

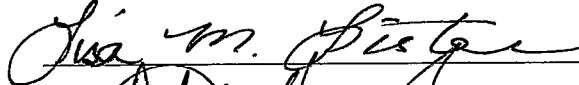

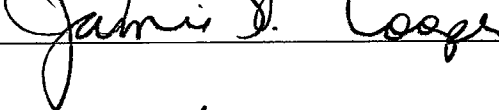


UPS AND DOWNS: STORIES OF FAMILY, COMMUNITY, AND DOWN  
SYNDROME

by

Erica M. Dolson  
A Thesis  
Submitted to the  
Graduate Faculty  
of  
George Mason University  
in Partial Fulfillment of  
The Requirements for the Degree  
of  
Master of Fine Arts  
Creative Writing

Committee:

  
\_\_\_\_\_  
  
\_\_\_\_\_  
  
\_\_\_\_\_  
  
\_\_\_\_\_  
  
\_\_\_\_\_

Director

Department Chairperson

Dean, College of Humanities  
and Social Sciences

Date:

April 30, 2014

Spring Semester 2014  
George Mason University  
Fairfax, VA

Ups and Downs: Stories of Family, Community, and Down Syndrome

A Thesis submitted in partial fulfillment of the requirements for the degree of Master of Fine Arts at George Mason University

by

Erica M. Dolson  
Bachelor of Arts  
Villanova University, 2008

Director: Stephen Goodwin, Professor  
Department of English

Spring Semester 2014  
George Mason University  
Fairfax, VA



This work is licensed under a [creative commons attribution-noncommercial 3.0 unported license](https://creativecommons.org/licenses/by-nc/3.0/).

## **DEDICATION**

This is dedicated to my family: my parents, Louise and Philip Dolson; and my sister, Angela Dolson.

In memory of my brother, Nicholas Mancini Dolson (1992-1996).

## ACKNOWLEDGEMENTS

I am very lucky to have many wonderful people who helped and supported this project along the way. First, I must thank the Guillaume family – Cori and Brian, and their children Anthony, Noah, and Anni. Thank you for your openness, honesty, and enthusiasm, as well as for welcoming me so warmly into your home and into your lives. I must also thank Noreen Wenner and Noreen Johnson for sharing with me their stories about and their love of their brother and uncle, Patrick.

I could not have completed this project without the sharp eye and perceptive reading of my advisor, Professor Stephen Goodwin, and my committee of readers, Professor Lisa Lister and Dr. Kyoko Mori. Thank you for the time and care you devoted to this project. I owe another debt of gratitude to my cohorts in the Master of Fine Arts program at George Mason University, specifically to the members of this past Fall’s advanced nonfiction workshop. Thank you for your constructive criticism and your support and enthusiasm.

Finally, I must thank my family and friends. My parents allowed me to write about a personal and difficult time for our family. Colleen Comerford, my best friend and favorite reader, offered her insight and expertise on an early draft. Each of these individuals, and my sister, Angela, supported me unconditionally in this endeavor, as they always have.

## TABLE OF CONTENTS

	Page
Abstract .....	vii
Introduction: A Chance Meeting .....	1
Birth Stories .....	2
Moments of Discovery.....	12
Dinner with Anthony .....	22
Talking about Nicholas.....	34
Swim Meet, February 7, 2013.....	55
Bowling, June 29, 2013 .....	68
Growing Up, Growing Old .....	89
Halloween Party, October 19, 2013.....	107
Twenty-One Pearls.....	120

## **ABSTRACT**

### **UPS AND DOWNS: STORIES OF FAMILY, COMMUNITY, AND DOWN SYNDROME**

Erica M. Dolson, M.F.A.

George Mason University, 2014

Thesis Director: Professor Stephen Goodwin

From the time my brother Nicholas was born, my family knew he was different – and we knew our lives would be different because of him. Nicholas had Down syndrome. His first days were spent in the hospital; his first years were spent at therapy sessions. In 1996, when I was in fourth grade, Nicholas died suddenly, leaving me to wonder about the ways that his life with Down syndrome and his early death both shaped and shattered the identity of my family.

In 2009, at my first full-time job out of college, I met Brian Guillaume, a young school board member whose first son, Anthony, was born with Down syndrome. Through the story of my family, the story of the Guillaume family, and the story of how our two families connected, this thesis explores the ways that Down syndrome affects a family and a community.

## INTRODUCTION: A CHANCE MEETING

On a muggy August day in 2009, I visited North Dickinson Elementary School in Carlisle, Pennsylvania to cover a ceremonial groundbreaking for a construction project. I was working at my first job out of college, as the education reporter at a small community newspaper. I was an unfamiliar face in the small town, where the people of Carlisle knew the reporters who covered them. One of the youngest school board members, Brian Guillaume, approached me immediately. He carried a hard hat that he had donned for the photo of the groundbreaking and wore a golf shirt tucked into his jeans. He had rosy cheeks, and wore his hair trimmed closely to his scalp.

First, we engaged in small talk. Where was I from? What would I be covering at *The Sentinel*? He pointed to my bag – a quilted Vera Bradley tote in periwinkle, yellow, and lime green – and told me that his wife Cori recently bought a bag just like it.

Then, he told me about the Central Pennsylvania Down Syndrome Awareness Group, the nonprofit organization that he and his wife Cori had founded after their first son, Anthony, was born. He also told me about the article my paper had recently published about his group. I should read it in the archives, he urged. I knew he wanted more coverage for his organization, but what he didn't know – couldn't have known – before he approached me was that the story of our two families dovetailed.



## **BIRTH STORIES**

It was November 13, 2003, the day after Brian and Cori Guillaume's third wedding anniversary. The night before, Brian and Cori, very pregnant with their first son, had celebrated over Hot-chee dogs and gravy fries at the Hamilton Restaurant in Carlisle, Pennsylvania, and then returned home for a quiet night. The next day, they both needed to be at work at 7 A.M. Brian as an inspector on a road-widening project in Waynesboro, about forty-five miles from their home, and Cori to the Carlisle Carrier trucking center.

Even while pregnant, Cori looked petite, with her tiny waist and skinny legs, and her thin face framed by jagged brown bangs. Only in those moments when her loose-fitting maternity tops billowed away from her body, or she turned to the side to reveal her protruding baby bump, did she look pregnant. When she woke that morning, she made her way to the bathroom. She lowered herself onto the toilet seat and listened to the trickle of water drip into the toilet without stopping.

"I think my water broke," she called to Brian.

Always collected, always calm, Cori showered. She and Brian lived in a one-story house outside of Carlisle. It was the same house where Brian grew up; he had purchased it from his parents after he and Cori got married. During the ten minute drive into town, they stopped at Faye's, an old-fashioned diner along Hanover Street, one of the main roads in Carlisle. They sat down at a table, and Cori ordered a bagel with cream cheese.

She chatted about her doctors and how they had warned her not to eat too much if she went into labor. Nervous, Brian sat quietly and listened to his wife, occasionally picking at his plate of eggs and bacon. When he finally spoke, it was to ask the waitress to please bring their check quickly – his wife was in labor.

When they got back into the car to head to the hospital, Brian, flustered, got lost. He had lived in Carlisle his whole life; he knew the turns to take and the roads to follow to arrive at the hospital. Instead, he had continued down Hanover Street, moving in the direction of West Louthier Street and the apartment he and Cori shared after they first got married.

\*

Brian and Cori met when they were 19-year-old college students, Brian studying environmental studies and geology and Cori studying nutrition and dietetics with a minor in psychology at Mansfield University, in north central Pennsylvania.

“She was stalking me,” Brian likes to say when he describes their courtship.

“I was not stalking him,” Cori likes to immediately reply.

The truth is, they both lived on the same floor in one of Mansfield’s co-ed dormitories. One day, while roaming the female wing in hopes of meeting girls, Brian stopped by Cori’s room. He puffed out his chest to draw attention to himself, making comments he can no longer remember or chooses not to share. Cori shot him an insult. Soon, the frequency of Brian’s visits increased.

Cori and Brian are the kind of couple whose early dates included groundhog and dove hunting trips (Brian hunted, and Cori tagged along). On days when Cori wasn’t

around, Brian spent time with her father, a burly man who excelled at repairing cars and who lived not far from Mansfield.

It was six months before the couple saw their first movie together – *I Know What You Did Last Summer* – during a visit to Carlisle. They ate dinner with Brian’s family and then left for the theater. Earlier that day, Brian’s mother had given him some money for his date, money that he immediately squandered on soda and snuff at the K-Mart. When it came time to buy the tickets for the movie, he had to borrow money from Cori.

In 1999, just after Brian proposed, he was laid off from a job he thought was stable. He lived at home while he looked for work, drinking Old Milwaukee and playing ping-pong with his dad, making bets for money. *I’m getting married*, he thought, worried. *I’m a loser. What will Cori’s dad think?* But he soon found work as a paint inspector at a local manufacturing plant, where he and his co-workers cracked open beers and celebrated in the parking lot after work on days when no one got hurt on the job.

Brian and Cori married almost a year later, in November of 2000. At the end of the night, their wedding guests pooled their money to book the DJ for an extra hour.

\*

It was 8 A.M. when Brian and Cori arrived at Carlisle Hospital. One hour later, the doctors gave Cori Pitocin to speed her labor. All day, she grew increasingly hungry and wished she had eaten a bigger breakfast. At 6 P.M., the doctors wheeled her into delivery, a room with tile floors and a single heat lamp.

Brian and Cori had tried for a year to conceive this baby before they sought the help of a fertility specialist. They thought Cori couldn’t get pregnant. As it turned out, she

could, but her body had such low levels of the progesterone hormone that she could not sustain a pregnancy. The specialist placed Cori on a regimen of shots, but just before she began her treatments, she discovered she was pregnant. Brian was driving to work when Cori called to tell him the news. As he went to answer his cell phone, his finger fumbled and hit the speaker button. Cori's high-pitched, garbled scream filled the car, and Brian, for a moment, thought his wife might be hurt. She wasn't; she was just excited.

In the delivery room, she pushed for forty-seven minutes, and then she and Brian had a son. He weighed 6 pounds, 9 ounces; was 20.5 inches long; and had strong muscles. While the nurse examined him, he spread his arms and his legs.

“How's he look?” Brian asked

“He looks good,” the nurse said, handing Anthony to Cori.

“That's my boy,” Brian said.

Brian and Cori knew earlier in her pregnancy that they would have a boy, and so chose a name for their first-born son: Anthony John. Anthony because it was Cori's great uncle's first name and her father's middle name, and John because all of the first-born males on Brian's side of the family take John as a middle name.

As she held him for the first time, Cori felt Anthony's rough hands and long fingernails. She kissed his chubby cheeks and his pursed lips. She saw the beginnings of his brown hair popping up on his bald scalp. She looked into his squinted eyes.

“There's my little Bubby,” she said, baptizing Anthony with the nickname that would stay with him.

Then, the doctors put Cori to sleep. It seemed very sudden that her placenta was stuck in three places; the umbilical cord delivering nutrients to Anthony had begun to tear, and Cori had already lost a lot of blood. If the umbilical cord tore completely, it was likely that Cori would have died from the blood loss.

Instead, her mother sat with her while she slept, and at some point, her heart monitor became unplugged. Cori awoke to the high-pitched, extended beep of her own flat line. She thought she had died.

Nine weeks later, a lactation specialist noticed that Anthony arched his back and that he wasn't gaining weight. It was then that he was officially diagnosed with Down syndrome.

Every year on November 13, Cori and Brian share a version of this story – his birth story – with Anthony. He likes the part when Brian gets lost. For Cori and Brian, tucking their son into bed on his birthday, reliving the first moments of his life, it's truly a love story; for Anthony, it's an adventure story: the moment when he entered this world was exciting.

\*

In 1992, my younger brother Nicholas was born with Down syndrome. By the time my mother was pregnant with Nicholas, she had had two daughters and a miscarriage in between. When I was born, she quit her job as a high school English teacher to spend her days playing with and taking care of me, and then my sister, and then my brother. While we were growing up, she sewed our Halloween costumes, first day of school dresses, and outfits for our school plays. She let us help her bake cookies in

our kitchen. As we got older, she gave good advice about friends, dates, and jobs. So, it was not surprising to me when she said she liked being pregnant because it felt “normal”; she was a natural mom.

My mom was 34-years-old when she was pregnant with Nicholas, an age that made nurses refer to her pregnancy, in passing, as “at-risk.” As she was aging, so were her eggs, and she was moving closer to the time when her body’s cells would be more likely to experience problems with cell division, increasing the chance of conditions like Down syndrome. At the time, though, my mom didn’t think about that. She felt fine. She monitored her nutrition and gained the right amount of weight. She attended pregnancy classes. She did everything she had done during her previous pregnancies, everything she was supposed to do. The only difference was that she and my dad learned the sex before the baby was born, at my mother’s final sonogram. By the time of that final appointment, my mother and father had studied, separately, the book *10,000 Baby Names*. They had merged their preferences into a master list and eventually narrowed the pool of names to either Natalie or Nicholas. The sonogram revealed that they would have a son, and that my sister and I would have a baby brother. Nicholas it would be, then, a name that means, “victory of the people.”

Near the end of her term, my mom’s pregnant belly began to shrink, and the doctors worried that Nicholas was absorbing the amniotic fluid into his lungs. They suggested inducing labor.

“I think I want to wait,” my mother told the nurse over the phone. She hadn’t started labor naturally and didn’t feel any pain.

“No,” the nurse replied, “you don’t.”

The nurse spoke with such urgency that my mother obeyed. She went to the hospital and roamed the sterile hallways. Her doctor sat in his office at the end of the hall, watching as my mother paced back and forth, back and forth. After hours trying to induce labor, she doubled over in pain. The doctor looked up from his paperwork.

“Maybe soon,” he nodded.

My mother returned to her room for a hot shower. She squatted on a stool underneath the water to coax Nicholas out. When the contractions finally began, she felt more than the “little discomfort” her doctor told her to expect. Instead, she felt what seemed like intense menstrual cramps, whose pain came in waves and then receded.

The nurse in the delivery room with my mom was named Jan. She was in her late 50s – the same age my mother is now. My mom still remembers Jan’s features: a petite frame, short brown hair, slightly buck teeth, an ever-present jovial expression on her face. Jan liked my parents and laughed with them during the delivery.

“Oh, wait – here comes another one,” my mom shouted as another contraction arrived after a long lull. Then, out of both silliness and relief, they all laughed.

Finally, Nicholas was born – 7 pounds, 11 ounces; 19 inches long, and bright blue, almost like a Smurf. Jan took him to examine him.

“He’s blue,” my mother said.

“He’s a boy,” her doctor replied before he left the room.

My mom observed as Jan cleaned Nicholas, as she checked his muscle tone and measured his pulse, as she monitored his breathing. She stared at Jan’s profile, studying

the features she would remember so well over twenty years later. She watched as Jan's always kind, always pleasant face turned ashen in color.

“Is he okay?” my mom asked.

Jan didn't answer. She wrapped Nicholas in a blue paper blanket and handed him to my mother. Then, she gave my mom a hug. The doctors – and Jan – knew immediately that Nicholas had Down syndrome. Most people who look at pictures of Nicholas would also recognize the common features of the condition: his eyes crossed and his tongue protruded from his mouth. The first time my mother looked down at Nicholas, she, too, saw the Down syndrome. Nicholas's eyes slanted upward, something my mom knew from her pregnancy books to be an indicator of Down's. My mother loves eyes and truly believes them to be “the windows to the soul.” On occasions when I wear eye make-up, she takes notice and tells me how pretty my eyes look. She talks often about my father's blue eyes, the same blue eyes both my sister and I had at birth. The same blue that peered out from the upward slant of Nicholas's. But, even with the Down syndrome, it was also immediately apparent that Nicholas belonged to our family. His fair skin, blonde hair, and blue eyes matched those same features in my sister and me. He had the same round face shape as my father, a similarity especially notable later in the photos of my dad carrying Nicholas in his baby backpack, their faces side by side. In the first years of his life, we learned that Nicholas tanned easily in the summer sun, just like my mother.

Jan returned to the room.



“The doctors want to know if you would have done anything differently,” she asked my mother. My mom can only assume she meant, “The doctors want to know if you would have ended the pregnancy.”

“No,” my mom said.

\*

Nicholas had health issues outside of Down syndrome. It was his infant apnea that had turned him blue at birth and necessitated his weeklong stay in the NICU before he could come home. Almost four years later, his urine started to crystallize, a symptom of the kidney failure that would cause his death just before his fourth birthday.

By the time I met the Guillaume family, Nicholas had been gone for nearly thirteen years, and Anthony was six-years-old and in elementary school. Soon, he would attend that new school, then under construction. He now had two younger siblings – a brother, Noah, and a sister, Anni. Cori had left her most recent job to stay at home with her children, and Brian, now far from the guy who had squandered his first date funds, had been elected to the school board in Carlisle.

It is not lost on me that certain parallels between my family and the Guilloumes first drew me to them. There are five of them; there were five of us. They have a son and brother with Down syndrome; we had a son and brother with Down syndrome. Although the plot lines are different, both Nicholas’s and Anthony’s birth stories are, essentially, about loss, excitement, and joy. But, the Guilloumes still live in a world we only briefly visited. They will watch Anthony finish school, find a job, grow up, grow old, whereas

my family will never know what Nicholas would look like, be like. And so we are left to find moments of our lives in families like Brian and Cori's; we are left to wonder.

## **MOMENTS OF DISCOVERY**

At Cori's twenty-week ultrasound, doctors discovered what appeared to be sandal-toe gap, a deep separation between Anthony's first and second toes, an indicator of Down syndrome. Cori's doctors assured her that the possible sandal-toe gap was most likely insignificant to a couple as young as she and Brian were. At the time, Cori was twenty-six, which meant, by today's numbers, she had only a 1 in 1,285 chance of having a child born with Down's.

"Should I get an amnio?" she asked her doctors.

If the doctors said "yes" to the amniocentesis, it meant they would stick a needle into Cori's belly, suck out some of her amniotic fluid, and test it for the presence of the extra genetic material that indicates Down syndrome. If the doctors said "yes" to the amniocentesis, they would be able to tell Cori and Brian – with slightly more certainty – whether or not their son would be born with a condition that would affect his appearance and his intellect.

"Would it make a difference?" the doctors asked her.

When Brian and Cori learned that they would be having a boy, they prepared in the ways any excited parents-to-be would. They had chosen a name: Anthony. They had readied Anthony's room, the same room where Brian had slept as a child. On one wall, there was a mural of a forest. Along another, they placed Brian's baby dresser, one that

had drawers on one side and a rack to hang clothes on the other. But in all their preparations for childbirth, the Guillaumes had not discussed prenatal testing.

In that moment, however, without even consulting with each other, they knew the answer was, “no.”

Brian and Cori left the ultrasound appointment that day and looked down at their own feet. Cori also had a pretty big separation between her first and second toes.

\*

Nine weeks after Anthony’s birth, Cori brought him to one of their regular appointments with Tammy, their lactation specialist. Anthony hadn’t been eating well, and hadn’t been gaining much weight. When Cori nursed him, he latched on at the breast, but had trouble drinking. Exhausted from the effort, he often fell asleep while feeding. Cori assumed it was because she was a first-time mom and Anthony was a newborn baby: this was a new routine for both of them. The lactation specialist agreed.

At today’s appointment, Tammy laid a blanket on the scale and placed Anthony on top. She always did this: weighed the blanket first and then placed Anthony on the scale, so he wouldn’t have to lie on the cold metal. That day, Anthony had the beginnings of an eye infection, but something else seemed off to Tammy. On the scale, Anthony extended his body and arched his back, mannerisms of babies with Down’s. His inability to suck during his feedings might be the result of the low muscle tone around his mouth. Tammy looked at Cori. She suggested Cori visit the pediatrician for Anthony’s eyes. When Cori left the appointment, Tammy called the doctor and also suggested they run some tests for Down’s.

At his appointment, Anthony's pediatrician ordered a karyotype, a test that would map his chromosomes.

"Why?" Cori asked.

"We think he might have Down syndrome," the pediatrician replied. The karyotype would produce a map of Anthony's chromosomes and determine if he had an extra chromosome – the defining factor in a Down syndrome diagnosis. But that day, she didn't explain this. Instead, abrupt and inconsiderate, she sent Cori to the lab for blood work.

