isber NEWS

Volume 14, No. 3, September 2014

BIOBANKING IN JAPAN: AN OVERVIEW AND LOOK TO THE FUTURE

Koh Furuta, *Head, Division of Clinical Laboratories, National Cancer Center Hospital, Tokyo, Japan*

There are many small biobanks all over Japan. Most are operated by various public organizations, in particular universities and hospitals. To my knowledge, no major biobanks funded by private sectors exist in Japan at this time. Most of the funding is public, including government sponsored grants of various types.

Read more »

MESSAGE FROM THE PRESIDENT

Andy Zaayenga, *ISBER President 2014-2015*

As I begin my term as President of ISBER I am encouraged by both the growth of the organization as well as the wide range of services it offers to the Biorepository community. ISBER membership continues to flourish. We currently have 1,056 individual members and organizational delegates representing 45 countries. Our **Regional Charter implementation** is generating activity in China, India, Europe, the Middle East, and Africa. As our society grows, ISBER leadership (your Board and Advisory Committees) actively examine the association to insure the best services to our members.

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BIOBANKING MARINE MAMMALS ON THE OPEN SEAS: THE TOP TEN LIST

Amanda J. Moors, *National Institute of Standards and Technology*

In 1989, the National Marine Fisheries Service, Office of Protected Resources (NMFS/OPR), in collaboration with the National Institute of Standards and Technology (NIST) began the National Marine Mammal Tissue Bank (NMMTB) for long-term cryogenic archival of selected marine mammal tissues. In 2002, NIST began partnerships with NMFS/OPR and various research institutions to conduct research on populations of wild marine mammals. Samples collected from health assessments are banked as a part of the NMMTB for long-term storage in liquid nitrogen vapor phase freezers at the Marine Environmental Specimen Bank (Marine ESB) in Charleston, SC. The NIST Charleston facility is located in the Hollings Marine Laboratory at the South Carolina Marine Resources Center.

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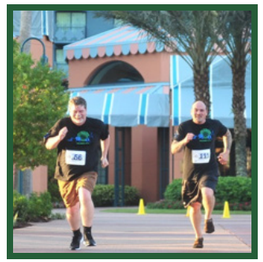
EDITOR'S CORNER

Take a look around this edition of the Newsletter, because changes are coming.

Rick Michels, *ISBER Newsletter Editor*

Beginning in the fall, we will be experimenting with the ISBER Newsletter format. Rather than a pdf document released quarterly, the newsletter will be continually produced as a blog. It is our hope that a blog format will provide the same great content, but on an as ready and as needed basis. This should also reduce the need for production resources, and improve the ability to search the newsletter archives. The newsletter format itself was designed for a bygone era, when news travelled by paper, carried by the postal service. The times, they are a changing. So, as Bob Dylan said, "ya better start swimmin' or you'll sink like a stone". Currently, we hold a collection of stories until they all get in so that they can be all put together in one complete package/edition. With the change, we will make them available as they are ready; giving you the ability to subscribe so that you will be alerted via email each time a news story is available. The email will offer a quick synopsis of the story or stories now up, so you can decide whether to go read it in its entirety. It does indeed seem like the difference between swimming to shore fully clothed vs. in a Speedo. So, we will see how it goes.



Now, try to erase the image of me in a speedo (I guess that's pretty much impossible to do now that I told you to do it) and instead, focus on this: former ISBER President **Bob Hanner** and yours truly racing to the finish line at the 2014 Run to Win 5K in Orando last May. The burning question of the moment: which of us might come in at the 35 minute mark?

Immediately below left see where I deviously informed Bob that our leisurely pace was over, and (without warning) I had to go into a sprint with the finish line in sight:

Resulting in this (Bob is a great sport, by the way):

So, unlike poor Bob here, consider yourself warned. Enjoy this abbreviated summer issue while construction is underway for the new ISBER News blog. I think it will be the difference between mom putting together a scrumptious sit down feast as opposed to mom's kitchen always being open, and always having something tasty and nourishing available. But feasts are good, and we may see a special PDF and print issue of the venerable newsletter pop up on special occasions. We're just full of surprises!

ISBER 2014-2015 BOARD OF DIRECTORS

ISBER NEWS

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BIOBANKING MARINE MAMMALS ON THE OPEN SEAS: THE TOP TEN LIST

Amanda J. Moors, *National Institute of Standards and Technology*

Continued from page 1

Specimens banked at the Marine ESB provide an important function in that they allow for retrospective analyses of environmental contaminants. In addition, banked specimens provide a means for future retrospective analyses for new contaminants of emerging concern, provide samples for future analyses with improved analytical techniques, and provide a resource of samples that have been collected and stored in a systematic and well-documented manner for comparing results over time to identify whether environmental trends in contaminant use exist.

To date, over 10,000 samples from several marine mammal species and health assessment locations have been collected and banked at the Marine ESB. Recently, banked health assessment samples have been analyzed for legacy persistent organic pollutants (POPs) such as polychlorinated biphenyls (PCBs) and chlorinated pesticides (i.e., DDT), as well as contaminants of emerging concern such as the polybrominated diphenyl ether (PBDE) flame retardants.

The continued collection of samples over many years will allow for an assessment of temporal trends in contaminant exposure. Additionally, the existence of samples banked prior to the Deepwater Horizon BP oil spill in 2010 in the Gulf of Mexico region provide an excellent reference for assessing contaminant exposure in marine mammals both pre- and post-oil spill.

A systematic well-designed specimen bank program, such as the Marine ESB, is not only a valuable component of real-time monitoring and basic research, but it also enables future investigators to extend their research into the past and provides for future verification of analytical results. Collaborations between NIST, other US government agencies and various research institutions will continue into the future and will provide a traceable record of contaminant exposure and health of marine mammal populations.

