

OBBR Interactive Timeline

Historical Milestones:

OBBR has achieved several major milestones that are driving improvements in biospecimen quality. Use this interactive tool to learn more about how NCI is addressing biospecimen issues that impact cancer research and patient care.

OBBR Interactive Timeline:

Scroll through our timeline to view milestones that have identified the need for standards around biospecimen collection, processing and storage and the vision for a national biobank resource. Watch the video from our Best Practices Forum, link to the interactive NCI Best Practices for Biospecimen Resources, and read *Time Magazine's* article naming biobanking #8 on the "Top 10 Ideas Changing the World Right Now."

2009

OBBR is featured in *Time Magazine* cover story on "Top 10 Ideas Changing the World Right Now"

Corresponding information:

http://www.time.com/time/specials/packages/article/0,28804,1884779_1884782_1884766,00.html

Video transcript: BRN 2009 Tuesday Afternoon session of Dr. Compton briefly describing caHUB

The culmination of what we've been thinking about and working on for many years now, the Cancer Human Biobank, or caHUB, which was the subject of the *Time* magazine article. And to put this into perspective, this is really a piece of infrastructure for the United States that does not currently exist. And that we have identified as a need for the community. The broad community, the private community, as well as the public community; government included. It's to be a unique centralized non-profit public resource that will ensure the adequate and continuously supply of biospecimens and associated data, And this is key...of measurable high-quality acquired within ethical framework. You have heard multiple speakers talk about the lack of one or more of these things in different settings. And to harp back to what Cliff Leaf said this morning, 'we need a story,' and in fact, Helen used this diagram in her introduction to put biospecimens into the context of the story. And we still do believe this is a story. That biospecimens are the glue that connects the patient and the research enterprise that will advance our vision of medicine to a new one, of personalized medicine.

2008

OBBR begins exploring the formation of national biobank resource.

Video transcript: Dr. Compton

We recognize there are gaps in the system and the HUB is an effort to build these gaps. We don't want to compete with what's already going on and is satisfactory. But we certainly want to fill in the gaps, on the unmet needs in the system. So, the key concepts, taken straight from the NBN Blueprint are the scientifically designed collection [indiscernible] with standardization of everything from top to bottom, done under contract. Under contract, this is not going to be left up to even people's good way. This is the only way we can insert and guarantee control in the system. And we have an elaborate planning process mapped out for market research. Unlike what Cliff said this morning, 'build it and they will come'. We did not want to take this approach. We want to build something the community actually needs. So, we went out there to ask them what they need. And all of our business and implementation planning will revolve around this market research, which has already begun. And we just started the market research. We are applying for the Office of Budget and Management approval to go out there and for those of you in the industry and audience, to do a survey, we need OMB

clearance. We did it only with our PIs who have a relationship with the NCI. We went forward and did some in-depth interviews and some online surveys with about 500 invited participants. They were mostly academic PIs. We learned quite startling things from this group of respondents. We learned that most people get their biospecimens for their science in their own backyard, their own patients, or their own institution. The vast majority and they don't share. We weren't cognizant of the degree to which this was true, but it was quite startling. And then we asked them, "Does this siloed system in your backyard and kept by your institution, make it difficult for you to get what you need?" And so we asked then, "how you would rate the ease of acquiring the quantity of biospecimens?" And 40 percent of them said it was difficult or very difficult. And another 31 percent said it was somewhat difficult. And then we asked them, "How easy is it to get quality of biospecimens you need?" And a full half of them said it was difficult or very difficult. And when you added in somewhat difficult, this is the majority of the scientific research community. This is not good news for the NCI who funds most of this science. And then, we asked them a scarier question, "Do you question your data? Because of the quality of the biospecimens that you use?" And 20 percent of them said they often or always question it. And another 40 percent said sometimes. And this is unacceptable, and even more unacceptable is we are limiting the innovative thinking of our brain trust; our scientific brain trust.

OBBR Deputy Director, Dr. Jim Vaught, testifies on standardized biospecimen procedures before the U.S. House Committee on Science and Technology.

Corresponding information:

<http://biospecimens.cancer.gov/global/pdfs/VaughttoCommittee.pdf>

OBBR hosts First Annual Biospecimen Research Network Symposium.

Corresponding information:

<http://brnsymposium.com/meeting/brnsymposium/2008/agenda.asp>

2007

OBBR hosts a series of NCI Biospecimen Best Practices Forums.

Corresponding information:

<http://biospecimens.cancer.gov/practices/forum/default.asp>

NCI Best Practices for Biospecimen Resources (revised First-Generation Guidelines) approved by the National Cancer Advisory Board.