"We'll call you in a week when we get the results," she said.

Cori arrived at the lab with Anthony and told the technicians she was there to have blood drawn to test her son for Down syndrome.

The technicians looked at Anthony, tilting their heads as though to consider the possibility. "There's no way he has Down syndrome," they assured Cori.

Their assurances echoed exactly what Brian and Cori had told themselves since the ultrasound revealed Anthony's possible sandal-toe gap: "There's no way our son has Down syndrome." Cori and Brian had spent the weeks since that ultrasound rationalizing away the possibility of Down's. They sat on the couch with the other members of their family, side-by-side and barefoot, staring at their feet and measuring the divot between their first and second toes. At a doctor's appointment shortly after the ultrasound, Cori told her physician about the possible sandal-toe gap and asked about the possibility of Down's. He produced a chart that measured a couple's age against the chance that they would have a child with Down syndrome. Looking at the numbers, he concluded there

was no chance. When Anthony was born, Brian, with the last of their concerns lingering in his mind, asked the delivery nurse if Anthony was okay. “He was,” she had said with certainty.

In the week between Anthony’s blood work and his test results, Brian and Cori turned to research. They searched the Internet for “signs of Down syndrome” and read about the upward slanting eyes, low muscle tone, the wide hands with short fingers that were listed as symptoms of the condition.

“But, look at Cori’s eyes,” they reasoned as they peered into her thin, almond-shaped eyes.

They found pictures of Brian when he was a child, his younger self looking at the camera through the narrow slits of his eyes.

“Look at Brian’s eyes when he was younger,” they said.

On the day that Anthony’s test results arrived, Cori was at home, getting ready to have lunch with her mother-in-law. The phone rang, and one of Anthony’s pediatricians was on the other line.

“This is the phone call you didn’t want to get,” she said.

Cori started to cry. What about all of the people who had assured her, “you’re too young,” and, “he looks perfect”? In three weeks, she was scheduled to return to work; would she have to quit her job? *What, she wondered, would happen now?*

The pediatrician told Cori she would contact a pediatric cardiologist, and that Brian and Cori should look into early intervention – physical therapy, developmental

therapy, and, later, occupational and speech therapy – when Anthony turned twelve-weeks-old.

“Do you want me to call your husband,” the pediatrician asked, “because you seem pretty hysterical?”

“No,” Cori said.

Cori dialed Brian. He was on his way to a recent job site in Waynesboro – the same town he was scheduled to visit nine weeks earlier, on the day Anthony was born. As soon as he answered his phone, he could tell Cori was crying. He knew why she had called, in much the same way he and Cori both knew, without talking, at the twenty-week ultrasound that they didn’t want an amniocentesis.

Brian climbed into his truck. The day before Anthony’s results were ready, a snow plow hit Brian’s truck. The damage was minimal – a scratch or two, maybe a dent – but enough to be noticed. He immediately left the job site and drove home to a house that would remain quiet that night.

\*

In medical terms, Down syndrome is the presence of an extra chromosome. In practical terms, Down syndrome means a person will look different – with slanted eyes, a protruding tongue, short stubby hands, a long separation between the first and second toes – and be at a greater risk for certain health problems, like heart disease and cataracts. In terms of causes, the condition still largely remains a mystery. Usually, doctors diagnose Down’s at the time of birth, based on the baby’s appearance, as they did when they saw my brother, or if they hear a heart murmur during the initial exam. But there are

also blood tests that can confirm the presence of an extra chromosome and a karyotype, a test that will map a person's chromosomes, the parts of each of our cells that carry most of our DNA.

John Langdon Down, a British physician, discovered Down syndrome by looking at clinical photographs and by measuring the head and the palates of his patients. His list of symptoms closely resembles the lists we see today: "flat, broad face;" round cheeks; slanted eyes; large lips; small nose; thick tongue; pleasant nature; low life expectancy. Down knew that the condition formed in utero, but he thought it might be related to tuberculosis. He described the condition as "Mongolian idiocy," for the Asian appearance of people with the condition; Mongolian idiocy comprised more than ten percent of the cases he saw. In 1961, the name would be changed permanently from Mongolism to Down syndrome, after the man who discovered it.

In photographs, Down is an older man with a tuft of white hair, but his birth story began in Torpoint, a working class town in Cornwall, where he was born in the room above his father's grocery store. He would go on to medical school at London Hospital, where he would receive gold medals for medicine, surgery, and obstetrics and be named the student of the year. He worked as the medical superintendent at the Asylum for Idiots at Earlswood in England and became an advocate for schooling and training programs for the handicapped. After his death, he would also become the grandfather of a child with Down syndrome.

In 1905, Down's son Reginald and his wife Jane had a little boy with Down syndrome. Despite Down's prediction that people with this condition would live a short



life, Reginald's son lived to be 65-years-old. And, despite the work that Down did for the people with the syndrome named after him, Reginald's wife Jane could never accept her son's diagnosis.

\*

My mom still remembers the sounds coming from the neighboring hospital rooms after my sister and I were born. Both times, she heard one woman crying while another offered comfort: "Everything will be okay. We're gonna be okay. Everything will be fine." She never saw these women or found out for certain what had happened during their deliveries, but after Nicholas was born, she felt a kinship with them.

My dad hadn't noticed anything different about my brother, not his squinting eyes or protruding tongue or short, stubby fingers. When the doctors confirmed Nicholas had Down syndrome, my father asked, "What does that mean?"

With only the knowledge she had gleaned from her prenatal books, my mom replied, "it's mental retardation."

When my mom and dad learned they were having a boy, they had a month to live in what my mom calls a "joyful moment." They spent the next weeks wondering what it would be like to have a son, how it would be different from having two daughters. After Nicholas was born, they had to wonder how a child with Down syndrome would affect their family.

There's an essay called "Welcome to Holland" that has become well-known among parents with a child with special needs. Written in 1987 by Emily Perl Kingsley, the essay likens raising a child with a disability to planning a trip to Italy and arriving,

instead, in Holland. It describes a traveler who purchases guidebooks for Italy, who learns important Italian phrases and expressions, who makes arrangements to see the Coliseum, *The David*, and the gondolas. A traveler who, filled with excitement and hope, boards a plane to Italy. But then, unexpectedly, the flight lands in Holland, with no way out. “Holland?!?” the traveler says. “What do you mean Holland?? I signed up for Italy! I’m supposed to be in Italy. All my life I’ve dreamed of going to Italy.” The traveler will never forget the pain of missing a stay in Italy, but Kingsley reminds her readers that Holland isn’t terrible – just different, and she advises them to buy new guidebooks, to learn a new language, to appreciate the people in Holland, to marvel at the tulips, the windmills, the Rembrandts – the unexpected beauty in this new place.

This essay provides special comfort to my mother because she is Italian. She knows the beauty of the country, the taste of the food, and the sounds of the streets. She has wonderful memories of her visits there. She speaks the language fluently. She knows nothing about Holland.

After Nicholas was born, she couldn’t help but compare her birthing experiences. After my sister and I had been born, the room had filled with people and noise.

In the NICU, no one was allowed to hold Nicholas. My mom couldn’t breastfeed him because he couldn’t latch on. My sister and I couldn’t even see him. In the hospital room, my parents were all alone.

A nurse asked if my mother wanted to speak with someone, and soon, a woman arrived at her room. She had a daughter with blonde hair, glasses, and Down syndrome. This woman sat and talked with my mom. She showed her a family photo album. My

mom turned the pages. She noticed that some photos were missing and wondered what should have filled that space. But she also noticed the photos that were present: they showed the little girl playing, opening Christmas presents, spending time with her siblings.

“It’s not bad,” the woman told my mom.

Later – months, maybe years – my mom was shopping at the mall and saw the doctor who had delivered Nicholas. After Nicholas was born, he had moved to a different practice, so this was the first time she had seen this man since he rushed out of the delivery room.

“How are you doing?” he asked my mom.

My mom looked at him. He was tall, and his dark hair had begun to grey.

“We are fine,” she said.

\*

At Anthony’s two-week appointment, another pediatrician had written “possible Down syndrome” on his chart. No one told Brian and Cori.

It turns out Brian and Cori were lucky. Anthony was a healthy baby with a strong heart, and so the lapse between the doctor’s suspicion and Anthony’s diagnosis was not fatal, or even dangerous. Instead, it gave Brian and Cori the time to get to know their son without a diagnosis, the chance to live in their own joyful moment. Anthony liked to sleep, they learned. He remained calm until he was hungry. He made noises when he wanted something. Except for the crook in Anthony’s right ear, one of Cori’s favorite things about Anthony, she didn’t notice anything different about him. Their new family

settled into a routine – Cori woke Anthony up every two hours to feed him; Anthony let his parents know when he needed something.

After the diagnosis, their routine changed. Every night, Cori gave Anthony an infant massage. She laid him on the living room floor and for thirty minutes, rubbed his back, legs, and neck with oil. She rolled him over and massaged his arms, belly, chest, face, and head. She rubbed his fingers and toes and the bottoms and tops of his feet to stimulate his muscles and calm him down at the end of the day.

Today, when Brian looks at photographs from Anthony’s first weeks, he can tell, only because of the time stamp on the picture, if it was taken before or after Anthony’s diagnosis. By the time Anthony was sitting in his high chair wearing his camouflage bib that said “Hunting Buddy” in orange embroidery, or lying on top of his Teddy bear sheets staring at the ceiling, or perching on Brian’s knee in his warm, fuzzy, blue onesie, they knew he had Down syndrome.

## **DINNER WITH ANTHONY**

It's been nine years since Anthony was born. The quiet that filled Brian and Cori's home the night Anthony was diagnosed has been replaced by the patter of Anthony's bare feet as he wanders into the kitchen and the swish of his toy broom as he sweeps the floor, by the digital music as his younger brother Noah plays a video game, and by the sound of his sister Anni's voice as she asks Brian and Cori to play with her.

Outside, it's a raw January night. The rain that fell earlier in the day had stopped, and fog had begun to settle around the family's home on Briarwood Lane. Removed from the noise at the center of town, Briarwood twists and turns in wide curves and has no sidewalks, only a single yellow line running down the center. The homes lining the street are modest, most of them one story with two-car garages. The Guillaume family lives at number 175, a one-story brick house with a burgundy door and shutters. Brian had planted the pine trees that line the backyard himself. The oak tree out front, which now rivals the height of the house, began as an acorn that Brian planted in a cup and placed on the kitchen windowsill to grow. It's the same home where Brian and Cori decorated Anthony's nursery, the same kitchen where Cori was standing when the pediatrician called to tell her that Anthony had Down's, the same house where Brian had grown up, that he bought from his parents two years before Anthony was born, that he and Cori filled with their family and made their own.

Inside, it's Friday night at the Guillaume house: no homework, no baths, and fun foods. It smells like dough, herbs, and sauce – pizza, that Friday's dinner. The wood-burning stove in the basement heats the whole house, making the inside feel warm and dry. I can hear the sounds from the kitchen: the soft murmur of the television, tucked in the corner, playing re-runs of *Law and Order: SVU* and the chatter between Brian and Cori.

Brian stands at the counter, drinking a beer and snacking on the chips and pizza dip that Cori had made. He is wearing a button-down shirt tucked into his jeans. The only time I have ever seen him wearing something different is in the wedding photograph displayed on top of the television set in the family's living room. In the photo, he and Cori sit next to each other with plates of cake between them; she in a wedding dress and he in a tuxedo. Brian's cheeks have a natural pinkness that always makes him appear jolly – I noticed it the first time I met him, in the wedding photograph, and in the kitchen that night. Occasionally, worry will creep into Brian's voice, and he'll speak in hushed tones as he wonders aloud what will happen when Anthony is 21 and no longer supported by the public school system in Pennsylvania. But, most of the time, he is playful and gentle towards his children, characteristics that are reflected in his demeanor. He often sounds more burdened by his role on the school board or his job as a bridge inspector. On Friday, there had been an accident at work, and Brian kept his cell phone snapped into a plastic case attached to his belt, close to him, in case he needed to take a call.

Brian walked across the kitchen to the stairs leading to the basement and leaned against the door frame.

“Buddy,” he called down to Anthony. “Pepperoni.”

Just a few seconds later, Anthony appeared barefoot in the kitchen. He tip-toed up to the counter, the bottoms of his jeans creating a quiet swishing sound as they brushed across the floor.

I can see why it took the doctors weeks to diagnose Anthony. At first, it’s hard to tell Anthony has Down syndrome. Tall and lanky, he has Cori’s thin frame, dark coloring, and almond-shaped eyes. He wears his brown hair trimmed close to his scalp, just like Brian. But when I look at him more closely, I see the narrower slant of his eyes; I see his tongue sometimes, involuntarily, poking out of his mouth. When Anthony talks, it sounds like he is trying to speak with his mouth open, as though every word he utters contains the long “O” sound. It’s easiest to understand one-syllable words: “hi,” “mom,” and “yeah.” If I were to look closely at Anthony’s feet, I would see a deep crease along the bottom, and I might notice his sandal-toe gap, that extended separation between his first two toes that appeared on his twenty-week ultrasound, the earliest hint that he might have Down syndrome.

Cori pulled the two trays of pizza from the oven and placed them on the countertop where Anthony and his younger sister Anni decorated them with pepperoni. They each picked up the pepperoni, one piece at a time, pressing each circle into the soft sauce and the freshly baked dough. Anni carefully placed hers one after the other in straight lines across the dough, creating a pattern of stripes that mirrored her outfit: a dress with pink, orange, brown, and grey stripes and matching tights. Anthony’s design

looked less carefully planned: one piece of pepperoni in the top corner, one in the center, one brushing the right edge of the tray, another along the bottom.

Occasionally, Anni turned to watch her brother.

“Mommy,” she finally said. “I wish Bubby would put the pepperoni in a line like me.”

Cori stood behind Anni and Anthony and watched as they placed the last of the pepperoni on the dough.

“The nice thing about pepperoni pizza is you can put it on anyway you want,” Cori said. “You can be creative with your pizza. I’m a line person myself, and since your birthday is the day after mine, that might explain it.”

Noah, Cori and Brian’s middle child, came upstairs from the basement and started to set the table. If Brian could have ten children like Noah, he would be happy. Noah is only in first grade, but already, he’s a guy’s guy: he likes to play sports, to hunt, to be outside. Last fall, Brian coached Noah’s touch football team, and in the spring, he will coach his little league baseball team. Every September, when the men in Brian’s family go dove hunting, Noah tags along to be part of the tradition. As the men shoot, Noah runs into the field to retrieve the fallen doves. These are the things Brian had imagined for Anthony when he found out he and Cori were having a boy. Brian didn’t know what to expect when Anthony was diagnosed with Down’s. He had volunteered briefly with the Special Olympics when he was in college, and had watched Corky on *Life Goes On*, a 1990s television series about a family with a son who has Down syndrome. But what it would be like to have his own son with Down syndrome, he had



no idea. So, here was his son, someone he always thought would become his hunting partner and fishing buddy, someone who was half of him, but he no longer knew what to expect.

Anthony helped Noah pull placemats from the drawer. Most were pale green with white flowers, but he also found a plastic placemat with a picture of Spiderman on it. Noah folded the napkins into triangles and placed forks on top of each one. Before he got to Anthony's seat, Anthony had pulled a large serving fork out of the same drawer where he had gotten the placemats.

"Do you really need a fork that big?" Cori asked.

"Yeah," Anthony replied. The corners of his lips raised in a smile.

"You're being silly. Look at that smile." Brian said. He pinched Anthony's cheek, and Anthony smiled again.

As they sat down to eat, everyone had a placemat in front of them except for Anthony. His old fashioned Coke glass sat on the tabletop with no buffer to protect the wood.

"Do you want Spiderman or this one?" Cori held up the two placemats. "Do you want Spiderman?"

"No," Anthony said.

"Do you want this one?" She held up the green placemat with the white flowers.

"No."

"Then, you can't eat."

Cori took Anthony's water glass away and placed it on the counter. Anthony sat still in his seat between Brian and Noah.

"You can't have a drink without a placemat, Anthony," Anni said. She straightened her back and re-adjusted the homemade placemat in front of her. She had made hers out of yellow construction paper at preschool. It had a large circle in the center to mark the place for her plate and a smaller circle in the top right corner for her cup. On the left, she had traced a fork, and on the right, a spoon and a knife.

Cori removed the trays of pizza from the oven, the cheese on top bubbling and sizzling. Little puddles of red-orange grease collected in the divots of the baked pepperoni. She sliced the pizza into squares and began serving it. Anthony watched as paper plates holding two slices each were passed around the table and immediately chose the green placemat with the white flowers.

With plates in front of everyone, the family held hands to say Grace.

"Bless us, O Lord, and these thy gifts, which we are about to receive, from thy bounty, through Christ our Lord. Amen," they said in unison.

Anthony pushed his chair away from the table, walked over to where Cori sat at the other head of the table, and the two of them tapped elbows. Anthony turned to Brian and gave him a high-five; then he turned to Noah and did the same.

"Mommy," Anthony said. "Whole."

"Pizza whole," Cori said, and knew this meant that Anthony wanted to pick up his pizza slices and eat them whole, the way he did before Anni started to eat solid food and

Cori cut it into bite-size pieces. That was when Anthony started to ask if Cori would cut his food, also.

Anthony opened his mouth wide to eat his pizza. He tilted his head back and let little drops of grease, hot and slippery, drip down his lips and over his jaw. The cheese slid off the pizza and looked as though it was melting into Anthony's mouth. Brian watched Anthony eat and reached over to stroke his hair.

"We need a haircut," he said. "What do you think? How about Sunday?"

Anthony didn't respond. To get a haircut, he doesn't go to the barber; he goes to the basement. The noise and vibrations of the electric razor used to buzz his hair irritate him, and he needs to be restrained by one parent while the other trims the sides, back, and top of his hair.

"Scuse, please," Anthony said when he had finished eating.

"Yes, you can be excused. Don't forget your paintbrush, Doodlebug," Cori said. "Doodlebug" is the term Cori uses while driving, in place of the expletives she uttered before she had children. When she uses it to address her children, though, the meaning becomes more affectionate.

Anthony carries his paintbrush with him almost everywhere; Cori calls it his "fidget." He had reached the top of the steps leading to the basement when he returned to grab it from the table.

After dinner, the children ran back and forth between the bedrooms and the basement, always passing through the kitchen. Cori poured herself another glass of wine while Brian did the dishes. Anni showed me a book she made at school; Noah went

downstairs; Anthony came upstairs. He disappeared into the bathroom, where he took off his jeans and sat on the floor in his underwear, using his paintbrush to draw imaginary circles on the tile floor. He sang “Amma” and “Papa,” the names he has for Cori’s parents, and only emerged when Cori set out dessert – a chocolate, peanut-butter trifle.

“Spoo,” Anthony said. He climbed onto one of the chairs in front of the small bar in the kitchen and stared at the television (Brian had changed the channel from *Law and Order* to cartoons) while he waited for Cori to give him a spoon. He dipped it into the thick, brownish pudding and placed it in his mouth, swallowing the pudding and chewing the bits of brownie and peanut butter cups scattered throughout the rich mixture.

“More,” he said, his eyes still glued to the television.

“Anthony, do you want to call Papa?” Cori asked.

“Yeah,” Anthony said.

Anthony walked toward Cori on his tip-toes, the way he had earlier that night when Brian had said “pepperoni,” the way he always did when he was really excited.

Cori had promised Anthony they would call her parents on Friday night.

Anthony’s morning routine that week had been the same every day: he put his pajamas in the hamper; he took his backpack into the kitchen; he sat at the bar; he asked to call Mama and Papa.

Cori’s parents still live on the 140-acre farm in New York where she and her two younger siblings grew up. Her father worked as a car mechanic, and her mother worked in the office of a car dealership. In high school, Cori was a cheerleader and played the flute and piccolo in the marching band and the oboe in the concert band. She and her

siblings used to help their father by removing rocks – on what always seemed like the hottest day of the summer – from the fields that needed to be plowed. Once a year, the family took a picnic to Watkin’s Glen in New York, where they hiked on the trails and climbed down the gorge. Now, Cori’s dad has a full gray beard. He has a strong frame, with wide shoulders, the same build Cori and Brian think Noah will inherit. When the Guillaumes visit New York, Papa and Anthony climb onto the four-wheeler and disappear somewhere in the vast acres of land.

