



Child's Name: Jeremy Murillo

Age: 2½ Years

Hometown: Duncan, OK

Diagnosis: Goldenhar Syndrome



Background: Jeremy was born with a heart defect called Goldenhar Syndrome or Oculo-auriculo-vertebral dysplasia (OAVD). He underwent two open heart surgeries, two brain surgeries at OU Children's Hospital. Jeremy has since been enduring intense neurology, cardiology, orthopedic, urology, hematology, and ophthalmology treatments. He is being fed by a J tube; has abnormal development of his eyes, ears, and spine; has bilateral hip dysplasia; and significant airway obstruction requiring intermittent supplemental oxygenation. Jeremy's mother stays home to provide full-time care while his father works to provide for a household of six.

Information: Goldenhar syndrome is a congenital defect that causes facial and spine abnormalities. Babies born with Goldenhar syndrome typically have birth defects that affect the formation of the eyes, ears, and vertebrae though it can impact other parts of the body. Severity of the symptoms can vary widely from person to person. This disease cannot be cured. Treatment is focused on helping people live their best life possible with the disease. Although specific statistics are not readily available in Oklahoma, Goldenhar syndrome is estimated to occur in about 1 in every 3,000 to 5,000 births in the United States.

Illness/Disease Color:

Goldenhar Syndrome Awareness Month: July

