Profile: Erica Erdman

By Trudie Mitschang

**WHEN ERICA** Erdman’s son Braxton was born, his Down syndrome diagnosis took the family by surprise. But, any concerns about that diagnosis were soon eclipsed by Braxton’s frequent illnesses and hospital stays. Suspecting something was wrong, Erica fought to get an accurate diagnosis, and at 3 years old, her son was diagnosed with a primary immunodeficiency. Since then, the family has faced numerous hurdles, including the recent nationwide immune globulin (IG) shortage that has threatened Braxton’s access to care. With a true mother’s tenacity, Erica fiercely advocates for her son daily, and she is actively raising awareness about the increased need for plasma donors.

**Erica Erdman’s son Braxton was diagnosed with Down syndrome and hypogammaglobulinemia, and while Braxton has not been affected by the immune globulin shortage to date, Erica is making every effort to encourage people to donate plasma.**

**Trudie:** You describe Braxton as your miracle baby. Tell us about that.

**Erica:** This is a bit of a loaded question. Despite having a Down syndrome diagnosis, Braxton was born relatively healthy and only spent seven days in the neonatal intensive care unit for a couple of issues. It was at about 2 months of age that he became very ill, and from then on, we have spent countless nights away from home in and out of a hospital. The doctors kept saying it was a “Down syndrome thing,” but I knew there was something more going on, and I had to advocate for almost three years to figure it out. I knew other Down syndrome families that only had to deal with ear tubes, and we were being med-lifted to our Children’s Hospital because our local hospital could not support Braxton’s numerous complications. Braxton had several bouts of pneumonia, sinus and ear infections, upper-respiratory infections, etc., which would always land us in the hospital on significant life-support measures.

**Trudie:** How long did it take to get an accurate diagnosis?

**Erica:** It wasn’t until Braxton was almost 4 years old that we received the hypogammaglobulinemia diagnosis. I had to advocate a lot to get an immunologist referral. Even now, we are coordinating a second opinion and working with the Immune Deficiency Foundation (IDF), since it is suspected he has additional diagnoses yet to be made. I have learned so far in this journey with Braxton’s immune condition that, as a patient, you often must advocate to be heard, understood and given support to have a fighting chance at a “normal” life, which is really unfortunate. I have to be Braxton’s voice because he is nonverbal, and that adds a whole other level of difficulty to everything.

**Trudie:** Braxton has had numerous hospital visits. How have you coped with the stress?

**Erica:** The time away from home has been very difficult for our family, and I ultimately had to quit my job to stay home to care for Braxton. I guess if there was anything at all positive about the numerous hospital stays, it’s that nurses and doctors get to know you pretty fast. We have amazing relationships with those who care for Braxton when he’s hospitalized, and because he is pretty cute, it doesn’t take much for them to be wrapped around his thumb. Our hospital room often looks like home as well. For simple appointments away from home, we are very lucky to have an amazing Ronald McDonald House, and yes, they all know us too! We recently got a puppy that will be trained as a service dog to help with some medical alert items, along with anxiety during treatments, appointments and stays away from home.

**Trudie:** Tell us about his intravenous
IG (IVIG) treatment plan.

**Erica:** Braxton started IVIG every 28 days in January 2019. He started off with a lot of the typical side effects and ultimately struggled with IV placement since his tiny veins would blow multiple times during treatment. It was very traumatic and subcutaneous IG (SCIG) wasn’t an option due to his medical complexity. Right now, we are in a standstill with treatment because Braxton’s IgG and IgM levels are both out of reference range, along with some other white cell count issues, and he has been pretty sick but they want him to get sicker before starting back on IG therapy.

**Trudie:** When did the IVIG shortage begin to impact your son’s care?

**Erica:** We have not been told Braxton can’t receive treatment, and the Children’s Hospital pharmacy has been pretty good at ensuring it’s in stock. But, his last treatment was different and it took a bit longer since they did not prepare things until we stepped foot in the treatment center the day of his appointment. We were told they would no longer prepare things the day prior due to the shortage. Considering the likelihood of Braxton having to go back on regular IVIG treatments, my fear is, at some point, we will be one of those patients receiving a cancellation call.

**Trudie:** How are you hoping to raise awareness and encourage people to donate plasma?

**Erica:** I have an amazing friend, Ally Peters, who works at a local television station (WAOW Channel 9), in Wausau, Wisc., and she filmed a segment about Braxton’s immune condition and encouraged our community to donate plasma because of the shortage. I share a lot via social media about Braxton’s immune issues and educate people at his school. I would like to work with our local plasma center and IDF at some point, and possibly host a local awareness event like a walk. Even with this, we still have family and friends who don’t understand why we cannot go to a party held at a water park or why we haven’t had a birthday party for Braxton in three years.

**Trudie:** Do you belong to any support groups for parents of kids with immune diseases?

**Erica:** Unfortunately, there is nothing local for those with immune conditions I am aware of. I am part of several immune groups via Facebook, but none are specifically for kids.

**Trudie:** What advice would you offer other parents who are new to this challenge?

**Erica:** Do what you can to learn about the diagnosis, what lab test results mean, common symptoms, side effects, IG therapy options, everything you can. The immunology world is complex and overwhelming, and things are not the same among patients with the same diagnosis. Don’t be afraid to ask questions, and don’t be afraid to question medical professionals about their recommendations (or lack thereof). You know your child best!

**Trudie:** How do you stay positive and hopeful?

**Erica:** I stay positive and hopeful through lots of coffee! Really, the one and only thing that helps is simply Braxton himself. When I see him have good days, which are few and far between, I capitalize on them. We run around the house, we bake something, we try to learn something new, we laugh and dance like nobody is watching!

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