

TOOLKIT FETAL SYNDROME AWARENESS MONTH





of all pregnancies in the US are characterized as high risk, meaning that there is a serious anomaly that may affect the life of the mother or baby during pregnancy



unborn babies die each day as a result of a fetal syndrome



weeks' gestation is when fetal syndromes are generally detected



Overview of National Fetal Syndrome Awareness Month

The leading causes of high-risk pregnancies include preeclampsia, gestational diabetes, and fetal syndromes. More than 800,000 pregnancies are affected by a fetal syndrome each year. There are currently 4,000 known syndromes, and the causes are largely unknown.

YOU can make a difference --- help spread the word about fetal syndromes to increase overall awareness and understanding around the fact that it can happen to any pregnancy, regardless of mother's age, race, socioeconomic background, etc.

How can National Fetal Syndrome Awareness Month make a difference? Through accurate and more widespread information, more families will be equipped with the knowledge to be better advocates for their unborn babies. Awareness will also increase the chances of:

- better familiarity around the diagnosis
- knowledge of treatment options available + the centers providing them
- more babies' lives saved

National Fetal Syndrome Awareness Month will highlight innovations from within the fetal health community that show the most promise in transforming the diagnosis, treatment, and management of fetal syndromes.

How can I help spread the word?

We've made it so easy for you to help make a difference! Use this toolkit for ideas in taking action today. A few things you can do might include:

- Adding information into your August print or digital newsletter {click here}
- Posting on social media about National Fetal Syndrome Awareness Month with the hashtag #FSAMonth {click here}
- Registering for the Hope=Life Virtual Remembrance Event August 19-25, 2019. Registrants will receive a t-shirt prior to the week of August 19th and then plan individual remembrance/awareness events (i.e. a run/walk, balloon release, candle lighting ceremony). Share photos via social media with the hashtag #HopeEqualsLife. Registration is \$35, with a discount for groups of 4+, and is available at hopeequalslife.com. All proceeds will benefit the Fetal Health Foundation's Grants program, in supporting much-needed research and emergency travel grants for families in financial crisis when travel for treatment is necessary.



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Sharing patient family stories from within your own organization

- Adding this badge to your website, blog, newsletter, or social media profile
- Replacing your Facebook profile picture with a frame available August 1st (*Profile Photo-Update-Add Frame-Search Fetal Health*)
- · Sharing this media advisory with your area media contacts
- Accessing and sharing materials for promotion including fact sheets, infographics, social media images, and customizable templates.

Partner Organizations + Support Groups

There are several leaders throughout the fetal health community helping lead the charge for Fetal Syndrome Awareness Month. They include {but are certainly not limited to} the following:

*Multiples of America

*Now I Lay Me Down to Sleep

*TTTS Hope and Connections - Support for TTTS and SIUGR (Facebook Group) *TRAP sequence mommies and daddies (Facebook Group) *Mono-Di Twins/Multiples Support (Facebook Group)

Sample Tweets + Facebook Posts

It's National Fetal Syndrome Awareness Month! Learn more about fetal syndromes and what you need to know if faced with a diagnosis. #FSAMonth {https://www.fetalhealthfoundation.org/story/coping-with-the-unexpected/}

800,000 pregnancies are affected by a fetal syndrome each year in the US. You are not alone. There is hope. #FSAMonth {www.fetalhealthfoundation.org}

17-24 weeks' gestation is when a fetal syndrome is generally detected. Early detection and monitoring is key. #FSAMonth {www.fetalhealthfoundation.org}

A fetal syndrome diagnosis leaves parents scared and confused for their unborn baby. One family shares their story of the diagnosis, delivery and where they are today. #FSAMonth {https://www.fetalhealthfoundation.org/ myelomeningocelespina-bifida/spina-bifida_fetoscopic-surgery/}

DYK? 200 unborn babies will die as a result of a fetal syndrome today. A diagnosis isn't always the end. Empowered with information and proper treatment, more babies' lives can be saved. #FSAMonth {https://www.fetalhealthfoundation.org/fetal-syndromes/}

6-8% of all pregnancies in the US are characterized as high risk, meaning that there is a serious anomaly that may affect the life of the mother or baby during pregnancy. Find hope through answers. #FSAMonth {fetalhealthfoundation.org}

National Fetal

Syndrome Awareness Month is aimed at increasing awareness around the 4,000 currently known fetal syndromes and starting conversations around them. It is hosted by the Fetal Health Foundation, a parent founded, 501(c) (3) national, non-profit patient advocacy organization. FHF provides a range of support for families when their unborn babies are diagnosed with a fetal condition, as well as supporting much-needed research.

CONTACT:

Talitha McGuinness, Executive Director 980-224-0398 talitha@fetalhealth foundation.org

www.fetalhealth foundation.org



