV: “thank you again for your great input with her application – I think she had the best PPI input I have ever seen on an application.”

**Miriam Johnson**  
Professor of Palliative Medicine, Hull York Medical School

“ICPV work closely with Professor Janet Dunn and her team at the Warwick Clinical Trials Unit, University of Warwick, on early breast cancer clinical trials and have been influential in helping with the design, information, consent, trial management and trial processes for the PERSEPHONE (Herceptin duration), OPTIMA (optimal personalised medicine) and MAMMO-50 (mammographic surveillance in patients diagnosed aged 50 years or older) clinical trials. Each trial is funded by the department of health through the health technology assessment (HTA) funding stream and seeks to determine the best treatment for these populations of early breast cancer patients. The OPTIMA and MAMMO-50 trials included some early PPI focus groups to determine the experiences and views of the trial design, information and trial question for which ICPV helped facilitate. Engagement of patients early in the trial design has helped with fine-tuning these important questions and has allowed the trial team to incorporate patients’ view throughout the trial process.

Janet continues to support ICPV with her clinical trial workshops in the ICPV training days where the various trial questions and subsequent designs are discussed. One workshop concentrated on follow-up which remains an important question throughout cancer trials but still needs guidelines to address optimal care. Professor Dunn quotes “The partnership with ICPV at the formulation of the trial question and subsequent trial design has significantly improved acceptability of the trial to both patients and clinicians.”



**Prof Janet Dunn**  
Professor of Clinical Trials and Head of Cancer Trials,  
Deputy Director, Warwick Medical School Clinical Trials Unit



" A continuing involvement with ICPV has had a huge impact on how I work, since I now 'hear' – or at least listen for – the patient voice in many situations I encounter, and I realise we, as medical professionals, can actually ask for input. As I am starting to consider ways of addressing research into secondary breast cancer, it gives me confidence to know that I can seek candid opinions and invaluable advice from ICPV. I don't think it is possible to move forward without this partnership, and for that ICPV is to be applauded."

**Louise J Jones**, Professor of Breast Pathology Centre for Tumour Biology, Barts Cancer Institute – a Cancer Research UK Centre of Excellence



## Conferences/events/posters

"I am writing on behalf of Dr Keeley to thank you and your colleagues for the thoughtful comments we received on our application. We made several changes to the study design because of these and feel that the input you provided us with has strengthened our application. We chose to include the feedback we received from the ICPV and also from Breast Cancer Care as an upload to accompany the application to demonstrate how patients with and at risk of developing lymphoedema feel about treatment."

**Katie Riches**

Senior Research Nurse, Lymphoedema and Palliative Medicine, Royal Derby Hospital

"Very good news! I am very pleased to let you know that I have been awarded the TRF Fellowship from the NIHR so now we get to carry out some really worthwhile research.

Many thanks for all your help and support, and please pass on those thanks to all the members of ICPV. Your involvement was certainly a factor in the successful outcome of the application."

**Dr Minty Ledger**

Post-doctoral Research Fellow, Institute of Cancer Research, London

**ICPV members regularly attend major conferences and meetings, both as delegates and speakers and frequently display posters detailing ICPV activity. These have included:**

- NCRI Annual Conference, Liverpool
- NCIN Cancer Outcomes Conference
- Britain Against Cancer – Westminster
- HTA AGM & Public Meeting
- CCB Public Events in Newcastle, Dundee & London
- NCRI Annual Trials Day London
- Breast Annual Trials Day London
- Breast Radiology Forum Annual Scientific Meeting – Glasgow
- Peninsula Cancer Event – Cornwall
- Annual Research Conference at the Christie Hospital
- Rare Cancer Foundation Conference London
- MRC Centenary Event – PPI in Clinical Trials – London
- Pan London Cancer Patient Experience Event – London
- UCL Partners Women's Cancer Conference
- APPG Cancer Across the Domains Workshops and Question time Event
- ABPI & LUTO Conference London
- HRA PPI Steering Group and Stakeholder Meetings London, Leeds and Manchester
- London New Cancer Drugs Forum annual Conference
- CRUK PPI Conference and Research Strategy Meeting
- Europa Donna Annual Symposium, London and Training Day in Milan

Members have also attended and presented at major International conferences and events including:

- Reach to Recovery, Capetown – presentation on lay involvement in tissue banking including work with BCCTB and CCB
- European Cancer Congress Amsterdam – Importance of Lay Involvement in Tissue Banking
- San Antonio Breast Cancer Symposium – displayed posters
- European Cancer Patients Coalition AGM – Presentation on Lay involvement in Biobanking
- ESSO-BASO Conference – video Presentation on Education for Effective Patient Advocacy – October 2014
- NCRI Conference parallel session on biobanking
- INVOLVE conference Presentation on Education for Effective Involvement in Cancer Research

“Independent Cancer Patients Voice continues to contribute very effectively and helpfully to the development of clinical trials and studies, including providing pivotal input where the “patients voice” has supported trials at key moments. ICPV members also ensure that clinicians get real world views that have in the last year or so stimulated the clinical community to reconsider the importance of symptoms in survivors through to supporting cutting edge research through tissue banking initiatives. We are fortunate indeed to have ICPV playing an active role in the development of improved treatments for cancer based on hard won evidence.”

**Professor Alastair Thompson**

Professor of Surgery, MD Anderson Cancer Center, Houston Texas and  
FORMER Chair NCRI Breast CCSG

## Publications

**Some ICPV members have been collaborators or co-authors for research projects and commented on articles in professional journals. Examples include:**

### **Always Putting Patients First**

ICPV members, Maggie, April, Mairead, Adrienne & Jacqui explain their work with the Tissue Bank PinkScienceSummer2013-TissueBank.pdf.

### **Biobanks**

POST Note published July 2014 as part of the POST series on Big Data Published 30 July 2014 | POST notes POST PN 473 Authors: Sarah Bunn. Topic: Diseases, Genetics, Medical ethics, Science.

### **Breast Cancer Campaign Tissue Bank human cell culture programme: Generating new biomaterials for breast research**

Jennifer Gomm, Adrienne Morgan, Linda Haywood, Louise Jones et al Poster at NCRI Conference, 2013.

### **Chemotherapy and Targeted Therapy for Women With Human Epidermal Growth Factor Receptor 2–Negative (or unknown) Advanced Breast Cancer: American Society of Clinical Oncology Clinical Practice Guideline.**

Ann H. Partridge, R. Bryan Rumble, Lisa A. Carey, Steven E. Come, Nancy E. Davidson, Angelo Di Leo, Julie Gralow, Gabriel N. Hortobagyi, Beverly Moy, Douglas Yee, Shelley B. Brundage, Michael A. Danso, Maggie Wilcox, and Ian E. Smith Journal of Clinical Oncology September 10, 2014 32 (26) – ASCO Special Article.

### **Comfort Blanket or Clinical Need? The Role of Follow-up for Cancer Survivors.**

Gasson S, MacKenzie M, Morgan A, Morris C, Randle K, Stobart H, Turner L, Wilcox M. Journal of Clinical Oncology 2014,26,10.

### **Independent Cancer Patients’ Voice - continuing to speak clearly and be heard.**

Adrienne Morgan, Maggie Wilcox, Mairead MacKenzie, Chris Finch, Jill Bartrop, Carolyn Morris, Linda Larter Poster at NCRI Conference, Liverpool 2011.

“The involvement of lay people in collections of tissue samples for research has been critical in many ways but particularly in allowing professionals to feel confident about what can reasonably be asked of patients in their research partnership with them. Lay advice has been and remains very important to us in our trials of presurgical treatments of primary breast cancer; without this it is highly unlikely that these trials could have been successful.”

**Professor Mitch Dowsett, PhD, F Med Sci**

Head of Academic Biochemistry  
Professor of Biochemical Endocrinology  
Professor of Translational Research at the Breakthrough Research Centre, Head Centre for Molecular Pathology Royal Marsden Hospital

#### **Endocrine Therapy, New Biologicals, and New Study Designs for Presurgical Studies in Breast Cancer**

Mitch Dowsett, Ian Smith, John Robertson, Laura Robison, Isabel Pinhel, Lindsay Johnson, Janine Salter, Anita Dunbier, Helen Anderson, Zara Ghazoui, Tony Skene, Abigail Evans, Roger A'Hern, Amanda Iskender, Maggie Wilcox, Judith Bliss  
J Natl Cancer Inst Monogr-2011-Dowsett-1[...].

