# Experiences and challenges of setting up biobanks and biobanking networks

Monday, 17 February 2014
Cineworld: The O2, London, SE10 0DX, UK
www.regonline.co.uk/biobanking2014

Biobanking 2014 will discuss the skills and efforts needed to set up and maintain the banking of Biospecimens used for basic research through clinical trials. How to set up efficient and effective collection, processing, storage, and tracking of biospecimens will be discussed. Bringing together biomedical and biopharmaceutical researchers, regulators, biorepository managers, and practitioners this event will investigate the best methods for effective storage of biospecimens in the 21st Century. This event has CPD accreditation and is part of BioBanking 2014 - www.biobanking2014.com

Meeting Chair: Kirstin Goldring - BioBank facilitator, UCL BioBank, London, UK

#### Who Should Attend

<u>Academic and Research Institutes:</u> Group and Lab Heads, Postdoctoral Scientists and Research Students, Technical staff

<u>Biotech and Pharma Industry:</u> CEOs, Chief Scientists, Group Heads, Senior and Junior Scientists, Research <u>Biobank Staff and Managers from the following departments:</u> Research & Development, Biobanking, Biorepository, Biological Sample Management, Biosample Management, Pharmacogenomics, Pathology, Genomics, Translational Medicine, Personalised Medicine, Lab Management, Inventory Management, Molecular Technologies, Biologics Research, Data Privacy/Protection/Security Officers and Quality Control and Quality Management.

Talk times include 5 - 10 minutes for questions

9:15 – 10:00 **Registration** 

10:00 – 10:15 Introduction by the Chair: Kirstin Goldring - BioBank facilitator, UCL BioBank, London, UK

10:15 – 10:45 **Mixed models for biobanking in Academia** *Kirstin Goldring* - BioBank facilitator, UCL BioBank, London, UK

# 10:45 – 11:15 Biobanking and legacy management of viable primary cells and cell lines from large cohort disease studies by Public Health England.

*Mr Jim Cooper,* Cell Biology Applications Scientist, ECACC Scientific Development Group, Culture Collections, Public Health England, UK

PHE's secure site at Porton Down has served international industry and academia for over 25 years through its service of processing human blood samples to accurately cryo-preserve, store and distribute viable primary lymphocytes, cell lines and nucleic acids from tens of thousands of individuals and their family members to help advance the study of hundreds of genetically associated diseases. Originally established to support the Human Genome Mapping Project (HGMP) the service has evolved and continues to enable the MRC DNA banking Network, the Wellcome Trust and dozens of industrial and academic groups and charity funded projects to achieve their goals. The service accurately processes thousands of samples in a high throughput manner with quality assurance provided by barcode tracking, testing of samples for sterility and ensuring genetic identity is maintained from blood

through to cell line and extracted nucleic acids. Cells are optimally cryo-preserved and stored in a dedicated liquid nitrogen warehouse where samples can be confidently retrieved decades after storage. There have been significant challenges in maintaining this high quality system, data management, HTA and quality compliance in a not-for-profit organisation. Looking forward, the Culture Collections of PHE are adapting this infrastructure to help serve the emerging field of personalised medicine and the development of large cohort Induced Pluripotent Stem Cell Banks.

### 11:15 – 11:45 Morning Coffee and Poster Session

## 11:45 – 12:15 **Challenges in Academic Biobanking-Once Bitten?**

*Dr Sayeda Abu-Amero*, Manager of Baby Bio Bank, Senior Teaching Fellow, Institute of Child Health, UK The Baby Bio Bank (BBB) project has been successfully collecting biological samples to aid future research into the four main complications of pregnancy: Recurrent Miscarriage (RM); Intra-uterine Growth Restriction (IUGR); Preterm Birth (PTB) and Pre-eclampsia (PET). We have also collected a normal cohort for comparative analysis. By obtaining biological samples from both parents (blood samples) and from the baby (term placenta which is normally discarded after birth, cord blood and fetal membranes)

together with demographic and clinical data we are now able to provide researchers with the tools they require to determine the biological and genetic aetiology of these complications.

#### 12:15 - 12:45 Harmonisation - a hot topic

Mrs Anne Carter, Portfolio Lead - Biobanking, NCRI, UK

Harmonisation is "hot" because it is highly topical - but also because it inspires great debate amongst biobankers. How can we harmonise without reducing standards to the lowest common denominator? The Confederation of Cancer Biobanks has devised a standard for biobanks, written by the cancer biobanking community but suitable for any biobank wishing to assess its own performance in light of its peers' expectations. The standard forms the basis of a voluntary peer-review audit system. Hear about how the standard was devised and how it is being used to improve the "fitness for purpose" of samples provided to researchers.

