

Inside this issue...

- **NCRI Appoints Pathology Leads for Biobanking**
- **New Governance Structure for CCB**
- **European Biobanking meeting**
- **UK Biobank: new phase in 2012**
- **Brain Banks Network**
- **Getting to know you: LLR Childhood Leukaemia Bank**

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CCB Update

Issue 5, December 2011

Note from the Editor

Caroline Magee, Communications Lead, NCRI (CCB Secretariat)

Welcome to this issue of CCB Update – the newsletter from the National Cancer Research Institute's Confederation of Cancer Biobanks (CCB).

We are excited to report that NCRI's support of cancer biobanking is being boosted with the appointment of two Pathology Leads as well as creation of a new Executive team to help grow and develop CCB.

This issue includes an update from the LLR Childhood Leukaemia bank and looks at other UK biobanking activities with articles from the Brain Banks Network and UK Biobank. We also look further afield with a report from the first conference held by a new European biobanking society (ESBB).

The website for CCB been relaunched so please visit the new site at www.ncri.org.uk/ccb

To provide feedback on the newsletter, please contact ccb@ncri.org.uk

NCRI Appoints Pathology Leads for Biobanking

The National Cancer Research Institute has recently announced the appointment of Professor Andy Hall as NCRI Pathology Lead for Cancer Biobanking and Dr Bridget Wilkins as NCRI Pathology Lead for NHS engagement in Biobanking.

They will provide leadership and professional guidance to NCRI's work in encouraging cooperation and coordination of cancer biobanking and assist in implementing the UK Funders' Vision for Human Tissue Resources.



Professor Andy Hall is a Professor of Experimental Haematology and Director of the Newcastle University Biomedicine Biobank and Northern Institute for Cancer Research. He is the Designated Individual for the Newcastle HTA licence and also acts as the Chair of the Biomarkers and Imaging Discovery and Development committee for Cancer Research UK.

Dr Bridget Wilkins is a Consultant Haematopathologist and Honorary Senior Lecturer at Guy's & St Thomas' NHS Foundation Trust (GSTFT) and King's College London. Bridget is the HTA Person Designate responsible for research activities relating to the GSTFT diagnostic tissue archive and the Chair of the GSTFT Human Tissue Group. She also chairs the South East London Cancer Network Pathology Group and the British Lymphoma Pathology Group.



They will be taking up their posts formally from 1st January 2012 and will be working closely with the CCB Executive Group to help shape the future for the Confederation.

Dr Jane Cope, Director of NCRI told CCB Update, "We look forward to working with Andy and Bridget in their respective areas of academic and NHS pathology to boost both the work of the CCB and NCRI's activities to support pathology in cancer research."

New Governance Structure for CCB

2012 will see the continued expansion of the CCB to become more fully representative of the cancer biobanking community in the UK.

To help take forward the Confederation, as well as guide activities, plan events and make operational decisions, a new Executive Group has been established and will meet for the first time in January.

The group will help to develop the CCB as a representative body by seeking members' opinions internally and reflecting them externally and will also ensure that the CCB works within the strategic context of the Funders' Vision. Executive group members will not just attend meetings but will be actively involved in taking forward actions between meetings.

The members of this group are

- Derek Stewart (Chair)
- Andy Hall (Pathology Lead for Cancer Biobanking)
- Bridget Wilkins (Pathology Lead for NHS Engagement in Biobanking)
- Jane Cope (Director of NCRI)
- Maggie Wilcox (Consumer Member)

CCB Member representatives:

- Sarah Chilcott-Burns
- Neil Formstone
- Chris Foster
- Aidan Hindley
- Alison Parry-Jones
- Massimo Pignatelli
- Phil Quinlan

European Biobanking Society's First Meeting



Anne Carter, Biobanking Portfolio Lead at the NCRI recently attended the inaugural meeting of the ESBB in Marseilles in November. She provides an overview and some key highlights of the conference.

Over 350 individuals attended ESBB's inaugural conference "Identifying the challenges and the opportunities for biorepositories today and in the next 5 years". A wide range of issues were covered, extending from the sample donor to the repository to the generation of research results and their return to donors, with particular emphasis on issues relevant for Europe, the Middle East and Africa. These discussions will guide future activities of ESBB.

