

THE ISAAC

LOVE, LAUGHTER, AND HOPE

FOUNDATION

WWW.THEISAACFOUNDATION.COM



FOR IMMEDIATE RELEASE

PROVINCE DENIES FUNDING FOR LIFE-SAVING TREATMENT

5-Year-Old Underwent Life-Saving Transplant in Minnesota; Province Refuses Reimbursement

(November 15, 2021) The Saskatchewan Ministry of Health has denied reimbursement for a life-saving bone-marrow transplant that saved the life of a 5-year-old Saskatoon boy. Conner Finn, then 4, was diagnosed with Adrenoleukodystrophy (ALD), a rare devastating condition that damages the membrane that covers nerve cells in the spinal cord and brain. Once diagnosed, the condition deteriorates rapidly and leads to blindness, deafness, muscle weakness, progressive dementia, and death. There is no cure for ALD, but a bone-marrow transplant administered at an expert centre can prevent damage and halt the disease if it's done early in disease progression.

Conner was diagnosed in June 2020. Because Saskatchewan does not have any ALD specialists in the Province, his MRI was sent to the Centre of Excellence for ALD at the University of Minnesota Children's Hospital. Dr. Troy Lund, one of the world's leading experts in the disease, advised that Conner's case was urgent and that a transplant needed to take place immediately if there was to be any hope of survival. Due to Saskatchewan not providing transplants of this type in the Province, Dr. Lund agreed to meet with Conner and his family. A donor search was initiated, a match quickly found, and two short months after diagnosis, Conner underwent the life-saving transplant at the Minnesota Children's Hospital.

Conner's parents, Kirsten and Craig, liquidated their retirement savings to pay for the transplant, with the hope that the province would reimburse them. When out-of-province care is necessary, the province funds treatments and procedures in other provinces or, in specialized cases like Conner's, out-of-country. While no referral was made to any other Province, and while the medical team advised that Minnesota was the best place for Conner to receive the best care possible, Saskatchewan Ministry of Health denied to pay for the treatment. The Finn family appealed to the HSRC, an independent body created by the government to objectively review requests for out-of-country care. The Health Services Review Committee (HSRC) reviewed Conner's case and recommended that the Moe government cover all costs associated with his care. Again, their application was denied.

Andrew McFadyen, Executive Director of The Isaac Foundation, an advocacy, research, and family support organization that specializes in rare diseases, is urging Health Minister Paul Merriman and Premier Scott Moe to immediately reverse their decision and fund Conner's treatment. "The facts of this case are clear. Conner needed an urgent life-saving transplant. Saskatchewan couldn't provide that transplant, nor could they refer him elsewhere in Canada to receive the care he desperately needed. His medical team properly referred him to Minnesota – where they treat over 70% of the world's ALD population – and his life was narrowly saved by the expert treatment he received at that centre. To undergo such trauma is devastating for a family, to then be told they have to liquidate their retirement savings to save their child is catastrophically wrong, and an affront to the universal health care system that Tommy Douglas passionately advanced in this very Province."

THE ISAAC

LOVE, LAUGHTER, AND HOPE

FOUNDATION

WWW.THEISAACFOUNDATION.COM



McFadyen calls for equity of access to life-saving measures for Conner, and cites the case of Vonn Chorneyko, as precedence to approve reimbursement for Conner. In 2019, Chorneyko received a very similar transplant for his rare condition. The treatment was provided in the same Minnesota hospital, by the same transplant experts, and proved similarly life-saving. Unlike Conner, however, Chorneyko's treatment was reimbursed by Saskatchewan. McFadyen applauds the government for their handling of Chorneyko's case, but questions why the Finns have been treated differently. "The fundamental principle of our universal health care system is equity of access. Tommy Douglas envisioned a system where every person – regardless of their financial situation – can have the same chance to access life-saving measures, and the ability to receive the best care possible no matter their circumstances. Vonn Chorneyko benefitted from that system, and his story shows just how incredible our system can be. Unfortunately, Conner's story dishonours the legacy of Douglas' vision and brings this family to near bankruptcy, simply because they chose to save their son's life."

The Isaac Foundation and the Finn family have been trying to receive all documents related to the government's decision to deny coverage for Conner's treatment, but have been met with numerous roadblocks. "We submitted a freedom of information request in June. The government has 30 days to provide all documents related to this case. They requested a 30-day extension, which they were granted. Today, we're still waiting for those documents, with no timeline given for release." McFadyen says those documents are important to help understand why the government went against the advice of their own independent guidance, and what – if any – expert opinion they sought while deliberating Conner's fate.

"The Minister of Health has refused to speak with Dr. Lund on this matter. He is the world's leading expert in this disease, so I can't understand why Mr. Merriman wouldn't want to seek that guidance. The people of Saskatchewan deserve to have a Minister of Health who will consult the experts on extraordinary cases like this, and they deserve a government that is transparent about decisions they are making. Most importantly, they deserve a government that will live up to the legacy passed down by Tommy Douglas – one that will protect our universal health system, one that will protect the most vulnerable in our society."

McFadyen continues, "I implore the government to do the right thing here and immediately approve reimbursement for Conner's treatment. It's the just thing to do for Conner, and is in line with previous decisions this government has made regarding similar cases. No government should pick and choose who gets to live and who must fight for life, and no family should ever have to bankrupt themselves in order to get the life-saving care they need."

###

For more information about this topic, or to schedule an interview to discuss, please call Andrew at 613-328-9136 or email Andrew at mcfadyena@me.com