

Final Program

Qatar BioBank Inaugural Conference

Biobanking in the context of personalized healthcare

DOHA, Qatar – 8-9 February, 2015



Registration on Line:

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Scientific Committee:

- *Asma Al Thani, Vice-Chairperson of the Board of Trustees, Qatar Biobank*
- *Hadi Abderrahim, Qatar Biobank Director, Doha, Qatar*
- *Ida Biunno, IRGB-CNR, Milan Italy*
- *Pasquale De Blasio, ESBB founding President, ISENET-USA*
- *Elio Riboli, Imperial College London UK*
- *Nahla Afifi, Scientific & Education Manager, Qatar Biobank*
- *Ghada Al Khater, Head of Business Support, Qatar Biobank*
- *Noor Al Mahmoud, Business Support Specialist, Qatar Biobank*
- *Fatima Qafoud, Head of Clinical Services, Qatar Biobank*

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08:00 – 08:30 REGISTRATION

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| 08:30 – 08:35 | Quran Recitation |
| 08:35 – 09:00 | Welcome Hadi Abderrahim |
| 09:00 – 09:30 | Building Better Health Care For The Future In Qatar <i>Hanan Al Kuwari, Chairperson of Biobank Qatar's Board of Trustees, Qatar</i> Healthcare in Qatar is changing, and at the center of this change is the National Health Strategy (NHS). The Qatar National Vision 2030, in particular the Human Development pillar, is a clear commitment to a future that supports a healthy population both physically and mentally. This vision is being delivered through the National Health Strategy 2011-2016 (NHS), the foundation of which is, encouraging healthy lifestyles, promoting public health, and providing quality community-based care as the basis of a successful integrated healthcare system. |
| 09:30 – 10:00 | Building Better Stem Cell Science For The Future Of Our Countries <i>Elena Cattaneo, Italian Republic Senator for Life, Director of Center for Stem Cell Research, University of Milano, Italy</i> Nowadays there is not a single domain in science that can be pursued by an individual scientist or lab. Opportunities are so challenging and technologies so demanding that the only way to advance is by bridging with other colleagues, disciplines, countries. In the last ten years, the European Commission has been supporting research in several disciplines by stimulating the creation of research consortia and by soliciting scientists to work together across national boundaries. This has been extremely rewarding in terms of gaining deeper understanding of the impact that science can have in our societies. European collaborations in stem cell science have also increased tremendously our competitiveness worldwide while providing tangible breakthroughs towards therapies for neurological diseases that benefit not only EU but the entire world as well. |

10:00 – 10:30 NETWORKING REFRESHMENT

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| 10:30 – 13:00 | Session 1: TRANSLATIONAL RESEARCH TOWARD PRECISION MEDICINE "A" Chair: Elena Cattaneo |
| 10:30 – 11:00 | The QATAR Biobank Project <i>Hadi Abderrahim – Managing Director of the Qatar Biobank</i> Qatar Biobank is a platform that will make vital health research possible through its collection of samples and information on health and lifestyle from large numbers of members of the Qatari population. Qatar Biobank, Qatar's long-term medical health initiative, was created to give Qatar's people better chances of avoiding serious illnesses, and to promote better health for our future generations |
| 11:00 – 11:30 | Qatar Biobank Pilot Study Results <i>Elio Riboli, Director, School of Public Health, Imperial College London – UK</i> The Qatar Biobank protocol includes questionnaire information on diet and lifestyle; cognitive testing; anthropometry; cardio-metabolic, respiratory and physical measurements; imaging and a range of biochemical and haematological markers. Biological samples (blood, urine, saliva) are being collected and stored for future research use. Following the initial study design and planning, we conducted a large scale pilot study, which ran from the 11 December 2012 to the 20 February 2014, during which time 1,209 participants were recruited. Overall the pilot study demonstrated that the Biobank protocol works very well, is robust, and provides high quality and reliable data. It is important to note that the Biobank activities are continuing successfully and by January 2015 the 2000th participant will be screened. During the next phase, moving toward full scale project, the number of participants will progressively increase when the newly refurbished Biobank facilities, building 17 Hamad Medical City, become operational in 2015. |
| 11:30 – 12:00 | "Personalized Medicine: The Changing Landscape of Health Care." <i>Edward Abrahams – President of Personalized Medicine Coalition, USA</i> Personalized medicine is changing the face of health care. In his talk, Edward Abrahams, President of the Personalized Medicine Coalition, an international educational and advocacy organization based in Washington, DC, will define personalized medicine; outline its benefits; explain how it is reshaping health care from drug discovery and development to patient care, and discuss public policy considerations that can advance or slow its development. |

