

Love Stories

21 *for* 21

by Beverly Beckham

PREFACE

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If you don't count, you don't matter, as the saying goes. My research colleagues and I estimate that there are more than 215,000 people with Down syndrome in the United States and around 4.5 million in the world. We also expect that these numbers will continue to grow, thanks in large part to the advances in medicine and surgery that are helping people with Down syndrome live longer, healthier lives. Of course, this narrative is unfolding at the same time that prenatal testing for Down syndrome is expanding across the globe. Advances in genetic technology now enable expectant couples to learn about a Down syndrome diagnosis sooner and with greater accuracy. As a result of elective terminations in the United States, we estimate that in recent years there are 36% fewer babies with Down syndrome than could have been born. The numbers are even higher around the world: about 51% in Northern Europe, 66% in Australia, 71% in New Zealand, and 72% in Southern Europe. Spain tops the list with an annual reduction of 83%.

Against this backdrop, Beverly Beckham takes us on a journey with her granddaughter, Lucy Falcone. Lucy counts, and Lucy matters. From the moment Lucy was born through her young adulthood, Beverly has shared her family's spirited moments with readers of the *Boston*

Herald and the *Boston Globe*. Now, we all get to travel this path together with this published collection of her memorable pieces. Lucy has taught her family to laugh when they were inclined to cry, sing when they might have preferred to whisper, and hug when they were at a loss for words. Lucy is living a life with purpose, and now we get to learn her lessons, too.

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INTRODUCTION

For a long time after my granddaughter, Lucy, was born, I looked at healthy, typical babies with envy. They were everywhere — at the mall, at the playground, cooing, smiling, sitting up, playing patty-cake, walking, talking, meeting every developmental milestone right on time, their perfection a constant reminder of Lucy's imperfection.

That's how I saw my first grandchild. As less than perfect. That's how most everyone saw her. The doctors with their grim faces. The nurses with their strained smiles. Family, friends, all of us mourning who Lucy might have been.

Stereotypes take a long time to die. My head was full of them. I boomeranged back to images I'd seen as a child and articles I'd read, and I worried about Lucy's future and our future as a family. How could we live with fear and sadness and the unknown for the rest of our lives?

In 2003, when Lucy was born, MDSC's (Massachusetts Down Syndrome Congress) First Call program did not exist. No human being with real-life experience visited us and welcomed Lucy to the world, allaying our fears and offering us guidance and support. We had never even heard of MDSC, a community that would nurture and educate us. The Internet with its links to families like ours was in its infancy. The knowledge we sought, the guidance, the wisdom, the assurance that we were not alone? All these things would come in time but in 2003, our family was flying solo.

The beginning of everything is the hardest. When you have a child with Down syndrome or autism or cerebral palsy or muscular dystrophy or cystic fibrosis or any long-term challenge, the beginning is extra hard. Twenty years later I'm keenly aware that the journey has not been without challenges. But everyone has challenges. And what's different today from two decades ago is today there is community. And inclusion.

The doctor who told us Lucy had Down syndrome told us so many things Lucy would never do. He had a list. He didn't say a word about the people who would make a difference in her life. Or about the importance of love and friendship. Or about who she would grow to become because of love and friendship.

If I could go back in time I would tell the frightened me I was that everyone lives with the unknown, and that, yes, there would be challenges ahead, frustrations and brick walls, many starts and stops. But that the highs would trump the lows, the victories outshine the defeats, and, most importantly, Lucy would be loved, and not out of pity. Not because she has Down syndrome, but because of the person she would grow to be.

I would ignore every negative developmental assessment that grades and degrades people. How is your child doing? Is she happy? Is she going in the right direction? Is she doing better today than she did last month and last year? Does she have people who love her? These are the questions that assessment tests should ask.

This is what we didn't know when Lucy was born: That she would grow into her own, unique self. That she would be a girl who loves show tunes and fancy restaurants and theater and dance and curly hair and movies and books and getting dressed up and going out and toasting to life and hanging with family and friends because these are all the things she has been exposed to.

When Lucy was born, I mourned the child she might have been. I know now that if we had been given the child we imagined, we would not have Lucy.

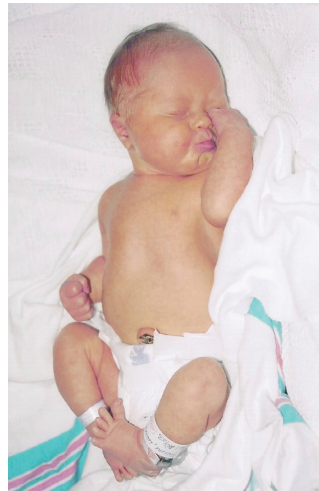
GRANDDAUGHTER'S A RARE GEM

July 2, 2003

I will have to apologize to her someday. I will have to tell my grandchild that I cried the day she was born.