“Do you like Papa?” Brian asked as Cori dialed the number.

“Yeah,” Anthony said.

“Does he take you on a four-wheeler ride?”

“Yeah.”

“Does he have a crazy beard?”

“No,” Anthony said.

“Yes, he does,” Brian said as Cori handed the phone to Anthony.

“Hi,” Anthony said into the phone. “Oh, Maggie.”

Anthony removed the receiver from his ear and placed it next to Maggie, the family’s Springer spaniel. Just a few weeks before, Maggie had run away and gone missing for a few days. The principal of one of the Carlisle middle schools found her roaming the yard, recognized her as the Guillaumes’ dog, and called Brian. For days after Maggie came home, Brian spotted Anthony stroking her head saying, “Maggie. Home.”

Anthony handed the phone back to Cori and returned to the living room.

“He’s been missing you real bad this week,” Cori told her father.

When she hung up the phone, she again settled into her chair at the end of the table. Anni had gone to get ready for bed. Noah had returned to the basement, and Anthony, still in his underwear, played an Indiana Jones video game in the next room. Cori looked across the table at Brian.

“Encouragement,” they said at the same time, quoting a scene from the movie *Couples Retreat*, and started to laugh.

From the next room came the soft clink of marbles hitting each other. Brian and Cori exchanged puzzled looks and walked into the living room. Anthony had stopped playing his video game so that he could move the furniture: the gray, plush loveseat underneath the picture window now faced the sofa against the adjoining wall.

“It looks like *Poltergeist* in here,” Cori said.

“Mom,” Anthony said as he walked towards her. “Woah.”

In his hands, he held a bag of marbles, a pack of tissues that had been printed to look like dollar bills, and two cardboard children’s books that Anni would ask her parents to read to her later, as she attempted to extend her bedtime. It was one of Noah’s stashes (he actually calls them “stacks”), piles of his things that he hides throughout the house.

“Go show Noah,” Cori said.

Anthony ran down the stairs to the basement. Anni emerged from her bedroom, her eyelids starting to droop from sleep and her bare feet flopping across the floor with tired steps, and scurried after him. Not long after Anthony and Anni returned Noah’s “stack” to him, Anni retreated to her bedroom.

“Mom, Anni sleeping. Too loud,” Anthony scolded his mother on his final trip through the kitchen, where Cori sat and continued to talk.

Anthony returned to the basement, where he and Noah lay sprawled on the couch. Anthony could while away hours in that basement, the room Cori and Brian call his “man cave.” Brand new beige carpeting covers the floor and a sectional sofa faces the television set. A dollhouse, tent, and other toys lie scattered on the floor. Off to the side is the room where Brian keeps his hunting gear. A stuffed fox stands on one side, staring at a work bench on the opposite side of the room. Brian’s gun safe is set against the center wall, standing as tall as my own five-foot frame. Inside, Brian stores each family member’s birth certificate and the doctors’ reports after Anthony’s Down syndrome diagnosis. They indicate that he is a healthy boy, with a heart with four strong chambers and good muscle tone.

“Time for bed,” Cori announced, looking at her two sons, still lying on the couch.

“Yep,” they agreed, although neither of them moved for several minutes.

“Privileges 1,” Cori said, breaking her stare with a countdown until they lost some of the perks of being a kid, like playtime or snack time.

“Two, three,” Anthony chimed in before Cori could finish.

Finally, the boys climbed the stairs and retreated to the bathroom to brush their teeth. Brian tidied the kitchen while Cori followed her sons. She stood behind them and watched as toothpaste foamed in their mouths, and the two brothers took turns spitting into the sink.

This was the first evening I spent with the Guillaumes. I left to drive home through the fog that had not yet lifted. When I told my mom about the events of the dinner – the family saying Grace, Anthony eating pizza, the children playing together – she smiled. Here was a family different from ours, yet not so different.



## TALKING ABOUT NICHOLAS

The first time I told anyone about Nicholas, I was standing in front of my kindergarten class. A few days after my brother was born, a room full of my five-year-old friends looked at me as I told them I had a new baby brother named Nicholas.

My friend Jamie gasped, looked at me, and smiled. She had a baby brother named Nicholai, and, for the moment, it was as if our families were exactly the same.

Before Nicholas was born, my younger sister Angela and I had taken sibling classes, so we were ready to hold Nicholas when he arrived. My parents brought him home from the hospital to find that my aunt had decorated our house with blue crepe paper and a sign that read, "Welcome home, Nicholas."

I didn't know that, just after Nicholas was born, my mother had watched the face of Jan, the jovial nurse who had laughed with my parents during the delivery, turn sullen as she cleaned my brother and realized something was wrong. I didn't know then that as soon as Nicholas was born, the doctor looked at his slanted eyes and protruding tongue and knew immediately that he had Down syndrome. When my father heard the diagnosis, he asked, "What does that mean?" Without offering much information, the doctor left the room and, later, sent a nurse to ask my parents if they would have done anything differently had they known my brother had Down syndrome. In addition to Down's, Nicholas had sleep apnea and trouble breathing, other issues that would negatively affect

his health. For my mother, these memories are so vivid that now, twenty years after Nicholas was born, she can still recall them and many moments that followed. Aside from delivering my announcement to my kindergarten class, I don't remember much about the days following my brother's birth – not my mother's asking to leave the hospital early to come home to her two daughters, not Nicholas' time spent in the NICU, not even the disappointment my sister and I felt because we couldn't hold our brother immediately, something my mother reminds me of now when we talk about the early days of Nicholas' life. I do remember the red patches on his face from the tape that held his oxygen tubes in place; in the first days that he was at home with us, his skin looked raw and chapped, like he had a cold. I remember stroking the soft blonde fuzz that covered his head, always stopping just above the soft spot on his scalp, gently feeling the indent. I remember the wooden rattles he played with – the ones that looked like small bird cages with bells inside – and the ringing as he shook them back and forth. I remember the day Nicholas learned to roll over. My mom had spread a blanket over our brown family room carpet, and my sister and I lay on top of it, flanking Nicholas, who lay in between us. First, I rolled over; then, my sister rolled over; then, Nicholas rolled over. We repeated this over and over until my mom grabbed the video camera and captured the scene – and our cheers for Nicholas and our giggles and shrieks.

While my sister and I went to school and my dad to work, my mom stayed at home with Nicholas. Each night at dinner, she shared stories of his antics with us. One day, she was chasing Nicholas around the house when her knee, injured years before in a skiing accident, gave out. She fell to the ground. In pain and unable to move, she called

out to Nicholas, who was running away from her, content to continue playing the game. He had moved beyond her reach, his little feet hitting the floor and his laughter trailing behind him.

On another day, my mom was cooking while Nicholas played at her feet in the kitchen. She had opened the spice drawer, which was inside a lower cabinet and almost eye-level with Nicholas when he stood up. Nicholas moseyed over to stand next to my mother and pulled the pepper from the drawer. He began to shake it up and down with the same quick motion he used with his wooden rattle, backing away from my mother with each shake.

“Nicholas, come over here with that,” my mother scolded.

Nicholas continued to walk away and shake the pepper.

“Nicholas, right now,” my mother said.

Nicholas just giggled at her.

“Nicholas,” my mother said again, but before she could continue to yell at him, the pepper in the air hit his nose, and he began to sneeze uncontrollably.

We laughed together over these stories, as Nicholas sat with us in his high chair eating his soup and pudding.

My mother recorded other stories and memories of Nicholas’s first three years in his baby book: the Pinocchio and Barney invitations she sent to our family for Nicholas’ first and second birthday parties; the time Nicholas cried so hard during a doctor’s appointment that he broke blood vessels in his face, leaving his cheeks and the skin around his eyes red and splotchy; the morning of Nicholas’ first birthday, when he fell

out of his stroller and had a black eye in every photograph. But Nicholas's baby book also contains newspaper clippings by Erma Bombeck – “Special Children Need Special Mothers” and “And That's How They are Chosen,” both columns offering comfort and advice to mothers of children with disabilities. Also pressed between the pages of Nicholas's baby book is the prayer card from his funeral. He died twenty days before his fourth birthday.

\*

In *The Shape of the Eye*, his memoir about his daughter born with Down syndrome, George Estreich writes:

People were, for the most part, incredibly kind. They were concerned. They offered help. They struggled to say something appropriate. That struggle, and not unkindness, characterized most of our interactions, and it seemed appropriate that a disorder so specifically affecting language should bring people to the edge of words. You could see it in people's eyes: they had no idea what to say. And yet *something* had to be said, if only to avoid the silence.

Any time I see someone who has a sibling or a child with Down syndrome, I know exactly what to say. Or, at least I know what I want to say: “My brother had Down syndrome. We have that in common. I know how you feel.” It's as though I long to be accepted into this community and camaraderie of those with Down syndrome. But, Nicholas's death complicates this, and leaves me almost always on the outskirts.

Once, my mom and I were eating breakfast at our favorite coffeehouse. We sat tucked in a booth along the wall. On the opposite side of the café, where a long bench sat

piled with pillows and magazines, we spotted two women with a little girl. We could tell the little girl had Down syndrome: her eyes slanted, and she had the stout figure and distinct flat-footed gait of those with the condition. She hopped off the bench and climbed back on, nestling herself between the two women. Occasionally, she moved her head from side to side to watch them as they talked over her.

“Sometimes, I wish I could say something to people like that,” my mom said. “Like, ‘your daughter is darling.’ But then, I’d have to share our story about Nicholas, and I don’t know how that would make them feel.”

She’s right. How were we to tell people about Nicholas – who died so suddenly at such a young age? How, especially, were we to tell those who themselves had a child with Down’s, a condition that causes not only an altered physical appearance and cognitive delays but also serious physical health problems – like heart trouble or cataracts or an increased chance of Alzheimer’s?

When we see families who have children with Down syndrome, my family catches a glimpse of our past. But we don’t want these people to hear our story and to worry that it might be a glimpse of their future.

\*

My brother died on a Sunday night in March, 1996. I was in fourth grade and lying on my bedroom floor, reading a teen magazine about Jonathan Taylor Thomas, listening to Celine Dion music, pretending to be older than I was, when I heard my mother scream. The yells continued. My mother is the kind of woman who sounds like

she is yelling even when she is speaking, so the echoes of her loud voice throughout the house were nothing new. The panic I could detect was.

My mom had been in the kitchen making dinner – turkey, mashed potatoes, and gravy, our favorite meal – as my father sat with Nicholas in the adjacent family room. Nicholas had been sick and only wanted to be held, so my father rocked him back and forth on our green rocking chair until he noticed something was not right.

“Nicholas,” he said. “Nicholas. Nicholas,” the panic in his voice increasing each time.

Because of Nicholas’s sleep apnea, both of my parents needed to become CPR-certified before they could take my brother home from the hospital. Now, my mother told my father to perform CPR on Nicholas. She called 9-1-1 to verify that he was doing it correctly. The operator assured her that the paramedics were on their way.

I walked downstairs and lingered in the hallway leading from our foyer to our family room, the same spot where my sister and I crouched to catch a glimpse of the PG-13 or R-rated movies my parents sometimes watched after they put all of us to bed at night. I saw my father performing CPR on my brother, who was sprawled on the floor. Since the video of the three of us rolling over, my parents had installed new carpet, this one beige with green flecks. My mother stood in the adjoining kitchen, the phone pressed to her ear while she shouted directions from the 9-1-1 operator to my father.

The whole scene exists in my memory as a fuzzy, out-of-body experience. I didn’t know where my sister was. I don’t think I said anything; I just stood there, absorbing everything.

While my parents went to the hospital with Nicholas, my sister and I stayed with my aunt and cousins, who, in middle and high school at this time and old enough to comprehend that something very serious was happening, distracted us with candy, games, and hours of television – activities so different from a quiet Sunday night at my own house.

For weeks before this night, Nicholas had not been well. He became cranky and tired and hardly ate or drank. The only activity that made him happy was watching hours and hours of *Barney*, his favorite show. When his urine began to crystallize, my parents took him to the doctor, who diagnosed him with nephritis, an inflammation of his kidneys. The doctor said that he, too, had had nephritis and advised my parents that they would need to be patient during what could be a long healing process.

“See, Nicholas,” my dad said to my brother in the doctor’s office that day, “when this is all over, you’ll be a doctor, too.”

Instead, my brother died of kidney failure. When my parents returned from spending hours at the hospital and told us, my sister Angela burst into tears. She and Nicholas were closer in age and, for the early years of his life, had been playmates. When I heard the news, I just stared at my parents, shocked. Something about the way I recall the rest of that night makes every detail seem out of proportion. I can picture my sister and me in our pajamas, sitting on my parents’ queen-sized bed. But, in my mind, we look like two tiny specks sinking into a huge mattress. I don’t recall the time of night when all of these events took place, but it felt like we stayed awake for hours receiving visitors –

my aunt, uncle, and cousins; my maternal grandparents – before we could finally fall asleep in our parents’ bed.

The next day, my mom’s best friend Ora Jane arrived at our door. It was a sunny, early spring day. She wrapped my mom in a tight hug, and then took my sister and me to the playground, where we played PIG and Around the World on the basketball court. That night at dinner, we ate a soup of little star noodles floating in my mother’s homemade broth – one of Nicholas’s favorite foods and the only thing he ate in the days before his death. After we said Grace, my dad rested his head in his hands and cried.

“Daddy’s crying,” my sister said.

“He is, and that’s okay,” Ora Jane said. “He might cry for awhile.”

We received many visitors in that first week after Nicholas died. My mom’s friend from high school brought us groceries, including a bag of Hershey’s chocolate kisses. Just a few weeks earlier, for her birthday, Angela’s friend bought her some clay and a book of instructions about how to mold and bake it into different sculptures. My aunt helped my sister and me create a blue swing set with a yellow swing. It looked just like the one in our backyard where Nicholas spent hours swinging while we pushed him; we would later place it in his casket. She also helped us to mold a bust of our pastor, who spent much of that week after my brother’s death at our house. Years later, during a homily about his favorite things, he would pull that bust out of his bag and talk about the “two little girls” from the parish who made it for him. At that mass, I sat next to my mother who gasped and then started to cry.



After Nicholas died, my sister and I didn't go to school for a week. We were students at a small Catholic elementary and middle school, a school where they made announcements about deaths in the family so that every student would pray for us. When my friends learned about Nicholas, the phone rang non-stop. Fourth grade was the year my friends and I discovered the telephone – and the first year we were allowed to use it for recreation. I spent much of that year chatting with my friends about nothing: boys who we liked, boys who liked us, Mariah Carey CDs we were listening to. This time, presumably, they had called to talk about something much bigger. I asked my parents to tell them that I was not available.

When I finally took a phone call, it was from my friend Lisa. She told me that the class would be at my brother's funeral later that week. I felt furious. Days before, my aunt had asked if I wanted my classmates at the service, and I had said "no." I didn't want them to feel sorry for me; I didn't want them to see me cry. My aunt was upstairs when I hung up the phone.

"Why is everyone coming to the funeral?" I demanded. "I said I didn't want them there." I had never spoken to my aunt in such a harsh, angry tone before.

She didn't scold me, or tell me to treat her with more respect. She just touched my shoulder. Mrs. Gill, one of the secretaries in the office, had explained to her that so many parents were taking their children out of class to attend the funeral that the school just decided to take everyone.

I can't even remember now how hard – or even if – I cried at the funeral. I didn't play a role in the service, except to walk down the center aisle with my family as part of

the opening procession. My uncles served as pallbearers and followed us with Nicholas's small casket. My classmates were there; in their navy blue, plaid uniforms, they formed a dark-colored wall along one side of the church. Our pastor delivered the eulogy my mother had written. In it, she called Nicholas an "angel" and said, although diagnosed with a disability, his "greatest ability" was to bring out the best in those around him – in his therapists at United Cerebral Palsy (UCP), where Nicholas received services like speech, physical, and occupational therapy; in my father; in my grandparents; in my sister and me.

The next week, my sister and I returned to school. At one of our weekly masses shortly after Nicholas died, I filed into the pew next to Beth, a girl in my class. Beth was a bit of a class clown who, with two older brothers, was also privy to information about curse words and sex which were still foreign to me. We shared a hymnal during communion, and I giggled incessantly as, instead of singing the words on the page, Beth made up her own rhymes – some silly, some dirty. After mass, our teacher pulled Beth aside. Instead of reprimanding her for her disrespectful behavior, she looked at Beth and said, "It's good that you're making Erica laugh." In those first few days, no one else mentioned Nicholas.

That year, my school's annual Family Fun Night carnival fell exactly twenty days from the night Nicholas died; it was scheduled, in fact, on the same day that Nicholas would have turned four. Instead of playing Plinko, eating pizza, and cashing in tickets for prizes like costume jewelry and stuffed animals, my family stayed home and ate soup in

memory of my brother. The week before, my friends had asked me if I was going to the fair.

“No,” I said. “It’s my brother’s birthday.”

“They’re acting like he’s still alive,” I heard a classmate whisper.

After Nicholas had been born, my mother worried that, as we got older and people recognized Nicholas’s differences and his disability, they would say cruel things about him. This was the first time anyone had ever made a remark about my brother or my family that I found hurtful. I never felt different because I had a brother with Down syndrome; I felt different because I had a brother who had died.

Months later, a substitute teacher spent a few days with my fourth grade class. Petite with frizzy, curly hair, she looked and sounded like Annie Potts. I knew her because her children attended school with my sister and me. One day, our religion class focused on family, and she went around the room so that each of us could share the number of people in our own families. I listened as row by row, students stated the number of people in their families, wondering what I should say when my turn came. Right now, there were only four of us, but wouldn’t there always, technically, be five?

“There are four of us,” I said when it was my turn to talk.

The next day, the substitute teacher approached me and apologized for asking such a question so soon after my brother died. Even as a fourth grader, I felt touched by her concern and her acknowledgment of Nicholas, both his life and his death. Yet her kindness didn’t give me any indication of whether or not I had given the right answer. I still don’t know how to answer that question because it remains unclear how Nicholas’s

birth and death both shaped and shattered the identity of my family. Sometimes, people will ask if I have siblings, and I always respond with, “I have a younger sister.”

“Just the two of you?” they push, and I imagine a knowing in their voice, as though they are testing me, wondering why I don’t include Nicholas. How am I to honor and remember him without, as my fourth grade classmate said, “acting like he’s still alive?”

By the time I entered high school, I had achieved everything I hoped when I had requested that my class not attend Nicholas’s funeral: no one felt sorry for me; no one identified me as the girl whose brother had died. This was largely my doing; with the exception of a short story I wrote in seventh grade – about a girl with a brother with Down syndrome – I never mentioned Nicholas. My new classmates had no way of knowing about my brother, and my peers from elementary and middle school seemed to follow my lead and remained silent.

The summer before my junior year, I hosted a party for some of my classmates, including Kyle, a tall, smart boy in my class. He played the guitar and made me laugh, and I had liked him from the moment I met him in my homeroom freshman year. The entire party, in fact, was an elaborate plan to get Kyle to notice me outside of school, to invite me to the homecoming dance that fall, to want to date me for the rest of our high school careers. Finally, I found myself almost alone with him in my family’s finished basement. My friend Mary lingered on the sidelines as Kyle looked at the family photos we had on display. On top of our television stood two photos from different trips to Disney World. In one, my family – including Nicholas – is dressed in costumes from

*Pirates of the Caribbean*. In the other, taken when we were obviously older, the four of us stand in front of Cinderella's castle. Kyle pointed to Nicholas.

"Who is this?" he asked playfully. "And why is he in this picture and not in this one." He moved his finger from one picture to the next, as though using a magic wand to make time pass.

"That's my brother," I began. I saw Mary give me a look that said, "good luck with this one," and then slink outside through the sliding glass door. As much as I had wanted to be alone with Kyle, in this moment, I wanted even more to follow Mary outside. Instead, I turned back to Kyle. "He died when I was in fourth grade," I explained.

"Oh, my gosh," Kyle said, and I can't remember if he paused for too long before responding, or if he reacted too quickly. "I'm so sorry. I didn't know. I'm so sorry."

I think it was in this moment that I developed my standard reaction to this response. I smiled what would probably be called a "sad smile," just a slight upturn of my lips, no teeth showing, and shook my head "no." I held a hand in front of me and moved it back and forth with my head, as if to say, "Don't worry about it. It's okay. No need to apologize."