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| 12:00 – 12:30 | <p><u>Linking Biobanking with Diagnostics – From Newborn Screening to Personalized Medicine.</u></p> <p>Joachim Thiery – <i>Director of the Institute of Laboratory Medicine, Clinical Chemistry and Molecular Diagnostics, University Hospital Leipzig. Speaker of the Leipzig LIFE Research Center for Civilization Diseases, Germany</i></p> <p>Biobanking of population- and disease-based cohorts provide a high potential for identification and translation of new biomarkers and therapeutic targets for personalized healthcare. Careful documentation of clinical phenotypes, efficient control of the preanalytical process, highly standardized bioanalytics/omics and statistical evaluations should be directly linked with the process of medical biobanking to guarantee the validity of the scientific outcome. An uninterrupted cooling chain and storage of the biospecimen in the gas phase of liquid N₂ should be realized to inhibit protein degradation in the samples. The prospective Leipzig LIFE Study and LIFE liquid and cell biobank (> 1 million specimen) consider this prerequisites and integrate a large cohort study of adults from the general population (10.000), a newborn and children cohort study (6000), the Leipzig Heart Study cohort (7000) and other disease-based patient groups with metabolic disorders, depression, mild cognitive impairment, allergy, macula degeneration and cancer. The first LIFE-survey was finalized in November 2014. Recently discovered GWA variants for myocardial infarction (Cardiogram Consortium) and results from the on-going bioanalytical analysis will be presented.</p> |
| 12:30 – 13:00 | <p><u>Collaborative Strategies for Global Biomarker Development: Biospecimen Quality Control, Advanced Scientific Methods and Innovative Technologies</u></p> <p>Andrew Brooks, <i>COO RUCDR Infinite Biologics, Ass. Prof. of Genetics, Rutgers University, USA</i></p> <p>In today's era of personalized medicine, new advancements in biospecimen management, science and technology are enabling researchers to introduce innovative medical therapies to the market. Science continues to be a key driver that is impacting how biological samples are being managed to support future research and is influencing the need for improved technology that enables better data sharing and management. The discovery of biomarkers in clinical research presents significant challenges – none more critical than access to properly preserved biological samples and data. These biomaterials are vital assets that are essential for biomarker identification, assay development and validation testing. Optimum preservation of research samples to support biomarker discovery requires standardized techniques for sample collection, use of efficient processing technologies, creation of renewable sample resources, pre-defined distribution guidelines and optimized biobanking methods. In addition, collaborative models are emerging among academia, industry and government to support the advancement of biomarker development and translational research. This presentation will focus on biomarker development and translational research optimization by taking into account how samples are collected, selection of the best technology for sample bioprocessing, global biobanking best practices and how information on each sample should be stored to enhance data sharing throughout the research process.</p> |
| 13:00 – 14:00 NETWORKING LUNCH | |
| 14:00 – 15:00 | <p>Session 2: TRANSLATIONAL RESEARCH TOWARD PRECISION MEDICINE “B” Chair: Paul Elliott</p> |
| 14:00 – 14:30 | <p><u>Biobanking Shifts To Precision Medicine</u></p> <p>Pasquale De Blasio, <i>ISENET, Milan Italy</i></p> <p>The shape of the global health care system is changing rapidly to an approach that is much more patient-centered focusing on “precision medicine.” This is particularly due to the large-scale “omics” biology results that relied on using and sharing sample collections and databases contained within bioresource facilities. “Personalized medicine” or “precision medicine” is the premise to help individuals to get the “right medicine for the right problem at the right time.”</p> |
| 14:30 – 15:00 | <p><u>The Qatar Biomedical Research Institute</u></p> <p>Hilal Lashuel, <i>Executive Director of QBRI, Qatar</i></p> <p>QBRI is growing a cadre of world-class researchers to develop a collaborative research network of national and international academic and industrial collaborations. The Vision of QBRI, is to develop a national center of excellence and a global hub for biomedical and translational research, aims to improve and transform healthcare through innovation in prevention, diagnosis and treatment of diseases affecting the Qatari population and the region. The Mission of QBRI is to be engaged in basic and applied medical research that strongly supports the translation of novel scientific discoveries into more efficient therapies and better preventative strategies for human diseases, ultimately leading to the development of Personalized Medicine</p> |

