

From Genealogy to Personalized Medicine: Utah Attracts Top Scientists

Family genealogy records dating back to the 1800s kept by the Church of Jesus Christ of Latter-Day Saints (the Mormon church) were key to Utah's emergence as a leader in personalized medicine. When geneticists asked church members in the 1970s to share the information and also provide DNA samples, they agreed, initiating a boom in genetic research and the launch of several personalized medicine-focused companies.

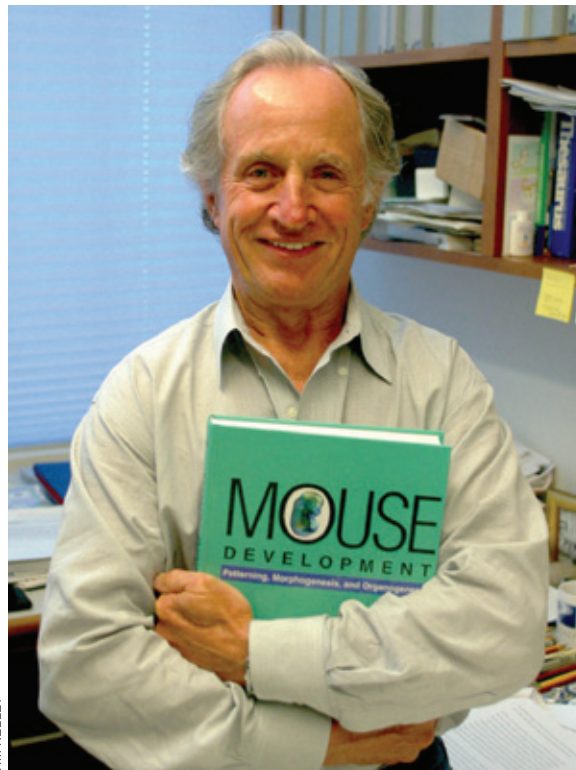
Bradley Cairns, Ph.D., senior director of basic science at the Huntsman Cancer Institute in Salt Lake City, which aims to develop individualized treatments based on the genetic makeup of both patients and tumors, says this deep pool of data from large families with several generations still living, combined with the number of scientists from many fields who are seeking to use it for new discoveries, makes Utah a unique place for scientific research. "We have families with a predisposition to cancers or diseases. We have teams of epidemiologists to research genetic mutations," he said.

University of Utah serves as catalyst for innovation

"We are about more than incorporating genetic research. We are personalizing our health care system to enhance individual patient care by personalizing their susceptibility, diagnoses, prognosis and treatment. We are facilitating not only patient care but research and education as well," said Michael Varner, M.D., interim director of the **University of Utah** Program in Personalized Health Care.

Utah's scientific contributions in genetics and biology were recognized with a Nobel Prize in 2007. Mario R.

Capecchi, Ph.D., distinguished professor of human genetics and biology at the University's Eccles Institute of Human Genetics, won the prize for pioneering development of "knockout mice" technology, a gene-targeting technique



TIM KELLEY

Mario R. Capecchi, Ph.D., a professor at the University of Utah's Eccles Institute of Human Genetics, won the Nobel Prize for pioneering development of a gene-targeting technique in mice.

that allowed the creation of animal models for hundreds of human diseases, including cancers in mice.

On the education front, the university is helping to raise a generation that understands the science behind personalized medicine through professional development forums for educators. It is also bringing gene science to the masses through its teaching website, Learn.Genetics™ (<http://learn.genetics.utah.edu>), one of the most

widely-disseminated education websites in the world, which has received in excess of 7.1 million unique visits from more than 180 countries annually. It also partnered with The Leonardo Museum to build an interactive genomics exhibit, opening in September, where visitors will be able to submit DNA samples for interdisciplinary research into genes' connections with cognition and behavior.

Scientific discoveries spawn personalized medicine-focused businesses

In 1980, Mark Skolnick, Ph.D., and Raymond White, Ph.D., both of whom were at the University of Utah, were two of the four researchers who proposed a method for constructing a genetic linkage map using restriction fragment length polymorphisms (RFLP) that was used in subsequent years to identify several human disease genes including Huntington's disease and breast cancer predictor gene BRCA1. Dr. White went on to found the Huntsman Cancer Institute. In 1991, Dr. Skolnick co-founded Utah-based Myriad Genetics, which among other diagnostic tests offers one for breast cancer predisposition.

Bill Harten, a computer scientist who developed GEDCOM, an open-source program that enables different programs to share genealogy information for the Mormon church, worked with Myriad Genetics' scientists to develop the sophisticated software they required to process the enormous amount of data involved in their genetic and genomic research. He also worked with **Celera** on the Human Proteome Project, among others. From that origin, a technology and company evolved, **UNICconnect**,

a company which provides software platforms that manage gene data workflow.

One of UNICConnect's clients is Utah-based **Axial Biotech**, a molecular diagnostics company that developed the ScolioScore™ test. The test, launched in 2009, helps determine whether or not scoliosis requires aggressive treatment by using a panel of genes to predict the risk of disease progression. Other clients include Clariant, which was recently purchased by **GE Healthcare**, and Vivia Biotech, based in Madrid.

Another Utah company, **Lineagen, Inc.**, introduced the FirstStepDx Test this year. The test is designed to help physicians evaluate and treat children with autism spectrum disorder and developmental delays.

Political and thought leaders support personalized health care

The state's political leaders have also played a key role in Utah's emergence as a leader in personalized medicine. Michael O. Leavitt, who served as both the state's governor and as secretary of the U.S. Department of Health and Human Services, used his authority to bring resources and attention to personalized medicine both in the state and in Washington, D.C. Republican Sen. Orrin Hatch of Utah has also played a key role in promoting personalized medicine on Capitol Hill.

Since 2008, leaders in personalized medicine from Utah and around the country have hosted the



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The Huntsman Cancer Institute in Salt Lake City is a National Cancer Institute-Designated Cancer Center, which means it meets the highest national standards for cancer care and research and receives government support for its scientific endeavors.

Personalized Health Care Summit in Deer Valley, Utah. At the 2010 forum, Utah native Clayton Christensen, DBA, Harvard University Business School Professor and author of *The Innovator's Prescription*, kicked off an effort to develop a "Roadmap for Personalized Health Care" to highlight the ways in which personalized medicine will upend traditional medicine.



Clayton M. Christensen, DBA, has described personalized medicine as a disruptive innovation.

Dr. Christensen said he attributes much of the energy in Utah to the Huntsman Cancer Institute. "Cancer is one area where we are now identifying the disease by cause rather than symptom, so personalized medicine is really

important," he said. "There was a time in cancer that the paradigm was geographic: breast, brain, bone, blood. Now, he noted, "we've got several thousand types of cancer identified," but new research must be integrated into clinical practice in order for the paradigm to be put in place.

Dr. Christensen's Roadmap for Personalized Health Care will lay the groundwork for this necessary transition. Slated for release later this year, it will be based on Christensen's analysis of how disruptive innovation can be harnessed to bring about top-to-bottom changes in the health care system.

"This is not like Route 66," he said. "In order to make any progress at all, you have to get through intersections—and you can't get through them unless all of the other players arrive at the intersection at the same time." The road map will show those "intersections" or nodes where different stakeholders will need to be in synch on solutions, he said.