



**EMBARGOED UNTIL TUESDAY, OCTOBER 2, 8 A.M. EASTERN**

## **HEALTHY NEVADA PROJECT SHARING CLINICAL RESULTS WITH CONSENTING PARTICIPANTS**

*Renown and DRI's Health Study Powered by Helix Notifying Volunteers of Familial Hypercholesterolemia Risk*

**Reno, Nev. (Oct. 2, 2018)** – The [Healthy Nevada Project](#) led by Renown Institute for Health Innovation (Renown IHI) is announcing another landmark milestone – returning clinical results to consenting study participants and if they choose, providing guidance for treatment and additional testing for family members. This is a key step as study researchers, care providers and scientists begin working on a number of clinical programs and scientific studies focused on Washoe County's high age-adjusted death rates for heart disease, cancer and chronic lower respiratory disease. Locally, these collective conditions are 33 percent higher than the national rate.

### **Healthy Nevada Project's Evolution & Expansion**

In just two years, the Healthy Nevada Project which combines genetic, clinical, population and environmental data has quickly expanded and evolved. Leveraging healthcare network [Renown Health's](#) forward-thinking approach to community healthcare and world leader in environmental sciences, the [Desert Research Institute's \(DRI\)](#) data analytics and environmental expertise, Renown IHI has grown its capabilities to lead a larger, more complex research study of significance that will analyze and model public health risks in the Silver State and serve as a national model for future population health studies working to improve overall health through clinical care integration.

In September 2016, the pilot project enrolled 10,000 participants in just 48 hours. In March 2018, phase two of this monumental project expanded to an additional 40,000 participants with genetic testing partner, Helix. Personal genomics company [Helix](#) uses Next Generation Sequencing technology instead of genotyping and operates one of the world's largest CAP- and CLIA-accredited exome sequencing labs. The Helix.com marketplace model also enables the Healthy Nevada Project to work with other research groups and industry-leading companies at the forefront of using genetics to drive better health outcomes. Through Helix's genomic sequencing, the Healthy Nevada Project provides both study volunteers and researchers greater depth and quality of DNA data to gain further insights to improve health.

### **Notifying Participants of FH, BRCA1/2 & Lynch Syndrome Risks**

Returning results for familial hypercholesterolemia (also known as FH) is a prime example. FH is an inherited defect in how the body recycles LDL or bad cholesterol. In late July, a paper published in the *Journal of the American College of Cardiology* [recommended genetic testing become the standard of care](#) for patients who have a definite or probable diagnosis of FH. Through the Healthy Nevada Project, Dr. Christopher Rowan, Renown Institute for Heart & Vascular Health cardiologist and Renown IHI medical director of research, is contacting study volunteers who asked to be notified of their risk. The Healthy Nevada team is also offering genetic testing at no cost to anyone in their family who may also be at risk and providing treatment recommendations to help reduce future risk.

"I just learned my FH diagnosis last week and am already changing my lifestyle," said Jordan Stiteler, a 29-year-old study participant who now plans to test her 1-year-old son. "My dad passed away suddenly at the age of 45. After he passed, I learned I had high cholesterol but still didn't know it was genetic until receiving these results. I didn't know the test could give me so much information, I thought it was only ancestry. I hope hearing my story will inspire others to test and help save someone else from going through the same things I did."

Additionally, Renown IHI has started advanced calcium score screenings for pilot phase participants at higher risk for cardiovascular disease. This will allow researchers to examine the link between genetics and calcium buildup in the heart.

"This is the future of health; not just reacting to sick people, but a coordinated effort between innovative technologies, data-driven researchers, and responsive practitioners to deliver personalized interventions to identify, prevent and treat disease," said Anthony Slonim, M.D., Dr.PH., FACHE, president and CEO of Renown Health and president of Renown IHI. "As care providers, we often don't see patients until they're already sick and that's a difficult problem. By embracing personal genomics, we can accelerate the ability of researchers to access data and apply those learnings back to our health system sooner."



Committed to providing study participants clinically actionable data that will truly help improve their health, FH notification is just step one as the Healthy Nevada Project begins to return clinical results. In the coming months, the Healthy Nevada Project will also notify study volunteers at risk for other CDC Tier 1 conditions including hereditary breast and ovarian cancer syndrome (caused by pathogenic mutations on the BRCA1/2 genes) and Lynch syndrome. The Project is focusing on these conditions because they are both the most common and early detection and treatment will save lives.

