a good and perfect gift

Faith, Expectations, and a Little Girl Named Penny

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BETHANY HOUSE PUBLISHERS
a division of Baker Publishing Group
Minneapolis, Minnesota

Published by Bethany House Publishers
11400 Hampshire Avenue South
Bloomington, Minnesota 55438
www.bethanyhouse.com

Bethany House Publishers is a division of
Baker Publishing Group, Grand Rapids, Michigan

Printed in the United States of America

Library of Congress Cataloging-in-Publication Data
Becker, Amy Julia.
A good and perfect gift : faith, expectations, and a little girl named Penny / Amy Julia Becker.
p. cm.
Summary: "A memoir of a young mom finding joy in her daughter with Down Syndrome, as she learns that unmet expectations can bring peace and freedom"—Provided by publisher.
ISBN 978-0-7642-0917-8 (pbk. : alk. paper)
1. Becker, Penelope Truesdell, 2005– 2. Becker, Amy Julia—Family. 3. Down syndrome—Patients—Biography. 4. Children with mental disabilities—United States—Biography. 5. Parents of children with disabilities—Biography. I. Title.
RJ506.D68B434 2011
618.92′8588420092—dc23 2011025204

Cover design by Greg Jackson, Thinkpen Design, Inc.
Cover photograph by Maria Jose Rivera/Trevillion Images

Author is represented by Foundry Literary & Media

Hope is the thing with feathers
That perches in the soul,
And sings the song without the words,
And never stops at all.
—Emily Dickinson

Every good and perfect gift is from above . . .
James 1:17

contents

author's note

The events in this book are true to life, although some details have been compressed. The names of individuals have been changed, with the exception of my immediate family and the Fords. Virginia is based primarily upon one brave friend. One day we were talking about this book, and she said, "I think you need to include the stupid things that people say. And I know I've said a lot of them, so I'll volunteer myself for the job." Some comments that Virginia makes, however, came from the lips of others, so her character has become a compilation of friends. Also, as I hope the story itself demonstrates, the "stupid" comments always occurred in the context of compassion and love, for which I am quite grateful.

Many thanks, therefore, to "Virginia" and to Mom and Dad, Kate, Brooks, and Elly, for your willingness to allow me to share parts of who you are. Thanks also for the support of friends from The Lawrenceville School, Westerly Road Church, and the Down Syndrome Association of Central New Jersey. Thanks to Matt Novenson, David Dicosimo, and Kevin Hector for offering your expertise on theological matters. Areta, once again I thank you for putting me through creative writing graduate school without needing to pay tuition.

To my agent, Chris Park, thanks for hanging in there with me and for your devotion to this project. To my editor, Andy McGuire, and the rest of the team at Bethany—I can't thank you enough for taking a risk with this book and for all your hard work and encouragement along the way. Thanks to Peter, for your tireless support as I wrote these words—both in journal form many years ago and in manuscript form more recently. And even greater thanks for your willingness to walk this road with me every step of the way.

I'm also grateful for all the other families out there with children with disabilities. Whether because of social stigma or as a result of physical suffering, countless parents and children have endured far greater hardship than we have. Your perseverance and love pioneered a way for us. Thank you.

Finally, thank you, Penny, for opening our eyes to a world of beauty, delight, and hope.

prologue

If only we had waited. If only I were due in the summer. Then I could have finished school. Then Peter would have three months free from teaching. Having this baby in June instead of January, that would make sense.

I jerked the car out of the parking lot and rested one hand on top of my round belly. As I drove past a little white church and a deli and a graveyard, I had a thought—and it was so powerful it was more like hearing than thinking—*But if you had waited, then you wouldn't have had* this *child*.

And all my objections ceased.

You wouldn't have had this *child*. . . .

PART
ONE

this child

I love the intimacy of feeling her kick and wriggle and push inside me. I love lying on my side pressed up against Peter and hearing him laugh whenever she moves and he can feel it on his thigh. I love that we are already loving her together.

From my journal, October 2005

1

"You didn't like dolls," my mother said. "You would put all your puzzles in a row in the playroom and dump their pieces onto the floor, then put them back together one by one."

She shook her head as she unloaded the dishwasher. Then she turned toward me with a smile. "The only word you said incorrectly was *raisins*. Those, for some reason, you called 'sha sha.' Otherwise, you wouldn't speak unless you could say the word properly."

I smiled, a little amused, a little self-conscious. Mom wiped her hands on a dish towel. Her curly brown hair was pulled back with two barrettes. Dressed in a Santa Claus sweater and snowflake earrings, she looked her part—preschool teacher, mother of four, grandmother-to-be.

It was the day after Christmas. I was helping put away the china and silver from dinner the night before, but I soon leaned against the hutch in her kitchen, my hand pressed against my lower back. My belly was a taut globe, an announcement to the world that our child would arrive any day now. Our child. Our daughter. Penny.

Mom stacked the plates and placed them on open shelves filled with holiday cheer in the form of elves, snowflakes, miniature sleighs, and jingle bells. She closed the top of the box that held the silver and tucked it under the counter. "I have a few different options for lunch," she said.

She poured chili into one pot and carrot-ginger soup into another as I stacked red bowls on the counter and retrieved the everyday silverware. "Anything else?"

She motioned toward the chairs. "I've got the rest. You sit down."

It all felt comfortable, familiar—the paper whites blooming in the window, the smell of another home-cooked meal, the kitchen drawer that needed repair, the skylights, the sight of Mom at work.

The house was filled with reminders of my childhood. The window ledge spanning the length of the dining room held a line of family photos—one from every Christmas since my birth. I could walk through my life, starting as an only child gazing with wonder at a tree full of lights. Then, with my baby sister Kate, wearing a "falalalala" dress that Mom had made of red corduroy with white letters. On down the line, with Brooks and Elly entering the family, and from there through the ruffles and taffeta of middle school to the long blond hair of high school to the black pants and sweater that had become my uniform as a young working woman. Still, through it all, I resembled the little girl Mom had described—the one who liked books more than toys, the one who always acted a little more grown-up than her age.

That evening we all gathered in the attic, a makeshift family room that remained unpainted and without heat, home to old dress-up clothes, rows of *National Geographic* magazines, an L-shaped couch, and a big-screen TV. Brooks and Elly shared a blanket. Kate curled up in a chair with a cup of hot chocolate. Mom and Dad sat side by side, their bodies not quite touching. I leaned against Peter, his hand resting on me, waiting for the sharp kicks and ripples that always came in the evening. It still seemed mysterious—that my body could join with his and form another person. That she would inherit my round cheeks or his dark hair or my grandfather's

chin. That she would be ours, and yet utterly herself all at the same time.

Brooks and Elly had decided we should watch some old home videos, but as they flipped through the choices, my mind lingered on the more immediate past, the preparations for new life among us. I had read a host of baby books and written thank-you notes for the dozens of presents we had already accumulated. We had attended a day-long session at the hospital for expectant parents. I learned techniques to breathe through pain, and a nurse walked us through the birthing process. We peeked inside one of the delivery rooms. I had already written all my final papers for graduate school, just in case she came early. And yet, despite the preparations, despite my body's insistence that a baby was coming, I couldn't believe we were going to be parents, I was going to be a mother. I squeezed Peter's hand when she kicked again.

Brooks and Elly agreed on a series of classics—first Brooks as a three-year-old making up a song for the camera: "Why do I have to live in this canoe?" Then Elly as a four-year-old newscaster reporting on the weather. Then the four of us, that same year, when I was thirteen, producing a video for Mom and Dad's twentieth wedding anniversary as we mimicked their daily routines. And then, there I was, two years old with bleach-blond hair and big green eyes, singing a college fight song. In the video it was summertime, and my mother was pregnant with Kate. Someone asked me when the new baby was coming. "In Octoder," I replied, and then corrected myself with a frown and a shake of the head. "In October."