TOP TEN THINGS ABOUT BIOBANKING MARINE MAMMAL SAMPLES ON THE OPEN SEAS

10. Field gear is fashionable… sometimes (i.e., swimsuit vs. drysuit).
9. Even the most seasoned marine mammal researcher can suffer from sea sickness.
8. A day on the open seas is better than a day in the office, except when there are storms! (See photo)
7. Pre-printed barcoded labels, for rough seas, provide an organized inventory of samples.
6. Field work involves sharing close quarters with complete strangers who become your friends!
5. You get to see the sunrise and sunset, often in the same day!
4. Full control of your samples from time of collection to storage in the biorepository.
3. New research collaborations (and friendships!).
2. Banked specimens enable investigators to extend their research into the past.
1. Peanut butter and jelly sandwiches every day for lunch!

BIOBANKING IN JAPAN: AN OVERVIEW AND LOOK TO THE FUTURE

***Koh Furuta**, Head, Division of Clinical Laboratories, National Cancer Center Hospital, Tokyo, Japan*

Continued from page 1

Although funding for research infrastructure is quite tight in Japan, the following three represent major "national project" based biobanks and are funded by the government:

- Biobank Japan (**http://biobankjp.org/english/index.html**) by the Ministry of Education, Culture, Sports, Science and Technology (MEXT),
- The Tohoku Medical Megabank Organization (**http://www.megabank.tohoku.ac.jp/english**/) by the Ministry of Education, Culture, Sports, Science and Technology (MEXT),
- The National Center Biobank Network: NCBN by the Ministry of Health, Labour and Welfare, or MHLW (**http://www.ncbiobank.org/** - the English home page of NCBN is still under construction).

However, this does not necessarily mean that these government-sponsored biobanks are guaranteed to be sustainable over the long term. They may be exposed to the various stringent evaluations and asked to show results to maintain funding.

BioBank Japan was established in 2003 within the Institute of Medical Science of the University of Tokyo. Located in that same city, peripheral blood leukocyte DNA, serum, and corresponding medical records of some 200,000 people from twelve cooperating medical institutions in Japan are stored at this hospital-based biobank. In the period from June 2003 to the end of October 2012, the biobank provided samples from 18,500 individuals to 36 external research institutions. Since 2013, the biobank has been storing additional DNA samples, information on lifestyles, and medical record data from 100,000 patients suffering from 38 diseases in order to identify genes associated with their susceptibilities to diseases, responses to drugs, and likelihoods of the side effects.

THE TOHOKU UNIVERSITY MEGABANK

The Tohoku University Tohoku Medical Megabank Organization was founded to foster the reconstruction from the Great East Japan Earthquake of 2011. The biobank combines medical and genomic information to conduct a long-term health study of residents living in communities which suffered major damage from the earthquake. Organized in the context of a population-based cohort, one of the aims of this biobank project is to organize the systematic digitization and networking of medical information in the local hospitals. As a result, the organization will create a database of standardized medical records in the region while working to prevent the loss of patient records in potential future disasters.

THE NATIONAL CENTER BIOBANK NETWORK

The NCBN is not operated by a single institution but by six national centers (NCs):

- National Cancer Center (**http://www.ncc.go.jp/en/index.html**) specializes in cancer (note: the author works for this center)
- National Cerebral and Cardiovascular Center (**http://www.ncvc.go.jp/english/index.html**) specializes in cardiovascular diseases
- National Center for Neurology and Psychiatry (**http://www.ncnp.go.jp/english/index.html**) specializes in psychoneurotic and neuromuscular diseases
- National Center for Global Health and Medicine (**http://www.ncgm.go.jp/eng/**) specializes in infectious diseases metabolic disorders and immune disorders,
- National Center for Child Health and Development (**http://www.ncchd.go.jp/English/Englishtop.htm**) specializes in pediatric diseases
- National Center for Geriatrics and Gerontology (**http://www.ncgg.go.jp/english/index.html**) specializes in geriatric diseases.

Each national center has its own hospital and research institute.

These six National Centers cover the main disease categories and are the institutions that study disease biology and seek the development of cures. These centers have established a joint biobank catalogue database and a structure that facilitates industry-academic-government cooperation of bio-resources through broad joint research. This biobank can be also categorized as a hospital-based disease biobank.

Traditionally, many researchers in clinical fields have already collected and stored samples. As a result, biobanks in Japan are mostly small and profoundly diversified based on individual research activities in the academic sector. Thus the terminology of "biobank" was still new to some in the population. However, once people recognize the word and meaning, biobanking in Japan may begin to progress rapidly.

QUALITY MANAGEMENT NOW AND IN THE FUTURE

The quality management level of laboratory medicine in Japan is high and the sample quality in biobanks in Japan is mostly good.

Additionally, over the past fifteen years, through adherence to ethical, legal, and social implication guidelines*, the ELSI related environment in Japan has reached an internationally acceptable level. One thing we need to accomplish is to establish good operational procedures, both domestically as well as an international networking environment. To accomplish this, active communication between international communities like ISBER, BBMRI and the biobanks in Japan is vital.

**i.e., Ethical Guidelines for Human Genome/Gene Analysis Research (2001); Ethical Guidelines for Epidemiological Research (2002); Act concerning Protection of Personal Information (2003); Ethical Guidelines for Clinical Studies (2003)*

MESSAGE FROM THE PRESIDENT

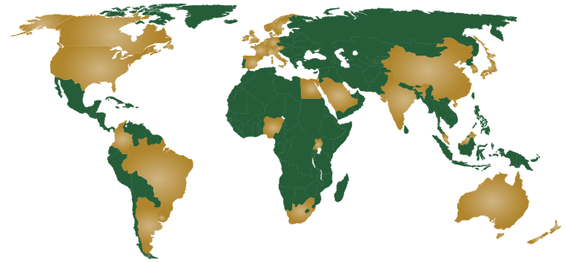
***Andy Zaayenga,** ISBER President 2014-2015*

Continued from page 1

What benefit of your ISBER membership is most meaningful to you? Your answer will likely vary depending on your type of organization, your job responsibilities and even where you live.