“This research allows us to look into cancer, cardiac, respiratory illness and beyond to identify underlying causes, assess real risks and eventually initiate appropriate preventive actions much earlier. Human subject research is often intangible to participants – we are treated as subjects. The Healthy Nevada Project is creating actionable information for our participants while engaging in leading-edge research on health determinants,” said Joseph Grzymalski, Ph.D., associate research professor at DRI, principal investigator of the Healthy Nevada Project and chief scientific officer for Renown Health.

### **Fastest-Moving Population Sequencing Project Continues to Expand**

The Healthy Nevada Project also announced 25,000 phase two participants have been tested in six months, making this project among the fastest-moving population sequencing projects in the world. By the end of 2018, the project plans to complete sequencing of 40,000 people – including a demographically representative set of Renown Health’s patient population – bringing the project’s total enrollment to 50,000 people which is approximately 10 percent of northern Nevada’s population.

Looking ahead, the Healthy Nevada Project is planning for the next phase which aims to reach more than 250,000 people with the aspiration to not only offer genetic testing to every Nevadan interested in learning more about their health and genetic profile but also expand to new communities across the United States to ultimately drive positive health outcomes nationwide. Simultaneously, the Healthy Nevada Project will expand Nevada’s access to leading-edge clinical trials and foster new connections with biotechnology and pharmaceutical companies.

The accelerated speed of this project is made possible thanks to the ever-decreasing cost of sequencing. Today, Helix is able to sequence an entire exome, which allows reporting on most actionable genomic knowledge, for a fraction of what it would have cost just 10 years ago. This is increasing the number of genomes that have been sequenced. At the same time, advances in digital health mean Helix and the Healthy Nevada Project can capture unprecedented amounts of health data digitally, making significant contributions to advancing precision health. The partnership has managed to remove the traditional barriers of population health studies, including the difficulty in recruiting participants, establishing quality high-throughput lab systems, and scaling interpretation and return of results.

“We are excited to leverage our core competencies in high-throughput sequencing, consumer experience, and a robust technology platform to give participants a more dynamic and educational journey with their DNA,” said Robin Thurston, CEO of Helix. “Because we’re sequencing and securely storing DNA data, participants can continue their learning and exploration on their own, whether it be for wellness, entertainment or beyond. We’re supporting actionable health outcomes on a population level and personalized DNA learning for individuals. The products available to participants who engage in health surveys continue to expand, and now include nutrition and fitness apps from Lose It!, Intelliseq and DNAFit, traits and ancestry apps by HumanCode and Insitome and a carrier screening product from Sema4 for couples interested in future family planning.”

Phase two of the Healthy Nevada Project is still recruiting participants over the age of 18. In addition to opting in to receive clinical results, study volunteers receive access to National Geographic’s Geno 2.0 ancestry app. If participants choose to complete a follow-up project survey, they will have the chance to pick an additional health and wellness app specific to their individual genetic results. Learn more and sign up at [HealthyNV.org](http://HealthyNV.org).



**Renown Institute for Health Innovation** is a collaboration between **Renown Health** - a locally governed and locally owned, not-for-profit integrated healthcare network serving Nevada, Lake Tahoe and northeast California; and the **Desert Research Institute** - a recognized world leader in investigating the effects of natural and human-induced environmental change and advancing technologies aimed at assessing a changing planet. Renown IHI research teams are focused on integrating personal healthcare and environmental data with socioeconomic determinants to help Nevada address some of its most complex environmental health problems; while simultaneously expanding the state's access to leading-edge clinical trials and fostering new connections with biotechnology and pharmaceutical companies. Learn more at [www.healthynv.org](http://www.healthynv.org).

**Helix** is a personal genomics company with a simple but powerful mission: to empower every person to improve their life through DNA. We've created the first marketplace for DNA-powered products where people can explore diverse and uniquely personalized products developed by high-quality partners. Helix handles sample collection, DNA sequencing, and secure data storage so that our partners can integrate DNA insights into products across a range of categories, including ancestry, entertainment, family, fitness, health and nutrition. Helix is headquartered in the San Francisco Bay Area and operates a CLIA-and-CAP-accredited Next Generation Sequencing lab in San Diego, powered by Illumina (NASDAQ:ILMN) NGS technology. Helix was founded in 2015 with support from Illumina, its largest shareholder. Learn more at [www.helix.com](http://www.helix.com).

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