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Person First Language

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Our personal journey in the importance of person first language began with the birth of our daughter Callie in 2011. I quickly learned how seeing someone as a person first – and not a diagnosis – as a mother, would influence how I cared for my patients in the future. That was not on my mind, however, when I heard the doctor announce after 29 hours of labor, "It's a girl. . ." and our Callie was placed onto my chest. I took a deep breath and thought, "We made it!"

The joy and exhilaration I felt hearing that first cry and cradling my child for the first time was indescribable. I counted her fingers and kissed her nose. Soon she was off to the warmer. As we texted friends and family with our news, I noticed many people in scrubs surrounding Callie.

"Tom, something's wrong," I said. "Go find out. . . "

"I think your baby has Down syndrome," said the nurse practitioner who came to my bedside.

"But she can't," I said, "she just can't. Our genetic testing was so good!"

"I'll have some of the doctors upstairs look at her to see what they think," she said in response to my disbelief.

"No, please get us Dr. B; I don't want a bunch of people looking at my baby."

After the initial flood of tears, Dr. B soon arrived, despite the snow and the end of the day. Both my husband and I had worked with him professionally and, while we respected his skills as a geneticist, we also trusted his straightforward approach. All I could remember learning in medical school about Down syndrome was the risks of leukemia and congenital heart disease, so naturally I couldn't wait for him to tell us the initial assessment was wrong … but he did not.

"Our baby is beautiful and perfect and the test said she didn't have Down syndrome, and I can't see it when I look at her," I sputtered. "What kind of doctor am I?,"

More tears, more tissues, and a gentle but firm discussion about the limitations of screening. A plan for definitive diagnosis and follow up quickly came together.

"I'll be back here tomorrow. Here's my beeper. You call if you need anything. Please remember – All of our kids come with their own special challenges and joys. Your expectations for Callie may be different than you thought, but she will also bring you unexpected joys and blessings!"

After Dr. B left there was more adventure as within the hour the nurse thought Callie looked a "little yellow."

"She can't be jaundiced," I thought, "that's a really bad differential diagnosis in the first few hours of life and it's already been a really long day."

The hospitalist came in to discuss the next steps as the bili lights went up and the CBC came back with platelets of 30,000.

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"We'll watch her closely here – this may all be related to her Down syndrome."

Suddenly Down syndrome seemed like a good thing, and much better than sepsis and the rest of the differential. Still, as Callie slept in only her little diaper and bili light goggles, and my husband snored in the next bed, I cried myself to sleep under the lights. I cried because I was tired, because I was scared, because I was sad, and then because I was sad that I was sad.

The next two days passed in a haze. My eyelids were a quarter inch thick from the tears and IV fluids. Good news and more visits from Dr. B and our OB as the bilirubin came down and the ECHO showed no major anomalies. Despite being two family doctors used to being on the other side of the stethoscope, we especially needed and welcomed the visits from our team as they took care of us and Callie. The call came from Dr. B five days later confirming her diagnosis. Callie was quickly started in an early intervention program and our learning journey about Down syndrome began in earnest. Dr. B and new friends we made who also loved people with Down syndrome helped us realize quickly Callie was first and foremost a beautiful baby who had quickly stolen our hearts.

At the age of six months, Callie's journey took a twist. A seemingly straightforward case of the croup turned into a six month journey of trips to the ER, prolonged hospitalizations and earned her the nickname "Darth Vader" from the sound of her breathing! With a respiratory rate frequently hitting the 60's, we struggled to find out what was wrong with her. We hit our first hard stop when one doctor told us, "Well, you know she has Down syndrome."

Yep, got that with her karyotype, but that didn't seem quite right as a cause for respiratory distress. The dismissal in the doctor's comments was painful, and led us to seek care elsewhere to have the chance to really figure out what was wrong with Callie.

Months later, as she was sleeping off the anesthesia the day before her first birthday after undergoing an esophagogastroduodenoscopy (EGD), bronchoscopy and having a pH probe placed, another physician walked in to do her preoperative consultation a little late.

"You know, she really doesn't need any scopes, she just needs a Nissen. All these kids with Down syndrome just have GERD."

I remained speechless until he exited, seemingly unaware that she had already had the procedures that showed no signs of GERD (Gastroesophageal Reflux Disease) but significant broncho- and tracheomalacia. She was already significantly better than she had been in a while with the introduction of thickened feeds for dysphagia, so arguably perhaps she didn't need the procedures - although they ironically led to her being weaned off all her meds for GERD which was a victory! What we experienced and observed in Callie's care seemed to relate to how she was viewed, treated and talked about. Those who could see past her diagnosis of Down syndrome and not limit her possibilities or their differential diagnosis because of it, stepped in, figured it out and advocated for her.