You may most appreciate broadening your knowledge by utilizing **ISBER Best Practices** to inform your operational decisions, accessing the **Proficiency Testing Program** or the partnership with CAP for Accreditation. Our official journal **Biopreservation & Biobanking**, **ISBER Newsletter** and **Weekly News Digest**, Publications and the **Forums** facilitate networking/problem solving and keep you current professionally with new technologies and innovations. **Working Groups** produce solutions for critical issues facing specimen science, and **Special Interest Groups** advise us on common topics.

Tools such as the **Self-Assessment Tool for Repositories**, **External Quality Assessment Survey** and **Standard Preanalytical Code** (SPRECalc) assist you in your operations. These tools are soon to be joined by the **Certified Repository Technician Training Program** and International Repository Locator. ISBER enhances your network with our **Membership Directory**, **Corporate Partners** and **Biobanking Jobs**.



ISBER Member Countries

Of course, our Annual Meeting is the most obvious facet which adds value in every area. This year's **Orlando Meeting** was a huge success with 675 participants from 34 countries and we look forward to another record-breaking participation in **Phoenix** next year.

Who is the common contributor to all these features? It is you, the ISBER Community. Our community enables the discussion and knowledge base which drives all of these initiatives. Volunteers from our community populate the board, advisory committees, and working groups. Community members contribute to the Scientific Program of our conference, the Journal, the Forums and the Special Interest Groups. ISBER is the community. The culture and lessons flow from you, and benefit you.

ISBER NEWS

Volume 14, No. 3, September 2014

www.isber.org

DUKE BIOBANK INITIATIVE TO STANDARDIZE BIOBANKING TERMINOLOGY

Helena Ellis, *Biobank Director, Duke University, ISBER Informatics Working Group Member*

I think we can all agree that word choices are important. Whether we are talking about our vacation plans, or biological samples, we must choose our words carefully. While selecting Duke's enterprise biobanking information management system, we quickly

learned we had a communication problem. "'Who's on first?" conversations were a daily occurrence...

Me: "How many samples do you have in your bank?"

Bank Manager: "What do you mean by samples? Do you mean specimens collected for each participant? Or discreet vials, like aliquots? "

Me: "I mean number of samples, you know, number of vials in your freezers"

Bank Manager: "Oh, we call those aliquots. To us, a 'sample' is the entire set of aliquots collected from a subject. We have 300,000 aliquots"

Me: "Are they all the same sample type?"

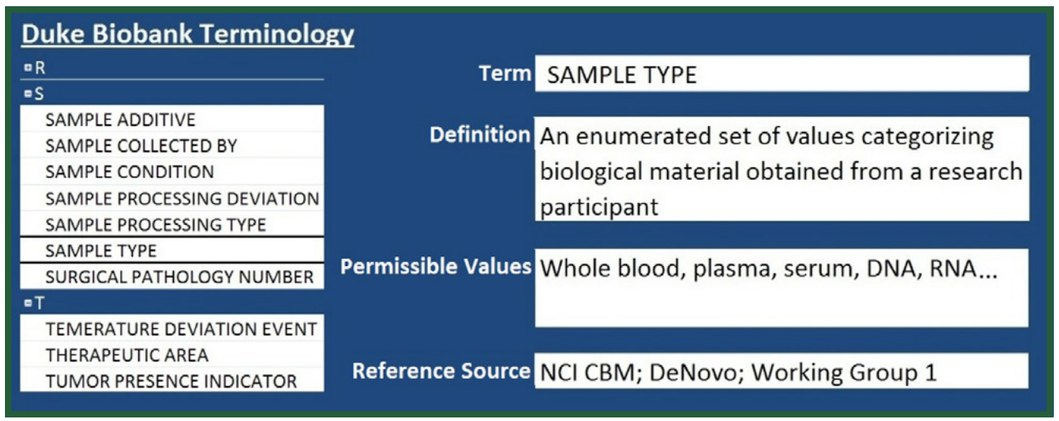
Bank Manager: "By sample type, do you mean blood, or plasma? Or do you mean Blood with Heparin vs. blood with EDTA?"

Me: "just the sample type, the material that comes from someone's body. Heparin and EDTA are additives to the samples"

Bank Manager: "Well to us, EDTA blood, or Heparin plasma is the sample type.

Me: "sigh"

We were fortunate to have internal Duke expertise to advise us on the value of addressing the issue of standard terminology early in the process of implementing a centrally supported, enterprise-wide biobanking information system (LabVantage). The Duke Biobank, based in the Duke Translational Research Institute, coordinated five working groups consisting of subject matter experts from its many diverse biobanking entities to identify and define common data elements related to the biospecimen lifecycle. The categories include: Study Administration (such as IRB Protocols and Consent), Sample Collection, Processing, Storage, Distribution and Analysis. As of December 2013, over five hundred data elements were been defined and are available for download (**http://biobank.duke.edu/biobanking-terminology-download**). See an example data element below.



Although the purpose of the initiative was to implement these common terms in the LabVantage system, the Duke Biobank plans to leverage this work product and move the terminology forward on a national level. A plan is being developed here at Duke to invite professional organizations, government agencies, software vendors, biobanking stakeholders and subject matter experts across the US, to improve and further refine the common data elements. The project will be aligned with other national initiatives (e.g. FDA and the Trans-NIH Common Data Elements Initiative) and the goal is to create a national standard through a standards development organization and store them in a terminology resource such as LOINC for management, curation and public access.

Conversations with the ISBER Informatics Working Group have begun to discuss how best to work together and include ISBER in this important initiative, since the members of ISBER will likely benefit most from this work.

As the project develops, there will be several ways to participate, such as 1) Providing the data elements in use at your institution, 2) Serving on a Committee or Working Group, 3) Participating in a public comment period and/or 4) Providing funding to support the project.

If you are interested in participating in this national initiative please contact the Director of the Duke Biobank, Helena Ellis (**helena.ellis@duke.edu**).

