

October 25, 2016  
Joel Windsor  
27 High Ridge Court NW  
High River, Alberta T1V 1Z6

Attention: Honourable Sarah Hoffman, Alberta Minister of Health  
423 Legislature Building  
10800 - 97 Avenue NW  
Edmonton, AB T5K 2B6

Dear Minister,

My name is Joel Windsor, and I am writing to request your intervention to assist a youth in the Highwood Constituency suffering from an extremely rare disorder. Haley Chisholm suffers from C3 Glomerulopathy, for which the recommended treatment is extremely costly, and all requests for aide from Alberta Health Services and other sources have failed.

Many studies have shown that Haley's prognosis is very challenging. Having been diagnosed with C3 Glomerulopathy (C3G) seven years ago, Haley is acutely aware that over 50% of diagnosed patients suffer from kidney failure within 10 years. Over 70% of those who receive a kidney transplant experience a recurrence of C3G. Needless to say, Haley's prognosis is not strong without adequate treatment as soon as possible.

Standard treatment of C3 Glomerulopathy involves aggressive immunosuppressant drugs and blood pressure treatment to reduce proteinuria. Such a treatment has not only proven ineffective for Haley, but continued use of this strategy would be hugely limiting to her quality of life.

Haley wants to be a nurse. She has had a difficult time, and has even isolated herself from her friends for fear of contracting simple infections like the common cold, which would be significantly damaging to her body. She works very hard at school, and diligently pursues excellence. After spending as much time as she has at the Alberta Children's Hospital, and through a great deal of prayer, she has concluded that she has a vocation in health care, and she is ready to pursue it. However, she must feel confident that her C3G is being treated appropriately to be able to turn this dream into a reality.

Haley's doctor, Paediatric Nephrologist Julian Midgley has recommended the use of Eculizumab, known by its trade name "Soliris". Eculizumab is a proprietary drug distributed by Connecticut-based Alexion Pharmaceuticals. As Eculizumab has exclusivity rights until 2019, Alexion Pharmaceuticals is under no obligation to make the drug more affordable than the projected \$700,000 cost per year for a patient such as Haley.

The largest challenge for the use of Eculizumab for a patient like Haley is that it has not been approved as treatment for C3G, but has been for other conditions that are very similar in nature. It is for this reason that Eculizumab has been administered to others around the world diagnosed with C3G with promising results. As C3G is such a rare disorder (2 in 1,000,000 will suffer from it), it is very difficult for Alexion to conduct randomized studies in order to obtain approval from Health Canada for the use of Eculizumab for this condition.

These challenges should not prevent your Ministry from intervening. The National Health Service in England is working on a proposal to approve treatment of recurring C3G following kidney

transplant with Eculizumab. More and more research continues to be produced indicating that patients should expect to see positive results in as few as 2 months of use of the drug. There are no reports of side-effects of the use of Eculizumab beyond cold symptoms and nausea. Eculizumab is also considered more effective than other drug therapies such as Rituximab. Yet Alberta Health's Short Term Exceptional Drug Therapy (STEDT) Program has denied the request for funding. STEDT has indicated that statistical evidence is required, but in such a rare disorder as C3G, it is quite likely this statistical evidence could not be produced (whether to support its use or not) before it becomes too late for Haley.

Therefore I would also like to point out that precedence for such an approval exists in Alberta. Aleena Sadownyk of St. Albert was approved in 2013 for the use of Naglazyme to treat her condition known as Maroteaux-Lamy Syndrome. Naglazyme was not approved yet for use in Canada, yet was granted funding. At the time, Health Minister Fred Horne was interested first and foremost that the drug was right for Aleena. I am confident that once your department looks more closely at Haley's file, and her prognosis with and without Eculizumab, you too will determine that the drug is right for her.

Haley has been inspired by the amazing medical team working on her case. She has been so inspired as to seek out her vocation in the same field. You can make this dream a reality. I urge that you collaborate with the various programs such as the Alberta Rare Disease Funding Program and the Short Term Exceptional Drug Therapy Program to approve funding for the treatment of Haley's condition with Eculimuzab. I urge you to do so quickly as is prudent so that Haley can continue to inspire others into the health profession, just as she has been.

Yours faithfully,



Joel Windsor

CC: Wayne Anderson, Member of the Legislative Assembly for Highwood  
John Barlow, Member of Parliament for the Foothills Electoral District  
Drew Barnes, Wildrose Official Opposition Health Critic  
Richard Starke, Alberta Progressive Conservative Opposition Health Critic  
David Swann, Alberta Liberal Opposition Leader  
Greg Clarke, Alberta Party Opposition Leader  
Jane Philpott, Minister of Health for Canada  
Dr. Colin Carrie, Conservative Party of Canada Official Opposition Health Critic  
Don Davies, New Democratic Party of Canada Health Critic  
Elizabeth May, Green Party of Canada Leader  
The Chisholm Family