

# TRISOMY 13 AWARENESS DAY

March 13, 2009



Trisomy 13, also known as Patau Syndrome, is a condition in which a third #13 chromosome is present in some or all of the cells of the body. The presence of this "extra" chromosome affects prenatal development, most often causing major disruption in the development of the brain, heart and other major organs. Trisomy 13 is estimated to occur in 1 in 10,000 live births and, sadly, many children born with Trisomy 13 do not survive the first days of life. However, there *are* children with Trisomy 13 that live well into their childhood despite the heartless, misleading prognosis that all children with Trisomy 13 are "incompatible with life"...all children with Trisomy 13 live...even if only for a short time.



Our daughter, Emma, was diagnosed with Trisomy 13 on March 10, 2008 at 23 weeks gestation. Emma was affected with a ventral-septal defect of the heart, alobar holoprosencephaly (failure of the forebrain to divide) and a proboscis. Emma lived for 36 weeks and was born at rest on June 10, 2008 weighing 3 pounds and 4 ounces. Emma arrived in this world a true angel, with a full head of curly, strawberry blond hair and a gentle, loving spirit. In her brief 36 weeks of life, she touched the hearts of many. The sadness we face

in living our lives without her pales in comparison to the love and joy she brought to us and everyone who embraced the time we were given with her; it is our hope that others who are faced with the diagnosis of Trisomy 13, will feel the blessing of these tiny miracles.

~Jared and Tamara Gavin