ISBER NEWS

Volume 14, No. 3, September 2014

Volume 14, No. 3, September 2014

ISBER NEWS

ISBER HOSTS 675 PROFESSIONALS AT THE ISBER ANNUAL MEETING AND EXHIBITS IN ORLANDO

The International Society for Biological and Environmental Repositories (ISBER) welcomed 675 participants from 34 countries at the ISBER 2014 Annual Meeting and Exhibits, held May 20-24, 2014 at the Walt Disney World Dolphin Hotel in Orlando, Florida, USA. The ISBER Annual Meeting and Exhibits is the premier event in the field of repository and specimen management.

The theme of the ISBER 2014 Annual Meeting and Exhibits program was 'Fact not Fantasy: Evidence-Based Biobanking' – and included 6 symposia comprised of 2 joint sessions with the Society of Cryobiology, 4 contributed paper sessions, abstract presentations, special topic sessions, as well as interactive discussions. The major focus was evidence-based biobanking from collection to use and highlighted unique and interdisciplinary best practices of both human and environmental repositories with regard to sample integrity, availability, interrogation and reliability of results. All accepted abstracts are available in the April/May issue of the ISBER journal, Biopreservation and Biobanking. Other activities included special topic sessions, working group meetings, networking receptions and 5K fun run.

The ISBER 2014 Annual Meeting and Exhibits included an exciting and engaging exhibit hall with 68 exhibitors in 79 exhibit booths – the largest exhibit hall in ISBER history. ISBER is pleased to announce that the peer-selected ISBER Outstanding Product Award was HEMAgene™ BUFFY COAT by DNA Genotek Inc.

ISBER acknowledged various successful leaders at the ISBER 2014 Annual Meeting and Exhibits, per the following peer-selected awards: ISBER Distinguished Leader and Service Award – Rita Lawlor (Italy); ISBER Award for Outstanding Achievement in Biobanking – Yeonhee Lee (South Korea); ISBER Special Service Award – Peter Watson (Canada) and Brent Schacter (Canada); and the ISBER Travel Award – Sureyah Nassimbwa (Uganda).

ISBER looks forward to continued success of the **ISBER Annual Meeting and Exhibits in 2015**, to be held May 5-9, 2015 in Phoenix, Arizona, USA.

To learn more about ISBER and its international activities, please visit: **www.isber.org**.

A LOOK BACK AT ISBER 2014 IN ORLANDO, FLORIDA, USA

ISBER President 2013-2014 Fay Betsou presents Rita Lawlor with the ISBER Distinguished Leader and Service Award.

Sureyah Nassimbwa (Uganda) accepts the 2014 ISBER Travel Award.

Fay Betsou, ISBER President 2013-2014, and Marcus Soderquist accept their 2014 ISBER 5k Fun Run winner awards.

Fay Betsou, ISBER President 2013-2014, hands incoming President 2014-2015 Andy Zaayenga the ISBER gavel.

ISBER President 2013-2014 Fay Betsou presents Kathi Shea, outgoing ISBER Past President, and Lori Campbell, outgoing ISBER Director-at-Large, ISBER Board of Director Recognition Awards for their service.

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ISBER NEWS

Volume 14, No. 3, September 2014

www.isber.org

ISBER 2014 Outstanding New Product Award winner: HEMAgene™ BUFFY COAT by DNA Genotek Inc.

One of the ISBER 2014 Biospecimen Science Poster Award winners, Olga Kofanova.

Debra Garcia is well attired for Disney as she signs up 5K participants for the chance to hoist the coveted Golden Shipper, ISBER's own prestigious answer to Hockey's Stanley Cup.

Our wildlife biobankers share war stories. Not to be outdone regarding tales of sampling beluga whales off the icy coast of Alaska by Amanda Moors and Rebecca Pugh, Paul Bartels whips out his lion scar as the women look on in horror.

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ISBER 2013 TRAVEL AWARD WINNER REPORT

Talishiea Croxton, Institute of Human Virology Nigeria

The Institute of Human Virology Nigeria (IHVN)- Human Heredity, and Health in Africa Biorepository (IHAB) and I are grateful for the opportunity I was granted to attend the ISBER Annual Meeting in Orlando, Florida from May 20-24, 2014*. I-HAB is a young biorepository located in Abuja, Nigeria; without the travel award, it would have been impossible for me to attend the meeting. My attendance was timely as I-HAB was awarded NIH Human Heredity and Health in Africa (H3A) funding to upgrade its operations to international ISBER standards to store and distribute high quality biological specimens in support of African investigators involved in genomic research in Africa.

As Manager of I-HAB, I looked forward to the ISBER Conference with great expectations for learning, networking, and a little fun. I was inspired by the meeting's theme "Evidence-Based Biobanking: Fact Not Fantasy" as IHVN is an institution, interested in symbiotic relationship between clinical, research and biobanking activities to foster diversity and sustainability. I attended pre-conference and conference workshops, poster presentations, and vendor exhibits to maximize my experience and to empower me to effect overall operations, infrastructure, policies, and protocols at I-HAB.

The pre-conference workshops I attended were: 3a) "Issues to consider in designing a repository" and "The nuts and bolts of operating a repository", 3b) "Essential concepts for effective specimen receipt", and 3C) "Creating successful training programs for repository staff". The presentations were provided by facilitators who demonstrated expertise and a passion to teach and learn from others. In their session on designing and operating a repository, Katherine Sexton and William Grizzle, introduced the idea of -80C storage being better than liquid nitrogen storage and provided evidence supporting this notion. In Nigeria, where access to liquid nitrogen is extremely limited and expensive, that information was very useful to me. Overall, the pre-conference workshops introduced new ideas in general organization, infrastructure and staffing that I could adapt in Nigeria.

During the conference, I attended many insightful sessions. The "Financial Sustainability of Biobanks" session was particularly useful to me as we are in the process of defining a business model for I-HAB. The presenters and representative biobanks were diverse and included disease based biobanks, biobanks receiving specimen solely from patients, international biobanking systems and others with a range of financial structures. Moreover, the Canadian Tumor Repository Network shared their website which contains useful resources for biobanks including a Biobanking Costing Model, strategies for biobank certification and over 40 SOPs. Notable discussion points and the online resources will be extremely helpful to me as we review our Business Model at I-HAB. Katheryn Shea's presentation on "Future Use Considerations for Global Collections of Human Biospecimens: Annotation to Ensure Compliance in an Evolving Global Regulatory Environment" highlighted the importance of harmonization and awareness of restrictions that govern data and specimen exchange. This has since been realized in my experience in global partnerships and collaborations.