#### 12:45 – 13:45 Lunch, poster exhibition and trade show

Please try to visit all the exhibition stands during your day at this event. Not only do our sponsors enable Euroscicon to keep the registration fees competitive, but they are also here specifically to talk to you.

#### 13:45 – 14:45 **Discussion session**

This discussion session is an informal question and answer session. This is an ideal opportunity to get advice and opinion from experts in this area. This session is not for questions about specific talks, which can be asked after the speakers session, but for discussing either general topics or specific issues. There are three ways you can ask questions:

- 1. Before the session you can submit your question to Euroscicon staff at the registration desk,
- 2. Before and during the session you can *submit a question or comments, by email*, which will be provided on the day of the event
- 3. During the session you can *put your hand up* and join in

### 14:45 – 15:15 The Bio-PIN, advantages for Biobanks and Biobank networks

Dr J.J. Nietfeld, Associate Professor / Senior Scientist, University Medical Center Utrecht, The Netherlands

A PIN code based on personal biological characteristics and unique for each participant of whom samples of body material and associated data are deposited in one or more biobanks, enables a new way of biobanking and international collaboration. Labelling such samples and data with this Bio-PIN allows registering and storing them anonymously, but keeping the possibility of 2-way communication between participants and the biobank(s), via a personal 'biobank account' on a secure website. Because of the anonymity privacy protection costs can be saved and differences between privacy laws of different countries do not impede international biobank networks.

#### 15:15 – 15:45 Afternoon Tea, last poster session and trade show

# 15:45- 16:15 The National Breast Cancer Campaign Tissue Biobank in Partnership with the Nottingham Health Science Biobank

*Dr Balwir Matharoo-Ball,* Nottingham Health Science Biobank Operations Manager, Nottingham University Hospitals NHS Trust. UK

The need for a specialist breast cancer biobank was highlighted in a survey carried out by the UK charity Breast Cancer Campaign where a Gap Analysis covering seven different research areas identified that a lack of access to appropriate clinical material was a significant barrier in accelerating translational research into clinical benefit. As a direct result of this report, Breast Cancer Campaign set about establishing a dedicated national breast cancer biobank in the UK: the Breast Cancer Campaign Tissue Bank, with the aim of filling this gap. The Breast Cancer Campaign Tissue Bank (BCCTB) was established in January 2010, when prospective tissue collections began, and is a four centre alliance of leading UK centres of excellence in breast cancer: Barts Cancer Institute, London, the Universities of Dundee, Leeds and Nottingham, in partnership with the Nottingham Health Science Biobank and with multi-disciplinary expertise in breast pathology, basic science, bioinformatics and information technology. The BCCTB collects a broad spectrum of biomaterials to meet the needs of a diverse research community, all ethically collected from breast cancer patients with written informed consent. The BCCTB collects consistent, comprehensive information including patient, pathology and clinical data all carefully mined from clinical and laboratory databases according to shared standard operating procedures. The informatics system developed for the BCCTB has brought together four centres in the UK, each with their own IT systems and associated data terms, yet presenting to the researcher a unified search facility and tissue application system. Following a pilot opening, limited to researchers funded by Breast Cancer Campaign, the BCCTB opened to all researchers based in the UK and Ireland in January 2012 and is expanding to receive material from other sites (collaborating centres). It will open internationally and to industry in the future. The BCCTB aims to provide fair access to all in order to maximise public benefit and advance medical knowledge.

#### 16:15 – 16:45 Talk title to be confirmed

Dr Glyn Stacey, UK Stem Cell Bank, Division of Cell Biology and Imaging, UK

16:45 – 17:00 Chairman's summing up and Close of Meeting

Registration Website: www.regonline.co.uk/biobanking2014

<u>Keywords:</u> Biobank, network, privacy, protection costs, international collaboration, harmonisation, accreditation, quality management, peer review, standards, biobanking, lymphocytes, genetic disease, iPSC, cryo-preservation, Biobank, Breast Cancer, Network, Nottingham, Breast Cancer Campaign, complications pregnancy international resourcce

# A meeting report from this event will be published by The Biomedical Scientist

#### **About the Chair**

**Kirstin Goldring** graduated in Physiology and Pharmacology (BSc) in 1991 and studied for her PhD on asthma research at Southampton University. She moved to London in 1994 to undertake Post-Doctoral research in to Muscular Dystrophy at King's College and Imperial College. Kirstin Goldring then managed the UK Parkinson's Disease Society Tissue Bank when it moved to Imperial College in August 2002, until June 2009. Kirstin Goldring has been working at UCL since 2009 as the Biobank facilitator. The role has involved in developing biobank infrastructure and support, dissemination of information to researchers on biobanking and providing advice on protocols, ethics and regulations for use of human. Since 2012, Kirstin Goldring has expanded her role to co-ordinate the UCL BioResource, part of the NIHR BioResource, which aims to develop a panel of healthy volunteers and patients consent for recall to future research studies.