Not immediately. Not when I first held her and she looked into my eyes and I looked into hers. There's a picture of this, Lucy, just minutes old, almost saying hello. I never shed a tear in her first 12 hours of her life when I thought she was USDA-approved top-of-the-line perfect Grade A baby girl. Then I was all smiles. I called my friends and said the baby has come. Lucy is here. Lucy is perfect - round cheeks, red lips, downy skin, blond hair, blue eyes.

We joked with her father, "Where are those Sicilian genes?" We hugged one another. We were so lucky. We got our miracle, we exclaimed. And there was no doubt that we had.



And then a doctor walked over to the bed where Lucy lay and he unwrapped her and inspected her. And he said the word test. And then he said Down syndrome.

We cried then. All of us. Instantly. Because what had been perfection just seconds before, what had been all joy and gladness and light, became, with two little words,

imperfection and fear.

Stupid, stupid us.

How will I tell Lucy that we wept while holding her? How will I explain that in those first few hours we looked at the gift God created just for us and wanted him to make it a better gift. To fix it. To make our little Lucy just like everyone else. There's been some mistake, God. This isn't what we prayed for.

But isn't it?

Give us a baby to love, we begged and we have her and what sweeter, better baby could there be?

People told us that it's only natural to grieve the loss of a dream. And that's what I like to think we did. We dreamed one Lucy, the perfect little girl - like Margaret walking with her mother, like Shiloh on stage in her toe shoes. In those first few hours it was this dream that tormented us. And it blinded us, too, because all we could see was what Lucy wouldn't be. Here she was, infinity in our arms, fresh from Heaven, in such a hurry to get to us that she arrived two weeks early. And we were judging her.

She left the angels to come here. She gave up paradise for us. And we cried.

Funny thing is she hardly cried. She opened her eyes and took us in, one at a time, and amazingly she didn't seem disappointed at all.

One in 800 babies is born with Down syndrome. The rarer the jewel, the more value it has. That's the way it works with things - with pearls and Lottery tickets and horses and art. But in our world and in our culture, we like our people to be all the same.

How will I tell her that I wanted her to be just like everyone else? That I was afraid of different when it's what's different that stands out? Are the black sand beaches in Hawaii sad because they're not soft and white? Do four-leaf clovers ache to be three? Does the life that grows above the tundra wish it were rooted in a valley instead?

The red rocks of Utah. Icebergs. The Lone Cypress. The Grand Canyon. And Lucy Rose.

We expected our life with Lucy to be lived on paved highways with well-marked signs, the rest stops never far from one another.

Lucy is taking us down a different road, a blue highway, instead. It's scary not knowing what's ahead. But no one, even on the wide smooth roads, knows the future.

We yearn for paradise. Lucy just came from there. She is heaven in our arms. We didn't see this with tears in our eyes. But we see it now.

STEP BY STEP - CHALLENGES MET

July 16, 2003

No one means to scare parents and grandparents and aunts and uncles. What they mean to do is inform, enlighten. The more you know, the better off you are, right?



Knowledge is power.

Except that sometimes it isn't.

My mother-in-law had a saying: "Wee steps and slow." She applied this philosophy to a pile of clothing needing to be ironed as well as to getting through a life-altering trauma, such as having her legs amputated. Wee steps and slow. Taken one day at a time, little by little, life - even when it's tougher than you could have imagined - is manageable.

When a baby is born, on time with no discernible problems, it's all about wee steps and slow. No one gathers around the bassinet and says, "Hmm. She's going to have at least six ear infections by the time she's a year old. And she's going to fall and hurt herself a dozen times. And childhood asthma is a possibility."

No one says to a baby's parents, "Oh, your heart will break when she leaves for first grade. And middle school? That's when your real problems begin. And just brace yourself for the teen years now."

And there will be a war and your daughter will have to fight in it.

And there will be a car accident and your daughter will be hurt.

You look at a newborn and all you see is a newborn. If you saw the future, you'd bolt. Babies are born small and cute for a reason. God is not dumb. But some of the smartest people are.

We have a new baby in our family: Lucy Rose, my daughter's daughter. She's not even seven pounds yet. She's not even four-weeks-old.