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| 15:00 – 15:20 | NETWORKING REFRESHMENTS |
| 15:20 – 17:00 | Session 3: RESEARCH STUDIES USING BIOBANKING SPECIMENS Chair: Elio Riboli |
| 15:20 – 15:40 | Using very large genomic and genetic datasets to understand diabetes and metabolic diseases Timothy Frayling, Prof. of Human Genetics at University of Exeter Medical School, UK Human genetics research is an exemplar of “big data” studies. Genome wide genotyping, exome and whole genome sequencing data are now available from 100,000s, 10,000s and 1,000s of individuals respectively. These individuals include 10,000s with common diseases. With the sharing of data from these studies, and the use of very large studies with genetic data available such as UK and Qatar Biobanks, we can use genetic variants to understand the subtle but biologically important effects of alleles involved in all diseases and human traits. These alleles represent the human “knock-in” and “knock-down” models of disease, in the most applicable in vivo model (humans) in physiological contexts. I will cover some of the biological insights gained from these discoveries in the field of type 2 diabetes and obesity. |
| 15:40 – 16:00 | Faroe Islands Think Big For DNA Project Bogi Eliassen, Faroe Genome Project Director & Copenhagen Institute for Studies - Denmark The FarGen project aims to sequence whole genomes of the Faroese population. Together with existing health and genealogical records, such a comprehensive sequencing project can improve health knowledge, treatment and prevention services in the Faroese health system. Faroes plans to decipher the complete sequence of the genome of each citizen, from fishermen to prime minister, and use the data for future medical treatment and research. Scientists see the Faroes as a valuable biological model for genomic and epigenomic studies. Privacy, ownership and the utility issues are still being contemplated. Questions range from how to protect information, when it's appropriate to use and whether it might heighten discrimination against the mentally ill and people with inherited diseases |
| 16:00 – 16:20 | Estonian Population Biobank Andres Metspalu, Professor and director of the Estonian Genome Center at University of Tartu - Estonia Estonian Biobank is a population-based biobank of the Estonian Genome Center at the University of Tartu (EGCUT). The Estonian Genome Centre was established on 1. April 2007 and was based on the Estonian Genome Project Foundation established in year 2000. The aim of the project is to bring the field of genomics in Estonia to a qualitatively new level in a technological, computational and infrastructural sense. The core infrastructure of the Estonian Genomics Centre is open to both the academic and private sector in Estonia and abroad. It is aimed to offer possibilities of application for scientists from diverse fields, incl. genetics and medicine, and guaranteeing access to quality data and offering world-class sequencing and genotyping services. The main goal is to introduce the personalized medicine into the Estonian health care. |
| 16:20 – 16:40 | Moli-bank, the biological bank of the Moli-sani project Licia Iacoviello, NEUROMED Director of Molisani Project The Moli-sani Project is an epidemiological cohort study that recruited 25,000 subjects (men and women) aged ≥ 35 years, living in Molise, a Southern-Italy region of about 330,000 inhabitants. The general aim of this study is to establish a permanent observatory/laboratory of the population and to identify new risk and/or protection factors for cardiovascular disease, malignancies and neurodegenerative disease. In particular dietary habits, genetics, epigenetics and their interaction will be specifically investigated. Health and disease status of the subjects and mortality will be recorded every 6 years through hospital discharge records and death certificate. |
| 16:40 – 17:00 | Seeking autographs of Health and Disease: A genetic and phenotypic resource for correlates of diseases in populations at a life style transition. Muntaser Ibrahim, Institute of Endemic Diseases, University – Khartoum Sudan In its attempt to understand the genetic basis of health and disease, the scientific community is increasingly turning to genome wide based analysis that requires both large biological data sets and well defined sets of phenotypic information. Few studies however, were carried out in Africans, due to the prohibitive cost, and the lack of well-defined cohorts of target diseases. There is a dire necessity to carry such studies in African population largely justified by the fact that the majority of biological and phenotypic traits in biomedicine is based on the measurements and indices of European or non-Africans, and that the bulk of genetic variations exists along the ancestral lineages of African populations, particularly in east Africa, where the largest effective population size as been documented. We envision the establishment of a phenotypic information and biological resource that could function as a future input material for trait mapping including genome re-sequencing, exome and individualized approaches. Two types of data bases will be established: a clinical phenotypic databases that encompasses various traits including anthropometric, biochemical and clinical data base as well as a tissue bank of normal and malignant tissues including nucleic acids, serum, urine, saliva etc.. The facility will also collect base line data on the distribution, burden and frequency of diseases of life style, communicable diseases, anthropometric measurements, languages, food habits and relevant traits from different parts of the Sudan and eastern Africa. We will seek to augment sufficient material for future Identification of genotypic and phenotypic correlates of infectious and non-infectious diseases in a population at transition from a traditional subsistence life style to a modern market economy and semi-urbanized life style, and finally to relate the genetic population structure of these population to the patterns of disease and their “focality” (or compartmentalization). |
| 17:00 -17:15 | Closing Remarks Dr. Hadi Abderrahim |
| 17:30 – 18:00 | Visit To The Qatar Biobank Infrastructure |
| 19:00 – 22:00 | Social Event |

