

## Why are Biobanks Important to Medical Research?

*Adequate access to biospecimens – tissue and blood samples – is often cited by the research community as the most critical of all issues.*

*With rapid and unfettered access to large quantities of high-quality biospecimens researchers can conduct a wide range of analyses that not only allow for a better understanding of the genetic and molecular changes involved in the progression of diseases, but can also be used for assessing the effectiveness of novel drugs and therapeutics in a particular patient population. Without such access, research is slow or disrupted.*

*Biobanks, comprised of large numbers of human biospecimens, are a critical resource for such molecular-based biomedical research. Thus, biorepositories play a key role in the pathway to the new era of personalized medicine in which treatments will no longer be “one size fits all”, but instead “tailored” to the molecular and genetic profile of each patient.*

*Biobanks – when implemented effectively – can harness the power of both genomic and clinical data and serve as a critical bridge between basic and applied research, linking laboratory to patient and getting to cures faster. **FasterCures** believes it is especially important that patients understand the key role that biospecimens and biobanks play in translational research, and how critical they are to future research discoveries.*

**Biobanks exists inside a variety of arenas, from academic medical institutions to pharmaceutical and biotechnology companies. There are also independent nonprofit and for-profit companies that provide biobanking as an outsourced service, or can serve as brokers of biological materials to other researchers. Biobanks’ primary activities are:**

- to recruit donors and to support them through an informed consent process,
- to collaborate with clinics in order to collect samples and to transport them to biobanks where they are catalogued and stored,
- to support laboratories in processing samples, and
- to handle the patient data associated with each sample in a secure manner.

*When biobanks collect tissue samples and important data regarding the source, the donors are identified by a code and only coded information is released to researchers, which is all done in accordance of federal regulations. This allows for future samples from the same source to be matched accordingly, which is especially useful in tracking the progress of therapeutic treatments, and addresses the issue of effectively preserving the donor’s privacy and confidentiality while still advancing research.*

## What are the challenges in biobanking?

There are many challenges that need to be addressed in order to improve biobanking. For example, there are currently in excess of 300 million clinical specimens in the U.S. alone, but the absence of high-quality clinically annotated tissue and a common information platform is seen as a major bottleneck in research.

## What are the barriers to patient involvement in biobanks?

Lack of trust in the protection of privacy laws and regulations impedes human participation in donating biospecimens.

Patients are inclined to participate and donate tissue to research when they have adequate information and when asked by their healthcare providers. Many donors report that they want “something good” to result from their disease, and they hope that by donating they will contribute to finding cures for others. Since many diseases have a genetic aspect, many patients believe that they will in this way be helping family members as well as society in general.

In addition to privacy issues, patients also lack information about ways they can donate, and for various reasons physicians usually do not solicit biospecimen donations from their patients.

## What is FasterCures doing?

In April 2006 **FasterCures** launched **BioBank Central** ([www.biobankcentral.org](http://www.biobankcentral.org)), a health information system that serves as an accurate and timely source of news and knowledge about biorepositories and their role in research and drug development.

### **BioBank Central aims to:**

- enable many different stakeholders to share best practices and contribute to the development of standard biorepository policies and operations;
- facilitate collaboration and cooperation within the biorepository community;
- educate the general public about the potential for biomedical advancements from the information captured in biorepositories and the need for contributions to such repositories if the potential is to be achieved; and
- facilitate the linkage between researchers and the specimen inventory and databases that comprise a national biorepository network.

**FasterCures** believes that the time to educate patients about tissue donations is not at the moment a consent form is being signed for a donation. Patient groups must be brought into the process as partners in helping to ensure that the patient community understands how biobanks work and the role they play in the clinical research infrastructure.

## What can you do?

Now is the time to contribute to advancing genomic medicine.

- You can learn more about biobanking by visiting **BioBank Central** at [www.biobankcentral.org](http://www.biobankcentral.org) and by talking with your physician.
- Ask your physician about opportunities to donate your tissue samples.
- If you are considering donating your tissue, be sure to inform your family about your wishes and about how and when you would want your samples donated.
- Contact disease-specific advocacy groups. Some advocacy groups have established disease-specific biobanks or they have additional resources on opportunities to donate tissue samples for research.

For more information on the latest advances in biobanking please visit our Web site at: [www.biobankcentral.org](http://www.biobankcentral.org)

**FasterCures/The Center for Accelerating Medical Solutions** is a nonprofit “action tank” formed under the auspices of the Milken Institute with a mission to identify and implement global solutions to accelerate the process of discovery and clinical development of new therapies for the treatment of deadly and debilitating diseases. **FasterCures’** webpage is [www.fastercures.org](http://www.fastercures.org)