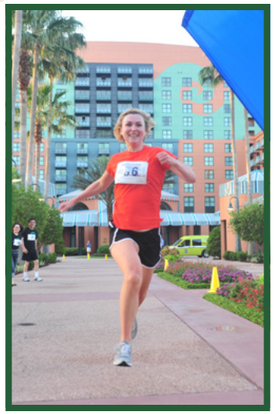
There was a host of networking activities to promote interaction and build relationships including Interactive Discussions and social activities. I participated in an Interactive Discussion on Low and Middle Income Countries (LMIC) facilitated by Maimuna Mendy. We discussed ethical and regulatory challenges and advances in Africa, including the importance of nontraditional stakeholders such as elders and chiefs. Furthermore, there were plans to create a network for African biobanks to learn from one another's experiences. For someone who spent decades of her life collecting Mickey Mouse memorabilia, there was no better way to top of my rewarding experience than meeting Mickey Mouse! Social events which included a meet and greet for new members, a 5k walk/run fundraiser in support of future travel awards, the IllumiNations fireworks and light show at Epcot Center and scheduled group trip to Downtown Disney. Well done to everyone who contributed to the success and overall experience of the 2014 ISBER conference.

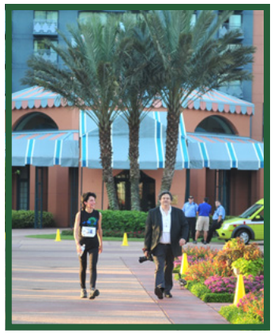
**Talishiea Croxton, ISBER 2013 Travel Award Winner, was unable to attend the ISBER 2013 Annual Meeting in Sydney, Australia. Instead, she attended the ISBER 2014 Annual Meeting in Orlando, Florida, USA.*

ISBER 2014 5K FUN RUN

The **ISBER 5k Fun Run** is a fundraising event held at ISBER Annual Meetings. Funds raised benefit the **ISBER Travel Award**, which provides support to individuals from emerging countries, who are planning or currently managing a repository, to attend the ISBER Annual Meeting.

At ISBER 2014, **81 participants** raced through the Walt Disney World Swan and Dolphin Resort to raise funds for the ISBER 2015 Travel Award.





ISBER NEWS

REGISTRATION OPENS FOR THE BIOSPECIMEN PROFICIENCY TESTING PROGRAMME

As everyone is returning from their summer holidays, it is again time for IBBL (Integrated BioBank of Luxembourg) to launch its annual Biospecimen Proficiency Testing (PT) programme. Co-developed and endorsed by ISBER, the PT programme allows laboratories working with biospecimens, to compare their performance to that of other expert laboratories from different sectors all over the world. PT works as an external quality assessment tool to verify the accuracy, precision and efficiency of laboratories' processing and testing methods. As such, it is not only crucial to laboratories seeking compliance with certification and accreditation norms like ISO17025 or ISO15189, but will also allow biorepositories to start preparing for the new ISO standards being developed by the technical committee ISO-TC276. In this context, it is also important that laboratories participate regularly in a PT programme, to ensure monitoring and prove consistency of performance over time.

Following the feedback from participants in previous editions of the PT programme, IBBL has added 3 new processing schemes this year. The number of test items (reference material) per scheme has also been increased. The 2014 Biospecimen PT programme includes 7 inter-laboratory schemes:

- DNA Quantification and Purity
- RNA Integrity
- Cell Viability
- Tissue Histology
- DNA Extraction Efficiency from Whole Blood
- RNA Extraction Efficiency from Whole Blood
- DNA Extraction Efficiency from FFPE Cells

For each scheme, reference material, produced by IBBL, will be shipped to the participating laboratories, which will then use their routine methods to extract or characterize the samples. Once all the participants have submitted their results online, IBBL will carry out the statistical analysis and evaluate individual performance relative to the assigned values and relative to other laboratories' results. Each participant will receive a Certificate of Participation, as well as a personalised report with detailed statistics that show how their laboratory's results compare to all the other participants' results.

ISBER and ESBB members get a 20% discount. In addition, there is an early-bird discount for registrations before September 15th and a free extraction scheme when you buy any 3 schemes. So, take advantage of these offers and **register before October 31st** on **www.ibbl.lu/pt**

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ANRRC SIXTH ANNUAL MEETING

September 17-19, Shanghai, China

Menghong Sun, *Fudan University Cancer Center*

On behalf of the ANRRC Board and the Meeting Organizers, I would like to officially invite ISBER members and friends to attend this year's ANRRC meeting in Shanghai. The meeting is mainly jointly organized by two Chinese institutions: Institute of Microbiology, Chinese Academy of Sciences and Fudan University Shanghai Cancer Center.

We are happy to organize this meeting and be ready to assist you to finish the process for the meeting paperwork. Please feel free to contact us any time for any information including an individual invitation letter with your name and institutional information on it for visa, accommodation and other information.

The registration website is: **http://anrrc.meeting-e.cn/**

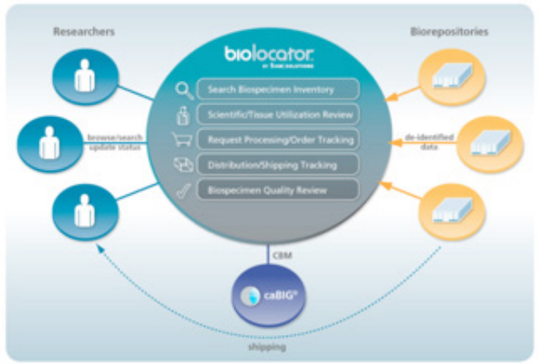
Please feel free to tell us if you encounter any inconvenience by registration online. It is also acceptable to send your information and your registration form back to this email address: **sixthanrrc@vip.163.com**

We are looking forward to meeting you and your contribution!