But her future is the subject of all kinds of books and medical dissertations. Lucy HAS Down syndrome. She IS NOT Down syndrome. She's just a baby who happens to have an extra chromosome. In most cases it's good to have an extra something in life. An extra tire in case one goes flat. An extra change of clothes in case you get rained on.

Already it's easy to see the extra good in her.

But we don't need to see her future. It's out there in the great unknown like everyone else's. It's not predictable. It's not a 13 percent chance of this and a 40 percent chance of that.

It's not even in the well-meaning, "Look at what so-and-so did. Look at him. Look at her. Look at what people with Down syndrome can do."

Look at Lucy Rose. That's what we want, people to see HER not as part of a group, but as part of our family. Sure, kids with Down syndrome have problems. But ALL people have problems.

My son stuttered. But his stutter didn't define him.

The future cannot be categorized or charted. There are thousands of young people in harm's way right now fighting a war that wasn't imagined when they were babies in their mothers' arms.

Wee steps and slow. One step at a time, you can make your way through anything. It's when you look up at the future that you lose your balance and can so easily lose your way.

FEAR'S VOICE IS LOUD

August 8, 2003

If my family were in the middle of nowhere, we would think we were happy. Plunk us on an island with no one else around and we would think it was Eden recreated.

That's how charmed we'd feel. That's how blessed.

Take away the doctors and diagnoses, the charts, the predictors, the lab work, the blood tests, the serious faces, the machines that see inside people and the people who see only the outside and we wouldn't know we had a care in the world. We would be picking coconuts and thanking God for Lucy Rose.

That's what we did for 12 hours. Sort of. We thanked God and said how lucky we are and how grateful. And happy? No parents and grandparents were happier.

And then came the doctor's words. And it was Paradise lost. But the words didn't change what was. Lucy was still Lucy, blond and blue-eyed and "wee." And we were still in love with her. And the world was still spinning on its axis.

And yet after the words, and since the words, and because of the words, we now see things differently.



Fear has done this. Fear and its long, dark shadows.

If there were a soundtrack accompanying my granddaughter's birth, it would have been full of high notes. Mozart on a tear. Mozart, whose music has spread light into all the dark corners of the world for centuries.

Then came the words "Down syndrome" - and because of them more words: electrocardiogram and VSD and PDA and blood flow and hypertension and heart surgery and "How much is she eating" and "How much does she weigh?" and "Is she laboring?" and "Is she tracking?" And every day there are tests and measurements, the soundtrack now bad organ music with too many chords off key.

Nothing has changed. Lucy is still Lucy, only in a little bigger size. Words are just words. And the operation she needs has been performed thousands of times.

But fear has a louder voice than reason.

Maybe this is what happened to Adam and Eve. Maybe it was fear that got the best of them, that made them look around and suddenly see Eden as a dangerous place. Animals that had been their friends they saw now as predators. The sun didn't just warm them, it burned them. Even the way they looked at one another was different. And worse was the way they looked at God. They were afraid. And so they hid.

What if they hadn't? What if mankind's big sin isn't

disobeying God but is not TRUSTING God? What if it was fear that separated Adam and Eve from Paradise and that now separates us all from God?

It is hard to trust when you're afraid of what's around the corner or who's on the phone and what the next person is going to say. It's hard to see Paradise when there's an operating room in the way. But it's easy when you're holding Lucy. That's when it's bliss. In the day-to-day things. In the now.

Nothing has changed. Lucy is still Lucy. Lucy has blond hair like her mother's and blue eyes and soft skin and rosebud lips that any day are going to turn up into a smile. She's teasing us. She's making us wait.

Throw away the words and she's just a baby.

Throw away the charts and the fear goes away.

Then there would be just Lucy. And Paradise regained.

FROM LUCY, A FULFILLING YEAR

June 18, 2004

It's one year later. One year after the ground caved in and the world blew apart and the center failed to hold. One year after we were told, "I'm sorry" so many times that we were sorry, too.



Three hundred and sixty-five days, some of them terrible. The day my granddaughter Lucy Rose was diagnosed with Down syndrome. The cold, rainy day she came home. The day the doctor said she needed heart surgery. The day of the surgery when the operation didn't go as planned. The days after, at the hospital, when we felt helpless at her side.

So many days at home, holding Lucy, begging, "Hang on, little girl. Don't leave us." Winter closing in, doors closing everywhere.

More surgery. More problems. Hope frayed.

Fifty days? 100?

We clung to each other - mother, father, grandmother, grandfather, aunt and uncle. It'll be OK, we said over and over. And when we didn't believe this anymore, friends came and took our hands and kept us from drowning in sorrow and fear.