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| 08:45 – 9:00 | Welcome remarks Hadi Abderrahim |
| 09:00 – 10:30 | Session 4: BIOBANKS IN REGERATION MEDICINE Chair: Ida Biunno – IRGB-CNR, Milan Italy |
| 09:00 – 09:30 | iPS Cells: A Tool for Accelerating Disease- and Patient-Specific Drug Discovery Oliver Brüstle, Director, LIFE & BRAIN GmbH; Coordinator, of the StemCellFactory Project, Bonn, Germany <p>Induced pluripotent stem (iPS) cells have the potential to transform drug discovery by providing physiologically relevant cells for disease modeling, target validation, compound screening and tool discovery. The technology for generating iPS cells is advancing rapidly, as is the repertoire of cell types that can be differentiated. Tissue-specific cells derived from iPS cells are currently being evaluated by pharmaceutical industry as highly relevant systems for modeling neurodegenerative, cardiovascular and metabolic disorders as well as for generating patient-specific cell types. In order to fully capitalize on the rapidly evolving science of iPS cell technology, pharma will need to leverage the expertise found in academia and biotechnology companies to apply iPS-derived cells in an industrial setting.</p> |
| 09:30 – 10:00 | "Regenerative Medicine by Somatic Stem Cells: the Paradigm of Epithelial Stem Cells" Michele De Luca, Università degli Studi di Modena e Reggio Emilia, Italy <p>Epithelial stem cell biology aimed at clinical application in regenerative medicine. Beside his work on the use of human epidermal stem cell cultures in life-saving treatment of massive full-thickness burns and in re-pigmentation of stable vitiligo and piebaldism, he established human limbal stem cell culture aimed at corneal regeneration in patients with severe limbal stem cell deficiency. This treatment leads to recovery of vision in patients with poor alternative options for therapy. Michele De Luca is currently coordinating the first (successful) ex-vivo epithelial stem cell-mediated gene therapy clinical trial for the gene therapy of junctional epidermolysis bullosa, a serious genetic skin disease. He is also studying molecular mechanisms regulating self-renewal, proliferative potential and clonal evolution of epithelial stem cells.</p> |
| 10:00 – 10:30 | Bank of fully validated human stem cells ready for research and clinical use and further exploitation in drug discovery Ida Biunno, Institute for Genetic and Biomedical Research of the National Research Council Milan Italy <p>The aim of a Stem Cell Bank is not to collect a large number of distinct individual cells but collect, store and distribute particular cell types based on strong scientific evidences. There is a growing demand for human stem cell lines of varying origin (embryonic, induced pluripotent and somatic) and grades (research and clinical) in response to the expectation that scientific knowledge gained from their use, will radically improve our ability to understand and treat diseases, enhance drug development, and generate new clinical therapies. A Stem Cell Biobank effort is to harmonize important parameters starting from the technology and conditions used for their isolation, derivation and culturing, long-term viability and stability. These parameters may vary according to the stem cell source and the type of technology used for their establishment. Here we address some fundamental principles in the establishment of a successful stem cell research repository able to answer specific experimental questions regarding their biology and safety.</p> |

