



## PRESS RELEASE

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### **HHS Secretary Adopts Newborn Heart Screening Recommendation Driven by Colleyville Organization**

**Colleyville, Texas, {09/22/11}** – On Sept. 21, 2011, Health and Human Services Secretary Kathleen Sebelius adopted a recommendation, driven in large part by a Colleyville organization, to make heart defect screening mandatory for newborn babies. Congenital Cyanotic Heart Disease will now be on the uniform panel of screenings for all babies, similar to PKU screening. The next steps are for each state to adopt the recommendation as endorsed by the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC).

One of every 115 babies is born with a heart or circulatory defect, according to the March of Dimes. It is the most common of all birth defects and the No. 1 cause of death from defects in the first year of life. Yet, those defects may go unnoticed until a crisis situation uncovers them – and sometimes, it's too late.

In January 2009, Colleyville residents Steve Kennedy and Vi Nguyen-Kennedy said goodbye to a new daughter who became one of those statistics, sending the couple on a journey they never expected to travel.

On Jan. 7, 2009, at 27 days old, Taryn stopped breathing at home, and Vi performed CPR. Taryn was stabilized at a local emergency room, then sent by air ambulance to a Fort Worth children's hospital, where she passed away two days later. Tests showed Taryn had two heart defects – anomalous pulmonary venous return and an atrial septal defect.

Vi and Steve founded a grassroots organization, Bless Her Heart, and Steve created the Web site: [www.blessherheart.org](http://www.blessherheart.org). They obtained 501(3)(c) status as a non-profit organization. They developed an informational pamphlet for new parents that the couple and other volunteers hope to distribute through hospitals, physicians or other means. Their dream is to someday sponsor larger community events to get the word out.

Bless Her Heart has been a part of the biggest impact at the federal level. Vi has reached out to the American Academy of Pediatrics and spoken twice in Washington to the Secretary's advisory committee. In September 2010, the SACHDNC voted to make the recommendation to Sebelius to screen for critical cyanotic congenital heart defects as a part of universal screening. Vi also was involved in the implementation meeting that occurred Jan. 13, 2011, in Washington.

“Losing a child is one of life's greatest tragedies,” says Vi. “This journey has been shared by many individuals and organizations, and the news by HHS Secretary Sebelius has a huge impact in the congenital heart defect community.”