

PIERRE ROBIN SEQUENCE

What is Pierre Robin Sequence?

A baby born with a small jaw, where the tongue falls back in the mouth and may cause difficulty breathing, carries the diagnosis of Pierre Robin sequence (PRS). It is called a sequence because it is a series of events that happen during pregnancy. Most children also have a cleft palate.

PRS can occur by itself or as part of a genetic syndrome. It is extremely important for an infant with PRS to see a geneticist, a doctor who will determine if PRS is isolated or part of a syndrome. We will help set up this appointment for you.



What are Treatment Options for Breathing Problems Associated with PRS?

The most important concern for babies with PRS is safety in breathing. When a baby lies on his back, the tongue may fall back and block the airway. This depends on the severity of PRS. If PRS is very mild, there may be minimal airway concerns. As the severity increases, so do the airway concerns.

A baby with mild PRS and minimal airway problems usually does well if positioned on the stomach - this allows the tongue to fall forward out of the airway. If positioning does not work, the baby may have a trial of a nasal trumpet. This is a small tube placed in the nose into the upper airway. When effective, it can save the baby from needing an operation.

More severe forms of PRS may need surgery to help the baby breathe. If there are no other airway differences, there are several surgical options available, including mandibular distraction. Each baby needs an individualized evaluation by a craniofacial surgeon to determine which treatment is most appropriate.

For babies who have issues in their lower airway in addition to PRS, tracheostomy may be needed.

If the baby has a cleft palate, it is usually repaired around a year of age.

How Do I Feed My Baby With PRS?



Adequate breathing is needed for adequate feeding. Any breathing/airway problems must be addressed before a baby can feed effectively. Sometimes, holding your baby in special positions may help with feeding. If a baby has a cleft palate, feeding with specialized bottles and nipples is very successful. Feeding strategies just like those used for babies with cleft palate promote good oral feeding.

If feeding remains a problem, other ways of getting nutrition will be used. A nasogastric tube may be used. This is a small tube passed through the nose into the stomach. Rarely, a baby may require a gastrostomy tube, a tube surgically placed through the abdomen into the stomach.

Taking care of a child with PRS is more than just performing surgical procedures. It requires very close follow-up. PRS can also affect a child's appearance, self-esteem, hearing, and speech. This is why all children with PRS are followed regularly by our multidisciplinary team. Experts dedicated to the care of children with craniofacial conditions from a wide range of pediatric specialties work together to make sure your child gets the best care possible.

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FOR MORE INFORMATION, CONTACT THE VCU CENTER FOR
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