



Kelly and Kyle Bruski, whose sons were born with Bruton's agammaglobulinemia, raised \$1,000 to purchase Cuddle Bear books and their accompanying plush toys for the kids at the infusion clinic where their sons are treated.

PROFILE: Kelly Bruski

By Trudie Mitschang

WHEN YOUR CHILDREN have a rare disease, you will do whatever is necessary to make sure they get the care they need to survive. For Kelly and Kyle Bruski, that means traveling nearly 500 miles round trip each month from their farm in Baker, Mont., to an infusion clinic in Billings. The Bruski's two young sons 7-year-old Taylor and 3-year-old Colton have an inherited immune disorder that requires monthly infusions of immune globulin (IG). And, although the family could get treatments closer to home, they have bonded with the staff and doctors at the Billings Clinic pediatric infusion room. Touched by the outpouring of support they have received, Kelly was recently inspired to give back by launching a fundraising project to support other families with sick children.

Trudie: Tell us about your children's diagnosis.

Kelly: Both of my sons have Bruton's agammaglobulinemia, an inherited disorder affecting only males (females can be carriers of the disease) and characterized by very low levels of protective immune system proteins called immunoglobulins that make it more likely for them to acquire infections. The disease my kids have is extremely rare; only one child in every 200,000 live births is born with this condition. I've been told there are less than half a dozen cases of Bruton's in the entire state.

Trudie: Were you aware of risk factors in your family?

Kelly: Yes, I knew that it runs in my family. My brother has it and so does my uncle (my mom's brother). My mom is a carrier and so is my grandma, and as far as we know, it may date back to the 1930s because there is some history of baby sons dying, and they could never figure out why.

Trudie: When were you and your sons tested for Bruton's agammaglobulinemia?

Kelly: I got tested when I found out I was pregnant. My oldest son, Taylor, got tested when he turned 1 year old (we waited a year because it took nine vials of blood to test for the gene at that time). By the time my younger son, Colton, was born, he could be tested as an infant. That was amazing, especially since the first year of Taylor's life he was constantly getting sick every month; Colton didn't have to go through that.

Trudie: Tell us about your treatment plan for the boys.

Kelly: We drive about eight hours round trip every month to Billings for intravenous IG (IVIG) treatment. Their infusions last about three hours so it is an all-day thing for us one day each month. Unless a cure is found, they will need these infusions for the rest of their lives.

Trudie: How has their health improved since being treated with IVIG?



Kelly: They are doing wonderful, and we haven't really had any major health issues, probably because they started the infusions at a really young age. Treatment options have really improved since my uncle and brother faced this diagnosis. We are very thankful.

Trudie: When your children are older, will you consider subcutaneous IG (SCIG) infusions at home?

Kelly: Yes, when my youngest is about 5 or 6 years old, we will consider SCIG at home for both boys.

Trudie: Has spending so much time at the clinic helped you connect with other families?

Kelly: We don't see any other families since it's like going to a doctor appointment. Maybe we would if we went to some of the annual events. Every year, the clinic holds an event for families who receive care there, but we haven't been able to attend one. We live on a farm, and the events usually occur during farming/haying season. My goal is to one day go to one of the events!

Trudie: Tell us about the Kelker's Kids program.

Kelly: Kelker's Kids is a program through the Billings Clinic Foundation that provides financial assistance to families of children with cancer or other serious blood disorders. It's staffed by amazing individuals who go out of their way to ensure the comfort and well-being of every child they treat. They treat us like we're family; we've been coming here for six years, and even though we could look for someplace closer, this is the place we want to bring them.

Trudie: Beyond infusions, how has the clinic helped you and your family?

Kelly: I love the clinic and the staff. They have a room with toys and games to keep the kids entertained, and they always give them gifts. We have been

going there since the kids were babies. It's like a second home once a month. They have also helped us with travel and lodging. We feel very fortunate.

Trudie: Tell us about your fundraising efforts for Kelker's Kids.

Kelly: I really wanted to give something back, so I joined a company that sells books to get the hostess benefits. In less than two weeks, I raised \$1,000 from our great little town to purchase *Cuddle Bear* books by Claire Freedman and Gavin Scott, and the bear plush toys that go with them. I donated these items so that the Kelker's Kids clinic could give a book and a bear to each child who has to go through the same thing my boys do. An infusion clinic is a scary place for a child,

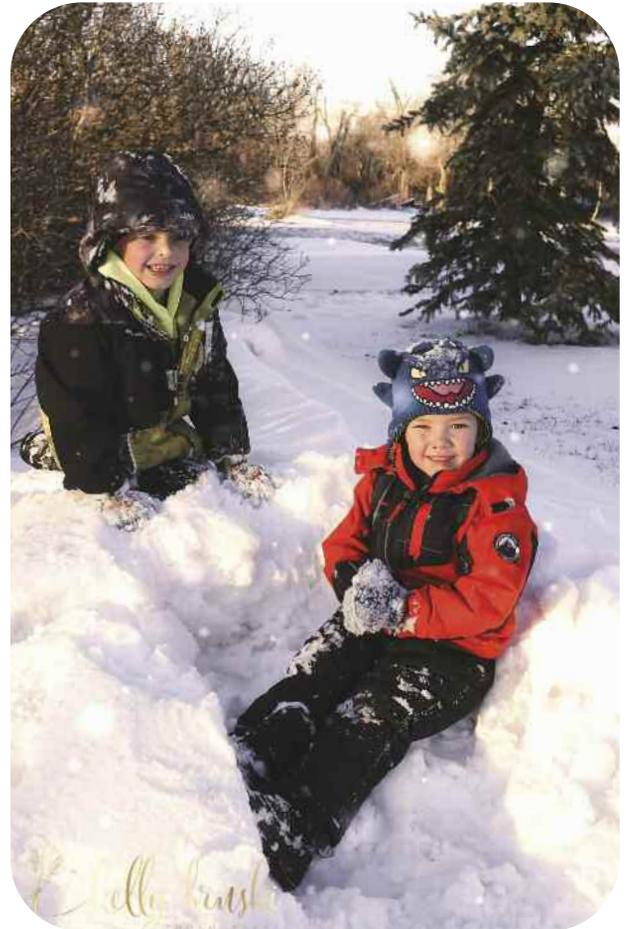
and it's scary for them to go through this type of medical procedure. This was a small way to help brighten a child's day.

Trudie: What has living with chronic illness in your family taught you?

Kelly: It's taught me that life is precious, something I see people take for granted every day. We live to the fullest each day, and we say I love you every day. It definitely has taught us to be strong together as a family.

Trudie: Any advice to other parents dealing with a similar diagnosis?

Kelly: Let your kids live a normal life. As long as they get their regular



The Bruskis strive to let 3-year-old Colton and 7-year-old Taylor live life to the fullest each day, something Kelly says she sees people take for granted every day.

infusions, they will be just fine. We let our kids run around on the farm and get dirty like normal kids. They go to a public school and have amazing friends. Their childhood years are worth living, so don't let their disease hold them back from anything. Medicine has improved so much in the last 40 years, and there have been significant advances that allow people with diseases like this to live a much more normal life. ■

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