We worried Lucy would die. We worried she would live and not know us, live and not respond, live and not see, not hear.

We worried about everything.

We still worry. But not the way we used to. We're standing on solid ground, for now anyway - and now is all any of us has.

Lucy is healthy and happy and is turning a year old Sunday. And we know, because of this year, just how lucky we are. We ask ourselves, why did they shake their heads when she was born? Why did they say "We're sorry" and not congratulations? Why, even now, do doctors say, "We have tests. This won't happen again," as if Lucy shouldn't have happened. As if they would erase her if they could.

Erase the heart problems. Erase the need for surgery. But don't erase Lucy.

Lucy is like a crayon Crayola has yet to invent. So many colors - burnt sienna, maize, mulberry, raw umber, razzle dazzle rose.

But no Lucy Rose. Because she is the color of wind. The color of moonbeams. The color of stars that are too far away to see.

She is rare and she is different and she is beautiful and bright and we have been blessed because she is ours.

Before she was born, I talked this prayer to her. "Throughout life you will be both a student and a teacher, for you have

much to learn and perhaps even more to teach.”

I imagined teaching her “Pat-a-cake” and “This Little Piggy” and the names of things. And I have done all this. What I never imagined is what she would teach me.

The children will lead you. And she has.

Lucy has led us through the toughest of times. The ground caved in, the world blew apart and the center failed to hold.

But Lucy endured. And grew stronger. And thrives. And because of family and friends, so do we.

We held her so much. Maybe that’s why some of her rubbed off on us, some of her joy, her good nature, her smile, her pluck.

When I was in second grade, Rosemary, the most popular girl in class, picked me to be her best friend. We walked arm in arm. We sang. She invited me to her house. We had fun all the time.

That’s how it is being with Lucy.

All children bring joy. Lucy brings something more. Maybe that’s because we came so close to losing her. “Eat, baby.” “Look at us.” “Say, Dada.” “Go to Mama.”

And she did.

And she does.

And life is good.

BABY STEPS CAME IN HER OWN TIME

May 28, 2006

Maybe I bought the book after Lucy was born, or maybe some well-intentioned someone gave it to me. I don't remember. But here it is, nearly three years later, still next to my bed.

Back then, I read it and lots of other books, looking for answers to questions. Lucy, my first grandchild, my oldest daughter's baby, was born with an extra chromosome. "We're sorry," people said when they heard. And we were too. Sorry and stunned and scared. "When Bad Things Happen to Good People" seemed an appropriate book to be reading at the time.



But I hold it in my hand now and think, bad things? Lucy wasn't a bad thing. It was bad that she had three holes in her heart, but we didn't know that when she was born. All we knew was that she had Down syndrome. And yet we were sad anyway.

What was wrong with us? Why all the worry and fear? And why, even now, do we still, sometimes, more times than we should, continue to worry and fear when Lucy isn't doing something that some chart says she should be doing? Why can't we just relax and let Lucy lead the way?

She has dark blond hair that curls at the ends and the prettiest almond-shaped blue eyes and the tiniest nose and rosy cheeks and a smile that we waited so long for that, even now, although she smiles all the time, it is still magic.

All babies are measured against charts. The average baby smiles at one month, rolls over at five months, walks at 13 months. Children with Down syndrome have charts, too. On them, in black and white, are the anticipated dates when the child you love is supposed to be crossing some milestone.

And you look at the charts and you worry every day when a child isn't on target. When the smile doesn't come when the chart says it should. When a first word isn't within first-word range. What do these things mean? That she will never smile? That she will never talk?

And then one day she does. She smiles and she talks and you wonder: Why were you worried?

I have been taking Lucy to church on Sunday mornings since she was 10 days old. People whose names I don't know enveloped her. And me. From the beginning. "What a beautiful baby. What's her name? Lucy? Hi, Lucy." They prayed for her when she had heart surgery. And they prayed for her when she had to have more heart surgery. "Look at how big she's getting. Look at her sitting up! And crawling! And standing!" They have been cheerleaders to her progress. And they have witnessed her wonder: She loves the church lights and the music and the man who collects the money.

Last Memorial Day weekend, her cousin Adam, who is 10 months younger, learned to walk. We were all in Maine and we watched him stand and take a step and grab on to a doll carriage and take more steps.

Amazing. Look at him. Look at him learn, we said.

Lucy sat on the floor and watched him, too.

Children with Down syndrome take a little longer to do things. The chart said she'd walk at 25 months. She was only 23 months. She had time.

