



## The Navajo Nation Office of the President and Vice President

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### FOR IMMEDIATE RELEASE

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## Navajo Nation signs data sharing agreement to advance uranium exposure research efforts



**PHOTO:** Navajo Nation President Jonathan Nez, John Hopkins University, subcontractor RTI International – Research Triangle Park representatives, U.S. Department of Health and Human Services Deputy Secretary Eric Hargan, and Leupp Head Start students during an agreement signing ceremony at Navajo Head Start in Leupp, Ariz. on May 7, 2019.

**LEUPP, Ariz.** –Navajo Nation President Jonathan Nez signed an agreement on Tuesday during a ceremony held at Navajo Head Start in Leupp, with John Hopkins University and their subcontractor RTI International – Research Triangle Park to allow for data sharing between the Navajo Nation and grantees of the Environmental influence on Child Health Outcomes (ECHO) grantees under the National Institutes of Health.

The agreement enables the Navajo Birth Cohort Study to continue as part of the ECHO program and for individual participant data to be shared with ECHO consortium members, which does not include genetic data or sharing of biospecimens. The Navajo Birth Cohort Study was developed to

better understand the relationship between uranium exposures and birth outcomes and early developmental delays on the Navajo Nation through the epidemiologic study of pregnancy and neonatal outcomes in a uranium-exposed population.

“Through this agreement I am confident that data sharing will benefit our Navajo people and allow us to further understand the relationship between uranium exposure, birth effects, and childhood development. I am optimistic that through this partnership, the Navajo Cohort Study will continue to progress and clarify the environmental impacts on our children’s health,” stated President Nez.

“The data sharing agreement is a monumental collaboration of true government to government relationships for Indian country. We appreciate the genuine efforts to further advancing research and examine health outcomes from uranium exposure for our population. We hope this serves as a model for other tribal nations,” added Navajo Department of Health Executive Director Dr. Jill Jim.

According to the National Institutes of Health, which facilitated the data sharing agreement, the final agreement was created to respect Navajo cultural beliefs, sovereignty, and community values. It is the first tribal data-sharing agreement for a nationwide research consortium creating a large-scale database, and lays the groundwork for discussion with other tribes considering participation in biomedical research programs.

U.S. Department of Health and Human Services Deputy Secretary Eric Hargan was also present for the signing ceremony and shared his appreciation for the partnership of the Navajo Nation.

“HHS is pleased that this collaboration has resulted in a data sharing and use agreement that respects the traditions and culture of the Navajo people and we hope will build trust in research,” said Deputy Secretary Hargan. “It is exciting that the Navajo Nation will contribute to a major nationwide research program in child health that is poised to benefit Navajo mothers and children as well as moms and kids across the United States.”

Launched in 2016, the Environmental influence on Child Health Outcomes aims to enhance the health of children for generations to come. ECHO investigators study the effects of a broad range of early environmental influences on child health and development. The program consists of 71 existing and ongoing observational studies, which now includes the Navajo Birth Cohort Study, as well as a pediatric clinical trials network.

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