



About the Fetal Health Foundation

The Foundation was formed in 2006 by a group of parents who had experienced a fetal syndrome diagnosis. Based on their individual struggles to find resources, support and treatment options, they made it their mission to fulfill this role for other families. FHF maintains strong relationships with fetal treatment centers across the country in order to serve as a direct liaison between families and specialists and provide the most comprehensive support process possible. FHF also works with a medical advisory board, which provides guidance and access to immediate medical care, when warranted.

Fetal Health Foundation

The Fetal Health Foundation (FHF) is a national nonprofit with a big mission – saving the tiniest of lives. At the heart of our mission is HOPE. We create hope by connecting families diagnosed with a fetal syndrome with maternal fetal specialists, fetal treatment centers, and other families who have experienced a similar diagnosis; by raising awareness of fetal syndromes and treatment options; and by awarding research grants to study promising new fetal syndrome therapies and treatments.

The cause for HOPE

There are more than 4,000 known fetal syndromes, which affect 800,000+ pregnancies each year. Sadly, 200 babies die each day as the result of a fetal syndrome. Fetal syndromes are typically diagnosed at 17 to 20 weeks gestation when expectant parents receive a routine ultrasound. With that diagnosis, joy quickly turns into fear, sorrow and overwhelming confusion.

While hope exists, many expectant parents don't know where to turn. Frequently, specialized medical care is required within a few weeks of diagnosis. There are over 100 maternal fetal treatment centers across the United States that can provide treatment and special care for even the most complicated cases. However, general practitioners in small communities may not be familiar with specific types of fetal syndromes. Or an expectant family may not have the resources to travel hundreds of miles to see a specialist. FHF assists these families by providing valuable information about the fetal syndrome and treatment options, connecting the family with a specialist and helping with travel arrangements when needed.

Programs and Services

Online information – FHF maintains a robust website that contains a wealth of information on fetal syndromes, treatment options and maternal fetal specialist centers. Hundreds of thousands of people visit www.fetalhealthfoundation.org each year seeking valuable information.

Social media – With nearly 5,000 followers on its Facebook and Twitter sites and membership in several Facebook groups, FHF shares inspirational stories, awareness messages and the latest in medical research pertaining to fetal syndromes.

E-newsletter – FHF distributes information from maternal fetal centers, stories of hope from families who have experienced a fetal syndrome and valuable resources monthly with nearly 20,000 people via a monthly e-newsletter.

Annual publication – Connexions magazine provides in-depth stories about prenatal health, fetal syndromes, maternal/fetal health and the latest in fetal syndrome research. This annual publication is distributed by fetal treatment centers and medical practices, and is available online in a digital format.



Research Grant – Since the first successful fetal surgery, which occurred in 1981, the field of fetal medicine has grown at an amazing pace. Recognizing the critical role research plays in developing new therapies and treatments – which can often be adapted to treat a variety of fetal syndromes – FHF began a medical research grant program in 2014. To date, more than \$300,000 has been awarded to further research studies taking place at various centers throughout the US and in Europe.

External Resources – the diagnosis of a fetal syndrome impacts an entire family. It can have physical, emotional and financial affects on the parents and siblings, as well as members of the extended family. FHF works closely with external organizations to provide a network of support for the entire family.



Travel Grants – The best maternal fetal center for a specific fetal syndrome may be hundreds or even thousands of miles from an expectant parent's home. Some of these families are struggling financially as one – or both – parents have to take time off or quit their jobs. In cases of demonstrated hardship, FHF provides funds to allow for travel to a maternal fetal center for treatment.

Awareness Campaigns – Creating a supportive community is the best way to ensure that families and referring medical professionals have access to knowledge about fetal syndromes and various treatment options. FHF promotes fetal syndrome awareness through media campaigns and special events and also attends and presents to a variety of medical and parent conferences.

Fetal Health Foundation Milestones

- \$300,000 awarded for research projects at six leading maternal fetal centers since 2014 (among a few smaller research projects):
 - * Children's Hospital of Los Angeles
 - * University of Colorado
 - * John Hopkins Center for Fetal Therapy
 - * Katholieke Universiteit of Leuven (Belgium) and the University College of London Institute for Women's Health
 - * Boston Children's Hospital and Harvard Medical School
 - * University of California San Francisco
- \$25,000+ support provided to maternal/fetal centers and minor research projects
- 300 people assisted financially
- 1,400 families assisted via phone and email support
- 30,000 website impressions per month
- 20,000+ monthly e-newsletter subscribers
- 2,500 print copies of annual Connexions magazine
- 4,000+ Facebook followers
- 900 Twitter followers
- 6,500+ participants in annual fundraising and awareness events

For more information about the Fetal Health Foundation, please visit www.fetalhealthfoundation.org or call 980-224-0398.

