

Research Describes Swallowing Problems in Infants with PWS

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Original article: Silent aspiration in infants with Prader–Willi syndrome identified by videofluoroscopic swallow study

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Everyone has experienced the sensation of something “going down the wrong pipe.” When this happens, we cough it out automatically. **Aspiration** is the medical term for this type of choking - food or liquid enters the windpipe (trachea) instead of going down the throat (esophagus) to the stomach. If the body cannot detect this wrong way path, the cough reflex will not help clear the airways and infection and damage can occur in the lungs.

Dr. Salehi presented new information about this problem at the PWSA (USA) Medical & Scientific Conference in November 2017 just before it was published in the journal *Medicine*. It is the first study of swallowing in infants with PWS. In 2016, Dr. Gross and her team published their study in individuals from age 4 years to 55 years which revealed high rates of aspiration. This was published in the *Gathered View* in Volume 42, Number 1, January-February 2017.

Dr. Salehi’s team at Seattle Children’s Hospital reviewed the records of children with PWS to identify babies who had been tested with a swallowing study called videofluoroscopy. Most of these studies were done after 2012. Ten infants with PWS had been evaluated with this special test; some babies were tested several times, which resulted in a total of 23 studies. These children were 3 weeks to 29 months of age. This test was performed on these children due to a variety of feeding, choking, or respiratory problems.

The children had a typical range of feeding abilities for children with PWS, with two children fully fed by mouth, 12 feeding by tube only, and 9 children feeding by both mouth and tube. Half of the children were on growth hormone at the time of the testing. In this small study, there was no difference in the results in the children who were on GH. There were also no differences in the genetic subtype of PWS.

During videofluoroscopy, there were no outward signs that the babies were having trouble swallowing, such as coughing or choking. However, 87% of the tests showed aspiration – liquid misdirected down the windpipe instead of going down the throat. Due to the lack of outward signs this is called “silent aspiration” but is just as damaging to the lungs. Thin liquids were the most likely to be aspirated and purees the least. In addition, swallowing was incomplete, with some of the feeding remaining in the back of the mouth (pharynx) in 71% of the tests.

It is not known if all infants have abnormal swallowing. The researchers looked only at babies who had been tested, and all of them were suspected of having a problem. The next step would be to test many babies who do not have feeding or breathing problems, to see if they also have hidden aspiration or do not swallow normally. Dr. Salehi’s team took the first step needed to bring awareness. In 2017, many infants are routinely tested, and we look forward to additional research about all babies with PWS, and how to keep them safe and healthy.

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