#### **Investment Biobanking – increased returns from tissue banks**

Val Speirs and Adrienne Morgan, Nature Reviews Clinical Oncology, 2013 Mar;10(3):128-9.

#### **Involving patients/donors in biobanking: get on board**

CCB Lay Members Maggie Wilcox and Derek Stewart provide their thoughts on patient involvement in biobanking  
CCB\_Newsletter\_Dec2012\_patient+involvement[...].

#### **Is it me or is it hot in here? A plea for more research into hot flushes.**

Adrienne Morgan, Deborah Fenlon NCRI breast CSG working group on Symptom Management, Clin Oncol (R Coll Radiol) 2013 Nov;25(11):681-3.

**Is it me or is it hot in here? Hot Flushes: an unmet need NCRI Breast CSG Working Party on Symptom Management (Vasomotor)**, including Adrienne Morgan, Lesley Turner, Carolyn Morris Posters at NCRI Liverpool, San Antonio, UKONS 2013 & EBCC 2014.

**Making patient and public involvement in cancer and palliative research a reality: academic support is vital for success.** Karen Collins, Jonathan Boote, Dave Ardron, Jacqui Gath, Tracy Green, Sam Ahmedzai. British Medical Journal 24th Sept 2014.

#### **NCRI-CCB-Breast Cancer Campaign - Data Standard**

Poster presented at NCIN 2013, Philip Quinlan & CCB Working Group 3 (inc Helen Bulbeck & Mairead MacKenzie)  
NCIN2013 - Data standard poster.pdf.

**Opinion. Too hot to handle.** Morgan, A. (2014) Cancer Nursing Practice 13(8) 13.

#### **Patient advocate involvement shapes UK's first national breast cancer tissue bank - Breast Cancer Campaign Tissue Bank (BCCTB)**

Jacqui Gath, Mairead MacKenzie, April Matthews, Adrienne Morgan, Maggie Wilcox. NCRI and San Antonio Conferences – Poster.

#### **Patient engagement. OPTIMA: Optimal Personalised Treatment of early breast cancer using Multi-parameter Analysis**

Adrienne Morgan, Rob Stein, Janet Dunn et al Poster at NCRI Conference, 2013.

#### **QUEST Trial, Breast Cancer Care Nursing Network News, June 2012**

Jane Nicholson and Mairead MacKenzie  
QUEST ARTICLE-Breast Cancer Care-June 20[...].

“We know cancer patients can make an important contribution to developing and delivering clinical research if they are given the opportunity to do so. ICPV plays a valuable role in this area, in particular by equipping patients with the skills and knowledge to work effectively alongside clinicians and academics. As CRUK implements its patient engagement strategy ICPV provides us with an excellent role model in this area of work.”

**Sarah Woolnough**

Executive Director of Policy & Information, Cancer Research UK

**Selecting breast cancer patients for chemotherapy: the opening of the UK OPTIMA trial**

Including Adrienne Morgan, Rob Stein, Janet Dunn et al  
Clin Oncol (R Coll Radiol) 2013.

**'The art of age appropriate care' reflecting on a conceptual model of the cancer experience for teenagers and young adults.**

Fern LA., Taylor RM., Whelan J., Pearce S., James Ashton., Grew T., Brooman K., Millington H., Starkey K., Gibson F.  
Cancer Nursing Sept / Oct 2013.

**The Information and decision support needs of older women (>75 yrs) facing treatment choices for breast cancer: a qualitative study.**

Collins K, Burton M, Caldon L, Lifford K, Brain K, Gath J, Revell D, Green T, Wyld L, Reed M. British Psycho-social Oncology Society Conference 27-28 February 2014 (Preston), European Breast Cancer Conference 19-21 March 2014 (Glasgow) and Association of Breast Surgery Conference 19-20 May 2014 (Liverpool).

**'Time for a low-risk DCIS trial: harnessing patient and public involvement'**

Leslie Fallowfield, Adele Francis, Susan Catt, Mairead MacKenzie, Valeries Jenkins  
Lancet November 2012.

"I think this patient-led group is a great example of novel teamwork that we need to promulgate – members who deliver quickly. Fantastic stuff everyone!"

**Prof Annie Young**

Professor of Nursing, Division of Health Sciences, Warwick Medical School

"I have found the input from ICPV invaluable. For example, really pertinent comments from its members have shaped the design of new clinical trials and tailored Patient Reported Outcome Measures (PROMS) to reflect what is really important for patients. In addition, the Radiotherapy for lay people conference day was thoroughly enjoyable and enlightening: I think I learnt more from the audience than they did from me!"