Even at age two I had to get it exactly right. It had to be perfect.

Back at our own apartment a few nights later, I woke up with a stomachache. After two hours curled in a chair reading, I padded down the long hallway from the living room to our bedroom, shaking my head. I had seen my doctor

the day before, and I could still hear her words: "You aren't dilated at all. You haven't dropped. It will be another week or two at least."

I reached the bedroom and nudged Peter's shoulder. "I might be having contractions."

He rolled toward me and squinted into the light. "Really?"

"It's probably false labor," I said, trying to sound calm. I glanced at the clock. Six a.m. "But I want to get the nursery ready. Just in case."

He looked as if he were holding back a smile as he pushed himself up.

I shrugged, a little embarrassed that all I could think about were the tasks I wanted to accomplish. But then my torso tightened. I clenched my teeth and breathed through my nose. *False labor,* I told myself again. With the contraction over, I forced a smile. "Ready?"

Peter was a teacher and a housemaster in a boarding school, so we lived in an apartment within a dormitory of thirty high school boys, a century-old building of burgundy brick with copper gutters and a slate roof. The back of the apartment held two bedrooms that once had been the quarters for a cook and a maid. They were odd configurations with slanted walls and uneven ceilings. Penny's room backed up to ours. It held a double bed, a crib, a chair, and a changing table, but the walls were bare.

That morning I washed all the baby clothes. We hung pictures, mostly keepsakes from our own childhoods. The embroidered alphabet my mother made me as an infant. Peter's christening announcement. A painting of a teddy bear. Peter bounded from pushing the crib into the corner of the room to hammering another nail into the wall, as though he were playing an intense and thoroughly enjoyable tennis match. I moved more slowly, without his giddy energy. If I allowed myself to feel excited, then I would have to think about what lay ahead, the unknown intensity of labor and delivery. Excitement would soon give way to fear, so I kept my thoughts

focused on arranging pictures and starting another load of laundry until, every twenty minutes or so, the pain would arrive, and I'd clutch Peter's hand or press my palms against the cool plaster of the yellow wall and say to myself, as if it were a mantra, *False labor. False labor.*

It took about three hours to get the clothes washed and folded and to fill the walls of Penny's room. "I guess I should call the doctor," I said, once there was nothing left to do.

Another hour and three contractions later, we arrived at the hospital. Peter had showered and shaved, and I had pulled my hair back into a ponytail and put on a little makeup. Dr. Mayer examined me and said, "I can feel your baby's head. You're here to stay."

I wanted to laugh and cry all at once. My eyes met Peter's. He leaned over and kissed my belly, then gave me a lingering kiss on the lips. "I'll run home and pack our bags."

"And would you call my mom?" I asked as he headed for the door.

I found myself attended to by two nurses at once, my clothes in a heap and a hospital gown over my head and a strap around my middle to monitor the strength of the contractions along with Penny's heart rate. A prick in the vein on top of my hand and an IV dripping fluid into my bloodstream.

And then, just as abruptly, they were gone. I noticed my surroundings for the first time—a small, windowless rectangle with bare white walls. I vaguely remembered a nurse saying, "We'll get you your own room as soon as possible," and I realized another patient lay on the other side of a curtain. She spoke only Spanish, but as nurses came and went, I understood that she was in labor at twenty weeks gestation. She was carrying twins.

Every time a nurse came to her side, I wanted to call out, but the words wouldn't come. My situation—the rather mundane pain of labor—couldn't compare to the fear she must have been feeling for the lives of those babies. I lay still, and my contractions marched forward until they arrived every five

minutes. I watched the screen that measured their intensity and felt an odd sense of awe as the line shot to the top of the graph and held steady for sixty solid seconds. Pain smothered me. It took me an hour to muster the courage to say, "Excuse me? I'd like an epidural. Please."

