When you see Jaxon Cope smile, you cannot help but smile back. But there is much more than just a charming smile to this little boy; he is a little boy of courage and determination. Jaxon was born with a rare genetic syndrome called Beckwith-Wiedemann Syndrome. Only 1 in 12,000 newborns worldwide are diagnosed with this overgrowth syndrome that affects many parts of the body. In addition to gross motor delays and impairments, Jaxon’s speech, vision and hearing are also affected. But don’t underestimate this little guy.

Jaxon was enrolled in the Lily Pad at Easter Seals West Kentucky at two months of age. The Lily Pad at Easter Seals West Kentucky is designed to give children who are medically fragile quality medical care in the least restrictive environment possible. When Jaxon started the Lily Pad he had difficulty eating and his muscles were so tight he stayed flexed and stiff, and didn’t want to bend. Now, just 12 months later, eating is no longer a challenge and Jaxon is sitting up, crawling, and pulling up. He is now a man on the move!

“Beckwith-Wiedemann Syndrome is a rare syndrome and for him to progress as well as he has is amazing,” says Michelle Walls, RN. “He is a happy boy with such a wonderful personality.” Becky Fortner, RN adds “We are thrilled that he is mobile now and interacting with other children, especially the girls. He’s such a ladies man!”

Enrolling a child with complex medical needs in quality child care can be overwhelming. For many of these parents, leaving the work force is not an option. They need income and health care benefits to help offset the costs associated with caring for a child with complex medical conditions. While attending the Lily Pad at Easter Seals West Kentucky, children can play and learn with other children in a safe, nurturing, and medically supervised environment, freeing their parents to work and/or attend school.

Brandi Cope, Jaxon’s mother shares how the Lily Pad at Easter Seals West Kentucky has benefitted not only Jaxon, but their family. “Coming home from Kosairs’ NICU with a baby on an apnea monitor and so many upcoming medical needs and surgeries was very scary. I knew that I needed to be there for him but that my maternity leave would be over soon. His father works on the towboats as well and with his schedule he could not take time off to stay with him either. Hearing about the Lily Pad was truly a miracle and perfect timing! It was comforting to know that the Lily Pad was staffed with nurses and trained personnel that would recognize anything out of the ordinary with Jaxon and know how to handle emergency situations that might come up. I can’t explain to anyone how much better I felt about leaving him with the wonderful staff there and knowing that my baby would be alright instead of being at work scared that something would happen and that no one would know what to do. I am surprised at all of the new things that he has learned over the past year and how he has learned to interact with other babies there.”

The Lily Pad at Easter Seals West Kentucky assists families in retaining independence, enables parents the ability to return to work or school, broaden resources, improve quality of life, and renew hope. Through your contributions to the Lions Club/WPSD Local 6 Telethon of stars, Jaxon and his friends enrolled in the Lily Pad at Easter Seals West Kentucky will continue to receive the services to meet their medical needs and maximize independence!