

**MEDICAL BREAKTHROUGHS**  
**RESEARCH SUMMARY**

TOPIC: BABY LUCAS SURVIVES EXENCEPHALY  
REPORT: **MB #4930**

**BACKGROUND:** Lucas had a condition called exencephaly; it's a condition where the brain actually is on the outside of the skull. Exencephaly is a rare malformation of the neural tube with a large amount of protruding brain tissue and absence of calvarium. It is considered to be an embryological precursor of anencephaly where the facial structures and the base of brain are always present. The incidence of exencephaly is 3 per 10,000 pregnancies and the absence of the calvaria causes brain destruction by exposing the developing brain to amniotic fluid and repeated trauma.

(Source: <https://www.sciencedirect.com/topics/biochemistry-genetics-and-molecular-biology/exencephaly>.)

**DIAGNOSING:** What causes exencephaly is the failure of the anterior neuropore to close during the 4th week of embryonic development. The underlying defect is due to a failure in mesenchymal migration. In pathologic studies, the exencephalic brain is noted to be covered by a highly vascular epithelial layer. The two relatively equivalent cerebral hemispheric remnants are present within a reddish mass of disorganized tissues, remnants of deep cerebral neural elements, blood vessels, fibrous tissues, and fluid-filled spaces. The remaining brain has been termed the "anencephalic area cerebrovasculosa." In exencephalic brain tissue, the gyri and sulci are shallow, flattened, and disorganized.

(Source: <https://obgyn.mhmedical.com/content.aspx?bookid=1306&sectionid=75204588>)

**NEW TECHNOLOGY:** Dr. Tim Vogel, chief of pediatric neurosurgery at North Jersey Brain and Spine Center was able to have a successful surgery on Lucas. Vogel's team also had to preserve the spinal fluid cavity so that the brain would be protected once they were done, and prevent any infection from setting in. Vogel explained that the dura, which is the brain's outermost membrane, has the ability to form bones in children under the age of 18 months. Since the operation, Vogel said bone is starting to form a protective layer around the brain, and that the scalp has grown over it, complete with hair. Future surgeries will include taking the bone currently growing and shaping it around other areas that are lacking, which makes the timing tricky.

(Source: <https://www.fox2detroit.com/news/new-jersey-baby-born-with-brain-outside-of-skull-believed-to-be-first-to-survive-condition>)

**FOR MORE INFORMATION ON THIS REPORT, PLEASE CONTACT:**

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**If this story or any other Ivanhoe story has impacted your life or prompted you or someone you know to seek or change treatments, please let us know by contacting Marjorie Bekaert Thomas at [mthomas@ivanhoe.com](mailto:mthomas@ivanhoe.com)**