**Dr Charlotte Coles**

Consultant Clinical Oncologist, Addenbrooks,  
Cambridge University Hospitals NHS Foundation Trust

**Tracking Genomic Cancer Evolution for Precision Medicine:**

**The Lung TRACERx Study, PLoS Biol. 2014 Jul 8;12(7)**

Mariam Jamal-Hanjani, Charles Swanton et al (incl ICPV members Tom Haswell, Mairead MacKenzie and Maggie Wilcox)  
PloS-2014.pdf.

**'Your place or mine?' Priorities for a specialist Teenage and Young Adult (TYA) cancer unit: Disparity between TYA and professional perceptions.**

Taylor R., Fern LA., Whelan J., Pearce S., Grew T., Millington H., James Ashton, Brooman K., Starkey C., Gibson F.  
Journal of Adolescent and Young Adult Oncology. September 2011, 1(3): 145 - 151.

See website for full details

<http://www.independentcancerpatientsvoice.org.uk/icpv-publications/members-publications/>

ICPV were invited to write a lay chapter for a new International book on biobanking in the 21st Century. The draft has been submitted for editing and we are awaiting further information about publication.

# Looking to the Future

## Working with Young Researchers

ICPV’s primary purpose will continue to be to work with our professional colleagues in cancer research to produce more effective treatments for future patients. ICPV has been developing links with young researchers to encourage collaboration with patient advocates early in their careers. When ICPV was invited to host a parallel session on tissue banking at the annual NCRI conference in 2013, our speakers included two of these young researchers, Dr Matthew Krebs from the CRUK Manchester Institute and Dr Mariam Jamal-Hanjani from University College London who supported ICPV by giving a joint presentation from a young researcher’s perspective.

ICPV has also been working with a group of Trainee Pathologists from Guys & St Thomas’ to raise awareness of the need for human tissue in research and conducted surveys to inform the potential joint production of a “Public Guide to Tissue Donation”. ICPV has also provided lay opinion for the West Midlands Consortium of young surgeons who meet regularly to share their interest in research and discuss potential surgical trials.

“ We greatly value the input we have received from our lay advocates (from ICPV) for our clinical surgical trials over recent months and years. We find having an opinion on the study from the point of view of the health service user provides an invaluable alternate angle on the project, and the way we portray it in the protocol and patient-facing documents. This also extends to the associated ethics and grant application forms, which definitely improve after PPI input. In addition to ensuring the language in patient-facing documents is appropriate and understandable, we are also starting to include lay members on our study management groups, in order that they are involved in all aspects of the study process, right through to results reporting and dissemination.”

**Mr Thomas Pinkney**  
Senior Lecturer and Consultant Colorectal Surgeon, University Hospitals, Birmingham NHS Foundation Trust



The following example from Dr Jamal-Hanjani demonstrates the appreciation of lay input by young researchers:

### Dr Mariam Jamal-Hanjani

The PEACE (Posthumous tissue donAtion in CancEr) study is a multi-centre prospective observational study intended to facilitate tissue donation, in metastatic cancer, from multiple tumour sites in the post-mortem setting. It aims to establish a model for tumour progression, and therefore the metastatic process, and to determine whether there is a relationship between intratumour heterogeneity and clinical outcome, including response to treatment and survival. Results from the PEACE study may have significant implications for personalised treatment approach in cancer, including the identification of prognostic and predictive biomarkers, therapeutic strategy and drug resistance. The PEACE study also aims to encourage collaboration with other research teams for whom access to post-mortem tissue has the potential to further guide their work in cancer research. Ultimately, through the integration of genomic and clinical data, the study aims to identify critical tumour subgroups that may preferentially benefit from specific clinical therapeutics.

ICPV have been involved in the conceptual and practical development of the PEACE study from the outset. Their experience and input has been invaluable in the protocol and patient document development, which was written in consultation with ICPV, as well as medical, palliative care and pathology experts. Their continued support has encouraged us to move forward with this study so that patients are given the opportunity to donate tissue and be involved in cancer research.