When I told this story to my mother, she said that maybe I would end up marrying Kyle. The first time she visited my grandparents' house, when she and my dad had just started dating, they stood together and looked at all of the family photos my grandmother had – and still has – on display. My mom spotted a snapshot of Robert, my dad's baby brother who had died from meningitis as an infant.

“There’s another Dolson,” my mom said as she looked at the picture. “All you boys look alike. Which one is this?”

“That’s Robert,” my dad said. “He died.”

“I wanted to kill your father,” my mother told me later. “Why wouldn’t he have told me this?”

This story sticks out in my mind, and I recognize it as important, although I’m not entirely sure what it says about my family or me, or the ways we thought about grief and discussions about death. Like my father, I am a private person. But, like my mother, I believe in the importance of sharing these things. Or, really, I believe in sharing these things when both the other person and the timing are right.

Part of me knew Kyle and I would never have dated. Even without the heavy revelation about Nicholas, I was much too serious and quiet for a guy like him. Our interaction that night in the basement furthered something I may have already known: I didn’t feel uncomfortable talking about Nicholas. I felt uncomfortable making other people feel uncomfortable about Nicholas.

During my last year in high school, I attended a religious retreat. In September of that year, nearly one hundred of my classmates and I traveled in school buses to a secluded center about an hour from our high school. The goal of the retreat was to remove us from our normal environment with the hopes that we would feel comfortable breaking down any walls we usually built around us. After four days, we were supposed to know each other and ourselves better.

On the first night, we made timelines of our lives. I listened to my group members talk about the major events that defined them: their parents' divorce, the time they realized they had a problem with drinking, the times they felt like they didn't fit in. I looked down at my notebook. My friend Kaity, who had gone on the retreat the spring before, made it for me. It was decorated with bright colors and inspiring sayings: "Like the Ocean, both Beautiful and Dangerous;" "When Life Gives you Lemons, Make Lemonade." Inside, I had written a timeline that included Nicholas – his birth and his death. But, when it came time to share, I wasn't ready to jump into the spirit of the retreat, to break down all of my walls, so I shared the events of my life in a way that showed a steady external progress, but no internal development: I was born, I went to school, my grandparents died (because losing a grandparent falls more into the natural order of the world), I applied to college. Those who read in between the lines of my presentation would have heard the following: my life is perfect; everything has gone according to plan. At the end of the week, I wished I could have gone back to that moment and told the truth. Instead of understanding myself better, I felt confused. In the past, I had kept Nicholas's death to myself because I wanted to protect people from not knowing how to respond. Now, though, around classmates who owned the less-than-perfect moments of their own lives, I felt guilty for hiding mine in the lines of my notebook.

\*

I met Brian about a year and a half after I graduated from college while working as an education reporter at a small newspaper in Carlisle, Pennsylvania. I was covering a

ceremonial groundbreaking for a construction project in the school district where he served on the school board. As he talked to me at our first meeting, he cradled the hard hat he had worn for the newspaper photo underneath his arm. He first pointed to the bag I had slung over my shoulder – a brightly-patterned, quilted Vera Bradley tote – and told me that his wife Cori had just bought a similar bag. Then, he told me about his son Anthony.

“Listen, our son Anthony has Down syndrome. Another reporter wrote a big story about our organization. You should look it up,” he said.

He continued to talk about the nonprofit group he and his wife established to provide grant money and a support network to families whose children also have Down’s.

I couldn’t help but notice that, before Brian knew anything about me, he spoke so plainly and openly about Anthony’s Down syndrome. And, as he spoke, I could feel it – that tug to belong, the pull to show that I understood, even if only a little bit, what he and his family were experiencing.

“Oh, yeah, I had a brother with Down syndrome,” I said. “He died when I was in fourth grade.”

I might as well have been back in the basement with Kyle. Brian paused. This time, I was certain the lull in conversation extended for too long.

“Oh, well, Anthony is doing really well,” he said, and I understood fully why my mother doesn’t talk about Nicholas, especially to parents of children with Down syndrome.



As I began to spend more time with Brian and Cori, they asked me to be very careful with Noah, Anthony's younger brother. Noah knows that Anthony – and some of his own friends from their group – has Down syndrome. He knows that it means Anthony's eyes are a little bit smaller, that sometimes Anthony has trouble talking. Beyond that, they are not sure what Noah knows about Down's. They didn't want any of my questions to make him look at Anthony differently.

I was in first grade before I recognized that Nicholas was different. My friend Sammi had a brother born around the same time, and she used to come to school and tell me that she and her younger brother Stephen had played together, that he said her name. One day, I asked my mother why Nicholas didn't do the same. She sat my sister and me down and looked at us.

“Nicholas has Down syndrome,” she explained. “It means that things will come more slowly to him. It means that he is a little bit different.”

My sister and I looked at each other.

“Oh, well,” we said. “We still think he's cute.”

Then, we ran off to play.

My mom loves that story because of its innocence. It is a reflection of the same childlike purity Brian and Cori see in Noah.

I understood and honored Brian and Cori's request because I knew all about the ways in which parents try to manufacture a sense of normalcy for their children, or the ways that a close-knit family like theirs – or like mine, for that matter – can protect and cocoon a person in a world that feels safe, familiar, and, yes, normal. I know now that

Nicholas was born with Down syndrome and other health problems, but I can't separate the sadness my parents must have felt in those days from the pride I felt when I got to tell my kindergarten class about my new baby brother. I know that Nicholas was different and that even small things would have been a struggle for him. As heartbreaking as that is for me to recognize now, I still think about my brother as a cute little boy with blonde hair, who had an infectious giggle and an affectionate nature. Even my recollections of the night when Nicholas died suddenly and the days following his death are confused by the people – our family and friends – who visited our house to play with us, who let us be little girls. Nicholas's baby book is filled with happy mementos, but also with reminders of his disability and his death. In her eulogy for Nicholas, my mother wrote, "When he was born, there was great joy in knowing we had a son, yet great sorrow in learning he had Down syndrome. That sorrow stayed with us every day, but it was overshadowed by what Nicholas himself brought to our lives." And, in this fashion, all of my memories of Nicholas are muddled together to create my family's story, to create our life.

\*

By the time I met Brian at that groundbreaking, I had become more comfortable talking about Nicholas. During my junior year in college, I volunteered for the Special Olympics on campus. When I came home from school for semester breaks, I worked at the day care at UCP, with some of the same therapists who had helped Nicholas. This was the first time in my adult life that I began to think about my brother, to wonder about him, and, in some cases, to miss him. This was also when I took my first nonfiction writing class with a professor named Mary Beth. She had grown up in Iowa before

moving east to teach writing at my liberal arts college in the suburbs of Philadelphia. She wore Prada glasses, argyle sweaters, and a watch with two faces. I looked at her and thought she fit perfectly into the wealthy community where she taught. But she also sat with us in a circle when we had discussions, she listened to what we said, she made jokes about us – and about herself. In those moments, I could also see the easygoing girl from the Midwest.

All semester, I toyed with writing about Nicholas. But each time, I reverted to my fears from high school: when we workshopped the essay as a full class, everyone would feel bad for me. Furthermore, I couldn't yet distinguish the shock of Nicholas's death from the joy of his life – or I couldn't yet accept that I would never distinguish the two – and I didn't want to write what I thought would be an overly dramatic account of the night he died that offered no insight.

For our final assignment, one that only Mary Beth would read, she told us to write about a photograph. I started to write about a trick photo I had taken while studying abroad in Paris. I had drawn eyes and a smile on my middle and pointer fingers and held them facing the camera with the Eiffel Tower behind them in the distance. I thought I would use it to write a children's book called *Les Aventures de M. et Mme. Le Doight*. But, as I started to write, the story about “the adventures of Mr. and Mrs. Finger” didn't seem as funny on the page as it did in my head. So, I looked closely at a photo of me kissing my dog, but I couldn't find a way to string a series of unrelated anecdotes about the two of us together.

I eventually wrote about a photo my family displays – still today – in our kitchen. It was taken a few years before my junior year, when my family and I took a vacation down the coast of California. At the end of our first day, we climbed onto the back of one of San Francisco’s famous trolley cars. My mom handed her camera to the man standing behind us in line and asked him to snap a quick photo. The four of us fill almost the entire width of the trolley. In the photo, our faces look sun-kissed and our smiles are wide. I am standing on one end, my hand grasping one of the trolley’s poles. My sister stands next to me, then my mom, then, on the other end, my dad. Next to my father is a little boy with blonde hair. His face is hidden by the pole, but he looks to be the same age Nicholas would have been, just a figment of my brother.

When my professor returned the essay to me, she had written that it was a beautiful way to remember Nicholas. She had used his name, as though she knew him. Later, she asked what it was like for me to write about him. I could not formulate an answer then, but it was as though she had given me permission to share this story, to think about what Nicholas meant to me, to think about how the action of remembering him affects me.

A few months after I wrote this essay, I interviewed for an internship at my local newspaper. Ron, the editor who would become my boss, studied my resume. He skipped over the bits about the journalism classes I had already taken and the work I did for my college newspaper and instead, paused when he read about my work with the UCP Capital Area Children’s Center.

“How did you get involved with UCP?” he asked.

I didn't know that in a few years, I would meet Brian, and that telling him and his wife about Nicholas would result in the start of a relationship with their family. I didn't know how Ron would react to the story of my brother, of my family. And, I certainly didn't know that he and his wife had just had a son, Jason, with Down syndrome. In the end, his question was more about finding a good place to send Jason to day care than about finding out about me. So, I looked at Ron.

“Well,” I responded, almost without hesitation, “I had a brother...”

## **SWIM MEET, FEBRUARY 7, 2013**

Anthony hovered along the edge of the pool, too hesitant, too cold to jump into the water. Around him, the other Special Olympics athletes and their college buddies splashed and kicked as they swam laps and competed in the relay race – the first event of the night. But Anthony stood back, his Spiderman swim trunks, still dripping wet from his practice a few minutes earlier, hitting him just below his knees; his orange goggles on his head, pushed away from his eyes; his hair raised in short spikes.

“Come on, Anthony. Come on, Bubby,” Brian shouted. At first, the noise from the rest of the crowd, all cheering for a different athlete, left Brian’s voice indistinguishable. Brian began to clap, clasping his hands together slowly and deliberately. Alone at first, until the crowd caught his rhythm and joined in. Soon, the whole audience clapped in unison, chanting, “An-thon-y, An-thon-y.”

We waited and hoped that Anthony would jump into the water.

\*

Anthony didn’t swim until he was three-and-a-half years old. He was floating in a mesh raft at a family friend’s pool when he watched his brother Noah jump into the water. Anthony followed him into the pool. This had always been part of Brian and Cori’s plans. So, in fact, had Noah. Their hopes and plans for a second child, a younger brother or sister for Anthony, had always existed. When Anthony was diagnosed with

Down syndrome, Brian and Cori expedited Noah's arrival. Now, they not only wanted another child, they wanted another child who was close enough in age to Anthony to be his friend and his peer. They wanted someone to model behavior and keep Anthony on track with things like walking and potty training. And swimming. That day, Noah dove into the water first, but Anthony was not far behind. Now, it's hard to keep Anthony out of the water.

Tonight, though, Noah got to play the role of friend and brother. He sat in the stands at the Heiges Field House on the campus of Shippensburg University, ready to cheer for Anthony as he swam in the Student Athletics Advisory Committee's swim meet, an annual Special Olympics event at Shippensburg.

Inside the Heiges Field House that February night, the humidity and smell of chlorine cut the cold from the outside. A string of red and blue pennants crossed the pool, strung from one side of the gym to the other. Each pressed with a different letter, the pennants spelled "Shippensburg University." The bright blue water that filled the pool seemed to rest on top of the tiled floor. Signs that read "Raiders Swimming" and "NCAA Division II" decorated the walls. It was about thirty minutes before the swim meet was about to start, and Anthony stood at the far end of the pool. His coach Allen, the same man who teaches his weekly swim lessons, lowered Anthony into the water.

"Ahh," Anthony said as soon as his feet touched the water. He eased into the pool – lane 1 of the four-foot section, where he always swims – until the bright blue water completely consumed his Spiderman swim trunks. Allen hopped in after Anthony and the two began to bob up and down. Allen looks like a swimmer – he is tall, trim, and

muscular. Except for the scruff of a five o'clock shadow on his chin, his body is smooth and free of hair. He's a math major and a member of Shippensburg's swim team, and he and Anthony had been working together in the pool for a few months.

Allen held up his index finger while Anthony bobbed up and down in front of him – one. Allen held up his index finger and his middle finger – two. He held up his index finger, his middle finger, and his ring finger – three. At the same time, Anthony and Allen took deep breaths and disappeared beneath the clear blue surface. They emerged from underwater, and Allen shook his head so that a few drops of water flew from his shaved head. Anthony did the same – shook his head back and forth, as if to say “no,” as beads of water splashed Allen. During their weekly coaching sessions, Allen and Anthony do these little bobs between laps – it's one of Anthony's favorite things to do in the water. They repeated their bobs, but this time, Anthony mirrored Allen's actions: when Allen held up his index finger, Anthony did, too. When Allen held up two fingers, so did Anthony. When Allen held up three fingers, Anthony did the same. Then, at the same time, they both disappeared underwater.

From across the gym, Cori approached Anthony with his goggles – bright orange, plastic ones that Brian had bought at the Dollar Store and that Anthony loves to wear.

Anthony floated on his kickboard, first using delicate flipper kicks to propel himself forward and gradually increasing power until water splashed each time his legs hit the pool. Allen waded alongside Anthony.

Brian watched Anthony from the bleachers, where he sat with Anni and Noah. Their friends Ed, Wendy, and Melodie climbed the stands to join them. Ed and Wendy



adopted Melodie, who has Down syndrome, when she was a baby. I had interviewed Wendy four years prior to this night, when I was still working at the Carlisle newspaper and when Melodie was just 20 months old. Brian and Cori's group had helped fund the purchase of a pediatric treadmill for the local United Cerebral Palsy children's center, the same place where Nicholas had received services, and Melodie was one of the first children to use it. The treadmill was meant to help children with Down's, who begin walking about a year after their peers, build strength in their legs and become more familiar with the pattern of movement required to walk – one foot in front of the other. "It builds her confidence," Wendy told me then. "It builds my confidence as a parent. You know you're doing something to help her in the future."

Tonight, Melodie, dressed in a leopard print skirt and pink cowboy boots, climbed the stairs toward Anni by herself. About halfway up the stands, she tripped over one of her boots and fell down. In the moment of silence before Melodie registered any pain, Noah jumped from his place on the bleachers to check on her.

"Are you okay?" he asked. "Are you okay?"

Melodie's face contorted as a few tears began to form. Then, she cried a little bit, but really, she was fine. Soon, she and Wendy pulled out signs they had made for Anthony, Styrofoam and poster board that they had cut into fish shapes. Across each fish, in orange, blue, gold, teal, and fuchsia block letters, they had written Anthony's name.

Anthony turned his head toward the crowd, his eyes covered by his goggles.

"Bubby does look cool in those goggles," Ed said to Brian.

“He loves those goggles. I bought them at the Dollar Store,” Brian said, adding that Anthony also has a pair that cost \$15, but he still prefers the orange ones.

“Because these look cool,” Ed said.

“The other ones are cool, too,” Brian said.

“Bubba’s a simple man,” Ed said. “Makes simple choices.”

Melodie had settled next to Anni. Although their families met through the Down syndrome group, Anni and Melodie became friends on their own, spending time together with their families, at group events, and at dance class. At their Christmas dance recital just a couple of months before the swim meet, Melodie would leave her place in the formation any time another dancer moved too close to Anni, as if to protect – or to claim – her friend. In the video Cori showed me, I could hear the audience laughing. Tonight, they sat beside each other. Anni rested her head on top of Melodie’s, and Melodie wrapped her arm around Anni’s shoulders.

Cori returned to the bleachers, and Brian touched the small of her back as she sat down next to him. He nudged her and pointed at Melodie and Anni.

“I know,” Cori said. “They love each other.”

She looked around the pool house.

“They don’t have a band this year,” she said.

“I liked the band,” Brian replied.

“I liked the band, too,” Cori said.

Instead of band members, the bleachers had begun to fill with Shippensburg student athletes, ready to watch the swimmers and cheer them on. Each team had been

assigned an athlete (the women's soccer team was there for Anthony), and the bleachers were soon crowded with students holding signs and posters for the athletes.

\*

Five years ago, I was one of those students – not at Shippensburg, but at another college that hosted a Special Olympics festival each fall.

I started volunteering for the Fall Festival as a freshman because I felt like I had an obligation to do so. At first, the connection between my motives for volunteering and my brother felt tenuous. I didn't think about the fact that Nicholas may have competed in Special Olympics or about the fact that I was cheering on athletes who were like my brother might have been. As I continued to volunteer, I began to wonder how my brother would fit into this world – which sport would he play? How would he interact with his teammates? Would my parents find comfort and camaraderie at these events? How might I fit differently into this world if Nicholas were still alive? While I loved volunteering on the Special Olympics committee and being around the athletes, I sometimes found it hard to connect with them, to talk to them about things other than their sporting events or what they were most looking forward to at the festival. I wondered about the ways Nicholas and I would have bonded, the things we would have talked about, the things we would have had in common.

Nicholas did not live long enough for me to recognize him as different, so, at the time, our relationship was that of a typical brother and his big sister: I loved him and played with him; I found excitement in his milestones, like the first time he rolled over, his first steps, the first time he “hung ten,” holding on to the bar in our bathtub and

balancing on the shelf; other times, I got mad at him and ignored him; largely, though, I was sweet and affectionate. Now, I can see the ways that Nicholas's short life shaped me into a kind, sweet, and compassionate person. But I wonder, had Nicholas lived, how I would have reacted to his differences, to the struggles he would face daily, to the ways those struggles would affect me. Would I have discovered moments when it would be difficult to be kind to him? Would I have been strong enough to defend him when others were unkind? Would I have found a way to relate to him?

\*

The Special Olympics began in the 1960s, when Eunice Kennedy Shriver, John F. Kennedy's sister, began her work for people with special needs. For three summers, she held a camp outside of her Washington, DC home to provide a place for people with intellectual disabilities to play. She raised awareness about the unfair ways people with disabilities were treated in society at the time. She pushed her brother to give funding to this cause.

In September of 1962, Shriver's essay, "Hope for Retarded Children," ran in *The Saturday Evening Post*. The article advocates for programs to help people with disabilities and their families. Although the language of the article is dated – she freely uses words like "retarded" and "normal" – many of Shriver's ideas still echo in current discussions of the disabled. She called for women's groups to provide information about prenatal services to pregnant women; she suggested the formation of recreation clubs to promote physical activity for the disabled; she wanted business groups to develop job-training programs. Perhaps the most notable part of her essay, however, is the story of

Rosemary Kennedy, her sister who, as Shriver writes, was “mentally retarded.” This article marked the first time any of the Kennedys publically acknowledged Rosemary and her disability, the first time they talked about Rosemary.

Shriver writes:

Forty-three years ago this month, in Brookline, Massachusetts, my mother and father were looking forward with great anticipation and joy to the birth of their third child...Rosemary was born September thirteenth at home – a normal delivery. She was a beautiful child, resembling my mother in physical appearance. But, early in life, Rosemary was different. She was slower to crawl, slower to walk and speak than her two bright brothers. My mother was told she would catch up later, but she never did.

When the doctors suggested that the Kennedys place Rosemary in an institution, they refused.

“What can they do for her that her family can’t do better?” Joseph P. Kennedy, Sr., her father, asked.

Rosemary’s birth story is eerily similar to Nicholas’s, to Anthony’s. The settings are different, but the arc of the story remains the same: the excitement about a new baby, the false hope that everything was fine, the initial feelings of defeat and disappointment when it wasn’t, the eventual and lasting determination, the strength of the family.

In photographs, it is impossible to tell that Rosemary has a disability. Like the rest of her family, she was attractive. She had a full, pretty face and wore her dark wavy hair

parted down the side and tucked into a low bun in the style of the time. In each photograph, she is dressed modestly, in blouses, jackets, and suits.

By the time Rosemary turned 22, her health began to decline. She talked less and turned sullen and irritable. It was then that the family decided to place her in an institution.

“It fills me with sadness,” Shriver writes, to think this change might not be necessary if we knew then what we know today.”

It was because of these questions that Shriver began her work with the disabled.

