



Thor undergoing chemotherapy to prepare his body to receive his sister's umbilical cord blood stem cells.



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Duke doctors perform unique cord-blood transplant to save boy

Allogeneic umbilical cord blood infusion in chronic granulomatous disease patient

Thanks to a procedure performed at Duke University, a little boy with a serious illness is on his way to a normal life.

While stem cell transplants using umbilical cord blood are becoming more common, doctors say this one was unique. Thor Uran is an active 2-year-old boy with a big smile and a habit of blowing kisses. He is already showing brotherly love to his little sister, Lila. “They’re going to be connected in a very unique way.

They literally have the same blood,” said Thor’s mom Justine Uran.

Just weeks after Lila was born, the blood from her umbilical cord was transplanted into her brother, who’s battling a rare genetic disorder called Chronic Granulomatous Disease (CGD). CGD put him at constant risk of infection.

CGD is a genetic disorder in which white blood cells called phagocytes are unable to kill certain types of bacteria and fungi. People with CGD are highly susceptible to frequent and sometimes life-threatening bacterial and fungal infections.

“There are certain bacteria and funguses he can’t fight off,” explained Justine Uran. Her husband, Dustin, added, “He couldn’t play in leaves he couldn’t play in dirt he couldn’t be in fresh water.

“Given the type of disease that Thor had, I would not have expected a normal life span for him,” said Dr. Vinod Prasad, with Duke University’s Pediatric Blood and Marrow Transplant Program.

Thor’s best chance for a normal life was a bone marrow transplant, but doctors couldn’t find a match. So the family, who lives in Minneapolis, looked into using cord blood. The Urans turned to Duke because of the hospital’s expertise when it comes to cord blood transplants.



Duke performed the first unrelated cord-blood transplant in the world in 1993. But doctors at Duke have only done a handful of transplants like this one. “This was actually very interesting and almost cutting edge at a number of levels,” said Prasad.

The Urans in hospital after Thor’s successful stem cell transplant.

At the time, Justine Uran was pregnant with Lila. Before Lila was born, doctors were able to determine that the baby did not carry CGD and that her cord blood was a match for Thor. The Urans left their jobs in Minnesota and moved to Durham for Lila's birth and Thor's transplant.

First, chemotherapy destroyed Thor's immune system so he could accept his sister's cells. The family was in the hospital for 42 days. More than three months after the transplant, Thor is acting like his old self but still waiting for his new immune system to get stronger.

Prasad said cord blood transplants generally cause fewer complications than traditional bone marrow transplants and the match does not need to be as perfect. "Cord blood units have been used to save now thousands of children with many different diseases including leukemia, lymphoma, immune deficiency, other inherited diseases," he explained.

The long term outlook for Thor is much different than it used to be. "He would be very limited without the transplant, but now there aren't any limitations or there won't be. He'll be just like a regular kid," said the Urans.



Healthy and mighty Thor 9 months after the successful stem cell transplant.

Thor has had a couple of complications, but his parents say they're not major setbacks. He needed surgery Tuesday afternoon to remove some fluids that had accumulated around his heart, but his mom and dad say he's out of surgery doing well.

From the latest update from Thor's social media, his transplant was a success and is doing exceptionally well. He is currently completely off from all of his medications.

Closer to home, the first hematopoietic stem cell transplantation for CGD patient in Malaysia was performed on a Melanau boy in 2016. The patient was diagnosed with CGD at 18 months old and hematopoietic stem cell transplantation was carried out five years later. He was discharged home 19 days after the transplant, without major complications and his superoxide production normalized two months after transplantation.

Disclaimer: Umbilical cord blood is a rich source of hematopoietic stem cells. Hematopoietic stem cells transplantation is an approved standard treatment for Chronic Granulomatous Disease in Malaysia.

Source:

- <https://pediatrics.duke.edu/news/duke-doctors-perform-unique-cord-blood-transplant-save-boy>. Accessed March 22 2022.
- Ismail IH, Jamli FM, Othman IS, Noh LM, Abdul Latiff AH. Malaysia's First Transplanted Case of Chronic Granulomatous Disease: The Journey of Overcoming Obstacles. *Children*. 2016; 3(2):9. doi: 10.3390/children3020009.

To know more regarding diseases treatable with umbilical cord blood stem cells, please scan this QR code:

