Newborn screening program comes home to Nevada

For 30 years, the clinical lab work performed on behalf of the Nevada Newborn Screening Program has been conducted at commercial laboratories in Oregon.

With the passage of Nevada Senate Bill 131 in 2011, that clinical lab work is coming home to Nevada, to the Nevada State Public Health Laboratory, which is part of the Division of Health Sciences at the University of Nevada, Reno.

Newborn screening is a state public health service generally performed by state public health laboratories. Every year, more than 4 million U.S. newborns are screened for genetic and metabolic conditions, and hearing loss as part of a process called “newborn screening.”

For babies who test positive for one of these conditions, rapid identification and treatment makes the difference between health and disability—or even life and death.

Nevada has historically used the Oregon Public Health Laboratory to perform these analytical activities. As Nevada looked for ways to diversify its economy in recent years, it looked to mandated services that were being performed outside the state that could be awarded to a Nevada company or institution. The Nevada State Public Health Laboratory was given this priority, through Senate Bill 131 during the 76th Session of the Nevada Legislature, which resulted in NRS 442.009, to provide newborn screening analytical services for the State of Nevada.

It is estimated that between 35,000 to
40,000 babies are born each year in the Silver State. The Nevada State Public Health Laboratory, in conjunction with the School of Community Health Sciences, will be responsible for testing for approximately 46 disorders in each Nevada newborn, resulting in up to 1,840,000 tests potentially being conducted by the laboratory on an annual basis.

“Having the newborn screening program in Nevada is a good carrot to potential highly trained employees,” says Trudy Larson, M.D., director of the School of Community Health Sciences, explaining one of the expected economic benefits of having all aspects of the screening program contained within the state’s borders.

Taken within 24 hours of birth and again at the age of two weeks, the testing done on blood spots taken from heel sticks screens for life-threatening diseases and conditions that fall into four main categories: hemoglobinopathies, such as sickle cell disease; cystic fibrosis; endocrine disorders including hypothyroidism and metabolic disorders.

In 2012, Thomas L. Schwenk, M.D., vice president, Division of Health Sciences, knowing that the testing outcomes from the newborn screening program are a matter of public health in Nevada, asked the University’s School of Community Health Sciences to work closely with the Nevada State Public Health Laboratory to ensure the success of the newborn screening program in the state.

Larson says the clear challenge was how to ramp up to administer and oversee the newborn screening program with no appropriated funding from the legislature.

Two solutions came to the forefront: an increase in the fees charged for gathering blood spots from newborns at hospitals and birthing centers to sustain the ongoing administration of the program, along with a generous gift from noted biomedical researcher Mick Hitchcock to purchase analytical testing equipment.

When Division of Health Sciences leadership identified that purchasing the equipment would significantly reduce the annual operating costs, Hitchcock happily stepped forward to provide the up-front purchase funds for the equipment.

“I am pleased to be able to assist in this endeavor to bring the Newborn Screening Program back to Nevada. This will keep jobs and money in Nevada and provide a stepping stone to the future of additional biomedical opportunities in Reno,” Hitchcock said.

In addition to purchasing new equipment, the Nevada State Public Health Laboratory has also hired staff to administer and coordinate the program and clinical scientists to operate the new equipment, conduct tests and interpret the results.

According to Larson, if the screening tests find one of the diseases or conditions, the newly hired newborn screening coordinator, Ofelia Gentscheff, initiates a series of notifications to the newborn screening program’s medical director, who may then consult with medical specialists regarding the newborn’s specific condition, followed by rapid notification of the infant’s primary care doctor and the baby’s family to make sure they have access to the support and services needed.

Stephanie Van Hooser, the long-time administrative director at the Nevada State Public Health Laboratory, has been busy reviewing other state programs for background and context in running newborn screening programs, developing work flow processes and laboratory program functions and looking at ways to grow over the long term so that the lab’s clinical services can be expanded to other health care agencies across Nevada.

“I see the State Public Health Lab as the anchor and base on which to grow educational opportunities, testing opportunities and training opportunities for technicians in our state,” she said.