

# HI, MY NAME IS EMALYN

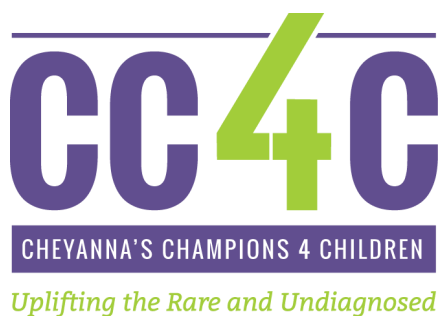
I am 7 years old and have been diagnosed with a rare condition.



Within 3 months, Emalyn's curvature progressed from 20 degrees to 53 degrees. The rapid progression concerned her orthopedic doctor, resulting in an MRI. The MRI showed an abnormality on the left ventricle of her brain, resulting in a diagnosis of colpocephaly. Emalyn is developmentally delayed and receives special education services to support her educationally.

Her neurologist then tested her for a genetic disorder. Results showed a rare genetic deletion that is so rare it was not associated with any particular syndrome, nor was it well tested. The rare genetic deletions contribute to a host of medical conditions. Emalyn had corrective heart surgery at 2 years old. When she was five years old she received a g-tube, because she was significantly underweight. She also was hospitalized for five months at Texas Scottish Rite Hospital to undergo Halo traction treatment and MAGEC rod surgery, because her spinal curvature progressed to 90 degrees.

Emalyn continues to be at risk to undergo emergency surgery related to the 200 percent complication rate associated with the MAGEC rod surgery. There is an art practice in Japan known as Kintsugi, referring to the art of previous scars, where they take broken ceramics and repair it with gold. This Japanese art teaches that the broken objects are not something to hide but to display with pride. Each surgery, or scar, or new diagnosis is something she takes with strides and contributes towards her resilient spirit.



Emalyn's Motto:

## “Get Your Cape On”