### Dr Mariam Jamal-Hanjani

Clinical Research Fellow to Professor Charles Swanton  
Translational Cancer Therapeutics Laboratory  
UCL Cancer Institute

## International Collaborations

ICPV recognises the need for collaboration with patient advocates as well as scientists in other countries but it has proved difficult to access patient advocates who are actively and effectively involved in cancer research rather than campaigning for better services and access to treatment. We are also grateful to the Alamo Advocates who have sponsored attendance at San Antonio.

We are currently working to build links with international researchers and scientists with a genuine interest in effective lay involvement. Professor David Cameron asked ICPV to discuss education for patient advocates with the Chief Executive for Europa Donna. This resulted in a presentation to their Board members in 2013 about effective advocacy in breast cancer research.

Members have attended and presented at those EU organised conferences which provided bursaries but, with a very limited budget, ICPV cannot fund registration fees or travel costs. For example, several members were extremely keen to attend the European Breast Cancer Research Conference which was hosted in Glasgow in 2014. Despite our many enquiries and demonstrating active and effective involvement in breast cancer research, we were neither invited nor assisted to take part, even when this was being hosted in the UK. However, later in 2014, Professor Riccardo Audisio, a long standing supporter of ICPV, invited us to attend the ESSO-BASO conference hosted in Liverpool and complimentary registration was provided.

ICPV President Maggie Wilcox gave a joint presentation with Professor Peter Reigman for the European Cancer Patients Coalition about the importance of lay involvement in biobanking. This was well received despite the difficulty some delegates have in accessing even basic cancer treatments. Patricia Fairbairn was invited to attend an EORTC imaging meeting in Brussels and members of ICPV sit on trial management groups for several EU Clinical Trials. ICPV is a signatory to the Statement issued by the Wellcome Trust about proposed changes to the European Directive on Data Protection and will continue to collaborate in work on this issue.

In many European countries, most advocacy appears to be limited to cancer service development, fund raising and campaigning for improved cancer treatments. ICPV's view is that there must be many European patients who, like us, welcome active involvement in Cancer Research. This is being confirmed by enquiries from such people – some of whom have been referred to our website by their clinicians.

We have long term links with the National Breast Cancer Coalition in the USA who provided excellent education for several founding members of ICPV and continue to show interest and encouragement.

Professor Alastair Thompson is an outstanding enthusiast of effective lay involvement in cancer research and, now working at M D Anderson in Texas, is helping establish a link with other American patient advocates whilst Professor Ian Smith was instrumental in Maggie Wilcox being invited to join a recent ASCO Guideline working group.

We recognise the need to expand this collaboration to other tumour groups. ICPV plans to continue its efforts to find and collaborate with research active advocates in other countries and looks forward to the support of health professionals, both at home and abroad.

Finally, but very importantly, at the suggestion of Professor Val Speirs, ICPV was invited to contribute a lay chapter for a new international book on biobanking. This was a very new and educational experience but also underlined how much ICPV has developed since the last review of activities and achievements.

## Membership

Reviewing our activity and membership is on the agenda at all Trustee meetings to ensure that we grow and develop in a sustainable way to maintain ICPV quality within available funding.

Our present aim is to improve organisational efficiency and, although the introduction of an ad hoc funded facilitator has been an enormous help, the Trustees recognise that our target should be for ICPV to become a properly funded and more structured organisation. ICPV has now gained a reputation for providing direct access to a patient perspective which is realistic, constructively critical and highly valued by researchers across the UK. ICPV recognises the need to protect its ethos whilst continuing to grow and develop.



### ICPV aspirations:

- to increase membership
- to expand geographically becoming less London based
- to recruit more members with less common cancers
- to grow slowly in order to continue to provide the opportunities for education, mentoring and support to all members
- for more effective involvement from all members
- maintain trust and support of our professional colleagues
- to develop international links
- to continue to collaborate with relevant organisations
- to raise the money to fund all of the above
- Fund the appointment of a chief executive

## What are the main challenges we face?

As we grow, we will face many challenges not least in supporting a growing number of members whilst maintaining the integrity of the ICPV 'brand'. Raising our profile amongst the research community and encompassing other types of cancer within our work are two big challenges. Funding is likely to be an ongoing challenge. We can face criticism that we are not truly 'representative' or an open membership group because we are convinced that our aims require a high level of commitment to ensure the development of effective advocacy which meets the needs of both patients and researchers. Potential members are welcome to attend one of our events before applying for membership and they will be given information about criteria for membership of ICPV.