ARIZONA BIOSPECIMEN CONSORTIUM

BACKGROUND

The Arizona Biomedical Research Commission (ABRC), under the direction of the Arizona Department of Health Services (ADHS), has established a centralized, web-based biospecimen tracking and review management system to support the viewing and ordering of biospecimens stored in physical repositories at member Arizona hospitals and research facilities. The ABRC system, the Arizona Biospecimen Locator (ABL), represents information about the available biospecimens in a consistent and virtual manner to allow researchers to browse and query the biospecimen universe and determine which biospecimens may be suitable for their needs. ABL provides Consortium members with the tools to review and manage biospecimen requests, configure approved orders, track shipments, receive shipments, and disposal of or return of biospecimens.



MARICOPA INTEGRATED HEALTH SYSTEM

St. Joseph's A member of CHW

PHOENIX CHILDREN'S Hospital

CHALLENGE

"Tissue is the issue" is among the loudest of common refrains heard from those committed to improving the pace of progress of translational research, both in Arizona and across the nation. Finding and acquiring quality biospecimens is one of the largest obstacles researchers face as they strive to advance medical science and improve patient care. The initiative proposed by the ABRC is a tremendous opportunity to change the way science works (collaboratively) and where scientists work (the web) to overcome institutional boundaries, and enhance awareness and access to resources that drive discovery.

PROCESS

ABRC sponsored the creation of the Arizona Biospecimen Consortium (ABC), consisting of the initial set of Arizona institutions participating in the Arizona Biospecimen Locator project: St Joseph's Hospital and Medical Center (A Dignity Health Member), Phoenix Children's Hospital, and Maricopa Integrated Health System. A custom software development vendor, 5AM Solutions, Inc., was selected to develop the web-based application. From March 2009, the ABC members met every month to discuss and determine the standard set of data about a biospecimen that should be made available on ABL (based on the data fields defined by the NCI's Common Biorepository Model) and other standardization needs. Members also defined and agreed to the process by which the ABC would be governed, including the rules for the release of biospecimens from member institutions and a standard Material Transfer Agreement for all ABC members.

RESULT

The Arizona Biospecimen Locator, as defined by the ABC, will increase the visibility, quality, quantity, and population coverage of biospecimens to the research community, thereby increasing research collaborations inside and outside of Arizona and accelerating the progress of research. Arizona has access to populations of children, seniors, Hispanic Americans, and Native Americans with both normal and diseased tissue that are rare and would contribute greatly to medical research and the advancement of science. Currently, the Arizona Biospecimen Locator holds information on over 15,000 specimens. More information is available at https://abl.azdhs.gov/tissuelocator-web/browse.action.

ISBER NEWS

SMART MOVES

Duke Biobank Team Expands

Duke added three new members to its team to support the implementation of LabVantage for the Duke Biobank. **Angel Morgan, Dianne Oliver-Clapsaddle,** and **Eric Hall** are a part of the Duke Biobank LabVantage Project Team and Duke's Office of Research Informatics.

Angel Morgan joined the LabVantage Project as a Senior Business Analyst in March, 2014. She came with 13 years of experience as the Lead Business Analyst for the American Red Cross's Blood Donor, Donation and Component Management system. As the Lead Business Analyst at the American Red Cross, Angel managed system requirements, developed test plans and facilitated user training for 36 national blood service regions. She has a Graduate Certificate in Clinical Pathology from the University of Massachusetts, a Master's Degree in Education from Virginia Tech, and a Bachelor's Degree in Integrated Science and Technology from James Madison University. Angel is PMP certified, holds a NC State Teaching License and is a certified YMCA Lifeguard and Swim Instructor Trainer.

Dianne Oliver-Clapsaddle joined the LabVantage Project as a Project Manager and Business Analyst in June, 2014. She comes to the team from the Center for Biomedical Informatics at Washington University School of Medicine in St. Louis, MO. Dianne has 13 years of experience managing large, interdisciplinary IT Projects in academic medical centers. She has a Master's Degree in Information Management and a Graduate Certificate in Project Management from the Sever School of Engineering at Washington University, and a Bachelor's Degree in Political Science from Southern Illinois University.

Eric Hall also joined the group in June as the Product Manager for the LabVantage Project. He has over 20 years of experience in a variety of academic and industry position primarily focused on laboratory operations and IT. Eric has experience in managing large projects in facilities and IT both domestically and internationally. For the past 10 years Eric has been focused on biorepositories with positions at Life Technologies, Gentris, and Bluechiip Ltd. He has a Bachelor's Degree in biology from Campbell University, and a Masters in Health Administration from the University of North Carolina at Charlotte.

PARTNERSHIPS WITH PATIENTS AND INDUSTRY: THE ITOR GREENVILLE BIOREPOSITORY MODEL

Rick Michels, *ISBER Newsletter Editor*

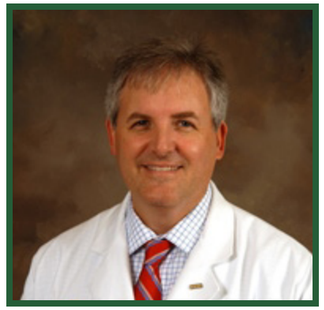
Lorie Allen *and* ***Lauren Baber*** *of the ITOR Biorepository, located in the Greenville Health System, Greenville, South Carolina*

"To be an international destination center that develops and delivers innovative, personalized cancer therapies"

The above is the vision statement of the **Institute for Translational Oncology Research (ITOR)** of the **Greenville Health System** (GHS) of South Carolina, USA. To meet that vision, the institute requires a biorepository that works closely with both clinical and research departments. A biorepository may have valuable samples, perhaps the most valuable collection of rare and hard to acquire samples in the world. However, unless they are properly and fully annotated, those samples cannot be used to their maximum potential. An annotated, searchable, powerful database can provide rapid, invaluable molecular data for research and therapeutic uses.

