

Foundation Projects

2023 FETOSCOPIC REPAIR OF OPEN SPINA BIFIDA

Working with the Fetal Institute out of Miami, Florida, the goal in 2023 is to complete the study on the fetoscopic repair of open spina bifida. They will also complete the animal study on congenital diaphragmatic hernia. In addition, they should be able to complete the outcome data on patients treated with the Q-shunt for bladder outlet obstruction. They will also complete outcome data on patients with TTTS at risk for membrane separation. Lastly, they are also conducting an analysis on the clinical value of the QLI as a gestational-age independent index of fetal lung size. This will include patients with pleural effusion and diaphragmatic hernia. These are major pivotal advancements that the Brianna Marie Foundation has been a part of in multiple stages over the past 11 years. These advancements will provide guidance to other medical institutions and providers and much continued hope for unborn babies and their families. <https://the-fetal-institute.com/>

2023 FETAL HYDROPS CENTER OF EXCELLENCE

Working with the University of California, San Francisco, funds from the Brianna Marie Foundation will be used to continue supporting genetic testing and expert multidisciplinary consultations for patients who receive care through their center (to which they would otherwise not have access), develop needed educational materials for patients and providers, and support hydrops research efforts that will continue to inform interventions for the best possible patient outcomes. <https://fetus.ucsf.edu/hydrops-fetalis/>

2021-2023 SPINA BIFIDA RESEARCH STUDY- GRANT CONTINUATION AND UPDATE

Partnered with the Fetal Institute, the physicians have been able to develop an altogether new surgical technique for babies diagnosed with Spina Bifida. In 2021 and 2022 they will be focused on increasing their patient accrual rate, the development of animated videos of surgeries for patient information and physician education. They will also be developing an endoscopic tower for their lab to aid in the ex-vivo surgical training modules. This equipment will be used to train in the Open Spina Bifida surgical technique, as well as for other surgical procedures that are currently in use and development. Publications from their work will be posted upon completion.

Update of funds used- Thanks to the Brianna Marie Foundation the 2021-2022 funds were successfully used for the following to include: IRB submission costs, outcome data collection, and video and marketing for the research study on the fetoscopic repair of open spina bifida. They were approved by the FDA to extend the number of patients in the spina bifida study which shows incredible confidence and advancements in this field. Additional funds are needed to continue to advertise the study to be able to complete the research and apply for FDA approval. They foresee that their surgical technique will become the new standard of care for open spina bifida.

For a listing of all projects since incorporation, please see <https://www.briannamariefoundation.com/our-accomplishments>

2020 NEW ENGLAND JOURNAL OF MEDICINE PUBLICATION - EXOME SEQUENCING FOR PRENATAL DIAGNOSIS IN NONIMMUNE HYDROPS FETALS

The Brianna Marie Foundation fully funded through the Fetal Health Foundation this study along with some other donors. This is a significant step for parents that had a child diagnosed with Fetal Hydrops. Journal Title: [Exome Sequencing for Prenatal Diagnosis in Nonimmune Hydrops Fetalis](#)

2020 CHILDREN'S HOSPITAL OF PHILADELPHIA - PSYCHOSOCIAL SUPPORT PROGRAM

Children's Hospital of Philadelphia (CHOP), along with its premiere Center for Fetal Diagnosis and Treatment (CFDT), partnered with the Brianna Marie Foundation, to help ensure that the best practices for psychosocial support being developed at CHOP can be shared widely among families facing challenging prenatal diagnoses. At CHOP, their belief is that caring for families facing fragile pregnancies requires more than excellent clinical care – it requires whole self-care for the entire family, encompassing the mental and emotional health of the pregnancy and birth journey.

2019 GRANT CONTINUATION - JOHN HOPKINS

In 2015 the Brianna Marie Foundation and Fetal Health Foundation funded a purchase of a 3D printer to be used with ultrasound to "print" a baby abnormalities that was diagnosed with spina bifida so that the surgeons were best prepared for surgery offering the least invasive options. They had a very successful outcome and data as a result of the 2015 study. The Brianna Marie Foundation provided additional funding in July 2019 to complete the next phase, which is creation of a digital library of fetal spina bifida lesions and optimizing the dimensions, form, and materials of the fetal host model. Although they have initiated the process, refinement of the model requires additional collaboration with colleagues in the Carnegie Center for Surgical Innovation. Funding will allow their direct support as well the option to generate several prototypes to create a final product.

Brianna Marie Foundation

**PO Box: 410402
Melbourne, FL 32941
Phone: 407.342.8979**

contactus@briannamariefoundation.com

www.briannamariefoundation.com

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Brianna Marie Foundation

Improving Advancements in Fetal Surgeries



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

www.briannamariefoundation.com

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. The foundation is contacted often by parents seeking advice, counseling, guidance, and friendship. With the precursor always given that we are not a medical institution or a staff of physicians, we do have the knowledge and resources to facilitate second opinions, grief counseling from a personal standpoint (many times it is more comforting to hear from a parent that has been in a similar situation), and offer the ability to help parents that may have experience a loss to fundraise in their child's memory.

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 \$704K to advance fetal medicine.

Thank you for helping us, help others.

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