Medical Alliance Pays Off: Collaboration Leads to Expanded Research Opportunities

December 15, 2008, Salt Lake City—A vast resource of information critical to cancer research is now leading to new opportunities for scientists—information that could lead to improved cancer treatments.

The collaboration known as the Huntsman-Intermountain Cancer Care Program is now yielding data that can be used for studies relating to genetics, health services and public health. Huntsman Cancer Institute (HCI) and Intermountain Healthcare (Intermountain) Cancer Services announced today that one of the main objectives of that alliance has been achieved: linking the Utah Population Database (UPDB), a research resource at the University of Utah, to medical records from Intermountain. The technology necessary to access linked data from the two institutions became operational in November 2008 and is now ready for use.

In 2005, HCI and Intermountain formed an alliance that would help both organizations maximize cancer research opportunities. While they are separate organizations and still compete in the treatment of cancer, both organizations recognized the value of sharing information that could expand cancer research and clinical trial opportunities in the region. The Huntsman-Intermountain Cancer Care
Program was designed as a way for researchers from both groups to share data used in clinical trials and other research.

Here’s what it means for doctors and patients:

- Information is now available from millions of patient records for scientists to use for genetic research (compliant with patient privacy regulations).
- Research opportunities exist that can lead to better clinical practice standards and patient outcomes.
- More opportunities are available for research funding.

Researchers use the UPDB to identify and study families that have higher than normal risk for cancer or other diseases. Several organizations contribute information to the database, including the Utah Department of Health, the Utah Cancer Registry and the Church of Jesus Christ of Latter-day Saints. The UPDB is the largest and most complete population database in the United States available for biomedical research. It contains many Utah family histories that go back as many as eleven generations.

By linking records from Intermountain and UPDB, cancer researchers now have an even larger amount of information to work with when conducting studies on genetics and inherited forms of cancer. In fact, 3.4 million patient records were linked to the UPDB. For Utah residents, 75.8 percent of Intermountain patient records were linked compared to 20 percent for non-Utah residents. Investigators at both institutions will use that information for further research and cancer treatment improvements. Three pilot studies are already using the linked data.

“It’s a great opportunity to expand cancer research for the benefit of Utah residents as well as make significant scientific contributions,” says Geraldine Mineau, PhD, director of the Pedigree and Population Resource at HCI. “We now have one of the most comprehensive resources in the world from which to conduct research,” she says.

During the process of linking these data, no medical information was released and the confidentiality of patients’ personal information was maintained at all times. Now that the records are linked, the joint resource file, which maintains patient privacy, is available for Intermountain and HCI to facilitate research.