10:30 – 11:00 NETWORKING REFRESHMENTS

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| 11:00 – 12:30 | Session 5 : BIOBANKS: INFORMATION GENERATION AND MANAGEMENT Chair: Marianne K. Henderson, M.S. – Division of Cancer Epidemiology and Genetics, and the Center for Global Health, NCI, NIH, USA |
| 11:00 – 11:30 | The Qatar Biobank in the context of large national and international population cohort studies Paul Elliott, School of Public Health, Imperial College London, UK <p>Over the past nearly 60 years large prospective population based cohort studies have made a unique contribution to the understanding of the causes of common chronic diseases. Early studies such as the Framingham Study in the United States developed the concept of risk factors for common diseases and identified the role of smoking, raised blood cholesterol and high blood pressure as major causes of cardiovascular disease. Similarly, the British Doctors cohort in the UK studied the major role of smoking and other lifestyle factors in premature mortality, documenting that lifelong non-smokers lived on average 10 years longer than smokers. Subsequent large-scale prospective cohort studies, for example Harvard cohorts and EPIC Study, have combined the collection of extensive lifestyle data with biological samples and have proven invaluable in helping to understand the role of metabolic factors in the causal pathway of cardiovascular disease, diabetes and many forms of cancer. More recently, extremely large Biobank studies have been established with national-scale funding, for example UK Biobank and the German National Cohort, which have expanded the amount and depth of the data, biosamples, and clinical measurements collected at baseline, with commitment to following up the health of the cohort over the long term. The Qatar Biobank joins this rich tradition with even greater emphasis on the depth and extent of phenotyping from questionnaire, clinical measurements, biochemistry and imaging. The Qatar Biobank provides unprecedented information at baseline, with long-term follow-up of the cohort, in order to better understand the causes and pathogenesis of the major chronic diseases affecting the Qatari population.</p> |