#### **About the Speakers**

For many years **Jim Cooper** played a key role in ECACC managing internal development, biobanking and custom projects for end users. Jim has recently moved to the Culture Collections' Scientific Development Group where he is developing and characterising novel *in vitro* models.

**Sayeda Abu-Amero** is the manager of the Baby Bio Bank (BBB) and is a senior teaching fellow at UCL. Dr Abu-Amero has a track record in academic research looking at the role of imprinted genes and other growth related genes in human fetal development. She took up the post as manager of the BBB in March of 2009 and has been responsible for its development and progress under the directorship of Professors Gudrun Moore and Lesley Regan. Dr Abu-Amero also teaches Core Skills on BSc and MSc courses at the university.

Anne Carter developed a passion for quality assurance when she joined the UK's National Institute for Biological Medicines and Controls in 1996. Becoming Quality Manager, she provided QA expertise in batch release testing of biological products, production and supply of biological standards, stem cell banking and CE marking of in-vitro diagnostic medical devices. Anne became involved in research tissue banking in 2006 when she moved to onCore UK. Her remit was to design, implement and manage a QMS for the biobank. Since December 2010, Anne has worked at the National Cancer Research Institute where her focus is the development of harmonised standards and a quality mark scheme for biobanks in the UK.

**J.J.Nietfeld** has a Ph.D. in Biochemistry and is certified as Pathobiologist. He is presently associate professor / senior scientist at the University Medical Center in Utrecht, interested in biobanking for therapeutic purposes (especially involving cord blood stem cells) and research biobanking (especially regarding data protection). Furthermore, he is director of INTRESCO, a biotech company, involved in R&D and exploitation of knowhow and technology in the biomedical field, in particular cryogenic storage, privacy enhancing technology and bioinformatics. Dr.Nietfeld has published in international scientific journals (e.g. Nature and Nature Reviews Cancer) and for his inventions patents have been granted.

**Balwir Matharoo-Ball** was appointed as the operational manager for translational research and Nottingham Health Science Biobank (NHSB) in January 2011. She leads a department of pathology based team of scientists, data analysts and a consent nurse who are sited at the David Evans Medical Centre in the City campus and at Queens Medical Center, Nottingham. Bal has a wealth of both research and NHS experience and prior to her appointment

within the NHSB she worked as a senior group leader at the John van Geest Cancer Research Centre at Nottingham Trent University. She was in charge of the Proteomics group and has published in number of peer-reviewed journals.

This meeting was organised by Euroscicon (www.euroscicon.com), a team of dedicated professionals working for the continuous improvement of technical knowledge transfer to all scientists. Euroscicon believe that they can make a positive difference to the quality of science by providing cutting edge information on new technological advancements to the scientific community. This is provided via our exceptional services to individual scientists, research institutions and industry.

#### POSTER PRESENTATION

#### CORD BLOOD BANKING EXPERIENCE IN SAUDI ARABIA

A. ALJEDAI

King Saud University, college of applied medical science, p.o. bOX 10219 Riyadh 11433

Hematopoietic Stem cell transplantation program at King Faisal Specialist Hospital & Research Centre in Riyadh, Saudi Arabia is the largest in the gulf region with more than 3,500 bone marrow transplants have been performed so far. Finding HLA matched sibling donors for stem cell transplantation is still an obstacle in about 40% of Saudi patients who are diagnosed with hematologic malignancies, bone marrow failure syndromes, selected hereditary immunodeficiency states and metabolic disorders. The first cord blood bank in the gulf region was established in 2003 at King Faisal Specialist Hospital & Research Centre in Riyadh, Saudi Arabia in order to fill the gap in hematopoietic stem cells sources available for patients in need for stem cell transplantation. The King Faisal Specialist Hospital and Research Center Cord Blood Bank is a non-profit public cord blood bank dedicated to make high quality cord blood units available to all patients in need of related and /or unrelated transplantation in the Kingdom of Saudi Arabia and in the neighboring countries through the development and maintenance of a center of excellence for the collection, storage, search and distribution of ethnically and racially diverse cord blood units. Between 2003-2008 most cord blood units (CBU) were imported from international registries at the cost of 40.000 US dollars per units. However, a successful public awareness program enabled a dramatic shift in the number of local cord blood units with the majority of 4464 cryopreserved CBU in the bank are now from local donors. Since the bank opened in 2003, the hospital has done 219 successful CBU transplants in which 113 of these transplants were from local CBU.

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