But 25 months came and she didn't walk. And then she was two-and-a-half and still not walking. And even last month, two months shy of her third birthday, she wasn't really walking. She'd take a few steps, then sit down and scoot. "Come on, Lucy," we said, clapping and cheering. But standing upright and putting one foot in front of the other was clearly not on her agenda.

Last Sunday morning, she walked into church with me. I asked her, "Do you want to walk?" And she said, "Yes." So I unbuckled her seat belt and she took my hand, and there she was, walking along the sidewalk, walking up the cement walk, walking up the big steps, walking into the church, walking into the foyer, walking down the aisle, her pretty spring dress sashaying with every step.

And when she reached the pews, she sat down and clapped.

People told us, “Wait.” Wait till she does something you’ve had to wait for. Wait until she accomplishes something you worried about.

I held her hand again when it was time for Communion.

But on the way back she pulled away and continued on down the aisle, my little Lucy Rose, walking all by herself.

LUCY'S LEARNING. BUT ARE THE DOCTORS?

February 4, 2007

When I brush my granddaughter Lucy's hair and put it in a ponytail, I always kiss the back of her neck. And she giggles. She is three. She talks. She dances. She goes to school. She plays house and tea, and kick ball and follow the leader. She loves books and Bambi and church and playing with her cousin Adam.



Lucy has Down syndrome. She looks and acts more like a two-year-old than a three-year-old. But is this so awful? Don't we say, "Children grow up too fast"? Lucy isn't growing up too fast. She's taking her time.

She had heart surgery when she was two-months-old. It was awful, but she survived. And so did we. Hospitals are full of children with problems. Should children with medical problems be eliminated before they are born? Future screening tests may make this possible.

Imagine if doctors told parents all the things that could happen to their child. He might get cancer at one, or diabetes at two. Or asthma; it's rampant, you know. Or encephalitis. Or meningitis. She could lose her sight, her hearing, her ability to walk, to talk. He could have an

allergy and bite into a peanut butter sandwich and die at school one day.

Many parents would choose not to have children.

For decades, doctors frightened parents into believing that babies with Down syndrome were better off in institutions. They can't learn, doctors said. They'll ruin your life. Pretend you never had him. And because doctors knew best, many parents did.

Of course, now we know these doctors were wrong. They continue to be wrong. Now they're identifying babies with Down syndrome in the womb so that these children don't have to be born.

In December of 2006, the American College of Obstetricians and Gynecologists gave its imprimatur to a simple new test that screens for Down syndrome in the first trimester of pregnancy.

Down syndrome, also known as Trisomy 21, is a genetic condition in which an extra chromosome alters an individual's physical and mental development. Women 35 and older are routinely screened later in a pregnancy. But the screening has many false positives, so to be certain, women have amniocentesis. Some 85 percent abort when told that their baby has Down syndrome.

That's how frightened pregnant women are.

The new screening is a blood test combined with an

ultrasound, which measures the back of the fetal neck. Thickness there is a marker of Down syndrome. I kiss Lucy's neck and think of this.

Women abort babies with Down syndrome because they are afraid. They are afraid of mental retardation. They are afraid of stares and "We're sorrys." They're afraid their child won't go to a prom. They're afraid of everything. And too many medical professionals don't assuage that fear. They stoke it.

Most doctors are unduly negative when diagnosing Down syndrome. Two surveys of more than 1,000 mothers conducted by Dr. Brian Skotko of Children's Hospital and Boston Medical Center document this.* One mother told how her genetic counselor "showed a really pitiful video first of people with Down syndrome who were very low tone and lethargic-looking and then proceeded to tell us [in 1999] that our child would never be able to read, write, or count change." Information that is not only negative, but wrong.

People fear what they don't know. And people, doctors included, don't know enough about Down syndrome.

A little known book, "Gifts," is changing this. Subtitled "Mothers Reflect on How Children with Down Syndrome Enrich Their Lives," it is the work of 63 women who were afraid, too, before they brought their children home and loved them.

A collection of short essays, it could be called "If I knew

then what I know now.” It is affirming and honest. Every member of the American College of Obstetricians and Gynecologists should read it. Because doctors need to learn what these women know: that children with Down syndrome are just children, full of life and curiosity and wonder. Some may have health problems, but the problems are treatable. They grow at a slower pace, and statistically may have shorter life spans, but so what? They’re turtles, not hares. They’re in the race with everyone else, but they go at their own pace.

And they will get to the finish line in their own good time - if, and when, they are given the chance.