It wasn't much longer until Peter returned. I caught a glimpse of him before we made eye contact, and I felt my shoulders relax knowing he was nearby. *After six years of marriage, he still makes me feel like a teenager*, I thought, as I took in his strong jawline and wavy black hair and broad shoulders. And now, even though I knew there was more pain to come, his presence steadied me.

They moved me into a private room—big and bright, with picture windows spanning the horizon. An anesthesiologist arrived to start the epidural, and soon it had numbed my body from the waist down. Now all I had to do was wait. Peter went about setting up speakers so we could listen to music. My mother and sisters arrived. They walked in quietly, but I could see the excitement on their faces. Kate's eyes sparkled. Elly looked as if she might laugh. Brooks clapped her hands together when she saw me, but then she stopped herself as if she needed permission to continue.

"Hello, everybody," I said, setting aside the most recent issue of *The New Yorker*. "No need to tiptoe. The epidural is working its magic. I can't feel a thing."

Kate let out a little cry. "I can't believe this is really happening!"

Mom gave me a quick kiss on the forehead and turned to greet Peter.

Brooks shimmied her shoulders, as if she might start dancing. The three of them crowded around the bed.

I said, "I'm so glad you can all be here."

"I'm glad you're early," Elly replied. "I would've been back at school if you'd waited until your due date."

I was seventeen days early—not enough to be considered premature, but enough to surprise us all.

"Okay," Brooks said. "Wait a minute. I still don't understand. How are you so calm right now?"

I pointed to the screen. "It's all about the epidural. When that line shoots to the top, it means I'm having another contraction. I just can't feel them anymore."

"I'd say you've been pretty calm all day," Peter said.

I told the family the story so far. Then they reviewed their afternoon—Peter's phone call, driving around town to find Mom on a walk with a friend, throwing clothes in bags and piling into the car.

"Dad's going to come tomorrow," Mom said.

I nodded, thinking that Dad wouldn't know what to do with himself through the hours of waiting. But Mom and my sisters seemed happy to be here now. The energy in the room was palpable, like the giddy anticipation of kids on Christmas morning.

We didn't have to wait long. About an hour after my family arrived, Dr. Mayer checked in again. "It's time to push," she said. "We're a little short-staffed, since this is a holiday weekend." She turned to my mother. "Mom, think you can help?"

Mom certainly had experience—four deliveries of her own, and one of those without a doctor present. He had walked in with my father, who had been away on a business trip, five minutes after Elly was born. Now Mom pushed up the sleeves of her white turtleneck and took her position holding my left leg. Peter, on the right, was my coach. He never stopped looking at me, and his voice held a mixture of gravitas and pride as he said again and again, "You can do this. Push."

But I couldn't figure it out. I couldn't feel anything. I was doing something wrong. I was failing. Failing. A monitor started to beep.

"The baby's heart rate is dropping," Dr. Mayer said. She turned to a nurse. "Page the neonatologist." And then she looked at me, equally stern. "When the next contraction comes, you have to push. You have got to get this baby out."

Somehow, my body knew what to do. With the next contraction, Dr. Mayer cheered. "You're on your way. Okay. Okay."

Two pushes later, Penny shot into the world. I caught a glimpse of her wriggling body and heard squawks from her little lungs. With a weary, delighted smile, I lay back. Peter held both sides of my face and choked out the words, "You did it. We did it. She's beautiful." He kissed me and held my hand tight.

"Eight out of ten on her Apgar," someone said.

I turned my head, following my daughter. The neonatologist had just arrived. Her presence seemed unnecessary now. She examined Penny and washed her off, wrapped her in a blanket, and placed her in my arms. Penny had a full head of black hair and pouty lips, and she opened her eyes just long enough for me to see that they were deep blue, the color of a lake on a cloudy day. And then she was gone.