I recognize, in Shriver’s essay, the desire to connect with her sister by connecting with others who are like her. Her questions express the same wonder of what might have been. I sometimes think my efforts to feel closer to Nicholas through Special Olympics are futile and too filled with questions I will never be able to answer. But then I think about the values that lead the Special Olympics, those of sportsmanship, leadership, bravery, perseverance, and unity. It is not lost on me that one of these guiding principles – unity – encompasses the commitment to inclusion, respect, dignity, and community-building. It is meant to bring people together. And I see that in creating the Special Olympics, Shriver was just another sister trying to understand her sibling.

\*

Anthony, with his wet hair spiked and his swim trunks sagging, heavy with water, walked in front of his cheering section, which now included his parents, grandparents, siblings, friends, and me, and stopped. He shivered and crossed his arms across his chest. Then, he raised his hand in a wave.

“Hi,” he said.

“Hi,” we responded.

One of the coaches came and picked Anthony up. Anthony kicked his feet back and forth in the air as his coach carried him off to join the rest of the athletes for the start of the meet.

“Everybody, welcome,” the MC bellowed into a microphone. He began to introduce each of the Special Olympics athletes, paired with their college athlete buddy.

“Eric and Chelsea. Demi and Jon. Shannon and Jill,” he called. Each pair walked through a gauntlet of Shippensburg cheerleaders and the Raider mascot. The crowd stood and cheered as each pair was announced.

“Anthony and Allen,” he yelled.

“Woo. Come on, Bubba,” Cori yelled. She turned to the college student who had taken the seat next to her. “We yell a lot,” she explained.

“Where’s he at?” Brian asked.

“There he is,” Cori pointed.

We could see Anthony, still dripping water and walking flat-footed across the tile floor. He had a towel draped across his shoulders, and his orange goggles dangled around his neck. When he reached the end of the gauntlet, one of the coaches walked towards Anthony and held up his hand. Anthony gingerly gave him a high-five.

The athletes took their places along the edge of the pool – Anthony and Allen at lane 5 – and waited for the sound of the foghorn to start the race. When it sounded, the athletes jumped into the water. They kicked and splashed. They reached their partners

and tagged them to continue the race. The MC narrated the race, and his voice, amplified by his microphone, sounded clearly over the cheers of the crowd.

As the race continued, Anthony remained along the edge, refusing to jump into the water. He doesn't always like to swim with the other athletes, not even during his weekly practices, and he often gets caught up in his routine. Each morning, he throws his pajamas into his hamper, gets dressed, and eats breakfast. When he swims, it is in lane 1. Tonight, lane 5 seemed too far away, too wrong.

"Come on, Anthony. Come on, Bubby," Brian shouted. He clapped his hands slowly at first. Strong, single clasps, separated by deliberate pauses. It soon spread through the crowd, who clapped together and chanted in unison: "Anthony. Anthony. An-thon-y. An-thon-y."

Allen turned to the crowd to find Brian and Cori.

"Take him to lane 1," Cori shouted to Allen.

"Allen, take him to lane 1," Brian shouted louder.

"That's what he wants," Cori said. She nodded her head to reassure him.

Allen moved over to lane 1 and hopped into the pool while Anthony remained outside, hovering just behind the diving line as the crowd continued to cheer for him. Allen boosted himself out of the water to sit on the edge of the pool and gave Anthony a high five. He stood and then squatted, making sure he was eye-level with Anthony. He talked to Anthony, tilting his head to the side as he tried to coax him to get into the pool.

"If you get in," he promised Anthony, "it's fun."



But Anthony backed away from the edge of the pool – and from Allen. He looked toward his family in the stands and waved for Cori to come over. As she started to climb down the stands, Brian watched Anthony, without blinking, from his seat in the bleachers.

“Grab him, Allen,” he said, almost under his breath.

When Cori reached Anthony, she lifted him into the water, where Allen quickly wrapped his arms around him. The audience applauded as Allen raised one arm and patted Anthony’s back with the other.

“Anthony’s ready to rock now,” Brian said.

Cori moved to a second set of bleachers closer to lane 1, where several other Shippensburg University athletes also sat. She held her fuchsia Smartphone just in front of her face and filmed a video. Later that night, the Guillaumes would email the footage to Anthony’s teacher, who would play it for his class the next day.

“Go, Anthony,” the MC yelled into the microphone, and the crowd erupted in cheers as soon as Anthony swam away from Allen and touched the wall. Then, floating on his kickboard, Anthony propelled himself toward a beach ball that Allen kept moving just out of his reach. Anthony turned toward the bleachers where Cori still sat and waved – to her or, maybe, to the other athletes sitting with her.

Anthony returned to his kickboard to kick violently as Allen floated beside him. Tonight, Anthony liked being at the 8-foot end of the pool because his entire body was covered with water, and he could protect himself from the cold, outside air. In the four-foot section, he had to crouch to stay submerged and keep his body warm. Allen spun

Anthony around toward the four-foot area of the pool. Eventually, he took the kickboard, and Anthony swam to the edge without help, his face submerged in the water.

“Atta boy, Bubby. Underwater,” Brian said.

When Anthony reached the edge, Allen gave him a high five.

Cori left her side of the pool and returned to her seat next to Brian.

“He’s good. Allen said I could go,” she said. “Apparently, the key is not to let him get out. Allen said the water’s freezing.”

“Last event, everyone,” the MC interrupted. “Let’s make some noise.”

In lane 1, Anthony floated on his kickboard with little flipper kicks. Allen walked along beside him, still in lane 1. Brian stood up and smiled as he took a video.

When he got out of the water, Allen wrapped Anthony in a towel and walked him to the bleachers where his family sat. Anthony still wore his goggles when he turned to wave to his family, who stood up and clapped for him.

The bleachers started to clear, and Anthony went to change into a fleece jacket and sweatpants, his wet hair the only indicator that he had been swimming. Before they left, Anthony and the other athletes posed for a group photo. They surrounded Shippensburg’s mascot, the Raider, a bright red parrot wearing a pirate’s hat. Everyone in the photograph smiled; Anthony stood in the center of the front row.

“You did a good job,” Cori said when he returned.

“Yeah,” Anthony agreed.

## **BOWLING, JUNE 29, 2013**

On a hot afternoon in late June, Cori took all three of her children bowling for \$2 - \$1 for Anthony's shoes and \$1 for Noah's shoes. Anni's feet are still too small for the bowling alley's neon orange and yellow shoes, so she got to bowl in her pink Crocs and rainbow-sequined Skechers. At the Midway Bowling Alley in Carlisle, kids bowl for free (except for the shoe rental fee) in the summer. Cori knows about deals like this. She also knows how to convert Anni's wooden closet doors into French doors and how to turn the sleeves of old shirts into leg warmers that Anni and her friend Melodie can wear to dance class. She knows how to make gluten-free tomato soup, graham crackers, pizza, and chocolate chip cookies. She knows how to make lotion and lip balm from beeswax, shea butter, and coconut oil. She presented me with these treatments one night when I came over to the house for dinner. She wrapped the solid, pale yellow balms in muffin cups and placed them in plastic containers. She knows that if Noah cops an attitude, all she has to do is tell him to "check it." She understands – always – what Anthony is saying when he talks to her. She knows the origin of each of her children's nicknames: Anthony is Bubby; Noah is Skeeter; Anni is Reej – short for her full name Anni Marie G. In fact, Cori is the origin of those names.

In other words, she knows how to be a mom.

Anthony, Noah, and Anni had already bowled a few frames when I met them at the bowling alley that Saturday afternoon. Theirs was the lane at the far end of the alley, close to the snack bar. In addition to Reej, Cori and Brian sometimes call Anni “Punky Brewster” because of the bright colors and mixed patterns she wears when she chooses her own outfits. Today, her accessory of choice was a pair of bright green plastic glasses that she had borrowed from her Mr. Potato Head set. It was her turn to bowl, and she carried a pink ball – larger than her head – to the line at the edge of the lane. She placed the ball on the top of a green plastic dragon meant to direct it toward the pins. Dull spikes lined the dragon’s back, which was indented with a groove just large enough for a bowling ball. A couple of feet tall, the dragon faced away from the lane. I sat behind Cori at the electronic scoreboard and stared directly at the dragon’s flat snout. Anni pushed her ball down the dragon’s back and toward the lane. As she watched her ball roll away, she perched on one of the dragon’s legs.

When the pins cleared and re-set, she pushed the dragon out of the way to make room for Noah. Today, both Noah and Anthony decided to use the nine-pound adult bowling balls, and Noah walked with his yellow ball toward the lane, his fingers in each of the three holes, and released it towards the pins. He watched as the ball rolled slowly down the center of the lane, knocking down all but two pins. When Anthony’s turn came, he held the ball close to his chest with both hands and ran towards the lane. Occasionally, Anthony has tried to bowl the regular way – with his fingers in each of the holes, with his arm extended behind him to wind up, with a strong follow-through as he releases the ball. But, his fingers always get stuck, so he has found his own technique. Just before he

crossed the line at the start of the lane, he threw the ball, almost as if pushing it away from himself. It arced slightly, and then hit the floor. As it rolled toward the pins, Anthony tilted his head to watch it. He crouched on one knee. The ball hit the pins and all ten fell. Anthony turned around, clenched his fists, and raised his arms in the air. Strike!

Cori watched her children from her seat behind the scoreboard. When she and Brian met in college, they went bowling on one of their first dates. This was before the time of electronic scorekeeping, so she and Brian tracked their progress with a pencil and paper. Although Cori had learned the rules of bowling in gym class, she did not feel all that familiar with the strategy of the game. That night, they made the mistake of counting out of nine pins, instead of ten. “Wow,” Cori said then, “we really suck at this.” So, today, she just sat and watched. The frames continued to fill automatically as each child repeated the same pattern: grab a ball, push it down the lane, watch as it rolls and strikes the pins.

“Your turn, Bub,” Cori said to Anthony, when his name once again flashed on the scoreboard. “Always after Noah.”

Anthony threw his ball and knelt as he watched it roll toward the pins. This time, he knocked down only seven pins. He stood up, his mouth open, and grunted as he pointed to a group of bowlers several lanes away.

“No,” Cori said to him. “It’s not their fault.”

“Know?” he shouted to Cori.

“How do I know?” Cori responded. “Because you threw the ball.”

I've seen Anthony do this to Noah, too. If Anthony's character dies while he's playing a video game, he'll look up from the screen and shout "Woah."

"No," Cori will respond, "it's not Noah's fault."

Anni climbed onto Cori's lap. That day, Cori wore short denim shorts that revealed the small paisley tattoo on her thigh. Her T-shirt was just fitted enough to hug her tiny waist. Cori is so petite that it's hard to believe she had three children. Her brown hair rests just above her shoulders, and today, she wore it down. A pair of polka-dotted sunglasses held her bangs away from her face. Anni faced Cori and ran her hands through her mom's hair.

"Is it my turn now?" Anni asked.

Anthony walked toward Cori and Anni and extended his hand in front of Cori's face. He bent his fingers so that the tips just barely touched and shook his hand back and forth. This is the way Anthony signs "drink." The sign is actually made by curving the hand and fingers, as though holding a glass, and moving the hand up and down towards the mouth, as if to take a sip from a cup. But, Cori knows what Anthony means.

"We have four more frames," Cori said to Anthony. "Then, we'll have a snack and a drink."

"Anthony might beat me," Noah said.

Cori looked at the scoreboard; Anthony had a slight lead over Noah and a comfortable cushion over Anni.

"Anthony might beat me," Anni repeated.

“Well, I’m pretty sure he will,” Cori said to Anni. “But he’s bigger than you and can move the ball faster. That’s a big part of it.”

Cori was sitting sideways, turned away from the computer screen in front of her, her legs off to the side of the bench so that she could hold Anni and talk to me at the same time. She missed when Noah bowled a spare.

“Yes!” Noah shouted. He turned around to look at Cori.

“Awesome,” Cori said. “The elusive spare. Five it.”

She held up her hand, and Noah walked over to give her a high five, something the family also does after saying Grace before dinner.

Anthony began to rustle through the bag Cori had brought that day – a miniature teal backpack with a picture of Ariel from *The Little Mermaid* and a little tulle skirt that hangs just off the bottom that she had borrowed from Anni – and took out his electronic game. He sat in a seat behind Cori and turned on the game “Lego City.” The kids had bowled almost a whole game now, and Anthony was bored.

*I’m done with this rolling a ball down and watching it, tilting my head to see if it goes,* he thought. At least, that’s what Cori imagines he was thinking.

He hunched over the handheld game, his tongue popping out of his mouth as he stared intently at the screen, watching as he became a yellow Lego police officer who jumped up and down on a trampoline in a jail cell, shimmied up the pipe to the roof of a building, and raced through a deserted street surrounded by warehouses until it was his turn to bowl.

“Just set the DS down, or I can hold it,” Cori said.

“Or I can hold it.” Noah appeared behind Anthony. He smiled in a half-helpful, half-mischievous way.

As Anthony stood to get a bowling ball, he shouted something I couldn’t understand. Cori held her two hands in the air in a mock defensive gesture. She made a face as if to say, “look at him,” or, maybe, “it’s not my fault.”

“No one is trying to take your DS, buddy,” she assured Anthony.

Anthony walked slowly toward her and started to place his game on the seat next to her. Then, as though he thought better of it, he quickly turned and placed it behind her, on a seat out of her reach.

As Anthony started to bowl, Noah grabbed his wallet from its place next to Cori.

“I’m going to get something out of the drink machine and something to eat,” he announced. He had arrived at the bowling alley that day with his wallet stuffed in the pocket of his gym shorts and only removed it when Cori suggested it might throw off his bowling balance.

Anthony turned around after his two turns bowling. He had missed only one pin.

“Awesome,” Cori said.

The final score showed that Anthony had won, with a score of 82; then Noah, with a 78; then Anni, with a 55.

“You had a third of a chance of winning,” Cori explained to Noah as she led her kids toward the snack bar.

“How?” Noah asked.

“Because there were three of you,” Cori said.



\*

The way Cori talks to her children reminds me of the way I used to address the children at the day care center where I worked after college – or even the way I have heard my own mother talk to small children. Cori sounds patient and pleasant, but not patronizing, her voice always laced with affection and pride. She uses simple sentences and speaks in a code that is familiar only to her children: if they misbehave, she'll say, "Chips 1" or "Privileges 1," beginning the countdown to the moment her children lose any treats. "You have to tell me 'capiche,'" she'll say after scolding them, making sure they understand that they did something wrong, and that what they did has consequences. She makes jokes that are mostly for her benefit. ("I bet I can break through the doors," Noah said later that afternoon as he stood in front of the double doors before leaving the bowling alley. "Hey," Cori responded. "I'm pretty sure The Doors sang about that.")

Cori has been a stay-at-home mom for about four years. In her family, she is a bit of an anomaly. Instead of getting married and having children right out of high school, she went to college. She graduated and worked for a few years before she and Brian married and had Anthony and then Noah and then Anni, who took them by surprise. But she always knew she wanted to have children of her own. She grew up the oldest of three children and helped to raise her baby brother, who is ten years younger than she. She says she never would have married Brian if he didn't also want children. Before they wed, they had agreed to have two kids, a fair compromise since Brian wanted only one child, and Cori wanted three ("You see who won that battle," Brian says now).

For the longest time, I never wanted to be a mother, but I assumed motherhood was inevitable because I grew up around families – most of the women I knew were mothers. I also thought, though, that I would feel okay if it never happened for me. Throughout high school and most of college, I harbored dreams of a career in journalism, a career that I felt certain would bring happiness and fulfillment on its own. Now, though, in my late twenties, I feel differently, and I cannot pinpoint exactly where this shift occurred.

I remember a family Christmas party when I was in high school. My dad's side of the family had gathered at my aunt and uncle's Maryland home. Tables of food had been set up in the living room, and my family members milled around, red and green sweaters on, drinks in hand. At the time, my cousins and I ranged in age from elementary to high school, and I watched one of my smallest cousins, barely able to see above the tabletop, ask my aunt – her mom – to help her make a plate of food. She tugged on her sweater to get her attention.

“Don't you want this?” my mother asked me that day.

For the first time, I realized I did want that. I wanted to feel the pull of a little hand – of someone still too young to distinguish between dependence and love – who wanted only me. I wanted to look at the family photo we took every year at that party and see a little face that looked a little bit like mine, but that was also its own. I wanted to feel the warmth and joy that I always felt at that party, that I came to associate with family.

I remember taking a job at a day care center to make money after I graduated from college, while I lived at home and applied to jobs at newspapers. This was not the

job I had wanted, but I still liked it when a child took my hand to show me something. Or when I sat on the floor to play with the children and one would spot my empty lap, pick up a storybook, and scoot backward until she or he plopped onto my lap. At that job, when the kids made funny faces, showed each other kindness, or reached out to me for a hug, I felt sad that their own mothers had missed that moment.

I remember finally landing a job at a small community newspaper, where I worked long days and night and weekend shifts. It was there that I really began to think long-term, and realized that, as my mother had predicted, I did want a family. When I left the field of journalism entirely – after only two years – one of the reasons I gave was that I couldn't see room for a life – one that included a husband and children – outside of work as long as I worked for a newspaper.

One day, about a year after I graduated from college, I sat on my parents' back porch contemplating graduate school. My mom came outside to sit beside me and asked what I was thinking about. When I said a two- or three-year graduate program in a city like Boston or Washington, D.C., her face soured. I knew she was mentally calculating my age by the end of the program. How old would I be when I finally settled into a career? When I met a husband? When I had children? Would I still be young enough to have children?

“A degree won't keep you warm at night,” she said and stormed back into the house, slamming the screen door behind her.

This was not the first time we had had this conversation, and I knew then that my mother worried that her oldest daughter, who had such drive and ambition, who planned

everything so carefully, may have forgotten to consider basic biology. My mom worries about everything, in fact. I often told her that of the two of us, she would have been the better reporter because she always looks for the worst possible angle to any situation. When I took a night class during my last semester in college, she felt certain I would be attacked as I walked back to my home. When I agreed to babysit a friend's child, she warned me that my life would be ruined if the child choked or bumped his head. If I got stuck in traffic and returned home from work later than expected, she assumed I'd been in a terrible accident.

When my mother recalls Nicholas's birth story, I can see the elements of the mom I know now converge with the mom she was in the delivery room. When she talks about Jan, the delivery nurse, I can easily picture them finding humor in the pain of my mother's contractions. It's easy for me to believe that Jan would connect with my silly, good-natured, and likable mother.

As soon as Nicholas was born, my mother asked if something was wrong. In her re-telling of this moment, the laughter and joy are a stark contrast to the realization that something was not right with my brother; it makes the sorrow of the moment even stronger. My mom once told me that she never worried before Nicholas was born – not about what could go wrong during childbirth, not about the possibility of anything being wrong with her child, not even about the fact that, at her age, she was an older mother. Up until that moment, her experience with family had not been perfect, but in its own way, it was blissful: she and my father had a happy marriage; she had two young daughters with blue eyes and long blonde hair, one who liked to read and one who liked

to draw. Nicholas was a reminder that things could and sometimes did go wrong. This worry, this anxiety – this is also a part of the mother I know now.

When Nicholas was very little, he began receiving physical and occupational therapy from United Cerebral Palsy (UCP). The UCP facility that would serve him was housed in a dingy, blue-sided building along a cul-de-sac just a five-minute drive from our home. The first time my mother saw the building where she was to take her son for help, she sat in the parking lot and cried. The façade looked old and rundown; inside, the carpets had stains on them. She had never had to take my sister Angela or me to this place, and she did not want to bring her new baby boy here, either. She knew what would happen when she entered with Nicholas: he would undergo physical, occupational, and, eventually, speech therapy. She knew it meant he was different.

One day, she stood inside and watched Nicholas's therapy session through the one-sided window. Nicholas sat in a square plastic chair, and his therapist, a woman with a British accent and a gentle, patient demeanor, sat across from him. A spoon rested on the table between them. The therapist placed the plastic spoon in Nicholas's palm and closed his fingers around it. She led it to his mouth. Nicholas dropped the spoon. Again, his therapist placed the spoon in his hand and moved it toward his mouth. Again, Nicholas let the spoon fall. My sister and I learned to hold a spoon so easily it was almost as though by instinct. And my mother cried as she watched another woman try again and again to help my brother do the same.