There isn't space here to cover all of the excellent talks but, for me, the following three topics were key highlights:

- An update on the progress of BBMRI (Biobanking and Biomolecular Resources Research Infrastructure). As reported previously in CCB Update, the first phase of this initiative is complete. The project leaders expect that the new legal entity, BBMRI-ERIC, will be in place early in 2012. Funding for this new organisation will come primarily from EU Member States with Germany, France, Italy, Netherlands, Norway, Sweden, Denmark, Estonia and Finland all having agreed to provide support and each setting up national consortia of biobanks.

ESBB - The European Middle Eastern and African Society for Biopreservation and Biobanking (www.esbb.org) was set up in 2010 to provide a focus for biobanking and biobankers in the region. It has been modelled on the International Society for Biological and Environmental Repositories (ISBER: www.isber.org) and has been accepted as a Chapter of ISBER. The CCB is a member of ESBB.

One example of the work undertaken by BBMRI, the definition of common datasets to connect biobanks, was reported by Jan-Eric Litton (Karolinska Institute).

- The need for and difficulty of integrating biobanking activities into routine clinical care was highlighted by several speakers. Dr Peter Doran, in particular, made a strong case for the collection of samples and data to be banked for research as part of the care of clinical trials participants.
- Prof Christian Brechot described the opportunities presented by public-private partnerships as well as the development of "thematic" networks and harmonisation across Europe to increase availability of well characterised, well annotated, high quality samples.

Presentations from the conference will be available on the ESBB website (www.esbb.org).

2012 heralds a new and exciting phase in the life of UK Biobank – the visionary resource created to improve the health of future generations.



The project, which will spearhead a wide range of research over the next 30 years, to tackle many common illnesses that cause pain, disability and kill, typically in middle age, will be open for scientists to use.

Key points about access include:

- Scientists will have to register to use UK Biobank.
- The resource is open only to bona fide researchers undertaking health-related research that is in the public good.
- Stringent measures are in place to ensure that participants are not identified.
- Results will be shared with UK Biobank and the wider scientific community so that advances are built upon by others.

The cost of making a preliminary application to UK Biobank is £250. Scientists whose applications are approved will also be charged the cost of the provision of the data or samples they require or, more likely, the cost of undertaking the sample analysis and provision of the results.



Wellcome Images

Scientists from the UK and overseas will be able to use the resource. “The priority is to ensure the resource is used, and used well,” said UK Biobank Chief Executive and Principal Investigator, Professor Rory Collins.

An Access Sub-Committee of the UK Biobank Board will oversee the process. It will be able to call on ethicists, legal experts, other scientists and the independent UK Biobank Ethics & Governance Council as required.

Between April 2007 and July 2010, UK Biobank collected a wide range of baseline data on 500,000 participants aged 40-69 years. It has been designed to allow scientists to examine the complex interaction of lifestyle, genes and environmental factors in causing disease.

At the same time, UK Biobank’s commitment to the long-term follow-up of health through medical records and the possibility of re-contacting participants, will allow scientists to investigate conditions that are rarer or those that are not well-diagnosed but cause a significant reduction in the quality of life - such as depression, decrease in cognitive function, joint and back problems and eye disorders.

For more information about the project and the UK Biobank Data Showcase and Access Management System, visit www.ukbiobank.ac.uk. Scientists can now view the UK Biobank Access Procedures online and the Resource will open in the spring. A list of research uses of the Resource will be published as these are approved.

UK Biobank is funded primarily by the Wellcome Trust, Medical Research Council, Department of Health, Scottish Government, Welsh Assembly Government and the British Heart Foundation.

CCB relaunches website



The CCB website has been redesigned and the content is being expanded to provide a better resource for the biobanking community. The new site will feature more information on CCB members, biobanking news and information as well as details of CCB and related biobanking events. Please take a look at www.ncri.org.uk/ccb and let us know what other content you would find useful.

You can also follow CCB on twitter at www.twitter.com/ccb_uk



The MRC is leading a UK Clinical Research Collaboration (UKCRC)-endorsed initiative to establish an independent and co-ordinated national network of existing UK brain tissue resources (banks). The network comprises 10 established brain banks across the UK and is led by Director Professor James Ironside, with an independently constituted and funded co-ordinating centre based in the University of Edinburgh.

