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www.ncri.org.uk/ccb

CCB Update

Issue 1, February 2010

Introduction

By Derek Stewart, Chair NCRI Confederation of Cancer Biobanks

Welcome to the first issue of CCB Update – a twice-yearly newsletter from the National Cancer Research Institute's Confederation of Cancer Biobanks.

Formed in 2006, this consortium of organisations in the UK aims to promote and disseminate a collective view on best practices for biobanks and to promote transfer of knowledge and experiences between banks.

Helped by our access to a national health service, the UK is one of the leading countries in cancer research with around 1 in 8 cancer patients now entering research studies, the highest proportion in the world. The growth of translational research and identification of biomarkers to help sub-divide cancers by their aggressiveness or likelihood to respond to certain treatments is leading to a greater research need for high quality tissue samples. We are seeing a corresponding rise in the number of tissue banks being established in the UK and enhanced interaction and knowledge sharing between these banks and their stakeholders will support the progress of cancer research.

We hope that this newsletter will help you feel better connected to the cancer tissue banking community and welcome your feedback and suggestions for future articles.

For more information on CCB visit www.ncri.org.uk/ccb

Tissue Banking in the NHS



This year started with some unpredictable weather but the team from the Wales Cancer Bank (WCB) was

undaunted and delivered a successful one-day satellite meeting at Imperial College as part of the Winter Meeting of the Pathological Society.

Although delegate numbers were down slightly on the day due to the snow storms in Greater London the speakers were passionate about the chosen theme of the meeting: *Tissue banking in the NHS – the advantages for pathology departments.*

The audience was provided with practical advice from a number of WCB speakers including their experience of setting up a tissue bank, management and governance of a tissue bank, what samples to collect and ensuring it is fit for the researcher's purpose and the important aspect of patient liaison. The potential uses of banked tissue in drug development were highlighted by the biotech example shared by Nessa Carey of CellCentric and Chris Womack's presentation on how biobanked samples complement AstraZeneca's research and development programme.

For more details of the day and to view the presentations visit www.walescancerbank.com

Patient Power

Cancer biobanks and those that use their services, depend upon patients for their willing donation of human tissue samples and also providing their supporting health and personal information.

In order to cater to the needs of these vital contributors to the cancer research effort, the CCB is in the process of establishing a Forum for donors/lay persons so that the lay/patient's perspective to cancer biobanking can help influence the direction of cancer biobanking. If you would like to be involved in this initiative please contact ccb@ncri.org.uk.

A progress update will be included in the next issue of this newsletter.

European Correspondent: update on BBMRI

At the end of 2009 Neil Formstone, Lay Member of Wales Cancer Bank and a representative for Macmillan Cancer Support, attended two key events in Paris organised by BBMRI (Biobanking and Biomolecular Resources Research Infrastructure, www.bbMRI.eu).



The first, on 15th December, was a meeting of the BBMRI Stakeholder's Forum Patient Working Group, where 11 patient group representatives from across Europe came together with other BBMRI stakeholders to discuss the patient role in biobanking. The meeting included presentations on patient partnership with examples from the USA and the Netherlands.

The participants discussed ethics and the variances across Europe regarding patient consent with agreement that an international structure should be worked towards. BBMRI plans to contact national and European patient groups to gain their feedback on the merits of a single

patient voice on biobanking and the afternoon workshop session focused on the development of this Patient Consultation Document.

The main BBMRI conference entitled *From Biobanks to Expert Centres* was held the following day and covered topics including the BBMRI expert centres concept, experiences and unmet need of both academia and industry and intellectual property and ethical and regulatory issues. The 230 participants representing over 20 European countries held impassioned debates on these topics with views of the expert centres ranging from advocates seeing them as centres of excellence to others as potentially polarising. Finding harmonisation across the widely differing views and some strong feeling will be challenging for the BBMRI working groups. Presentations from the meeting can be found at www.bbMRI.eu and a meeting report is expected in the coming months.



Getting to know you: Tayside Tissue Bank's Philip Quinlan

Philip Quinlan is the IT Lead from the Tayside Tissue Bank (TTB) and joined the University of Dundee in 2004. He has played a key role in establishing the TTB's IT systems and databases. Tayside Tissue Bank can be found at www.tissuebank.dundee.ac.uk

What's coming up for TTB in the next 12 months?

Seeking to integrate further into a national IT framework to allow the greater use of tissues to a wider research community.

What is TTB doing to engage with patients/donors and the public?

An updated TTB website has just been released with a section dedicated to patient information. In addition, Dundee has recently been designated as one of CRUK's Cancer Centres and a person with particular responsibility for public engagement is to be appointed.

What's the best feedback you've had from a researcher who's used your biosamples?

The best feedback has to be in the form of a good quality publication, which demonstrates that the tissue has been put to good use and enhanced our know ledge within cancer research.



What single thing would improve the quality of your biobank service?

Closer integration with other tissue banks within the UK to allow greater sharing of knowledge and expertise.

What's your prediction for the future for tissue banking in the UK?

Tissue banking hopefully will move from individual small silos to a coordinated, integrated network of banks offering high quality samples to researchers across the UK, which is supported by more sustainable sources of funding.

What's the most enjoyable/satisfying part of your job?

Seeing first hand how the IT can bridge and integrate a large multi disciplinary team.

How do you relax?

The only answer has to be finding a pub and a nice cold pint after a stressful week, offset of course by having a gym membership and occasionally actually going!

Can increased availability of human tissue help create safer medicines?