For a long time after Nicholas died, my mother said our family motto should be, "Hope for the best; prepare for the worst." It sometimes seems, though, that her fears are

not the hypothetical musings of a woman wondering about the worst things that could happen; rather, they feel like the assertions of a woman who knows with certainty that the worst things that could happen to her family, will happen to her family.

As her child, I could feel the implications of this attitude on my life. I did not have the freedom of my friends in high school and college. I felt embarrassed when, as a teenager and later as a working adult, I had to consistently and frequently check in to reassure my mother that I was alive. When looking for jobs and graduate school programs, I felt a pull to stay somewhat close to home and narrowed my search to a two-hour radius from my family because, as I told others, “if something bad happens, I want to be able to hop in my car and get home.”

While I once resented my mother for this attitude, I seem to have inherited it. I can see it in the way I worry about my sister, in the way I keep in touch with my parents, in my desire to build a life closer to my family. Part of the reason for this, I’m sure, is that I like my family and want to spend time with them for the small, everyday moments – having dinner together, attending church together, going shopping on a weekend afternoon. But I also know that another part of the reason for this is that I am older now, in my late 20s, at an age when most women become mothers.

\*

Cori asked the snack bar attendant for a few cups for their drinks. At the same time, she grabbed a few napkins from the dispenser on the counter and watched as Noah, Anthony, and Anni chose a table. She moved with the same grace and comfort I had seen from her while in her own kitchen.

I helped Anni climb onto the stool at one of the tall tables outside the bowling alley's lounge. She curled her legs up onto the seat and crossed them while Cori and Noah walked toward the soda and snack machines. They came back with a bottle of orange soda and a three-pack of Reese's peanut butter cups that Noah had bought for himself. He ate the first one with a single bite.

"I wish I could stay here all day buying more and more," he said. Noah would rather do anything but save his money, Cori told me. A few weeks earlier, he had bought a bottle of strawberry-flavored water that he shared with Anthony. Both boys thought the drink was disgusting. Yet, it remained in their refrigerator at home. When Cori asked Noah what he was going to do with it, he claimed he was "saving it."

Cori lined up the Styrofoam cups and filled each one with an equal portion of orange soda. She spread out the napkins and placed a homemade chocolate chip cookie on each one, including one for me and one for herself.

"Did you bake these?" I asked, although I was pretty sure I already knew that the answer would be "yes." Cori likes to bake, and she needs to create everything – pizza crust, cherry Danish, cookies – from scratch to make sure the food she feeds Anthony is gluten-free. The night before, she had made the family pizza (with a baked-from-scratch crust) that Noah described as "bangin'," a word I had once heard Brian use to describe Cori's cooking.

Anthony had already finished his snack and his drink and leaned against the back of his chair to continue playing "Lego City." As Anthony played, he assumed his gaming stance: he hunched his shoulders, jutted his neck forward, and looked intently at the

screen. His eyes focused on the Lego man. His fingers deftly hit the buttons. His tongue poked out of his mouth. Cori leaned over and whispered to him.

“No!” he shouted.

Most of the time, Anthony keeps his tongue tucked into his mouth because, unlike some children with Down syndrome, his mouth has room for it. But in moments when he is really concentrating, it pops out. This is when Cori and Brian tell him to tuck it back in, a reminder that makes Anthony mad. Although, he always puts his tongue back inside his mouth anyway.

“I did bake them,” Cori answered me.

“They’re good,” I told her.

When Anthony heard me compliment Cori’s baking, he smiled. Then, without peeling his gaze from his video game, he extended his arm toward her in the thumbs-down sign. Cori looked at him and laughed.

“Whatever,” she said, and playfully pushed his arm away. “You ate it all.”

We looked down at Anthony’s napkin, where there were a couple of grease stains from the cookie, but very few crumbs.

“What did you have for snack this morning that Daddy let you have that I would never let you have?” Cori asked Anni.

“What?” Anni said.

“You had it, too,” Cori said to Noah.

“What was it?” Noah asked, unable to remember.



“Peanut butter and fluff,” Cori answered, and the kids nodded, remembering spooning the mixture straight out of a bowl.

Noah crumbled the wrapper of his Reese’s Peanut Butter Cups.

“Did you eat all three?” Cori asked.

“Yes. And this,” Noah said, holding up his napkin where his cookie once sat.

“And this,” he added, holding up the empty bottle where he had guzzled his share of the orange soda.

“Maybe it’s good daddy and I aren’t going to be here tonight,” Cori said, imagining her children running on a sugar buzz. She was speaking to Noah, but I think she shot me a glance with a sparkle in her eye. That night, Brian’s parents were coming to watch the kids while Cori and Brian went out.

“Why?” Noah asked.

“Because Daddy needs new clothes,” Cori answered.

“Are you eating dinner?” Noah asked.

“We’ll eat something while we’re out,” Cori said.

“A fancy one?” Noah asked.

“We’ll probably just stop at the Back Door Café in town,” Cori answered.

“They give us sugars all night,” Noah said of his grandparents.

Before the group retreated from the table to play another game, Noah asked if he could go to the other end of the bowling alley to fill his bottle with water.

“Walking feet. Indoor voice. Be a gentleman,” Cori said.

\*

Sometimes, I'll see a mother with her children at the grocery store, and it reminds me of shopping with my mother as a child – she always let me choose the designs I wanted on our napkins and paper towels. Or, I'll see children with their mother at the park, and I'll remember the long afternoons my mom spent outside with my sister and me, pushing us on the swing set in our backyard or watching as we played together in the sandbox. I am filled with a calm joy as I watch these mothers and their children, and I felt the same way that day at the bowling alley with Cori, Anthony, Noah, and Anni.

One fall, when I was in college, my mom and I were running errands on a Saturday afternoon when John Mayer's song "No Such Thing" began playing on our car radio. I loved listening to John Mayer's autumnal, acoustic chords when the leaves began to change colors, and I had memorized the lyrics to all of the songs on *Room for Squares*, the album on which this song appeared, since I got my own copy in October of my sophomore year in high school. I had always been especially struck by one line in "No Such Thing," and now it played: "All of our parents, they're getting older, I wonder if they've ever wished for anything better."

I looked at my mom. She stared ahead at the road.

"Did you ever wish for anything better?" I asked.

"Well, yes, with Nicholas," she said, even though we rarely talked about my brother, and even though she hates when I want to have discussions like this with her. That's all she said before we both let the conversation fall.

I still don't know if she meant that she wanted Nicholas to have lived, or if she wanted him to have been born without Down syndrome. I think it was probably a little bit

of both. I recently discovered my mother's copy of *Babies with Down Syndrome* on a bookshelf in our basement. When I opened it to look inside, a stack of prayer cards tumbled out. Nicholas's baby book is filled with articles by Erma Bombeck that offer comfort and humor to mothers of children with special needs; my mother clipped and saved each of them with the same care she took with the clips I would later write in my first job as a newspaper reporter. One of Bombeck's columns, "And that's how they are chosen," offers possible reasons why some women are the mothers of children with disabilities. It was re-published in our local paper on September 6, 1993, my mother's 38<sup>th</sup> birthday, a publication date she now imbues with significance.

The column begins with a list of reasons a woman would have children: choice, accident, outside pressures, habit. But mothers of children with special needs are chosen with "great care and deliberation," Bombeck writes. She imagines God and his angels watching the expectant mothers on earth to pick the one woman who is happy, strong, patient, and selfish enough to love and care for a child who would bring his own gifts and burdens to the world.

As I read the column, I see that God, in choosing my mother, chose perfectly. Where else would he find a woman who would laugh at labor pain? Who would cry because the building where she took her son for therapy was ugly? Who would take him there anyway, because she knew it was the best thing for him? Who was currently raising two daughters who had very different personalities and would add a son, who was different still because of his genetics? A woman who would still let that son become his own person?

Nicholas's bedroom was long ago converted into a guest room, but his curio – where we display the items that were most important to Nicholas – remains along one wall. It's here where I most clearly see the ways my family's expectations for Nicholas met with the reality of his life. My Nonno loved cars and bought fancy models for Nicholas, toys I imagine he thought the two of them would play with when Nicholas got older. My family vacations at the beach, so the shelves of his curio display figurines of dinosaurs made out of seashells and ceramic lighthouses, even though Nicholas did not especially love the sand and the ocean. Instead, he loved Barney, so we saved the books about the purple dinosaur that he used to read and little toys that showed Barney dressed in a yellow rain slicker, in a fireman's uniform, in swim trunks. In the corner of one shelf, we placed his Playskool tape player, special only because Nicholas loved music.

This is what happens in all families: there is the expectation and family ideal that is, eventually, replaced by the reality. For my family, it meant the fact that my brother had a disability and then he died. When I decided I wanted to have children and began to imagine my own ideal family, I pictured a husband and three children – two boys and a baby girl. The brothers would be friends and, of course, watch out for their baby sister, who I would probably spoil like a princess. I still hope to get married and have children, but I have already begun to revise my own imagined ideal. As I write this, I am 28, younger than my mother when she had Nicholas but older than Cori when she had Anthony. When I now imagine my future family, I wonder what will happen if I have a child with Down syndrome, although I know the answer will be to raise the child with the

care and love I would any child. It is both as overly simple and as dauntingly complex as that.

After Nicholas was born, my mother asked her doctor if it meant that Down syndrome ran in our family, if my sister and I had a greater chance of having a child with the condition. His answer was no. When I imagine my ideal family now, I think maybe three children will no longer be possible when – or if – my chance to be a mother arises; perhaps one healthy child will be ideal. This hyper-vigilance, this wondering about what Down syndrome might mean for a family, is part of Nicholas’s legacy.

Scientists still do not know exactly how the extra chromosome that causes Down’s affects a person’s development. They know that a person with Down syndrome will have a nose, but that it may be a little smaller because of an underdeveloped nasal bone. They know that a person with Down syndrome may stick his tongue out, but only because the roof of his mouth is a little shallower than most. They know that a person with Down syndrome may have a fully functioning heart, but one that is surrounded by an underdeveloped wall. In other words, they hypothesize that the extra genetic material results in growth that is incomplete.

When I look back on that family Christmas party – “Don’t you want this?” – or to that moment on our back deck – “A degree won’t keep you warm at night.” – I realize that a family that was full, healthy, and “complete” was the “something better” my mother wanted for me.

\*

Anni and Noah wanted to bowl one more game, so they returned to the lane while Anthony sat along the seats in the back, still engrossed in his game. Each time his name flashed on the scoreboard, Cori turned and asked if he wanted to bowl. Each time, Anthony shook his head “no.” Anthony sometimes keeps to himself, and Brian and Cori let him in the same way they let Noah squander his money on snacks and let Anni wear plastic Mr. Potato Head glasses. Even at a bowling alley, they fell into a familiar family rhythm.

“I won’t ask you anymore,” Cori said to Anthony after a few turns. “If you want to bowl, you can tell me.” Cori sat at the console and hit the “Skip Bowler” button each time Anthony’s turn came. If Brian were there, he would bowl for Anthony, even though Noah would claim that Brian and the precision with which he bowls were “slowing them down.”

Soon, Noah sprawled himself across the chairs near their lane or sat on the floor close to the edge of their lane. Anni opened *The Little Mermaid* backpack and changed from her pink Crocs into her rainbow-sequined Skechers.

“They light up,” she told me. As she moved toward the lane, I saw the little lights blinking on her feet.

Anni had decided to bowl without using the dragon. She pushed the ball a little too lightly, and it started to slow down before it got even halfway down the lane. We all cringed as we watched.

If Brian were here, Cori explained, he would grab another ball and send it down the lane to give a little push to the ball that was stuck. It makes a terribly loud noise, and the workers at the bowling alley look unhappy. Luckily, today, the ball slid back to Anni.

“It wants to be with Anni,” Noah exclaimed when it reached the start of the lane, and Cori laughed.

At the end of the game, Noah had won, and Anni had come in second.

“I got gold,” Noah said.

“Anni, you got silver,” Cori added.

“I’m actually the best today because I got a silver and a gold,” Noah said, recalling the medal count for that day. “Anthony and I got gold; Anni and I got silver; Anni got bronze.”

“A lot of medals today,” Cori agreed, and Anni pouted because she didn’t get a gold.

“I like silver better myself,” Cori consoled her. “If you keep practicing, one day, you might get a gold.”

Just as they were ready to leave, Anthony surged toward the console, grabbed a bowling ball and bowled a couple of frames.

“We’re all done,” Cori said. She had slung the miniature teal backpack over her shoulders. In her hands, she carried her keys, wallet, and travel mug. When Anthony would not listen to her, she approached him and took his bowling ball, cradling it in her already full arms.

## **GROWING UP, GROWING OLD**

In June of 2013, a building permit hung on the picture window of the Guillaumes' house. Cori and Brian had a clear idea of the work they wanted done, but no concrete plans on how to achieve the end result, except that Brian would do some of the work himself and that they would rely on a contractor friend for the rest. Once the renovations to their home are complete, they will have converted their garage into a living room with French doors and floor-to-ceiling windows. They will have angled their driveway into their side yard, where it will lead to a new garage. They will have turned their current living room into a dining room and completely renovated their kitchen. They will have the space to, one day, turn their basement into an apartment where Anthony can live, if he wants to.

As Anthony's gets older and his cells multiply, they produce more of that extra genetic material that caused his Down syndrome. That means more extra twenty-first chromosomes, more rapid aging, more of a risk for early Alzheimer's, more worries about job prospects, more concerns about living arrangements and affordable housing, more questions about guardianship and Social Security insurance, more plans about special needs trusts.

When Nicholas was alive, these same thoughts most likely preoccupied my parents' minds, adding to the already overwhelming situation they found themselves in:



trying to create a sense of normalcy for their two young daughters while also raising a young son with Down syndrome and other intense, some unrelated, health issues. While Nicholas was alive, I never sensed this stress in my home. And, in the years after he died, I didn't often think about him. I don't wish to sound callous because, of course, I remembered by brother: we display his pictures all over our house. I keep a small statue of Saint Nicholas on my dresser. My family hangs his Christmas stocking and favorite Christmas ornament every December. We regularly visit the cemetery where he is buried. What I mean is that I never wondered about him, about the person he would have become or the place he would hold in our family, or in the world, what would happen to him as he got older. I later attended college at a school where the Special Olympics Fall Festival is one of the largest student-run events of its kind in the country. It's there where I found a community of people like me, who had siblings or aunts or friends with a disability. And it was there where I began to wonder about the Nicholas I was missing.

Notes in Nicholas's baby book reveal that he hit his physical milestones at all the right times. Photos of him, as a two-year-old "hanging ten" during his bath (standing on the little shelf in our bathtub while holding himself up by the towel rack) reveal the beginnings of physical strength and athleticism. He would have been a tremendous Special Olympics athlete. And so, I began to look for a reflection of Nicholas in the faces of the 1,000 or so athletes who crowded campus each fall for the festival. Which sport would Nicholas play? What would he look like? I imagine him playing soccer, a sport that values speed, strategy, and teamwork. I can see him running back and forth across the field, short and a little stocky through the stomach, hips, and thighs, like most

of my family. His blonde hair would be long enough to bounce up and down as he chased the ball. I imagine my family on the sidelines, cheering him on.

The closest I got to Nicholas was finding Greg, a man with Down syndrome who, I think, was a power lifter. He had light-colored hair and seldom spoke, but he would wrap his arm around any pretty girl in the room, pulling her in for a hug or, sometimes, a kiss on the head. On the Saturday night of the festival, when the athletes took a break from competition to celebrate at a dance, he wore boat shoes and a button-down shirt tucked into khaki pants. This is exactly how my father dresses.

Greg stood out among the throng of athletes, many who arrived at the dance still clad in their sweatpants, whose uncombed hair looked greasy, whose mouths showed gaps where teeth should have been. I could always tell, or so I thought, which athletes had a good home life, with a good family and caretakers, and which athletes had a family unwilling or unable to care for them, who lived in group homes I imagined as institutions in rapid decline, with barren walls and questionable sanitation.

In her essay, "Hope for Retarded Children," Eunice Kennedy Shriver describes the institutions of my imagination. She writes:

I remember well one state institution we visited several years ago. There was an overpowering smell of urine from clothes and from the floors. I remember the retarded patients with nothing to do, standing, staring, grotesque – like misshapen statues. I recall other institutions where several thousand adults and children were housed in bleak, overcrowded wards of 100 or more, living out their lives on a

dead-end street, unloved, unwanted, some of them strapped in chairs like criminals.

While I recognize that this is a dated description, and one that is only true of a handful of institutions from one family's experience, the questions it raises about the life of an adult with special needs, and the tensions between what the state provides and what a family environment might provide for a person with a disability are still relevant today.

In Pennsylvania, students with special needs are supported by the state school system until they graduate or until they reach age 21. After that, the resources for leading a fulfilling life dwindle, a problem that has grown as the life expectancy of people born with Down syndrome has increased, a result of better health care for congenital heart defects, one of the most common health problems in people with Down syndrome. In the early 1900s, the life expectancy for a person with Down's was nine years old; in 1983, it increased to 25 years of age; today, people with Down syndrome can expect to live into their sixties.

\*

I was born into a world that held certain expectations for me. I grew up in an upper-middle class, Catholic home where we valued family and education. I would go to college and get a job. I would marry, buy a house, and have children. It's not as if these goals were ever formally decreed; it's more that I picked up on the fact that those exact milestones dotted the life trajectory of nearly everyone I knew. When Nicholas was born with Down syndrome, my mother had to call into question many of the goals and hopes she had already imagined for him. Would he marry? Maybe. Have children? Probably

not. Work? Hopefully. At this time, she didn't know anyone with a young child with Down syndrome, let alone anyone who was an adult, so there was no model to follow.

Even now, although my family knows several people with Down syndrome – the Guillaumes, of course, but also some of the families we met while Nicholas received services like speech and physical therapy, we still don't know many adults. If Nicholas had lived – he would be in his twenties now – helping him navigate his adult life would still be new territory for my parents.

One of the few people with Down syndrome we know who is older than 20 is Patrick Corcoran, the uncle of one of my elementary and high school classmates, Brendan. Brendan was the type of boy whom every girl had a crush on, and who most boys wanted to befriend. He was always smart, without being nerdy or overly conscientious. In elementary and middle school, he played sports well. In high school, he grew his hair into shaggy curls and played the guitar. He was much more popular than I ever was, but he was always nice to me, and I sometimes wonder if he didn't have a soft spot for me because he knew about my brother.

One day during a class discussion – I no longer remember the topic or which grade we were in – Brendan raised his hand and said, “My uncle has Down syndrome.” This was one of the first times I remember someone openly speaking about Down syndrome. At the time, I was surprised to learn about Brendan's uncle. When I look back on that moment now, I am proud that Brendan said something.

Years later, I would meet Brendan's Uncle Pat. My family and I were getting ice cream on a rainy day at the beach when we ran into Brendan's family: his mom and

sister, both named Noreen; a couple of his brothers; and his Uncle Pat. Pat stood near the back of the group and didn't say anything. He had light brown hair and eyes that looked bright and alert. I smiled when I saw him because I remembered the day Brendan mentioned him in class.

Pat is now 47 and lives in a group home. I recently met Brendan's mother and sister for bagels after church, at the deli where the two Noreens are regulars. Brunch after church is a tradition Brendan's mother Noreen has carried into her adult life from the days when she was a young girl growing up in York, Pennsylvania, a 30-minute drive south from the town where she now lives and where Brendan and I went to school. She comes from a family of nine children. She falls sixth in the line-up; Patrick is the baby. Every Sunday during her childhood, the family dressed up – the women in dresses and the men in ties – and went to church, where they sat in one of the first pews, and then to breakfast, where they ate near the front of the restaurant.

This was during the 1960s and 1970s, when Down syndrome was still called Mongolism, so named for the seemingly Asian appearance of those with the condition. It was before 1975 when Public Law 94-142: The Education for all Handicapped Children promised a “free and appropriate education” to all children. It was long before the Individuals with Disabilities Education Act (IDEA) protected students with disabilities and encouraged inclusion in the classroom until they reached the age of 21. It was at a time when pre-natal testing was not made readily available to pregnant women. And it was a time when people with disabilities were swept off to institutions shortly after being

born, and their families often wrote their obituaries, preferring to pretend these babies had died than to acknowledge they had a disability.