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NEVER SAY NEVER

April 15, 2007

“The tooth is missing. It will never come in. Missing teeth are common among children with Down syndrome,” the specialist told my daughter and son-in-law months ago.

He didn’t cushion his words. He didn’t say, “May not.” He said never.

And then last week, there it was – a lower right lateral incisor, next to her lower right central incisor, exactly where it belongs.

“Well, what do you know, Lucy Rose,” I said, standing all 35 inches of her in front of a mirror. “Look at what you have - a brand new, shiny, white tooth!”

I called my daughter at work. “I know,” she said. “I saw it this morning. Can you believe it?”

I can now. Because it is here in front of me. But I thought never, too. Because the specialist said. And once again, I believed someone I shouldn’t have, someone who doesn’t know Lucy.



She will never walk.

She will never go to college.

She will never have a full set of teeth.

When you have a child with special needs - with Down syndrome, with autism, with diabetes, with muscular dystrophy - with anything that's chronic and defies a cure - you hear "never" all the time. Doctors say it. Strangers think it. And it rubs off.

It's what we thought - Lucy's mom and dad, grandparents, aunts, uncles - in the beginning after Lucy was born and doctors and nurses looked at her, and us, with a "There, but for the grace of God, go I" in their eyes. It's a great misstatement, this phrase, a huge spiritual falsehood because it means that God withholds his grace from some people and bestows it on others.

This isn't true. God doesn't withhold grace. In fact it was through the grace of God that Lucy came to us.

Lucy, who is almost four now. Lucy with her new front tooth. Lucy who has surprised doctors and keeps surprising us.

She made a joke the other day. We were in the kitchen and the window was open and I said, "Listen to the birdie, LuLu," because something was crowing madly in the back yard. And Lucy, who has heard me tease a million times that a cow says oink and a pig says meow - (And then she corrects me, because she knows it's a game) - looked me straight in the eyes, shook her head and signed, "Mouse." Mouse. Not bird.

See how clever I am, Lucy was saying.

She is clever. And resourceful. Two days ago, she was trying to tell me something about a rainbow and was signing and saying “bow” over and over. But I wasn’t understanding. So I was guessing. “Cookie? Ball? Outside? Plane? I don’t know, Lucy. I’m sorry. I’m not getting it.”

And instead of screaming in frustration or giving up - she never gives up - she sat still for a moment. Then she hopped off the couch, walked over to the TV, opened the cabinet door, rifled through about a dozen DVDs, found the one with a rainbow on the front and handed it to me.

“Oh! Rainbow!” I yelled like a contestant on a game show who, through no skill of her own, wins first prize.

“Yes,” Lucy said. Then she hugged me and forgave me my incompetence and smiled.

Pre-natal tests target children like Lucy and doctors apologize when children like Lucy are born. Lucy is a child the world would choose not to have.

Foolish, foolish world.

She will never do all the things that typical kids do. That’s what the experts say. What they fail to mention is all that she will do.

I read this on a website recently and copied and pasted it in my journal. “Common characteristics observed in

[people with Down syndrome]: natural spontaneity, genuine warmth, penetrating clarity in relating to other people, gentleness, patience and tolerance, complete honesty, and the ability to engage in unfettered enjoyment of life's gifts."

I watch Lucy and her unfettered enjoyment of life's gifts. I watch and I learn from my first grandchild, who is life's gift to me.

VICTORIES COME SWEET AND SIMPLE

August 12, 2007

“The victories, when they come, will be sweet,” someone, many someones, told us after my granddaughter Lucy was born.

But we didn’t believe in victories then or that life would ever be sweet again. We were stunned and scared and grieving the child Lucy wasn’t. The words “Down syndrome” had rocked our world.



We should have listened to the people in the trenches, mothers and fathers and sisters and brothers, people who knew and loved someone with a disability who kept telling us: She will be fine. You will be fine. You will be better than fine. Wait. You’ll see. We’ve seen.

In the beginning it was milestones that made us hold our breath and when Lucy reached them, exhale. Victories? Not quite. Just markers on the progress chart, things to check off, to tell doctors and therapists: Yes, she can do that. But sweet, too. Definitely sweet.

If only Lucy would smile, we said. She should be smiling. Why isn’t she smiling? Peek-a-boo, Lucy. Tickle, tickle, tickle. We made funny faces. We stood on our heads. We did everything but hire a clown.

And she was only two months old.