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| 11:30 – 12:00 | <p>Biobanks and Big Data Bartha Maria Knoppers, McGill University, Montreal Canada Founded as resources for future research, the time for biobanks to "share" has come. This is all the more important as international initiatives such as the Global Alliance for Genomics and Health (GA4GH) foresee building the tools for bringing genomic and clinical data together. Maintaining the trust of biobank participants in Big Data research is key. Hence, the importance of GA4GH's <u>Framework for Responsible Sharing of Genomic and Health-Related Data</u>. Moreover, what are the <u>specific</u> policies needed to guide biobanking researchers wishing to "compute in the clouds"? What are the available tools <u>being built</u> for GA4GH by the international <u>Public Population Project in Genomics and Society (P³G)</u>?</p> |
| 12:00 – 12:30 | <p>Disease Biobank: TMA Key Technology For Biomarker validation and discovery Kurt Zatloukal, Medical University Graz, Austria The use of the Tissue Microarray Technology in recent years has drastically increased particularly in biomarker discovery and validation. Combined with Digital Pathology Analysis, is identified to be the most appropriate technology available in the detection and analysis of rare cancers. TMA will become fundamental in individualized medicine and companion diagnostics and will give to the pathologists reliable information which will be important to the health system to select and administer the most appropriate medication. Thus both patients and medical health care system will benefit enormously from the use of TMA in routine practice, in addition pathologist can be more productive and assured their diagnostic decisions since data storage and data organization will be documented.</p> |

12:30 – 13:00 NETWORKING LUNCH

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| 13:00 – 15:00 | <p>Session 6 : INTERNATIONAL BIOBANKING INITIATIVES Chair: Pasquale De Blasio – ISENET Italy</p> |
| 13:00 – 13:20 | <p>ISBER - International Society for Biological and Environmental Repositories Jim Vaught, Ph.D. President-elect, ISBER Editor-in-Chief, Biopreservation & Biobanking ISBER is the largest international forum which addresses the technical, legal, ethical, and managerial issues relevant to repositories of biological and environmental specimens. ISBER is a professional society of individuals and organizations who share an interest in promoting consistent, high quality standards, ethical principles and innovation in biospecimen banking by uniting the global biobanking community. ISBER invites all sub-components of government, academia, the private sector, and manufacturers to become active participants of the society.</p> |
| 13:20 – 13:40 | <p>Networking And Harmonization Of Biobanks: The BBMRI Project Jan-Eric Litton – Director General of BBMRI- ERIC BBMRI-ERIC, is one of the largest health Research Infrastructure in Europe aims at establishing, operating, and developing a pan-European distributed research infrastructure of biobanks and biomolecular resources. This will facilitate the access to biological resources as well as biomedical facilities and support high-quality biomolecular and medical research. BBMRI-ERIC was founded on 3 December 2013, three days after the Statutes were published in the Official Journal of the European Union making it one of the few existing Research Infrastructures opting for the ERIC legal framework.</p> |
| 13:40 – 14:00 | <p>Biobanking Science: a transfrontier challenge Manuel Morente, Coordinator of the Spanish National Biobank Network- ESBB Past-President, Spanish National Cancer Centre – CNIO, Spain Advances in molecular high-throughput assays for molecular signatures have generated the parallel need for well-annotated properly preserved biospecimens. Samples from both diseased and unaffected normal tissues are often required. Like traditional banks, biobanks are meant to be used and are most useful when the needs of end-users (researchers) are considered. Thus, a well-managed biobank is a critical prerequisite for high-quality biological research. Furthermore, an adequate management is the most important key for efficient and sustainable biobanking, more than technical aspects. Health, disease and research are currently global phenomena. International collaboration and cooperation is essential for normalized and harmonized biobanking-based science. In this lecture, we will briefly present the role of international biobanks societies (ESBB, ISBER, P³G, etc.) and networking initiatives in the global promotion of health and knowledge.</p> |
| 14:00 – 14:20 | <p>The Global Emerging Pathogens Consortium experience in West Africa Ebola outbreak. Biobanking and biodata storage are critical components of the response mechanism. Akin Abayomi – Professor of Hematology, University of Stellenbosch, Cape Town South Africa. The prevailing Ebola outbreak has taken the region of West Africa and the world by surprise, leaving devastation and disrupted economies in its wake. Ebola spread rapidly across international borders in the setting of severe lack of both human capacity and infrastructure following decades of strife in that region. In the absence of a known cure, rapid reaction by the scientific community to test therapeutic options in clinical trials posed immense logistical and ethical dilemmas. This presentation describes the effort of the Global Emerging Pathogens Treatment Consortium (GET), an African led initiative in setting up clinical trials using convalescent plasma and other therapeutic options and the key aspect of banking samples and biodata of a highly contagious pathogen in an environment with almost no capacity for such an intervention.</p> |