Noreen's mother was 41-years-old when she had Patrick, the last of her nine children. When he was born – on Saint Patrick's Day in 1965 – no one said anything. He was a healthy baby with a good heart and strong lungs, but Noreen's father, a family physician, sensed something was wrong and left York immediately to take Patrick and his wife to the Children's Hospital of Philadelphia (CHOP).

Noreen was 7 at the time.

*If they come home soon, things are good, she thought. If they stay longer, maybe things are not so good.*

At CHOP, the doctors diagnosed Patrick with Down syndrome. Although they still did not know the severity of his case, they told Noreen's parents that, if they didn't want to get too attached to their son in the event that he would have serious health issues or die young, they should consider sending him away.

“He's our child. He's a child of God,” Noreen's mother said. And they brought Patrick home.

Patrick's parents expected him to do what all of their other children did: clean his room, make his own bed, help with chores around the house. In a family that big, Patrick also had eight other people to help raise him. One sibling was responsible for reading to him. Another for bathing him. Another for playing basketball with him. That's part of the reason why when Noreen had children of her own – she had six – she never even considered pre-natal testing. She knew what it was like to raise a child with Down

syndrome, and she knew if she had her own child with Down's (she didn't), she could handle it.

Noreen's mother always used to say, "I had eight kids. Then, I had my angel."

I almost gasped when Noreen told me this – my mother says the same thing, only for different reasons. She insists all three of her children are her angels: I was born on the Feast Day of the Guardian Angels; my sister Angela was named for the angels; and Nicholas, when he died, became her angel.

\*

When I talk to people about Down syndrome and the story I am writing, they often ask about the religious mindset that seems to influence many of the decisions and discussions of these families. It's faith that is responsible for beliefs about angels, for the refusal to undergo pre-natal testing, for the use of phrases like "child of God" to describe a person with Down syndrome – or any person.

I never know how to respond to these comments because this mindset has been such a part of my upbringing – part of the beliefs and expectations into which I was born – that I don't see it as unique or special. I don't even notice it at all.

My mother teaches English at a Catholic middle school, and one of her current students has a baby nephew who was born with Down syndrome. A couple of times, this little girl has spoken about her nephew in class.

"What is one of the things you value the most?" my mom asked her students one day.

"My nephew," this little girl answered.

When the topic of pre-natal testing – as related to a novel they were reading in class – arose, this little girl told my mother that her brother and sister-in-law never considered it because they were so young. When her nephew was born, they thought, *this is who is he is, and we love him.*

\*

Patrick was born into a family that also shared this mindset, but into a world that rarely spoke or thought of the futures of people with Down syndrome – or any disability – with much hope. At the time, people with disabilities were labeled “trainable” or “educable,” based on their IQs. “Trainable” meant they could successfully learn the skills necessary for work. “Educable” meant they could learn to read and write. Patrick’s IQ registered at 49: trainable.

When it came time for Patrick to attend school, he went to a special education class while the rest of his siblings attended St. Joseph’s, a Catholic school in York. Each day, Patrick’s mother took him to a room where he learned to tie his shoes alongside peers with a wide range of disabilities. Adamant that all of her children would learn to read and to write – and certain that Patrick did not belong in this class, Noreen’s mother approached the pastor of Saint Joseph’s.

“Patrick is our son,” she said. “He is a child of God. We want him to go to school here.”

The pastor conceded, and Patrick soon began classes at Saint Joseph’s, before the time when the now-prevalent practices of inclusion existed in schools. Patrick was about five years older than his classmates. He studied religion and spelling with his peers, but



received individual tutoring, paid for by his parents, when his classmates got older and began to study more complex subjects. At age 16, he graduated from eighth grade and took a job bagging groceries at a local supermarket.

I shop at the same grocery store chain when I visit my parents, and I see a lot of special needs employees. In the world of special needs, there is a maxim that says, “food, filth, and flowers.” It refers to the three fields where people with disabilities can expect to find work – as grocery baggers, janitors, or clerks in a flower shop. Patrick worked at the grocery store for nearly 15 years, until he developed early onset Alzheimer’s at the age of 30.

Now, Patrick moves more slowly. When he dines with a group, he examines his food and socializes, sometimes for nearly an hour, before taking a bite. In the group home where he now lives, his caretakers come to his room to wake him up several hours early so he has time to get out of bed, brush his teeth, and get dressed.

Patrick moved to the group home in York about a year-and-a-half ago, after his mother died. His siblings moved the contents of his old room in his mother’s house to his new room in the group home. They filled its corners with his furniture, covered his bed with the same bedspread, and decorated the space with family photos. For Patrick, the move was like going away to college. It was his first time living away from home, the first time he was responsible for his own decisions. Now, he could stop going to church, something he and his mother did every Sunday until she died; he could wear sweatpants and flip-flops any time he wanted.

Noreen's mom used to dress Patrick in nice clothes, like pressed pants with his shirt tucked in, a tie on special occasions. When her friends see Patrick around town, they call Noreen.

"We saw Patrick today," they say and then pause as though for emphasis.

"Wearing sweatpants."

Implied in their voices is the disapproval that Patrick's mother would have felt. She always made sure her son was dressed well and appropriately. When Patrick insisted on taking out his comb and combing his hair in public (the action Noreen called his "obsession;" what Cori and Brian might call his "fidget"), she encouraged him to put the comb away.

"You don't see Dave combing his hair like that," she used to say, referencing Noreen's husband. "You can't comb your hair like that all the time."

On the day my parents took Nicholas home from the hospital, my mother dressed him in a blue Dior outfit.

"Not the real Dior," I said when she recently told me.

"Yes, the real Dior," she replied.

My mother made it a priority to dress Nicholas well his whole life: jeans and a red polo shirt with Mickey Mouse embroidered where the breast pocket should be; khaki corduroy pants with a purple and green argyle sweater over a button-down white shirt when it was cold outside; white denim overalls with pictures of caterpillars over a blue T-shirt (my favorite of Nicholas's outfits).

Her motivations were the same as Patrick's mother when she dressed him up and made him put his comb away, the same as Brian's and Cori's when they remind Anthony to tuck his tongue back into his mouth. When people first saw Nicholas, they commented on his nice clothes, on how cute he looked and, just for a moment, his Down syndrome faded into the background.

\*

When Noreen's mother died and her siblings were left to decide what was best for Patrick, they decided to place him in a home in York, the city that was familiar to him. Pat's siblings live scattered around the country, and Noreen, one of the closest geographically, works long hours. The stability and schedule provided by the group home seemed like the best decision.

Had Nicholas lived, I know my family would have cared for him in the same way – by doing what was best for him. I could see this care for Nicholas in the way my mother lovingly kept his baby book, preserving newspaper clippings, photographs, and birthday invitations. I can see it in the way my father still gently cares for Nicholas's grave each time we visit the cemetery. He trims the grass around Nicholas's headstone and then brushes the clippings away, clearly revealing Nicholas's name, the dates of his birth and death, the small angel my parents had engraved on the stone. Before he returns to the car, my father remains kneeling, and gently rubs the grass covering Nicholas's plot, as though holding his hand.

My dad's Aunt Joan was born in 1934 with a vaguely diagnosed developmental disability. She spent most of her life in schools and institutions in New Jersey and

Pennsylvania before she died in the winter of 2007. My Great-Aunt Barbara – Joan’s oldest sister and her guardian – recorded Joan’s life story in a document she sent to our family; my dad keeps his copy in a manila folder with other important emails about Joan in the bottom drawer of his desk.

Joan’s story mirrors many of the experiences my own family had with Nicholas. My Aunt Barbara and Grandma played Patty Cake and Peas Porridge Hot with Joan, just as my sister and I played with Nicholas. My Grandma, the middle child in her family, wondered why Joan “couldn’t talk and do what other babies do,” as I eventually wondered about Nicholas. My great-grandparents wanted a good life for Joan and a seemingly normal life for their two other daughters, and worked hard to achieve that balance, just as my parents did. When Joan died, my Aunt Barbara wrote in an email to the family, “The question still is, was her life precious, important, sacred? It’s hard to be positive about a life that was so limited...” She concludes, though, that Joan did, in fact, have a good life because she brought joy to her grandparents, parents, sisters, and caregivers, a conclusion almost identical to the one my mother reached in Nicholas’s eulogy. When my Grandma and Aunt Barbara began to age, they decided to choose a new guardian to act in Joan’s best interest, in the event that Joan would outlive her two older sisters. They chose my father.

Were Nicholas alive, the same responsibilities would have fallen to my sister and me. My mom always says she hoped we would have taken care of Nicholas, maybe even invited him to live with one of us. But, at the same time, she did not want to put that kind of pressure on us.

The Guillaumes feel the same way about their second son, Noah. Right now, Noah protects Anthony the way any brother would. When the other students on the school bus asked Anthony to blow raspberries to get Anthony in trouble, Noah told the bus driver. When Anthony took a treat that was not gluten-free from the bus driver, Noah knew it would make Anthony sick and made sure his brother didn't eat it. One day, taking care of his brother might mean something more.

I like to think my sister and I would have cared for Nicholas, and I like to think Noah will do the same for Anthony. But, I am left to wonder what might have been, while the Guillaumes still wonder what will be.

\*

One of the first times Noreen went to visit Patrick at the group home, he showed her Images, the place where he spends most of his days. Images is, essentially, an adult day care center that serves people from several local group homes. Inside, it looks like a fitness center. There's a locker room, a fitness room with treadmills, a snack room, and a quiet room.

As Noreen looked around that day, she saw someone sitting on a chair, staring blankly as drool dripped from his mouth. Another man sat in a corner and rocked back and forth. She looked at Patrick, clad in his Nike shorts and Adidas sneakers, ready to hop onto the treadmill, and had the same thought her mother had years before when she took Patrick to his special education classroom, the same thoughts my mother had about Nicholas when she first saw the rundown UCP facility: *He doesn't belong here.*

Patrick motioned for Noreen to lean towards him.

“That guy,” he said, pointing to one of the other visitors, “is handicapped.”

*Patrick, Noreen thought, so are you.*

As she relayed this story to me, she laughed.

Patrick was – and is – lucky. He had a father with a medical degree who knew about Down syndrome. He had a mother who insisted he receive an education, like all of her children. He learned to read and write so that today he can devour entertainment magazines and write letters to his siblings, two daily activities that give him a good quality of life – one that engages his intellect and connects him to the people he loves, the people who love him. He has an older sister who cries when she talks about his purity – if she becomes anxious about the state of the world or the economy, she can visit Patrick, because he won’t be concerned about those things – and who worries about him because, in his group home, there is no one to hug him before he goes to bed each night as his mother once did. He grew up in a home where he was expected to contribute to the daily responsibilities of the house, and so, even now at age 47, he does not recognize his own disability.

\*

Right now, Anthony’s Individualized Education Plan (IEP) – a document covered with grids and goals that each special education student in Pennsylvania receives – includes goals for his behavior, for math and reading, for speech, for occupational therapy. “Anthony will improve fine motor skills by completing the steps to tie his shoes,” one item states. Out of five steps, he can do the first two. After he wraps the lace around the loop, he can’t see well enough to pull the string through. “Anthony will

correctly imitate sounds,” another goal says. He can make the sounds for the letters “d,” “t,” “m,” and “w” and is working on “k” and “g.” He uses an iPad with a speech app that shows him the correct placement of his tongue for every letter. Cori recently added the names “Ed,” “Melodie,” “Allen,” and “Wendy” – friends the Guillaumes see regularly – to the list of words to practice. “Anthony will continue to demonstrate an increase in the amount of numbers he can identify,” another item says. Brian has said that he knows Anthony won’t take a calculus class at the high school, but both he and Cori would like to see Anthony go to college, to see him included where he can succeed.

When Nicholas was alive, my mother met many parents of children with special needs who she called “fighters.” With the exception of a letter she once wrote to the newspaper calling for inclusion in schools (a letter now tucked away among the other clippings in Nicholas’s baby book), my mom never fit this role. She felt overwhelmed by her son’s health problems, and just wanted to spend time with him and with her family. But she was always grateful for the parents who did fight, for Nicholas would reap the benefits of their battles. Like my mother, these “fighters” wanted the best for their children, but they also understood that they had to advocate for it, just like Patrick’s mother. Just like Brian and Cori.

On their refrigerator, Cori and Brian hung an 8 ½ by 11 inch photograph that shows a small special education class at a local high school. In it, at least one student with Down syndrome smiles and poses next to the cash register that the Central Pennsylvania Down Syndrome Awareness Group, the organization Cori and Brian

founded, bought with some grant money. The teacher had requested it, hoping to use it to prepare her students for a future job in retail.

“I would rather die than see Anthony work in retail,” Cori said one night when we looked at the picture.

I felt slightly taken aback by the harshness in Cori’s remark, and I didn’t respond to her in that moment because I did not know how to. I think, partly, that a career in retail is a respectable job. But, then I think of people like Patrick, and I understand the value that can come from being blind to or pushing past any limitations – real or perceived – of the ones you love. Had Nicholas lived, I would have wanted him to find fulfillment in family, in friends, in satisfying work. I would have wanted him to have had a job he attended every day with pride, just like Patrick had. Just like Cori wants for Anthony. I would have wanted him to have a support network to love and push him, like Noreen and her family are for Patrick. Like Cori and Brian have created for Anthony. I would have wanted Nicholas to be blind to his disability, as Patrick and Anthony are. That way, he would believe he could accomplish anything – and try to accomplish anything. Perhaps it wasn’t harshness that I heard in Cori’s voice that day but determination – and hope.

\*

During one of my first visits to Brian and Cori’s house, I sat on the back porch with Brian, Anthony, Noah, and Anni. It was a cool but humid morning in early September, and the kids played with a Blade Runners spinning toy. They huddled around a shallow plastic tub and clipped circular blade runners to a toy gun.



“Anthony cheats,” Noah announced. Anthony held his gun poised over the tub ready to release his spinner into battle.

Noah shot his spinner and watched as it balanced like a top, following the curve of the plastic tub. It slowed and began to lose steam, teetering close to the base of the tub when Anthony finally released his spinner. The toys spun in circles, ricocheting off the edges of the tub, colliding with each other. Eventually, Anthony’s toy overtook Noah’s. Victory.

Brian crouched on the deck with his children.

“What do you want to be when you grow up, Noah?” he asked.

“A bridge inspector,” Noah said. Without even looking up, he named the career Brian had chosen for himself.

“Anni, what about you? What do you want to be when you grow up?”

“A firefighter,” she replied.

“And Anthony, what do you want to be?” Brian asked.

Anthony sat silently, focused on securing his spinner so he could launch it with the others once again.

## **HALLOWEEN PARTY, OCTOBER 19, 2013**

I had received my invitation to the Central Pennsylvania Down Syndrome Awareness Group Halloween party via email. It displayed an image too large to fit fully on my computer screen. On one corner of the invitation, a giant orange jack-o-lantern stood out against a black background. At the bottom of the invitation, written in a jagged, spooky font were the words: “Everyone is invited for our Halloween party.” At the end of the email, the group had included its signature, “If more is better, 47 chromosomes must be exquisite.” When I called to RSVP, Cori told me to bring my friends. At the group’s events, it always seems that more is better: more people, more music, more games, more fun.

When I arrived at the party two weeks later, I spotted Eeyore, from Winnie the Pooh, and a lion across the street. They toddled toward the entrance to the party, one behind the other, the same height, the same bouncy walk, both covered by costumes made of the same furry fabric. From my parking spot across the street, I could not tell which child was older, or if they were twins. I couldn’t tell which child had Down syndrome.

I crossed the street toward Prosser Hall, the township building in Camp Hill, Pennsylvania. Prosser Hall stands just a few blocks from the main street in Camp Hill; it’s where borough officials meet to talk about budgets and taxes. On that Saturday in

October, however, it had been decorated for the group's Halloween party. Inside, high school students manned the registration table; they had dressed in costume – one as a superhero in red, white, and blue; one as Hermione Granger in a black cape with a burgundy-and-gold striped tie; one as a doctor in scrubs; one as an equestrian in tight beige pants with a dark blazer and a helmet. Next to them, a caricature artist had set up her easel and paper, and on the other side, there was a photo booth where guests could have their pictures taken with props meant to make them look as though they were monsters, or as though they had lost their heads and were lifting them above their necks with their own two hands. A sign above the door leading to the party room said, "Enter if you Dare."

I walked in.

Orange twinkle lights glowed from one corner of the room, where a small group of three or four children played with a ring toss game and bowled with plastic balls and pins. Halloween doo-wop music, like "The Monster Mash," drifted from the back of the room, where the DJ, a friend of Brian's from high school, had set up his equipment. Every year, he drives the thirty minutes from his home in York, Pennsylvania, to DJ the party.

A semi-circle of chairs surrounded the dance floor, and I sat down near the window, right between the lion's (who had Down's) and Eeyore's mom. A little girl dressed as Dorothy from *The Wizard of Oz* danced in front of me. She had long, thin hair that she wore in two braids that hung below her shoulders. Her blue and white dress was sequined, as were the red spats that covered her sneakers. She couldn't talk, but she

approached me, grabbed onto the winter vest I was wearing, and tried to push it off of me.

“Do you like my pin?” I asked her. I had clipped my favorite Halloween pin – with a friendly-looking black cat popping out of a smiling jack-o-lantern – to my vest. I had worn this pin for years as a child, and, for me, it always signified the start of the excitement of the fall and winter holiday season.

The little girl didn’t respond. Instead, she again grabbed the front of the vest and tried to take it off me.

“Sidney,” her mother, who was sitting next to me, said.

“You know what?” I said to Sidney. “I should take my jacket off. It’s silly to wear it inside.”

I removed my vest and placed it on the chair next to me. Sidney grabbed it and walked away. She placed the vest on a chair a little further around the circle, and I laughed.

“Sidney, bring that back to her,” Sidney’s mother said with a laugh that sounded forced and tired, almost like a sigh. Sidney picked up my jacket, but instead of returning it to me, walked past me and gave it to her father, who was sitting behind us at one of the long tables set up for dinner.

“Sidney,” her mother admonished again. Then, she looked at me. “Do you have kids here?”

“No, no,” I said. “I’m a friend of Brian and Cori’s.”

The DJ had transitioned his play list to dance music and started to play “Gangnam Style.” I spotted Cori with Noah and Anni on the opposite curve of the makeshift dance floor. Cori stood with her feet shoulder-width apart and bent her knees slightly. She extended her arms in front of her, crossed at her wrists, so that her fists hung limply and bounced with each of her movements. Noah and Anni bounced around and tried to imitate her movements but instead ended up running around Cori in circles. Noah had taken off his costume, a green, boxy contraption that Cori made for him so he could dress as one of the creepers from the *Minecraft* video game. When he wore it, he almost waddled and made me think of Scout Finch in her ham costume. Anni wore a floor-length pink gown and carried a wand. Her ponytail flowed like a plume through her plastic silver tiara. I had seen her earlier and asked if she was a fairy princess.

“No,” she responded. “Just a fairy.”

Anthony sat in the circle and played on his iPad next to his grandmother – Brian’s mother – who was dressed as Hello! Kitty. She wore a pink skirt and white top pinned with a Hello! Kitty mask. Anthony was wearing a yellow Spongebob Squarepants costume. Cori pranced over to him and held out her hands.

“Dance with me,” she said.

But Anthony shook his head “no” and returned his gaze to his iPad. Parties have never been Anthony’s scene. Once, the Guillaumes had thrown a birthday party for Anthony and found him hiding in his bedroom.

Cori returned to the dance floor as the song changed to “Born this Way.” “I’m beautiful in my way,” the lyrics state, “’cause God makes no mistakes, I’m on the right track, baby, I was born this way.”

Later, while the families ate dinner, I wandered outside to the registration table, where there was a photo booth and a caricature artist. A little dinosaur with Down syndrome and his two sisters had posed for a drawing, while their mother looked on and smiled. Later, I sat down and faced the artist, another party regular from past years. Within a few minutes, she rendered a cartoon of me. She drew my striped shirt and vest, making sure to also illustrate my Halloween pin. She made my face look long and thin, with small cheeks and a chin that juts out when I smiled. My long wavy hair fell below my shoulders.

I re-entered the room in time for the costume contest. The junior class officers, who were serving as judges for the contest, gathered near the front of the dance floor as Cori took the microphone and called anyone who was ages 0-5 to come forward to be judged. A small group assembled that included Anni, in her fairy costume; her friend Melodie, dressed as a cupcake with a little blue skirt and a puffy top onto which her mother had sewn the plastic tops of markers to look like sprinkles. There was a Cookie Monster, a tiger, and the Eeyore I had seen from the parking lot when I first arrived.