Video transcript: Stacy Jannis

We needed to start out with the state of the science as it exists now. Defining it; publishing it; making it widely available, so that everyone is on the same page. And we did that at the NCI through an extensive process of due diligence by inviting the community to weigh in; series of workshops. We created a strawman document that represented the best practices in biobanking. We put it on the Federal Register. We got the public to weigh in. We revised the best practices, based on public contribution to this problem. This has been all about the community working together. And then the NCI published it Best Practices for Biospecimen Resources. That document is on our Web site and is downloadable, but it represents policy for the NCI. It's the baseline that the NCI expects biobankers to comply with, in order to at least be harmonizing what they're doing. To create a community of biobanks that are abiding by the least common denominator. This can all be built upon in better ways with more science. But the least common denominator as we know it now in terms of the best way to do things. That was a start point.

2006

First-Generation Guidelines for NCI-Supported Biorepositories is published in the Federal Registrar.

Biospecimen Research Network is established.

Video transcript: The Biospecimen Research Network: Program Update and Symposium Overview, Helen Moore, Ph.D.

Dr. Moore begins "The big picture is we study the biology of cancer using biospecimens collected from cancer patients. We look for molecular changes in the specimens; try to find meaningful biomarkers, hopefully clues for new therapies. We look forward to a day when we can have sophisticated personalized cancer care made possible by these new markers which is a very exciting idea, and many of us have spent a lot of our lives on that goal thus far. But there are a couple of significant obstacles to progress. Here are two of them which our office deals with. The first, the lack of standardization of biospecimen collection, processing, and storage. We need to do this in order to provide robust testing of patient samples. It's an issue for R and D. Secondly, the reason we are all here, the lack of knowledge about how different methods of biospecimen collection, processing, and storage alter the biological picture presented by the specimen. This is turning out to be a significant confounding factor in research. So what do we know about the biology of the specimen? This is kind of a silly view but something that we think is helpful in terms of visualizing the problem. If we have a cancer patient, and we think of the specimen as a picture of the disease, we can use this information derived from that specimen in translational research, and apply new findings from personalized medicine to cure the patient. But this specimen is a creature of stress, biological stress. We simply need to understand more about what the contribution of that stress is to the picture of disease that we're presenting. And so this entire program is devoted to the biospecimen as an object of investigation."

2005

NCI Office of Biorepositories and Biospecimen Research is established.

Corresponding information:

<http://biospecimens.cancer.gov/about/default.asp>

Two national workshops are convened, on "Best Practices for Biorepositories that Support Cancer Research" and "Biospecimen Ethical, Legal, and Policy Issues".

2004

NCI forms Biorepository Coordinating Committee to gather and evaluate all existing authoritative best practices in biobanking.

Corresponding information:

<http://biospecimens.cancer.gov/about/bcc.asp>

NCI conducts an internal inventory of NCI-supported biorepositories.

Corresponding information:

<http://biospecimens.cancer.gov/patientcorner/faq.asp#q5>

2003

National Biospecimen Network (NBN) Blueprint is published.

Corresponding information:

http://biospecimens.cancer.gov/global/pdfs/FINAL_NBN_Blueprint.pdf

2002

NCI undertakes an unprecedented internal and external review process of biospecimen resources, with surveys and community forums.

NCI leadership identifies biospecimen resources as critically important to post-genomics cancer research.

Video transcript: Best Practices Forum Bethesda Webcast, Dr. Compton

This started back in 2002, with the recognition that this problem of heterogeneity among biospecimen resources was in fact of the most critical issues facing cancer research and indeed translational research in all realms. The issue really started for me back in 2002 before I came to the National Cancer Institute in a forum, a think tank, held by what was then called the National Dialogue on Cancer, now known as C-Change. This was an initiative that was started by Former President Bush and his wife, Barbara, who had a child who had died of childhood cancer and who were still dedicated to the issue of cancer. Basically, the question arose and was put to the group in the Think Tank of why it was that it had been 30-some years since 1971 in fact when President Nixon declared the “War on Cancer” that 30 years had passed and we really weren’t winning the war on cancer as rapidly as one would have hoped, in 1971. And this Think Tank was composed of 300 individuals from industry, from academia and from government, all realms of government, in fact, FDA, CMS, and the NCI and NIH and we were basically asked to define the top 10 roadblocks for curing cancer and after three days of much perseveration and discussion, the presentations were made on the last day and this was a life altering moment for myself, because at the top of the list, the number one, the number one bottleneck to curing cancer and I quote here was defined to be the “lack of availability of high-quality, highly characterized human biospecimens for translational research.”