With the increase in requests for ICPV input from our professional colleagues we face a continual challenge of meeting deadlines for responses and urgently need more facilitator time.

ICPV members also need to make time for some 'normal' activities!

## Finances

ICPV is a charity (registered number 1138456) with the objects of “the promotion of good health among those suffering from cancer by participating in clinical research and the sharing of information with health professionals and patients.”

Our income in our first five years has come from a variety of sources, including Pharmaceutical companies (31%), members’ fundraising (18%), cancer charities (17%) and clinical trial units (11%). We are aware that we need to remain independent of pharmaceutical companies. However, it is in the interest of all cancer patients that effective drugs are developed, and we feel that donations from pharmaceutical companies are therefore appropriate. We believe that it is important for researchers to budget for lay input to new trials when making funding applications and we aim to recoup some of our costs in this way; this is needed to enable the participation of some members. Members receive no payment from ICPV, except travel expenses. The funds are used in the main for members’ education and for attending conferences and meetings.

For a copy of ICPV’s latest accounts please contact [chris.finch@icpv.org.uk](mailto:chris.finch@icpv.org.uk)

### Do you shop on-line?

**John Lewis, M&S, eBay, Amazon, Sainsbury’s,  
Tesco’s or over 2,000 other retailers?**

If you do then raise money for free for ICPV  
everytime you shop online. There’s no catch.  
[www.easyfundraising.org.uk/causes/icpv/](http://www.easyfundraising.org.uk/causes/icpv/)

“I have worked with ICPV on the development of several clinical trials, most notably OPTIMA for which I am the chief investigator. ICPV has played an important role in ensuring the success of OPTIMA from very early on in its development through securing funding for the feasibility phase of the study, OPTIMA prelim, which successfully met its recruitment target in April 2014. Adrienne Morgan has been a member of the study development and trial management group throughout this period. Through Adrienne, we have had access to the advice and opinions of other members of ICPV. These helped shape the initial study design and led to an important modification for the proposed design of the main OPTIMA study, which is now being considered by the funder. ICPV members made important contributions to the initial patient information sheet for OPTIMA prelim and facilitated three crucial patient focus groups that resulted in important insights into the attitudes of potential participants, resulting amongst other things in changes to patient information materials. Without the involvement of ICPV, it is likely that OPTIMA would have followed a much more difficult road than has been the case.”

**Dr Rob Stein**  
Consultant and Senior Lecturer in Oncology, UCL

## Acknowledgements

ICPV would like to acknowledge the support it has received from many people including:

Riccardo Audisio	Richard Grose	Phil Quinlan
John Bartlett	Shaun Griffin	Amanda Ramirez
Judith Bliss	Andy Hanby	Dan Rae
Elaine Blowers	Bec Hanley	Alastair Ring
David Cameron	Aidin Hindley	Karen Scanlon
Chris Carrigan	Karen Inns	Abeer Shaaban
Anne Carter	Val Jenkins	Sapna Sheth
Kerry Chester	Louise Jones	Ian Smith
Vicky Chico	Kate Law	Peter Schmid
Charlotte Coles	Caroline Magee	Val Speirs
Rob Coleman	John Marshall	Rob Stein
Jane Cope	Dr Balwir Matharoo-Ball	Jacquie Stringer
CRUK	Delyth Morgan	Charles Swanton
Jack Cuzik	Dion Morton	Alastair Thompson
John Dewar	Norma Morris	Diana Warwick
Clare Dickinson	NCRI	Bridget Wilkins
Mitch Dowsett	Carlo Palmieri	Janet Wisely
Janet Dunn	Emma Pennery	Tracey Woodcock
Lesley Fallowfield	Wayne Phillips	Sarah Woolnough
Adele Francis	Thomas Pinkney	John Yarnold

ICPV is grateful to everyone who has supported the group in any way since it was founded in 2009. The many examples of feedback and valediction scattered throughout this year book are illustrative of the many working relationships ICPV has established with researchers both in the UK and internationally. If anyone has been missed from the above acknowledgements we apologise sincerely – it is not intentional.

More detailed information about ICPV, activity, achievements and the future can be found on the website [www.independentcancerpatientsvoice.org.uk](http://www.independentcancerpatientsvoice.org.uk)