Brain banks provide a source of well characterised human tissue that has already made a huge contribution to progress in clinical neurosciences.

Significant recent advances in genetics and bioinformatics mean that more searching research questions can now be addressed, provided high quality brain tissue linked to clinical history can be made available to researchers from brain banks. The network aims to provide operational efficiency for the benefit of donors, researchers and future patients.

Member banks are being asked to help define and sign up to common 'gold standards' for brain tissue banking, including donation, access and availability, protocols and procedures.

The network will also help speed up the collection of tissue that is currently in short supply for research, including tissue from individuals unaffected by disorders of the central nervous system, as this is critical for use as a baseline for comparative studies.

The MRC has recently funded a new research proposal to enhance the collection of this 'control' tissue.

A searchable database is being developed on the website to allow researchers to ask about tissue availability through a single portal that will include data from all the banks in the network.

The network is working with other UK biobanks, including the Confederation of Cancer Biobanks, to develop common standards and policies in biobanking that will benefit this important field and facilitate research into complex and devastating neurological diseases.

Impact of research using brain tissue

A pivotal early example was the discovery of deficient brain dopamine levels Parkinson's disease (Figure 1), which led to the development of L-dopa treatment.



Figure 1. A pigmented neurone in the brain of a patient who died with Parkinson's disease contains 2 abnormal inclusions known as Lewy bodies (arrows), which are largely composed of a protein called alpha synuclein.

The recent introduction of anti-cholinesterase treatment as an effective treatment for the symptoms of early Alzheimer's disease (Figure 2) came from research using autopsy tissue from UK brain banks.

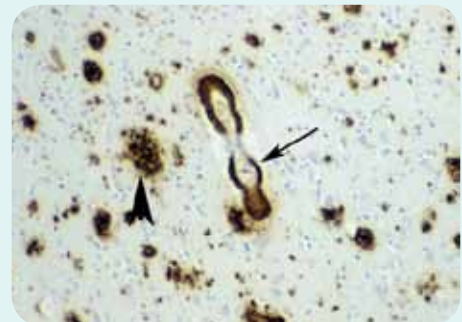


Figure 2. In Alzheimer's disease, an abnormal protein known as A β accumulates in the brain as extracellular plaques (arrowhead) and within the walls of small blood vessels (arrow), giving rise to an amyloid angiopathy

Visit www.mrc.ac.uk/Ourresearch/Resourceservices/UKBrainBanksnetwork/index.htm for more information about the work of the network.



Getting to know you: LLR Childhood Leukaemia Cell Bank's Anne Thomson

Anne Thomson is the manager for the Leukaemia and Lymphoma Research (LLR) Childhood Leukaemia Cell Bank. Anne joined the bank in June 2008 and is responsible for the administration of the bank and has been closely involved with the recent centralisation.

The Childhood Leukaemia Cell Bank started as a virtual bank storing excess diagnostic samples from the ALL2003 trial for use in research. Samples were stored in the four NHS labs that provided diagnostic services for the trial. The success of the bank means that it has outgrown the facilities in these labs and has now been moved to a central facility at UK Biocentre. The range of samples has been extended and they now collect samples from all children with leukaemia who have consented to banking.

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

Knowing that the samples we send out to researchers will make a difference to the future diagnosis and treatment for children with leukaemia.

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

Over the next 12 months we will be accepting a wider range of samples from both ALL2011 trial patients and from other children with leukaemia. We are implementing a new consenting procedure and a new approval process for research projects.

What are you doing to engage with patients/donors and the public?

We have produced a range of patient and parent information leaflets aimed at patients of different ages. These are bright and colourful and are designed to inform and engage. We have updated our website so that it now includes information for parents and patients, clinic staff as well as researchers.

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

I have had a lot of good feedback, particularly about the speed of dispatch once a decision to release the samples was made.

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

The move to UK Biocentre. This is a specialist biobanking facility and means that our samples are all housed in one location.

What's the most useful thing you've learnt from your tissue banking colleagues in the CCB network?

The range of banking activity in the UK and that there is so much help and support out there.

How do you relax?

I run a Guide unit so you may well find me building rafts, lighting fires, camping or kayaking – is that relaxing?



To provide feedback on this newsletter or to contribute articles please email us at ccb@ncri.org.uk