I don't know when Lucy decided to grace us with her first grin, or why we didn't record it after obsessing about it for weeks. But I know she was laughing and smiling when she was only three months old because I pasted a picture of her in my journal and wrote. "Lucy was amazing in church today. She was wide-eyed and smiling."

And so Lucy smiled. And rolled over. And crawled. And cooed.

And still we fretted. We were so scared back then. Why isn't she sitting up by herself? Why isn't she standing? Cruising? Walking?

Walking took Lucy a long, long time.

We held out our arms to her. She sat and scooted to us. We placed her favorite toys out of her reach. She sat and scooted to them.

We said, "She'll walk when Adam walks." But Adam, her cousin, walked and then ran. As Lucy continued to scoot.

And then one day Lucy got up and walked. And that was it. She still scooted sometimes. But mostly she got where she was going one little step at a time.

We checked off another milestone on the progress report.

Her mother, my daughter, has been telling me for about

a month now that Lucy knows most of the words to her favorite songs. And that she can recite dialogue from “State Fair,” “Babe,” “Mary Poppins,” and “Cinderella.” “Sure,” I’ve said, smiling. “Sure.”

Children with Down syndrome have trouble talking, not because they don’t know the words, but because they have low muscle tone and their mouths are small. So forming the words and saying them correctly is hard. They understand but, especially when they’re young, they cannot always be understood. This happens with Lucy. Sometimes I know what she’s saying and sometimes I don’t.

I gave her a bath last week. It was a hot day and the bath was cool and a good place to linger. “Let’s sing,” I said. And we did.

And then she did, all by herself.

“Doe, a deer, a female deer. Ray, a drop of golden sun. Me, a name I call myself. Far, a long, long way to run,” she sang, amid bubbles and rubber turtles and ducks and my total amazement.

Lucy has my father’s beautiful green eyes but she also has his not quite so melodic voice. Let’s just say that even Julie Andrews wouldn’t have recognized the notes coming from Lucy’s mouth.

But the words?

The words were as clear as glass.

Lucy even sang the intro, *“Let’s start at the very beginning, a very good place to start.”* And the riff, *“When you know the notes to sing, you can sing most anything.”*

Let’s sing it again, I said when she finished. And she did. She sang it again and again, until the bubbles were gone. Lucy transformed by music, Lucy pretending to be Maria, singing not in a bathtub but in a meadow, under the sun.

The victories, when they come, will be sweet, people said. Sweet and simple and unexpectedly profound.

LEARNING LOVE FROM BABY GRACE

July 20, 2008

She wasn't the prettiest child in the room, because they were all the prettiest, babies still, not one of them over three, flawless skin, bright eyes, shy, sweet smiles. But my daughter and I were drawn to this particular baby because she reminded us of Lucy, my daughter's little girl, with her sweet round face and her light wispy hair and the thin pale line on her breastbone that told us she had had heart surgery, too.

"How old is she?" we asked her mother.

"Six months," the mother said, and we gushed and said something like, "So cute." And "Lucy is five now. Hard to believe."

"What's your baby's name?" my daughter asked.

The mother said Grace. And we echoed the word, which means blessing, and it hung in the air, a name so weighted with truth.

Then we sat down, my daughter and I on one side of the room, Grace and her mother on the other. And the speakers began their program.

This happened at the Seaport Hotel in Boston, where we



were attending the National Down Syndrome Congress. We had signed up for the “New Parent’s Survival Guide” not because we are new parents, though my daughter is new enough, but because we wanted to meet the two speakers.

Kathryn Lynard Soper lives in Utah, has seven children, and contributed to and edited the book. “Gifts - Mothers Reflect on How Children with Down Syndrome Enrich Their Lives.” Jennifer Graf Groneberg lives in Montana, has three children, and has just published “Road Map to Holland - How I Found My Way Through My Son’s First Two Years With Down Syndrome.” Both women have blogs. Both are prolific writers. And both have sons with Down syndrome.

When Soper’s son Thomas was born, there wasn’t a book for her to read that told her what she wanted to know. There were guides and charts and medical treatises and a few stories about choosing to have a child with Down syndrome, but not a single book in which mothers talked about their experiences, their feelings, their lives, and their children. Soper wrote about her life with Thomas in her blog, and hundreds of mothers wrote back. And, in time, hundreds of stories were shared.

Soper collected and organized them, added photos and got her book published and though the stories address fear and worry and preconceptions and misconceptions, the common denominator, which holds them together, is love.

