



ELLIANNA GRACE FOUNDATION

The **Ellianna Grace Foundation** (EGF) is a **non-profit** organization that helps families who have chosen to undergo a **Fetal Cardiac Intervention** (FCI) at Children's Hospital Boston and Brigham and Woman's Hospital. The **EGF** provides **grants** to assist families with travel, food and lodging costs related to the **FCI** and follow up care. The **EGF** facilitates parent-to-parent **networking** which allows families to share information and learn from other families' experiences. In addition, The **EGF** also provides access to recently published **research** and **current news** articles related to **Congenital Heart Disease** and FCI at www.egfblog.org.

The **EGF** was founded by two families who know first-hand what this journey is like; it is their **mission** to bring **HOPE** to other families facing the same journey.





Facts about Congenital Heart Defects (CHD)*:

- » **Congenital Heart Defects** are the **most common of all birth defects**
- » In the United States, **36,000** babies are born each year with a **CHD**
- » **CHDs** remain the leading cause of all infant deaths in the United States
- » There are more than **40** different types of **CHDs**. For the majority of them, the cause is unknown. There is **no** known **prevention** or **cure**
- » For the first time, more than **50%** of the **CHD** survivors are adults

Facts about the Fetal Cardiac Intervention (FCI):

- » The **FCI** is a procedure that is performed in utero and is reserved for two **life-threatening CHD's**:
 - **Critical Aortic Stenosis** with evolving Hypoplastic Left Heart Syndrome (**HLHS**)
 - **Pulmonary Stenosis** with evolving Hypoplastic Right Heart Syndrome (**HRHS**)
- » The **primary objective** of these procedures is to dilate the narrowed aortic or pulmonary valve with the hope of halting the evolving **HLHS** or **HRHS** resulting in a two ventricle circulation after birth.
- » In addition, **FCI's** are performed near delivery on babies with established **HLHS/HRHS** who have an intact or restricted atrial septum. In these cases, the septum is dilated to prevent an emergent procedure after birth and to increase **survival rates** for these babies.
- » The **FCI Team** at Children's Hospital Boston and The Brigham and Woman's Hospital was the first to successfully perform a **FCI** with measurable results. Over the last 10 years they have performed approximately 140 interventions.
- » There is a large spectrum of outcomes after a **FCI**. Some babies go home with two ventricle circulations and do not require open heart surgery. Other babies require surgery for single ventricle palliation. Regardless of the **FCI** outcome, it is an emotionally and financially challenging road for babies and their families. **EGF** is committed to assisting parents for the duration of pregnancy, newborn period and throughout childhood.



We are here to help you and
would love to speak with you!

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