

Foundation Projects- More details on website.

2020-2022 Sponsorship Grant:

Sponsoring additional trails, equipment, and training simulators for the Multi-Centered Fetoscopic Treatment of Open Spina Bifida.

2019-2022 Grant Continuation: University of California:

Further support the completion of your research project titled "Non-Immune Hydrops Fetalis: Toward a Precision-Based Approach."

2019 Grant Continuation: John Hopkins: Creation of a digital library of fetal spina bifida lesions to be used in present and future research with fetal surgeries.

2019 Sponsorship Grant:

Sponsoring Phase I trial for the Multi-Centered Fetoscopic Treatment of Open Spina Bifida

2018 Brianna Marie Foundation Research Grant: The University of California San Francisco will further their research titled: Non-Immune Hydrops Fetalis: Toward a Precision-Based Approach.

The group at UCSF is focused on prenatal evaluation and diagnosis for cases of non immune hydrops fetalis, with an emphasis on the ultimate development of innovative in utero treatments to improve perinatal outcomes. In nearly half of all hydrops cases, the cause is unknown and their goal is to uncover the wide spectrum of potential reasons with thorough genetic testing during pregnancy. This will be a multi-center collaboration to create a large and diverse NIH registry.

2017 Brianna Marie Foundation Research Grant: Brianna Marie Memorial Research Grant sponsored Dr. Gholipour's team in conjunction with Harvard Medical School and Boston Children's Hospital. The grant will fund their research around improving prenatal prognoses of pulmonary hypoplasia, with a focus specific to improving current fetal imaging techniques.

2016 Brianna Marie Foundation Research Grant:

Partnering with the Fetal Health Foundation, Dr. Jan Deprest of the University College of London Institute for Women's Health was named the recipient of the 2016 Brianna Marie Memorial Research Grant. The funds awarded to Dr. Deprest's study will be used to target prevention of congenital diaphragmatic hernia (CDH), an anomaly that disturbs lung development during fetal life. Final results on the study and outcomes will be available early 2018. Website updated with more information.

2016 Clinical Outcome Study: Clinical trial for a new method of treating babies with spina bifida via fetal surgeries that will seek FDA approval to be used in the US. The object of this study is to find a new, safer way to perform this surgery via fetoscopy (surgery that is minimally invasive where there are small incisions made and the fetus is not removed from the uterus) and different materials used as a safer option for mothers and babies. Working with Dr. Ruben Quintero and a world renowned lab we are funding the toxicity testing required to gain FDA approval to move onto the next phase of this trial. Results were positive and additional steps being taken to move forward with additional trials.

Continued:

2015-2017 Fetal Therapy Outcome Study: The Brianna Marie Foundation has sponsored Dr. Quintero and his team in the conduction of outcome studies on complicated monochorionic multiple pregnancies who received Fetal Surgeries.

The purpose of these studies is to assess the merits of different management options in these complicated pregnancies. While antenatal expectant or medical management may be of help in some of these pregnancies, in utero endoscopic surgery (also known as FETAL THERAPIES/ SURGERIES) may be warranted in others to offer the babies a better chance to survive and to have a better quality of life. An assessment of the outcomes of such pregnancies will allow Dr. Quintero and his team to share with the rest of the scientific community the achievements and potential shortcomings of such surgeries long term.

2015 John Hopkins 3-D Printer Grant Award: Partnering with the Fetal Health Foundation we sponsored the first Brianna Marie Memorial Grant and awarded the purchase of a 3D printer for the Johns Hopkins Center for Fetal Therapy.

The Johns Hopkins Center for Fetal Therapy suggests has found much success by "printing" out an image of the fetus prior to surgery allows for better preparation and planning and has resulted in some key findings and successes during surgeries.

2013- Present: Fetal Hydrops/ Fetal Therapy Resource:

The Brianna Marie Foundation is proud to be able to help other families that receive in-utero diagnoses of fetal hydrops or other conditions that may require pre-birth surgical intervention.

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*Brianna Marie
Foundation*

Improving Advancements in Fetal Surgeries



Mission

*To be thankful, to be purposeful, and
to give hope.*

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BRIANNA MARIE FOUNDATION

OUR STORY

In August 2011, Aran and Patrick were thrilled to find out they were expecting their third child. They already had two boys (2 and 5 years old at the time) and while they were praying for a healthy baby, deep down they were also hoping for a girl.



In November, at 18 weeks pregnant, they were given the devastating news that their unborn daughter had a fatal illness known as non-immune fetal hydrops. This fetal condition is caused when abnormal amounts of fluid build in two or more body areas of a fetus or newborn. In their daughter's case, it was in her lungs and stomach and the fluid prevented her lungs from developing.

After meeting with dozens of doctors and praying for a medical miracle, Aran and Patrick were given hope by a team of specialized surgeons, nurses, and healthcare professionals to continue the journey with their daughter, Brianna. They knew the odds of survival were slim, but none of Brianna's tests suggested that she had a genetic disorder and all of her other organs were growing and functioning as they should. Aran and Patrick knew they had to continue to fight for their daughter.

Aran had three serious fetal surgeries, one of which had never been done on a baby with fetal hydrops before. A total of four shunts were inserted into Brianna's chest cavity and a device known as an intraluminal tracheal occlusion was placed through Brianna's mouth to promote her lung growth. These operations were performed by Dr. Ruben Quintero, a fetal surgeon and the inventor of the device used on their child.

CONTINUED...

Aran and Patrick's daughter, Brianna, was born on March 16, 2012. She was with them for 15 of the most memorable hours before God took her back as His angel. Brianna ultimately died of cardiac and pulmonary failure. Aran and Patrick, along with their team of doctors, learned a great deal about fetal lung development and growth while on their journey with Brianna. It is their hope that more research can be done to teach medical professionals about fetal lungs as well as train, teach, and educate more doctors on the options available in fetal surgeries.

WHAT ARE FETAL SURGERIES/ THERAPIES?

Fetal surgeries/therapies are operations performed on a baby prior to birth. Fetal therapy is a therapeutic intervention used to correct or treat a fetal anomaly or condition. In almost every case where fetal therapy is needed, the fetus's life is at risk due to a diagnosed condition.



Fetal Therapy can improve the survival rates for babies suffering from fatal disorders and can prevent or reduce the likelihood of unfavorable outcomes, enhancing a baby's overall quality of life.



Fetal therapy can significantly reduce the surgical risks to mothers and babies and the total costs of providing care to babies born with serious disorders and birth defects.

A parent can never fully prepare for the loss of their child. There will forever be a hole in our hearts left by her absence, but we would not change a thing that was done during our time with Brianna. Aran got to know her on an intimate level as mothers do with their babies. We just pray that research prevents other families from having to go through the heartache that we have endured.



Brianna Marie Hissam
March 16, 2012

This is the reason for the creation of their public charity in Brianna's honor. To read the entire journey with Brianna, please purchase: [My Journey with an Angel](#)-- 100% of proceeds goes directly into the foundation.

FOUNDATION SUCCESS

*Since incorporation in 2012
the Brianna Marie
Foundation has raised
more than \$600,000 to
advance fetal medicine.*

**Over 90% of all proceeds coming into this
foundation benefit Fetal Therapies.**