It was all action and congratulations from there—Peter announcing the good news, my body starting to respond to the intensity of what it had just experienced, shaking, teeth chattering, my sisters exclaiming how cute Penny looked when they saw her through the glass walls of the nursery. We called my dad, his dad, his brother, a whole list of friends. Peter even called his boss so he could send an email to the rest of the faculty: Penelope Truesdell Becker, five pounds, five ounces, nineteen inches, born at 5:22 p.m. on December 30, 2005. Alleluia and Happy New Year!

Amidst the euphoria, amidst the doctor's report that Penny was a little cold and they would bring her in when she had warmed up, a nurse called Peter out of the room. In the back of my brain, a warning signal flashed. I was in the middle of giving directions for Mom and my sisters to get some dinner and was more attuned to my own body than anything else—this mushy midsection that hours before held a baby, these shaky limbs, the ache that began to creep into my back. My legs tingled. Adrenaline seeped out of my bloodstream, leaving me dazed, content.

When Peter returned, my eyes were drawn to a speck of blood on the collar of his red-and-white checked shirt. It took me a minute to realize the blood was mine. Only then did I notice that his eyes were brimming. He grasped my hand. "The doctors think Penny has Down syndrome."

I kept staring at that speck of blood, trying to differentiate it from the red of the shirt, wondering whether it would come out in the wash or whether it would be a permanent reminder of Penny's birth. That speck of blood.

Peter said, "Age?" using his nickname for me.

I shook my head. The only word that came to mind was *No*.

The lines in his face were soft and his tone was gentle, careful. "She has some of the features of a Down's baby, I guess. The doctors said they can come talk to you if you have any questions."

"Okay," I said with a nod.

The world began to break into pieces, as if I had been looking at a scene through a plate-glass window that suddenly cracked, jagged lines distorting my vision. I had a flash of anger—*How dare they talk to Peter without me?* And then a flash of concern—*Is Penny okay?* And soon they were standing there, the neonatologist, a woman with thin brown hair who never smiled, and the pediatrician, a round-faced man with sweaty palms. I thought, *They don't know what to say.* My voice clenched, but I didn't cry. I argued with them a little, as if I could convince them to take back their pronouncement. But I couldn't register their words, with their grim faces and somber tones. Whatever it was couldn't overcome the narrative inside my head. The lines that began with *No* and concluded with *I want to run away. Far away. Now.*

The day before, I had been reading about the tsunami that had devastated the island of Indonesia a year earlier. I read that before the wave hit, all the water had rushed out to sea, leaving a dry floor littered with fish. It must have been

an eerie calm, watching, waiting, wondering if the water would return.

After the doctors left the room, I felt like a woman standing on that beach. I didn't believe what was happening, and so I watched, as if it were someone else's life. As if the water would never come back. As if there weren't a tidal wave on its way.

They brought Penny into the room, swaddled tight, her head covered in a blue-and-pink striped hat. All we could see was her little round face. She felt so light as she gazed up at me with those big blue eyes. Her cheeks looked splotchy. When Peter held her, his long arms enveloped her body. He rocked her and stroked her cheek.

As I looked at them together, questions flooded my mind, stealing me from the sweetness of seeing Peter become a father. *How could this happen? What does this mean for her? Will I be able to be proud of her? Will I be able to love her?*

A nurse entered the room and handed me a pamphlet about breast-feeding. I scanned the page. "You may have difficulties," it read, "if your baby is more than three weeks early . . . If your baby weighs less than six pounds . . . If your baby has Down syndrome." It struck me as such a terrible introduction to nursing that I almost laughed out loud. But Penny nestled in and began to eat. It was awkward, and she kept falling asleep, and yet she latched on and sucked. She did it just right. The nurse said, "She's doing better than any other newborn I've seen today."

