The Clinic for Special Children has been a part of our family for many years. For our daughters Joella, Cailey, and Terina, they provided us with the relief that comes from a diagnosis that they were unaffected by spinal muscular atrophy (SMA). For our children Miranda, Jeremy, and Kirklyn, they walked alongside us on each of their unique journeys with SMA...

Twenty-two years ago, we were hugging our 2 1/2-month-old baby girl, looking on with tear-filled eyes as the doctor gently explained to us that Miranda had SMA and what it would mean for her. "Her mind will be normal; but she will never be able to sit or walk on her own, and she will continue to grow weaker. Babies with this disease die before a year old, since there is no cure, no medicine that helps." These were the words we heard that day. We cherished every moment as his words became true and she passed away at six months old.

On Christmas Day of 2003, we were blessed with Jeremy. His cord blood was tested by the Clinic and three weeks later we had his diagnosis of SMA... He had no symptoms to make us suspicious, but as the weeks went by, he grew weaker instead of stronger. During a check-up at the Clinic we could sense the doctor's frustration as he squeezed his chubby leg, and said "The muscles are still there. If only we could find a way to make them work before they atrophy completely." We started watching the clinical trials for drugs for SMA, but it was fail after fail. We strongly felt we would participate in a trial, but time with these children is so short, and Jeremy passed away at six months old.

The Sensenig Family

Over the next 15 years we read all we could about these trials. In early 2018, when we were expecting our son Kirklyn, we had a meeting with the doctors and research team from the Clinic where they explained to us the available drugs for SMA. One had recently been FDA approved, the other in a clinical trial. We needed to decide, and have a plan in place for when our son was born, if diagnosed with SMA. We had seen first-hand the need to move quickly before SMA babies begin to lose strength.

Kirklyn Jase was born Saturday, July 7, 2018, and diagnosed with SMA at three hours old. The Clinic team was there for us. A day later we handed our tiny baby over to them and said, "Do what you need to do to get him cleared for the gene therapy trial. Kirklyn needed to be asymptomatic to be entered into the trial, and he was! The Clinic had followed the research and was activated as a clinical trial site for the SMA gene therapy study, seeing the need for this approach in their SMA families. Kirklyn was dosed at one week old at Penn Medicine Lancaster General Hospital, a red-letter day for us and the Clinic.

We had many visits, blood tests, etc., but they were mostly joyful visits as we experienced a miracle! He moved like normal, he sat, he crawled, he walked! The Clinic is his primary doctor to this day and have been there for us whenever he's been sick. When he suddenly grew weaker, they were in contact with doctors from all over the world to find out how to handle his situation. Since the therapy is so new, there really isn't data out there on what is normal for a treated child. The Clinic began a research study to learn more. They have never made us feel like a bother calling after hours and have even met us on their day off to help us when we needed them.

Today our five-year-old runs after daddy, asks tons of questions, teases his sisters, and talks about going to school in the future...because Lord willing there is a future for him. He does have minor weakness, but nothing that can compare with our first two SMA children.

We stand amazed! I will praise Thee for I am fearfully and wonderfully made. Psalm 139:14 May you be blessed as you support the Clinic for Special Children, in their work of making life easier for their patients and their families. Your contribution means more than you'll ever know as it touches the lives of those with special needs.

Terry and Lynette Sensenig and family