With the opening of ITOR's **Rare Tumor Center**, the nation's first center dedicated exclusively to the research and treatment of rare cancers, along with its innovation zone attracting promising new therapeutic biotech companies, ITOR is poised to make South Carolina a vital destination for integrative approaches to fighting cancer. As with most, if not all health centers, a strong biorepository is a bridge to success in facilitating progress in both treatment and research.

According to ITOR Medical Director **W. Jeff Edenfield, MD,** the biorepository samples and data will serve as a valuable asset to the institute, and in particular the Rare Tumor Center. Utilizing its database to store and access data on both samples and patients, the biorepository is a vital link helping to match its patients to the most promising clinical trials available to treat their condition.



ITOR Medical Director ***W. Jeff Edenfield, MD***

"Patients at the rare tumor center have, by design, higher level molecular annotation associated with them," Edenfield explained. "We're looking for therapeutic options for them.

"Rare things are by definition 'rare', so it's hard to accumulate them in high numbers. But we can do molecular screening for patients who might have specific abnormalities, and help them join a trial, perhaps in our research unit, or maybe somewhere else, where they have a drug that matches their mutational target," Edenfield said. "We can do specific kinds of queries to help us find cohorts of patients that might fit on trials."

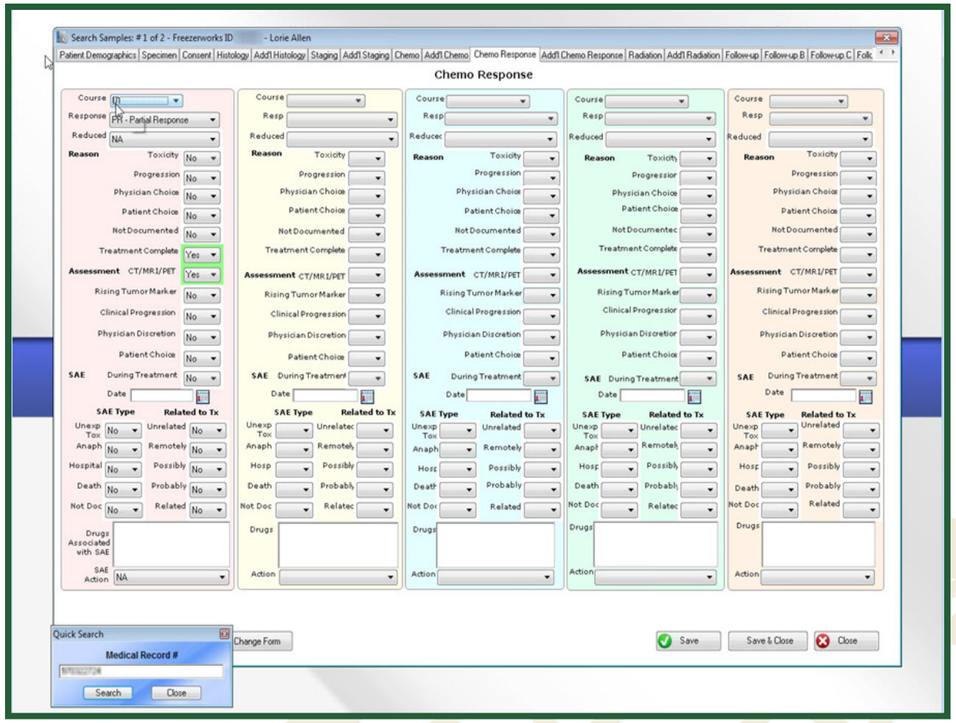
The key is data management. As cancer patients at Greenville come for treatment, they have the opportunity to gift their excess tissue samples for research. Samples of blood and tissue are collected and processed in a timely manner. But the data behind those samples offer the clues to pathways to effective treatment. Behind every sample taken and stored are the following:

- Demographic information on the patient
- Information on the broad or narrow granting of consent, for both this and any possible samples taken in the future
- Tracking of all tissue and blood samples at first operating appointment, including amount of each aliquot type, and freezer location
- Ischemia and other important time points recorded to ensure specimen quality
- Tests and test results
- Data on post-surgical treatment – radiation and/or chemotherapy
- Data on patient follow up: including the efficacy of treatment, and if additional procedures are necessary. If additional tissue samples are taken due to further treatment, these can be traced back to the original tissue and procedure.
- Genomic biomarker information

THE ITOR BIOREPOSITORY INFORMATION MANAGEMENT SYSTEM

ITOR uses its biorepository information management program to fully and accurately document each patient's treatment program and associated tissues, from surgery to treatment to follow up visits to additional surgery (if needed)*. In doing so, the biorepository serves as a library for tissue samples. Every good library needs a good cataloguing system, so that the right samples are located for the right researcher. Like a library book, each specimen stored tells a story.

"We get a picture of what's going on with the patient and the disease. What we are doing with data collection is painting a picture, for months at a time, and with the presentation of the data, it is actually telling a story of what's going on," Clinical Research Nurse **Lorie Allen** explained.



** The author of this article serves as Vice President of Marketing for the company that developed the program on which the ITOR program was configured.*

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ISBER NEWS

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Specimen and patient information is easily accessed through a series of Clinical Annotation pages, with tabs running across the top of the program. Above, the details for each chemotherapy course are tracked.

Time management savings

To tell the story behind each specimen, the ITOR staff designed a screen layout that fits their needs: a series of data field screens accessed by tabs across the top. It matches the data management needs in a way that makes the most sense.

The way this has been set up, when we go into a patient record we can quickly access information by simply clicking the specific tab across the top which contains the related data fields," Allen explained. "It has been a time management help for us; when you are in a large organization, time is money," she added.

"We just love it," is how Clinical Data Coordinator **Tina Pettry** described the design, and added that researchers have been amazed at times at the amount of data collected by the Biorepository under one system.

"As I was describing the system to a researcher recently, he was incredulous, and told me, 'Nobody else has this!'" Pettry said.

