UNTIL RECENTLY, THESE IMPAIRMENTS WERE BELIEVED TO BE CAUSED BY THE CARDIAC SURGERY THE INFANTS UNDERWENT TO SAVE THEIR LIVES, BUT NEW RESEARCH SUGGESTS THAT THE STAGE WAS SET FOR THESE PROBLEMS NOT ONLY BEFORE THE INFANTS UNDERWENT SURGERY BUT BEFORE THEY WERE EVEN BORN.

In an effort to understand why infants with major congenital heart disease are so neurologically vulnerable, researchers led by Dr. Steven P. Miller from the Division of Neurology at the University of British Columbia, in Vancouver and the University of California, San Francisco, scanned the brains of 41 babies with severe congenital heart abnormalities right after they were born, before they underwent any surgery. These scans are safe and noninvasive technologies that provide a window into brain structure, chemistry and functioning.

The scans revealed a pattern of microstructural and biochemical abnormalities in these infants’ brains that are typical of premature babies, even though these babies were born at term. “This suggested to us that there were changes in how the brains develop in the womb in the babies with heart disease,” says Miller.

It remains unclear what causes the abnormalities in brain development, but Miller says that animal studies suggest it may be related to impaired delivery of oxygen, in utero, to the brain. “The next important link we need to make is between these abnormalities in the brain that we see on imaging and the outcomes that we recognize in the clinic,” he says. “I also think we need to recognize that brain injury in babies with heart disease is complicated. It’s not entirely the result of things that happen during surgery.”

Dr. Annette Majnemer, from the Division of Pediatric Neurology at the McGill University Health Centre, has done extensive research in the area of development among infants with severe congenital heart abnormalities but was not involved in this research. “These types of studies are very important in helping us to understand the mechanisms and causes of brain injuries so that we can prevent them, or if we can’t prevent them then minimize the events that can occur in the immature brain,” she says.

While standard magnetic resonance imaging (MRI) detects brain injuries well, more sophisticated MRI technology was needed to detect the abnormalities in the brain development of these infants.

“The study also demonstrated that children born with severe congenital heart abnormalities are a high-risk group, much like premature infants,” she says. As a result, they may similarly benefit from years of close follow up and screening for developmental disorders so that problems can be identified and addressed early on. Families of these infants also need support to help them cope with the very stressful situation of having a sick child who may need special care for years to come.

In fact, research conducted by Majnemer’s team has already suggested that, by school age, many of the children born with severe congenital heart defects are having trouble. “Many of the children were not receiving educational and rehabilitation services even though the parents felt they needed it,” she says.

Another important implication of this research is the need to scan the brain of the babies with congenital heart disease to recognize brain injury and help counsel families.

“I also think that there were changes in how the brains develop in the womb in the babies with heart disease.”