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| <p>14:20 – 14:40</p> | <p>Toward Sustainability in Biobanking Marianne K. Henderson, M.S. – <i>Division of Cancer Epidemiology and Genetics, and the Center for Global Health, NCI, NIH, USA</i></p> <p>Across the world, there is a clear understanding for the need of high quality biospecimens to support research and clinical care. Sustainability can be described in three dimensions: Social, Operational and Financial. Social sustainability focuses on the acceptability of the biobank and its activities at large by the major stakeholders (e.g. successful involvement of and collaboration with engagement of the patients and donors). Operational sustainability covers different aspects of efficiency including whether the biobank is managed professionally, its environmental footprint and also whether the biobank collects the biospecimens and data that the potential end-user will eventually need (fit for purpose). The third dimension of financial sustainability is a struggle across the world. Tight economic realities in clinical and research operations have spurred the need to re-examine financial models that support the infrastructure of biobanking. ISBER hosted a discussion of financial sustainability in 2014 with examples from biobanks from all over the world were presented to share the challenges to maintaining their sustainability and the different solutions to those challenges. The presentation will discuss financial sustainability and potential avenues/next steps to achieve it, based on these discussions and those at the presenter's biobank at the U. S. National Cancer Institute. Information about the NCI-CGH's efforts with IARC on the Biobank and Cohort Network (BCNet) will be introduced.</p> |
| <p>14:40 – 15:00</p> | <p>The Return of Research Results and Incidental Findings in Population Biobanks: Past, Present and Future Tense Ma'n H. Zawati, <i>Centre of Genomics and Policy, McGill University, Canada</i></p> <p>Population biobanks constantly face ethical and legal challenges ranging from issues associated with the informed consent process to procedural concerns related to access by researchers. Yet, with the availability of novel technologies, one topic is emerging as the focus of ongoing debate: the return of individual research results (RoRs) and incidental findings (IFs) to participants. Should RoRs and IFs be returned? If so, how much should be fed back and how? Will returning such findings strengthen the therapeutic misconception? This presentation examines this topic from an international perspective, where policies and guidelines discussing the matter will be presented.</p> |

15:00 – 15:30 NETWORKING REFRESHMENTS

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| <p>15:30 – 17:10</p> | <p>Session 7: MIDDLE EASTERN BIOBANKING INITIATIVES <i>Chair: Jim Vaught & Manuel Morente</i></p> <p>Objective of session 4: Presentation of the Biobanking project focusing on: goals, organization, objectives, problems, cultural barriers, legislation constrains, and expected outcomes</p> |
| <p>15:30 – 15:50</p> | <ul style="list-style-type: none"> • EGYPT: Rania Labib – Head of Biorepository and Biospecimen Research, Children's Cancer Hospital-Egypt (CCHE)-57357 <i>Power of Having a Biobanking Network: Healthcare Research & Practice-a marriage solution!</i> <p>Samples and data are important pillars to having good quality research. The vision of a biobanking network is to produce a coalition of researchers and clinicians from different countries looking into research- practice inquiries. This will provide a widespread of ownership of research activity and motivate dissemination of research findings. Networking should have a coherent framework structure to help pave a wave for clinicians , researchers and ideas to come together searching for answers to improve practice and promote cure.</p> |
| <p>15:50 – 16:10</p> | <ul style="list-style-type: none"> • JORDAN: Maher A. Sughayer, <i>Director of KHCCBIO, Amman, Jordan</i> <p>“Biobanks in The Middle East are just a few and they are all emerging and therefore are young and with a small number of samples. Creating a network that unites these Biobanks together would tremendously benefit researchers from the area by providing access to a larger number of specimens that come from populations with similar ethnic and cultural background.</p> <p>In addition a network would provide for exchange of expertise and resources among the members of the network creating stronger individual members than would have been if each stands alone.”</p> |
| <p>16:10 – 16:30</p> | <ul style="list-style-type: none"> • SAUDI ARABIA: Mostafa Abolfotouh – <i>KAIMRC Riyadh Saudi Arabia</i> <p>Saudi Biobanking (SB) project was initiated and is conducted by King Abdullah International Medical Research Center (KAIMRC), King Saud bin-Abdulaziz University for Health Sciences (KSAU-HS), and funded by the NGHA and King Abdulaziz City for Science and Technology (KACST). It is a large-scale prospective study of the combined effects of genes, environment and lifestyle on common diseases of adult life, with nested case-control studies within the cohort. Its goal is to increase the quality of patient care and accelerate the impact of research on such care. It will implement the highest standards of biological banking to provide outstanding clinical, medical, demographic and analytic data through the use of upfront broad consent forms.</p> <p>This study is concerned with two biobanking groups: (1) population-based study group, with an expected sample of 100,000 people of all ages, and (2) Disease-specific biobanking group of 100,000 of patients with certain common diseases such as; cancer, diabetes, hepatitis, chronic renal impairment/failure and stroke allocated from the specialized clinics. Disease registries are being conducted for these conditions under study.</p> |