Fast forward ten years, and Callie is now double digits and in the fourth grade in an inclusive education setting (albeit virtually as we contend with COVID-19). Individuals with Down syndrome are at high risk for complications due to multiple factors, that likely include immunodeficiency, low muscle tone and multiple co-morbidities. This fall, we celebrated the fifth anniversary of the Christiana Care Teen and Adult Down syndrome program in the Center for Special Healthcare Needs. I am proud to have co-founded the program with Callie's geneticist Lou Bartoshesky, Dr. B, who started us on our journey with Callie reminding us about

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joy and great expectations. Our mission there is to improve the health and well-being of individuals with Down syndrome. I'm otherwise at Jefferson full time where, in a mid-career twist, I have re-focused my clinical work inspired by Callie and motivated by the health disparities individuals with intellectual and developmental disabilities contend with. I lead a primary care medical home for individuals with intellectual and developmental disabilities, and other complex childhood-onset conditions. I also have the opportunity to teach, work with learners at all levels clinically, and advocate.

Jefferson was awarded a one-year competitive grant by the National Curriculum Initiative in Developmental Medicine (NCIDM) last year. We're striving to develop a future workforce with enhanced skills to optimize care for patients with intellectual and developmental disabilities (IDD). All third-year medical students during their family medicine rotation now learn about the care of patients with IDD, as a result of program development supported by funding through the NCIDM. As we focus on healthy equity and health disparities at Jeff, it is important to know that there is no formal requirement to teach medical students about the care of patients with IDD. Jefferson is now one of the ten percent of medical schools in the country to take this step! While good news and a start, the fact that this education is so rare is a little hard to believe in 2021. I remain hopeful that, among other things, this educational focus will prevent others from facing the obstacles to care and wellness we encountered from some on our journey with Callie.

All my didactics start with three things: a picture of Callie on my disclosure slide because she started me on this transformative career journey (and her smile really warms up the audience), defining and discussing the importance of person first language, and general language guidelines that influence the tone and substance of care.

Callie is a child with Down syndrome and not a Down syndrome child. Person first or people first language (PFL), is placing the person before their diagnosis. PFL is more than just disability etiquette, although individuals and caregivers will likely appreciate your word choice. It's a powerful term that may help us as clinicians think about bias and avoid diagnostic overshadowing. While clinicians do need to think about conditions associated with Down syndrome when caring for someone with Down syndrome, you need to think about the patient holistically and without blinders, and compare the individual to their own baseline, like we do with someone with congestive heart failure. As this issue of the journal has undoubtedly illustrated, people with disabilities – especially those with IDD – face huge health disparities and premature death. Using PFL is about serious medicine and thoughtful differential diagnosis that makes a difference in the lives of our patients and those we love, and may help us reduce health disparities. Like every good rule in medicine, there are always exceptions and many in the autistics, individuals on the autism spectrum, prefer the use of identity first language. As we've been taught from our first communication class in medical school, center your care and put the patient first by asking the patient how they want to be addressed.

After introducing Callie and PFL, I move on to the next slide about language, and talk about Special Olympics. For those of you not familiar with Special Olympics, it is an international organization with a prominent place in the Delaware community. It is the largest sports organization in the world for individuals with IDD, and both children and adults compete. In Delaware, athletes with and without intellectual disabilities play unified sports to have fun, get fit and to get to know each other as individuals. In 2009, Special Olympics launched the "Spread the Word to End the Word" campaign based on the "audacious" belief that "the world would be better if all people were valued, respected, embraced, and included in our schools, workplaces,

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and communities." By focusing on the word "retard(ed)," a starting point was found to begin a discussion and move away from a term that is exclusionary and hurtful. We know that the environment of care is critical to patient outcomes (and Press Ganey scores), and we should do our part and choose a word other than the "R" word when things don't go our way with the Electronic Health Record or scheduling. If it comes up in the lunchroom, think about tools used in our bias and diversity training, like saying something - even if all you can think of is "ouch." It is also way past time to change the documentation in our medical records to use the descriptor intellectual disability, and not mental retardation. In 2010, Rosa's Law (in honor of a young girl with Down syndrome) was signed by President Barack Obama and mandated the use of the term *intellectual disability* in place of *mental retardation* in federal statutes. Nick Marcellino, Rosa's brother, was quoted as saying at the time: "What you call people is how you treat them. If we change the words, maybe it will be the start of a new attitude towards people with disabilities."

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