For the first time since Peter had told me the news, I smiled. And by the time Penny had finished nursing, I heard a whisper of peace. I sat there without words, without tears, looking at her and wondering what lay ahead. Earlier in the day, the epidural had numbed me from the waist down. Now, its effect worn off, I winced with the effort of trying to sit up. But my emotions seemed to have followed my body, as though an anesthesiologist had found a way into

my soul, temporarily protecting me from the fear and sadness and guilt.

I was still sitting there, calm and solemn, when my sisters and mother walked in. I had heard them in the hallway, the cheery cadences of their conversation wafting into the room. But they knew as soon as they saw us. And then the first tear trickled down my cheek. I tried to tell them, but I had to wave in Peter's direction. He said it again, "The doctors think Penny has Down syndrome."

Mom nodded, almost as if the news had confirmed a suspicion. Kate's eyes got big. Brooks jerked her head a little, as if she had been slapped. Elly looked at the floor.

"May I hold her?" Mom asked. With Penny in her arms, she said, "I knew something was wrong from the way the nurses were looking at each other after the delivery. They kept catching each other's eyes and trying to catch your doctor's eye, and they weren't smiling. And Penny's body didn't look like all of you when you were born. I wondered if she had dislocated her shoulder or something."

I thought back to Penny naked, her limbs splayed as they washed her after birth. I hadn't seen it then, but Mom was right. Her body had looked different from those classic images of newborns curled up tight, arms and legs pulled in.

"And they took her away so quickly," Mom said. Her voice held relief, as if she had been worried she would return to news far worse.

Again, I hadn't thought anything of the timing. I hadn't held Penny for long, but it hadn't struck me as odd. I just didn't know any better.

A nurse interrupted. "Penny's body temp is on the low side, and we need to run some more tests," she said, extending her arms.

Kate said, "But I haven't gotten to hold her yet."

"I'll bring her back as soon as we're done."

Silence settled upon us once Penny was gone until I said, "I need to call Dad."

"Do you want me to do it?" Peter asked.

I shook my head even though I didn't want to pick up the phone, to call him back, as though I were retracting the good news from a few hours ago.

It was the first time I said it out loud: "The doctors think Penny has Down syndrome."

"Oh," Dad said.

"But she seems healthy," I added.

"Good."

"See you tomorrow?"

"See you tomorrow."

When I had told my family I was pregnant, Dad had jumped up and down in the middle of our living room with exclamations of delight. I had never seen him so happy. "Nancy," he said to my mother, intertwining his fingers with hers, "we're going to be grandparents."

After I hung up the phone, a stone of fear dropped into my stomach. *What if our families don't love her?*

Mom went back to our apartment around ten o'clock, but my sisters waited two more hours until Penny was back in the room. They stroked her cheeks and rocked her and kissed her forehead. Aunt Kate. Aunt Brooks. Aunt Elly. I was the oldest child and the oldest grandchild. Penny was the first daughter, the first niece, the first granddaughter, the first great-granddaughter. And they all wanted to be with her, even though everything I thought we had known about her had been swept away.

By midnight I had been awake for almost twenty-four hours. My sisters said their good-byes. Penny nursed again, and Peter curled up to sleep in the fold-out cot next to my bed, his hand resting upon my thigh.

A nurse came in. She recorded my temperature and my blood pressure and asked about my pain. I handed Penny to her, and she turned to walk out of the room. Almost as an afterthought, she stepped toward me and said, "I had a special child, too."

I couldn't see her face in the dim light. I was lying down, on the edge of sleep.

"How old is your child now?" I asked.

Her tone stayed the same—even and soothing—when she said, "He died a long time ago."

I closed my eyes for a moment. I didn't want it to be true. I said, "I'm sorry."

She looked past me and shook her head, as if I didn't understand. Before she took her leave, she said, "He was a gift."

I am crying because of you. Because of joy and love that run deeper than any logical construction. Because of sorrow that you are not who I thought you would be.

You are beautiful. You are my daughter. We are delighted to meet you.

And yet I cry . . .

I don't want to cry over the birth of my daughter.

January 2006