This was the question posed at the House of Lords in October during a half-day meeting organised by the Safer Medicines Trust that brought experts from Government, industry, academia and tissue banks together to discuss the future of human tissue access in the UK.

This was part of their work to promote their Early Day Motion (EDM 212) on Access to Human Tissue for Health Research. The programme focused on two key areas: is human tissue the answer to making safer, more effective medicines and successful models for the provision of human tissue. The speakers included representatives from pharmaceutical and biotech industries, tissue banks and researchers who are using human tissue in research. Discussions focused on finding a way forward to ensure that medical researchers have an ethical and reliable source of human tissue to carry out their vital work. The meeting was attended by many of the key players in tissue banking and translational research including several CCB members and also featured in an edition of BBC Radio 4's You and Yours programme (www.bbc.co.uk/radio4/youandyours/items/05/2009_42_wed.shtml).

The increased regulation of human tissue provision was highlighted as a potential barrier and it was suggested that greater emphasis

should be placed on improving the availability of non-transplantable tissues and organs from brain-stem dead but heart-beating donors. It was acknowledged that this is an increasingly small population of donors however and is often compounded by the organ transplant donation consent challenge where there is a disconnect between those who support the theory of organ donation (95%) and those who are actually registered organ donors (25%).

As Jane Hair, of the CCB Member Biorepository NHS Greater Glasgow & Clyde, and others commented this is in marked contrast to living donor consent – where over 90% of patients who are approached to donate tissue for research typically give their consent.

Following this meeting a working party has been established to look at issues including access to surgical tissues, bureaucracy and conducting a comparison between human biology-based methods and animal-based methods.

They will also be looking at potential actions to raise the profile of human tissue research. Visit www.safermedicines.org/humantissues for more information on the meeting programme and working party.

New Members



CCB is pleased to welcome the Children's Cancer and Leukaemia Group (CCLG) Tissue Bank as a new member.

The CCLG Tissue Bank collects samples from children and young people with a diagnosis of cancer from across the UK & Ireland. The bank is currently a co-ordinated virtual biobank, with over 7,000 patients' samples held in sites across the Childhood Cancer and Leukaemia network of primary treatment centres. The CCLG Tissue Bank has been collecting samples for almost 12 years and has supported approximately 40 projects in the last 5 years.

Sue Ablett, Director of the CCLG Tissue Bank told CCB Update, "We are very pleased to be accepted into the CCB and look forward to working with you."

For more information on CCLG visit www.cclg.org.uk

For details of CCB membership benefits and how to apply contact ccb@ncri.org.uk

"A high quality, user-friendly and clear package, which is a useful introduction to the key issues in the regulations of human tissue research."

Human Tissue Authority

"The module is really excellent and will be a great resource for all those involved in these issues, including REC members."

National Research Ethics Service

MRC launches e-learning module on research and human tissue legislation

MRC

Medical Research Council

A new e-learning module developed by the MRC Regulatory Support Centre, in consultation with the Human

Tissue Authority, National Research Ethics Service, Scottish Government and others is launching during February.

The module was designed for researchers working with human tissue in the lab and will be of interest to a wider research

audience. It provides an overview of the legislation in the UK; practical tips for compliance; what constitutes best practice and where to find help. It has been designed to be interactive and engaging, using both exercises and real life scenarios, and providing practical take home messages. The module is free and available to anyone and can be found on the MRC Regulatory Support Centre website (www.mrc.ac.uk/Ourresearch/Ethicsresearchguidance/RegulatorySupportCentre/Training/Distancelearning/index.htm).



Upcoming events

CCB Workshop on *Biobanking in Support of Clinical Trials* in association with **Wales Cancer Bank** and **Experimental Cancer Medicine Centre Network (ECMC)**

12 March 2010, The King's Fund, London



Following our successful previous conferences we are excited by the upcoming programme for our next meeting.

Biological samples are being increasingly collected and banked as part of clinical trials. Concerns are often raised about the best means of managing clinical trial related sample collections to ensure compliance with ethics, laws, quality management requirements and recommended good practice.

This Workshop will be of practical value to those planning or currently managing a clinical trial or the sample collection / biobank aspect of a trial. Contributors include

- **Professor Tim Maughan**, University of Cardiff
- **Professor Sir Kenneth Calman**, Chair National Cancer Research Institute
- **Professor Chris Womack**, AstraZeneca
- **Dr James Brenton**, University of Cambridge
- **Professor Andy Hall**, Northern Institute for Cancer Research

For more information and to register visit www.oncoreuk.org

NCRI Cancer Conference

7-10 November 2010,
BT Convention Centre, Liverpool



cancer conference
ncri
national cancer research institute

The NCRI Cancer Conference is the major forum in the UK for showcasing the best British and international cancer research.

The conference brings together the leading experts across all disciplines and features a compelling mix of high-quality plenary speakers, symposia and parallel sessions, including focused satellite meetings and workshops.

Visit www.ncri.org.uk/ncriconference for more details

NCIN Conference

17-18 June 2010,
Hilton Birmingham Metropole



national cancer intelligence network
Using information to improve quality & choice

This year sees the first joint conference of the National Cancer Intelligence

Network (NCIN) and the UK Association of Cancer Registries (UKACR), bringing together researchers, epidemiologists, clinicians, charities, the NHS and associated organisations to showcase the vital work being undertaken within the registries and throughout the Network.

Visit www.ncin.org.uk for more details

To provide feedback on this newsletter or to contribute articles please email us at

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www.ncri.org.uk/ccb