With each age group, came another parade of costumes. Here was Noah in his *Minecraft* costume. Cori had cut armholes into a large box that Noah wore like a T-shirt. She had used another box to create a hat that Noah strapped to his head. She had wrapped the boxes in green wrapping paper covered with geometric shapes. A family friend first

introduced Noah to the game, in which the players build a world entirely of blocks. “No one can tell you what you can or cannot do,” the game advertises. “With this adventure, it’s up to you.” I couldn’t help but think of Brian and Cori, the Central Pennsylvania Down Syndrome Awareness Group, and all the children with Down’s when I heard the game’s tagline. And it seemed fitting for Noah, one of Anthony’s biggest supporters, to unknowingly advertise such a sentiment.

Carson, the son of one of the group’s founders, was also there with Noah. Carson was born severely premature: at 26 weeks, he weighed only one pound, fifteen ounces. Within 24 hours of his birth, he had a stroke and was diagnosed with cerebral palsy in addition to Down syndrome. His parents adopted him anyway. After three months in the hospital, Carson’s parents were finally allowed to take him home. They had filled his nursery with equipment to monitor his heart rate and pulse and machines to pump oxygen through his body. Before his first birthday, he would be hospitalized six times, and his mother worried that anything – even a cold – would send his health into a downward spiral.

Today, he entered the costume contest with a soccer ball on his head. He took the microphone from Cori, who let him yell into it before the contest started.

A little blonde boy dressed as the Incredible Hulk also stood in this group. I had noticed him before – blonde boys with Down’s remind me especially of my brother. This one wore a black unitard whose top portion was padded with muscles. He had gloves that gave him the Hulk’s huge hands. Occasionally, I saw him running around the dance floor, dancing and boxing with his father, a man who also had blonde hair. But, at other times, I

saw him sitting in front of the DJ booth, staring at the flashing lights that decorated the table.

When Cori called the next age group, a skinny boy dressed all in black moved toward the dance floor. He had mousy brown hair and wore a hearing aid and glasses.

“Good luck,” his mom said to him and kissed him on the head as he joined the group.

Finally, Cori called the last group – ages 16 and older. Another Sidney – this one dressed as Cyndi Lauper – was the only teen with Down syndrome in the contest with the other adults who had dressed up, including two new parents who had come as a cow girl and a wizard. The man almost looked like a real wizard, with a full beard and a ruddy face. He wore a full-length brown cloak and carried a walking stick with a white owl perched on top. The judges conferred and gave the prize to Sidney.

I had walked across the room to say “hi” to Brian’s mother.

“You didn’t enter the contest,” I said.

“I thought for sure the wizard was going to win,” she replied. “I think it was rigged.”

If Nicholas had been there, he would have won the costume contest. My mom always made unique and elaborate costumes for us. One year, she dressed as a Native American woman and carried Nicholas as her papoose in his baby carrier. Another year, she made him a Barney costume out of warm, purple and green felt.

As the party died down, I said good-bye to Brian and Cori. Outside, it had started to rain. Anthony stopped me before I left to show me the background on Cori’s phone. It



was a close-up of Noah posing with a plate of breakfast food shaped like a person, his “egg man,” Cori called it.

“Did you get your caricature drawn?” Brian asked me when he saw that I was carrying a piece of paper.

“Yes,” I said and unrolled the drawing.

Anthony studied it.

“Does it look like me?” I asked. He grunted and instead pointed to Cori.

\*

Earlier that night, when I first arrived at the party, I spotted Cori immediately. She stood at the entrance in jeans and a Central Pennsylvania Down Syndrome Awareness Group polo shirt, talking with a woman who held her little girl propped against her hip. The little girl had Down syndrome and a wave through her light-colored hair, and I listened as Cori talked about support braces for the little girl’s legs and named physical therapists who would be good resources for the family. Then, Cori gently pinched the little girl’s thigh.

“We’ll get you walking by next year,” she assured the little girl, and her mother.

When the music started, Cori grabbed the little girl who needed leg braces and swayed back and forth on the dance floor while the little girl’s mother sat and watched.

Brian told me that Cori knows all of the families in the group. As I stood with her at the Halloween party, she looked around at the crowd who had gathered in Prosser Hall. Except for the new family who had arrived, she knew everyone’s name and most of their stories. She talked about Hailey and Gauge. She also talked about the Sidney dressed as

Cyndi Lauper with wild hair, a headband, and an off-the-shoulder shirt. She talked about Mason and Sara, who were about the same age even though Mason looked really little. Both of their mothers had called Cori when they found out that they were pregnant with children with Down syndrome. Today, Mason was the one dressed as a dinosaur. His mother pushed him around in a stroller, and he was flanked by his two older sisters. Sara had red hair and dressed up like a ladybug.

I was watching Cori dance with the little girl when Sidney's mother asked me if I had children of my own at the party.

The previous summer, as I began to research Down syndrome, I took a trip to the library to look at parenting books. I walked through the children's section, smiling at the little kids who had entered the library with their moms to escape the summer heat. I was wearing shorts and a loose-fitting tank top that flowed away from my body. I walked to the check-out counter laden with a stack of books: *Babies with Down syndrome: A New Parents Guide*, *The Down syndrome Transition Handbook*, *The Guide to Good Health for Teens and Adults with Down syndrome*, *Down syndrome Parenting 101: Must-Have Advice for Making your Life Easier*. The librarian smiled as she scanned the bar code of each book. It was a kind, comforting smile; I wondered if that was her nature or if she looked at me, a woman in her late 20s, apparently healthy, looking somewhat longingly at the children playing in the library, wearing a shirt that could easily be mistaken for maternity clothing, checking out a stack of books about raising a child with Down syndrome, and felt sorry for me. When I returned to my parents' house that day, my mother spotted the books stacked on the kitchen counter and paged through them.

“I don’t want you doing all this research,” she said. “I don’t want you to be too prepared.”

But when Sidney’s mother asked at the party if I had children there, I could not sense any fear or pity in her voice. Instead, she told me she also had an autistic son who was staying with his grandparents that night. It’s nice to have just one child to care for for a moment, she confided to me, a total stranger, because caring for Sidney sometimes seems to be too much. More, it seems, is not always better.

But Cori never seems to be overwhelmed – not by her responsibilities, not by her family, not even by Down syndrome. She moved around the dance floor with the grace and confidence, the seeming carefree-ness, I imagine she exuded when Brian first met her.

\*

Just before dinner, Brian took the microphone and welcomed everyone to the party. This was the first time he spotted me. “Hi, Erica,” he said into the mic before continuing his remarks. He invited the guests to eat, to get their caricatures drawn, to dance, to do crafts.

“Thank you for your support and camaraderie,” he said as he shut off the microphone.

The first time I ever attended a group event, my family came with me. We had gone to the group’s annual Buddy Walk, and as we waited for the event to start, my mom looked around at all of the children with Down’s and their families.

After Nicholas was born, the doctors isolated my mother in her own room in the hospital. She stayed by herself – no roommates and only occasional visitors. Because of his apnea, Nicholas could not be left alone with anyone who was not CPR certified. So, even after my parents brought him home, they felt isolated and stuck. Except for Nicholas’ therapists and a few mothers whose children also received services at UCP, my mother knew no one.

Carson’s mother had a similar experience. Afraid Carson would get sick, she stayed inside, visited only by Carson’s therapists who came to her home. Like my mother, she didn’t know anyone else with Down’s.

At the Buddy Walk that day, though, there were over one hundred people, all of them with a connection to Down syndrome.

“I never had this when Nicholas was born,” my mom said that day, without meeting my eye. “But I didn’t start it, either.”

Brian and Cori began the Central Pennsylvania Down Syndrome Awareness Group for Anthony. But I wonder if it isn’t more accurate to say that they founded the organization *because of* Anthony, and perhaps continued it for themselves, for Noah and Anni, for the other children and families who felt isolated when they first received their child’s diagnosis.

After the costume contest, the junior class officers who had served as contest judges joined the dance party. Hermione Granger danced with Cyndi Lauper. The superhero boxed with the Incredible Hulk. I am not sure when the idea of difference and what makes us different begins to register – or when we learn to make a judgment call

about those differences. Cori and Brian have said they don't know what Noah knows about Down's, other than to say it's something his brother and his friends from their group have. He and Anni don't necessarily recognize these children as people with Down's; they must just register them as people they see regularly, people they have come to love. Hermione and the superhero must know about Down syndrome – or at least recognize it to be something that set Sidney and the Incredible Hulk apart from them, but they treated them nicely anyway. When I returned to my parents' house that night, my mom asked if the party made me sad. I told her no, that seeing this community and the kindness shown to these children and their families made me happy. But neither word – happy or sad – seemed quite right. My feelings fell somewhere in the middle because it seems that the group has the difficult – and maybe impossible task – of at once celebrating and masking difference.

As the music played, the boy dressed all in black – the one whose mother had kissed his head before the costume contest – danced by himself. He bobbed up and down to the music, and I could almost see Nicholas doing the same. He used to lug his Playskool tape player with him everywhere he went and bounce up and down to the music.

The next day, when I went to the symphony with my parents, this same boy and his mother sat a few rows in front of me. I nudged my mom and pointed to the little boy.

“He was the one dancing at the party yesterday,” I whispered to her.

“They love music,” my mom said, and I knew she was also remembering Nicholas and his Playskool tape player.

She turned to my father.

“That little boy was at the party yesterday,” she told him, nodding her head towards the row where he sat with his mother.

Usually, I can’t help but notice people with Down syndrome. When I see them, I smile and stare – probably a little too long. If I’m with my mother, I’ll nudge her and point. If my father is with us, she’ll nudge him and point, as though we are playing a game of telephone or whisper down the lane. This is exactly what we did at the symphony.

When Nicholas was alive, it seemed so rare to see a person with Down’s. Now, I often catch a glimpse of someone with Down’s at the mall or at the farmer’s market or working in the grocery store. At the Halloween party, though, I didn’t really notice who had Down syndrome and who did not. I am not sure if it was because so many of the children there had Down’s or if I had somehow prepared myself to see a group of people who had Down syndrome in common. All I saw were a group of kids, dressed in costumes, dancing, taking pictures, and eating dinner. All I know was that I failed to notice Down syndrome.

## TWENTY-ONE PEARLS

Just after Anthony was diagnosed, Cori was shopping at Wal-Mart when she spotted another mother with a son with Down syndrome. This woman's blonde-haired son looked to be about two years old. He picked up items from their cart and dropped them on the ground; he knocked things off the shelves; he munched on French fries. Cori watched, as if glimpsing her future with her own son, then still only six-months old. She approached the woman and introduced herself. They talked about their sons and about Down syndrome.

Cori wrote about this chance encounter in an essay titled "Green Onion" that appeared in the book *Gifts: Mothers Reflect on how Children with Down Syndrome Enrich their Lives*. In the essay, she describes Anthony as her "green onion," a vegetable that is different and uncommon, one that most people don't notice until they taste what it can add to a recipe. Before Anthony's diagnosis, Cori had not paid much attention to Down's. In a different life, she would have completely dismissed – or not even noticed – this woman and her son. Instead, she stopped to meet this woman, who would later become her friend.

Alone in her home, Heather Fox-Kauffman read this essay. She and her husband had just adopted their son, Carson, and brought him home. Carson would later befriend Noah, and enter the Central Pennsylvania Down Syndrome Awareness Group's 2014

Halloween Costume Contest wearing a soccer ball hat. For now, though, Heather kept him in his nursery, amid equipment like heart rate monitors and oxygen pumps that made his bedroom feel more like a hospital room. Almost as soon as he was born, he had been diagnosed with cerebral palsy and Down syndrome; he also suffered a stroke. Afraid to take her son out of the house, Heather isolated herself inside, receiving only occasional visits from Carson's therapists, including the one who brought her a copy of *Gifts*.

Heather read the author's note at the end of "Green Onion:" Cori Guillaume and her family live in central Pennsylvania, it said. That was just a few miles from Heather's home.

*I am going to be friends with these people, she thought.*

The result was the Central Pennsylvania Down Syndrome Awareness Group (CPDSAG), started by these three families, to offer support and grant money to other families of children with Down syndrome. As its logo, the group uses an image of the bottom of Anthony's foot, a reminder of the first clue the Guilllaumes received that Anthony might have Down's, a memory of the first moment Brian and Cori decided Anthony's Down's would not matter because he was their son. The image appears on the group's website, on their brochures and other promotional materials, on the emails they send, on the T-shirts they sell. The photo had obviously been taken when Anthony was a baby: the foot is small and the toes short and stubby. In the image, there is shading along the bottom of the foot, where the arch should be, where Anthony's feet are a little bit flat. A space exists between the first and second toes; unless you focus on it, you might not even notice the difference.



\*

Each year, the CPDSAG hosts a Buddy Walk, one of the key programs of the National Down Syndrome Society; its goal is to unite families and friends of those with Down syndrome and promote inclusion and advocacy. In 2011, my family and I attended the Buddy Walk – the group’s fourth – for the first time.

That day, a chilly Saturday in September, my parents, sister, and I huddled near the entrance to Carlisle High School in Pennsylvania, the site of the walk, while over 100 people milled around us. Anni’s friend Melodie wore a grass skirt with a lei around her neck. She bounced in front of the DJ, whose speakers blared “The Electric Slide” and “Celebrate.” Just a couple of years earlier, I had interviewed Melodie’s mother about Melodie’s progress on the pediatric treadmill. Now, she tottered on her pudgy, slightly unsteady legs as the music played. Her family stood nearby with a “Team Melodie” banner decorated with hibiscus flowers. Another family wore t-shirts that said “Team Nicholas” and showed a silk-screened photo of a little blonde boy with Down syndrome. My family and I couldn’t help but notice the resemblance to our own Nicholas.

As she looked at the attendees, my mom said, “Where were all these people when Nicholas was alive? I would have loved something like this.”

When Brian and Cori reflect on the reasons they wanted to start this group, they always return to the idea of a supportive community, the same kind of community my mother had craved when Nicholas was alive.

Anthony was not even a year old when Cori and Brian attended their first Buddy Walks. They went first to Elmira, New York, near Cori’s parents’ home and then to

Mansfield, Pennsylvania, the town of their alma mater, where they met up with a friend from college who works as a special education teacher. At the Buddy Walk in Mansfield, Brian met Brett, a man about his age who was living with Down syndrome. Brett worked three jobs – at a Wendy’s, at a saw mill, and as a delivery man for a company that made baked goods. In the forty minutes he and Brian spoke, Brian noticed Brett’s strong work ethic and his love of the outdoors. In Brett, for the first time, Brian saw a glimpse of what his son’s future could look like.

It was 2008 before Brian and Cori decided to bring their own Buddy Walk to Central Pennsylvania. That first year, they hoped eighty people would attend. Instead, more than 300 local people with ties to Down syndrome came to the event. The birth story of the group and the Buddy Walk tradition follows the trajectory of many families who know what it’s like to live with Down syndrome: that first year, they were totally unprepared. Now, the event, like much of their lives with Down’s, has become routine.

It is in this way that Brian and Cori have begun to fill the space that their doctors noticed in Anthony’s ultrasound. Not merely the space between his toes, but the space between a life with Down syndrome and a life without, between their expectations for their son and the reality, between their current lives and their uncertain future.

\*

Cori and Brian designed the path of their Buddy Walk to follow a one-mile loop that circles around the high school – from the doors leading to the gym, past the entrance to the auditorium, around the back of the building, and past the football field, ending, eventually, at the place where it started. Along the way, they posted signs with

information about Down syndrome: “Life expectancy for people with Down syndrome has increased dramatically in recent decades – from 25 in 1983 to 60 today.” “The incidence of births of children with Down syndrome increases with the age of the mother. But due to higher fertility rates in younger women, 80 percent of children with Down syndrome are born to women under 35 years of age.” “All people with Down syndrome experience cognitive delays, but the effect is usually mild to moderate and is not indicative of the many strengths and talents that each individual possesses.”

In a way, the Buddy Walk represents a full circle for these families, including my own. We found another blonde Nicholas, who helped us remember our brother and son. Brian met Brett, a man who helped him see what lay ahead for Anthony. All of the people present that day in September walked together, some slowly, pushing strollers or holding the hands of children too young to walk much faster than a stroll. My family and I stayed together, walking with them.

When we left the Buddy Walk, we spotted Anthony sitting on the ground, painting the sidewalk with his paintbrush, surrounded by a crowd of people who understand him, who care about him, and who love him.

\*

My family and I have places where we keep Nicholas: in the photos we have displayed; in his Christmas stocking that we still hang; in his baby book that contains his obituary; in the face of any young, blonde boy with Down syndrome; in the white squirrel that lives in our neighborhood; in the Saint Nicholas medals my sister and I wear around our necks; in the twenty-one pearls around our wrists.

We won these bracelets in the silent auction at that first Buddy Walk. My sister, mother, and I each wear one. Each has twenty-one pearls strung along fishing wire, separated by red and blue crystals and secured at the ends by a silver toggle. Although the make-up of each bracelet is the same, each one looks different. Mine alternates between smaller and larger pearls.

The twenty-one pearls that surround my wrist are meant to represent the extra twenty-first chromosome found in the cells of each person with Down syndrome. When drawn in diagrams in genetics textbooks, chromosomes look like large, block-letter Ks; old-fashioned wooden clothespins; or short, stout molars. For the Central Pennsylvania Down Syndrome Awareness Group, chromosomes look like pearls.

One night, my sister and I were driving home along Route 15 when she noticed my bracelet.

“Do you ever tell people about Nicholas?” She asked me as she nodded toward the string of pearls circling my wrist.

“Sometimes,” I said.

“Me, too,” she said.

After I met the Guillaumes, the stories about Down syndrome and disabilities seemed to multiply, rippling around the stories of our two families. My dad showed me an article about Kevin Grow, an 18-year-old high school student and basketball player in Bensalem, Pennsylvania who has Down syndrome. He started in his high school’s recent Senior Day game and became the day’s high-scorer. There’s George Will, a *Washington Post* columnist who has a grown son with Down’s. There’s Archbishop Joseph Kurtz of

Louisville, the president of the U.S. Conference of Catholic Bishops who has a brother with Down syndrome who lived with him in the parish rectory and while Kurtz served as the bishop of Knoxville, Tennessee. There's my yoga instructor, who has a young cousin with Down syndrome. There's my mom's student, whose nephew has Down's. There's my great Aunt Joan. There's Anthony. There's Nicholas.

The last time I visited the Guillaumes, Noah gave me a red and blue fishtail bracelet that he made on the Rainbow Loom he got for Christmas that year. This bracelet is made out of red and blue rubber bands, the colors of the Central Pennsylvania Down Syndrome Awareness Group.

He told me he wanted to make at least 20 bracelets to sell at next year's Buddy Walk. He thought he could make \$10, maybe \$20 to be a nice bonus for the group. I told him that was a really cool idea.

"Where did you come up with that idea?" I asked him.

"I just thought of it," he said.

He showed me how he made the bracelet, carefully looping each rubber band along the loom, careful to place them in a pattern of one on top of the other. When he pulled the bands away with a crochet hook, a single chain formed. A complete circle. And so we continue – all of us – tightly weaving together our memories, our ideas, our chances, and our lives as we continue around.

\*

The important thing to remember about Down syndrome is that its causes are random: an error in cell division, a refusal of the cells to separate, a willingness of the

cells to stick together. And so it was with Brian and Cori, with CPDSAG, and with me. Had it not been for that chance meeting at the Wal-Mart, the CPDSAG would not have begun. If it had not been for Down syndrome, Cori would never have paid any attention to that other mother and her young son. Had it not been for Down syndrome, I, too, might have not paid much attention to the Guillaumes.

## BIOGRAPHY

Erica M. Dolson worked as a newspaper reporter in central Pennsylvania for two years before beginning her graduate work. She has been recognized by the Pennsylvania Newspaper Association and the Pennsylvania Associated Press Managing Editors for her journalism. She earned her Master of Fine Arts in Creative Writing from George Mason University, where she also taught Composition and Literature in the University's English Department and served as a nonfiction editor for *Phoebe: A Journal of Literature and Art*. Her nonfiction has appeared on the website *Culinate.com*.