



# THE NAVAJO NATION

OFFICE OF THE PRESIDENT & VICE PRESIDENT

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## Navajo President Joe Shirley, Jr., praises AP news report about ‘severe combined immune deficiency’ among Navajo kids

**WINDOW ROCK, Ariz.** – Navajo Nation President Joe Shirley, Jr., has complimented the Associated Press for reporting on a rare but deadly disease that affects a small percentage of Navajo and Apache children.

The Albuquerque bureau of the Associated Press broke the story on Saturday.

It reports that Navajo and Apache children show a higher incidence of “severe combined immune deficiency,” a disorder commonly referred to as “bubble boy disease” because it leaves children with virtually no immune system.

One of every 2,500 Navajo children inherits SCID, the AP reported.

In the general population, SCID is much more rare, affecting one in 100,000 children, it said.

“This is an important work of journalism in the field of health because it informs Navajo parents and the Navajo Nation about a devastating disease that affects some of our families,” President Shirley said. “I congratulate the Associated Press and reporter Felicia Fonseca for bringing this story to the public’s attention, for the research behind it, and for work that reflects the highest standards of professional journalism.”

The news story, datelined Tuba City, Ariz., begins with the description of mother Lorria Trujillo’s concerns and fear regarding the health of her late 6-month-old daughter, Charlotte.



*Dr. Morton Cowan (left) listens to the lungs of 8-month-old Sean Frank during an exam at the UCSF Medical Center in San Francisco. Associated Press Photo by Eric Risberg.*

The story reports that Ms. Trujillo “never felt she knew enough to question doctors ... she didn’t second guess them when they insisted Charlotte merely had a viral infection after months of being sick; she didn’t question them when the girl’s lungs collapsed.”

“Trujillo watched as her baby was unhooked from life support and held her until she died,” the story reports.

Without treatment, children have no chance of surviving severe combined immune deficiency, the AP reports. Prior to the late 1970s, the illness baffled doctors working with Navajo children.

Over generations, families would lose children without explanation.

Dr. Morton Cowan, director of the Pediatric Bone Marrow Transplant Program at the University of California-San Francisco who has worked with SCID patients for more than two decades, encountered his first case in the mid-1980s when he was asked to watch over Navajo patients for a doctor in Denver who went on sabbatical, according to the AP.

He told the AP that the disease appeared to be linked to genes, so in 1986 he and a research geneticist decided over lunch to find the gene — a quest that would take 15 years.

"When we ultimately found the gene and went back, we were able to show that it was the same gene mutation in every Navajo and Apache child that had the disease," he told the AP.

Researchers have identified about a dozen genes that cause SCID, the AP reports. Dr. Cowan says Navajos and Apaches suffer from the most severe form of the disorder in

which they lack a gene called Artemis. Without it, the children's bodies aren't able to repair DNA or develop disease-fighting T cells and B cells.

About 3,500 babies are delivered each year at hospitals on the Navajo Nation. A hospital policy manual developed by Dr. Diana Hu, chief pediatrician at the Tuba City Regional Health Care Corporation, outlines what diseases commonly are seen on the Navajo Nation and what to do if a health provider suspects SCIDA.

"Most of us have been here for 10 years and have seen it happen," Dr. Hu told the AP. "Our kids who are diagnosed earlier and transplanted earlier tend to do better," she said. "Our goal is to spare families from this tragedy."

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FOR MORE INFORMATION, SEE THE STORY AT:

<http://www.abqtrib.com/news/2007/dec/15/fighting-bubble-boy-disease-among-navajos-apaches/>