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Dear Parents, Families, Friends, and All Concerned with Vein of Galen Malformation –

I have been leading a multidisciplinary group of physicians at Boston Children's Hospital and Brigham and Women's Hospital in the development of a fetal interventional procedure for the treatment of vein of Galen malformation in utero. The goal of the procedure is to significantly diminish flow through the malformation before birth. The physician team has significant experience with vein of Galen malformations and its members have been worldwide pioneers in the development of similar fetal interventions for congenital heart conditions. The intervention is being offered as a clinical trial, with the aim of assessing whether the fetal intervention is safe and whether it improves prognosis in terms of survival and neurocognitive development. The trial now has IRB and FDA approval, and is open to patient recruitment.

While many of our vein of Galen patients do very well with conventional treatment after birth, there remains a significant fraction who will develop severe symptoms within a day or two after delivery, and this subgroup has a high risk of morbidity and mortality, even with expert care. We have developed a method, based on fetal MRI scans, for predicting which fetuses are likely to have this kind of aggressive clinical presentation, and the new fetal intervention is aimed specifically at this group.

The Interventions will be performed at Brigham and Women's Hospital by a team of physicians from both institutions; I will perform the brain embolization, while the Brigham and Women's team is led by Dr. Louise Wilkins-Haug (Division Director, Maternal Fetal Medicine & Reproductive Genetics).

Candidates for this intervention must have in utero diagnosis of vein of Galen malformation, and will be assessed at the Boston Children's Hospital Maternal Fetal Care Center for appropriate fit for the trial. Interested patients should contact the Maternal Fetal Care Center at Boston Children's Hospital, at 617-355-6512.

Best regards,