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| 16:30 – 16:50 | <ul style="list-style-type: none"> UAE: Hinda Daggag, <i>Diabetes Centre, Imperial College London</i> <u>ICLDC Repository- A Research Platform for Biological Sample and Data Collection</u> ICLDC Repository is a unique initiative for the storage and management of biological samples linked to clinical data, led by and integrated into Imperial College London Diabetes Centre (ICLDC), Abu Dhabi. The general purpose of the repository is to set up a resource that can support a diverse range of research intended to improve prevention, diagnosis and treatment of illness, and promotion of health throughout the UAE society. The added benefits of the repository are reflected in the collection of samples and data for genetic analysis. In countries with high parental consanguinity such as the UAE, the incidence of monogenic disorders is very high. Thus genomic research has a valuable input to dissect new phenotypes by identifying novel genes. |
| 16:50 – 17:10 | <ul style="list-style-type: none"> TUNISIA: Houda Yacoub, <i>Pasteur Institute de Tunis, Tunisia</i> <u>Biobanking: preliminary experience in Tunisia</u> Collection and conservation of biological material for health research has been practiced for several decades in Tunisia. However, structuring of these collections and biobanking is a relatively new initiative. Current biobanks in Tunisia suffer from several limitations. Most of them are “individual” biobanks, consequently, there is a very limited and unequal access. Sample management systems are inexistent and samples are registered manually and/or in multiple excel files. In Institut Pasteur de Tunis (IPT), setting of a biobank is planned for 2015-2016 and a task force was created. Furthermore, within the International Network of Pasteur Institutes, a similar approach is underway to strengthen clinical research by establishing a "Center for Global Health Research and Education". Among the challenges encountered in Tunisia, is the “fear” of open access and sharing of patient’s data given the absence of a dedicated infrastructure that ensures the security and integrity of stored and exchanged patient’s data. In addition, a national regulation on the use and share of samples and associated data for genomic and health research, and indirectly on bio-repositories, has been discussed and drafted but not yet finalized. Participation to international research collaborative projects, to networks and consortia would help on the one hand raising awareness on the vital role of biobanks in improving health research and on the other hand, to innovate in the way of doing biobanking by strengthening not only good practice but also ICT tools to support bio-repositories. |
| 17:10 – 17:30 | <u>Roundtable discussion: Chair Hadi Abderrahim</u> “IS THERE A NEED FOR A BIOBANKING MIDDLE EAST NETWORK?” Rania Labib, Maher A. Sughayer, Mostafa Abolfotouh, Hinda Daggag, Houda Yacoub |
| 17:30 - 17:45 | <u>Closing Remarks</u> Dr. Hadi Abderrahim |