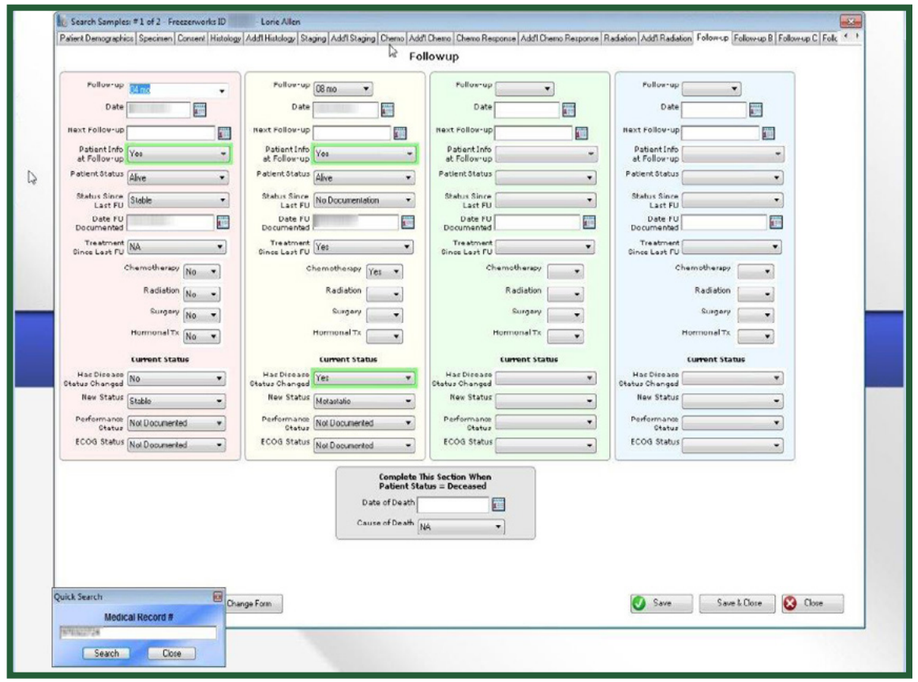
Quality research results

Allen also stressed how valuable quick access to the data is to ongoing cancer research efforts:

"To get the best research results possible, you need thorough data, and when you have that, it gives [researchers] more to work with; a complete picture as opposed to just having a piece of tissue and a path report. When you have a piece of tissue with a path report, plus you know certain genes have mutated, you are giving them more to go on. From a cancer research standpoint, that's good, that's helpful."

Follow-up

An important aspect of the ITOR approach to research and treatment is regular and detailed follow-up procedures. The patient is tracked throughout the treatment and recovery process and well afterwards. In the screen below, a patient was followed up at four-month intervals. At the first follow-up, the patient was stable. However, at the next follow-up, the patient's status had changed, and the cancer metastasized. With data like this, the ITOR Biorepository can play a vital role in helping the Rare Tumor Center locate emerging and promising clinical trial treatments for cancer patients.



Follow-up screen: the patient is tracked throughout the treatment and recovery process and well afterwards, a vital part of the translational research done at ITOR for which the Biorepository plays a critical role in treatment.

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ISBER NEWS

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Industry partnerships: filling the pipeline of exciting new therapies for cancer care

Edenfield also gave an example of how a data rich biorepository can help drive drug discovery:

"If I, for example, have a contact at a small pharmaceutical company looking to see what is the prevalence of a certain mutation in our biorepository, I can tell them that relatively quickly through a [database] query. This can help them determine if we are a good institute to do the trial with… and it also can give them an idea whether that mutation is a worthwhile target to pursue," he explained.

David E. Orr, Ph.D., co-founder and Chief Operating Officer of **KIYATEC Inc.,** a cancer diagnostics firm operating in the Greenville Medical Center's Innovation Zone, said the close proximity and partnership with the ITOR Biorepository has allowed rapid access via IRB approved protocols to primary tissues. These samples have been instrumental in advancing technology to develop what he calls "more relevant" 3D cell culture models. Building on 3D modeling technology that Orr developed in his own research a decade earlier at Clemson University, KIYATEC is working to develop tissue cultures that are, in Orr's words, "more emblematic of in vivo biology."

***David E. Orr, Ph.D.**, Co-founder and COO of KIYATEC*

With fresh biopsy tissues accessed through the services of the ITOR Biorepository, Orr explained, 3D modeling is enhanced and becomes an effective tool in cancer care treatment.

"By taking cells from a biopsy of a patient's tumor, we can incorporate that into replicates in our system, and then treat each replicate with a different chemotherapy agent to find the optimal therapy for that particular patient's cancer."

KIYATEC is still in blinded pilot studies, developing drug response profiles that will prepare the way for future trials.

Through a special arrangement, certain tissues are received fresh by KIYATEC as well as the biorepository. But although the studies KIYATEC performs are blinded, the additional data collected in [database] by the Biorepository (e.g., the pathologist report) can be shared in redacted form with the company to improve and enhance their processes and their overall knowledge, as it designs future trials.

Allen explained how the data rich environment the database offers makes the Biorepository a real asset for the different research companies leasing space at ITOR's Innovation zone.

"We can help them in varying different ways with our biobank. Not only with tissue, but we can help with the data," Allen said.

Orr pointed to a recent Phase I award KIYATEC received from the National Cancer Institute to develop a "more relevant" 3D breast cancer model. The biorepository played an "instrumental" role in the award because of its data management services, according to Orr.

Orr also pointed to KIYATEC's ovarian cancer blinded pilot study in which biorepository samples and data from ITOR were key in providing retrospective analysis. KIYATEC was able to correlate the company's phenotypic drug response profile with genomic data collected on tissue samples provided by the Biorepository, which allowed KIYATEC to assess appropriate tumor sensitivity to a specific targeted agent based on the presence or lack of a genetic mutation.

"The relationship (with the ITOR Biorepository) allowed us to effectively execute the study and generate the necessary data, paired with appropriately redacted clinical information, to more efficiently move our cancer diagnostic forward," Orr said.

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