



Child's Name: Oliver DeCarlo

Age: 10 Months

Hometown: Marlow, OK

Diagnosis: Myelomeningocele (Spina Bifida)

Background: Oliver's parents found out Oliver would be born with spina bifida when Karen, Oliver's mom, was six months pregnant. This was devastating for his family and left them with lots of doubts and questions. When Oliver was born, his parents were able to see him quickly, but after less than a minute he was admitted into the NICU. He had a large hole in his lower back that was leaking out spinal fluid. Just four days after he was born, Oliver started undergoing neurological and plastic surgeries to repair the damage, stop the leak, and patch the skin. His second round of surgeries came when he was two weeks old. A stint had to be placed due to the spinal fluid continuing to build up after his first surgery. Due to the surgeries and risk involved Oliver had to lay flat on his stomach for two weeks and his parents were not able to hold him during this time. Oliver spent one month in the hospital and thanks to the outpouring of love from friends and family, his parents were able to be with him during that scary time. Even though Oliver had a rough start, and each day comes with challenges and new lessons learned, he has brought lots of joy to his family. He is a very happy baby and loves to laugh! His family shared that the only time he cries is when he is hungry! When Oliver got to attend the meet and greet with the VHR band and ACTS team, the first thing he did after entering the room was flash a big bright smile! Joy was definitely present in that room. Oliver has overcome so much already and is making strides every day. His family works very hard to provide the care he needs. He goes to monthly appointments, and needs catheters four times daily, and may likely need that the rest of his life.

Information: Myelomeningocele - A severe type of spina bifida, a neural tube defect that occurs during the early fetal development. In this condition, a portion of the spinal cord and the surrounding nerves protrude through an opening in the backbone, forming a sac on the baby's back. This sac is often visible at birth and may be covered by skin or exposed. In Oklahoma, approx. 3.74 babies per 10,000 births are born with spina bifida. The most common permanently disabling birth defect in the U.S. affects about 1,500 babies each year. Hispanic women have the highest rate of having a child born with the illness compared to non-Hispanic women. Lifetime care for spina bifida costs in excess of \$1.4 million in some cases.

Illness/Disease Color: Yellow

Spina Bifida Awareness Month: October