That’s what no one tells you when you have a child who

is not perfect. That love changes everything. That love propels you from the bed to the cradle in the middle of the night. That love is why you sing even when you're bone tired. That love is what fills your heart with pride and your eyes with tears, sometimes many times. That love is the reason all parents, even parents whose kids have challenges that seem burdensome and overwhelming to everyone else, say with certainty, "I wouldn't trade my child for anyone else's." Love is what the tests can't measure.

When Lucy was born, "Gifts" and "Road Map to Holland" hadn't been published. Someone gave us "When Bad Things Happen to Good People." Someone meant well, but Lucy was never a bad thing.

Sometime in the middle of the 90-minute workshop, when Soper paused and asked for questions, Grace's mother raised her hand, stood up and thanked Soper for compiling her book. Then she went on to explain how this little collection of simple stories written by 63 ordinary women saved her baby Grace's life.

"We had a week to decide," she said. Her test had come back positive, the doctors were somber, the literature bleak. And every bit of life experience she and her husband had was limited to feeling sorry for and frightened by every disabled person they had seen but didn't know. "Gifts" took them beyond the stereotypes and showed them that "disabled" is a loaded and ommissive word with all the bad left in and all the good left out. "Road Map to Holland" does the same thing.

Two books of love stories. Two books that are already changing the way people think.

SMILES AND SONGS FOR HAPPY GRANDDAUGHTER

March 1, 2009

Five hours in a car. It's a long time for a five-year-old to be confined. But Lucy never complained. Not a tear. Not a tantrum. Not even a pout.

My granddaughter was happy, listening to Rodgers and Hammerstein's "Cinderella," (sung by Julie Andrews; the child has good taste) and singing along. She ate chicken fingers in a nice restaurant overlooking the water, then she was back in her car seat, singing again.

She and her mother and I were on our way home from New York City. We had taken her to see her 19-month-old cousin. We had been to parks and museums, bookstores, and toy stores. We had walked and shopped and eaten and played. And even when Lucy caught a cold and was all stuffy and sneezy on the day we had tickets to "Mary Poppins" she remained a trouper.

I was thinking about this, about what a great kid she is, when I walked into my house and read the cover of the Boston Globe Magazine, which had come while I was away: "Pregnancy and Down syndrome; the agonizing decisions." Lucy has Down syndrome, so I sat and read it. I wish I hadn't. Its



negativity made me question reality. Did I invent this perfect week with my grandchild? Lucy's smiles and her songs. Lucy reading books and running through Central Park, raising her glass of milk and saying "cheers." Lucy remembering to say "please" and "thank you" to every person who held a door or brought her food or handed her a ticket.

The article was about two families who were told that their unborn babies had a 1-in-6 chance of being born with Down syndrome. One couple continued the pregnancy, the other aborted. As background, the author, Dr. Adam Wolfberg, wrote that Down syndrome "results in mental retardation and often a host of medical problems." That prospective parents use early prenatal testing to identify a baby with the syndrome "so that they can prepare to raise a child who will have profound medical, cognitive, and behavioral challenges." And that a determination of Down syndrome is "like a lottery no one wants to win."

The words Wolfberg chose to use - profound, a host of medical problems, a lottery no one wants to win - stung not just because they make sweeping generalizations left over from a time when children with Down syndrome were excluded from the community, institutionalized, and not given the opportunity to learn and to thrive. But because, before Lucy, I would have believed them.

You see things one way when you're on the outside looking in. You see all the can'ts and all the problems. But when you're on the inside looking out?

All you see is a child.

Our family had hoped for a baby without extra challenges. Doesn't everyone? Isn't this why we say, "I don't care if it's a boy or a girl, as long as the baby is healthy." When Lucy was born, she wasn't healthy. She had holes in her heart. She needed surgery. And she had Down syndrome.

Negative words decimated us. In the beginning they're all you hear. You play them over and over in your head and you worry and watch and wait. And you miss so much that is good because you are a wreck anticipating disaster all the time.

And then you stop worrying. You stop projecting and imagining and you look at this child in your arms, whom the world deems inferior, and you think how wrong the world is. And how perfectly right she is.

Happy disposition. Big heart. Plain goodness. Kindness. Perseverance. Loyalty. Fun-loving. Musical talent. Contentment. These are the attributes people with Down syndrome share, said Dr. Jose Florez, Physician-in-Chief and Chair of the Department of Medicine at Massachusetts General Hospital in a speech he gave. Why aren't these words part of genetic counseling?

Lucy listens as Julie Andrews sings. "Impossible for a plain yellow pumpkin to become a golden carriage! Impossible for a plain country bumpkin and a prince to join in marriage!"

Then she belts out in her raspy child's voice what is true for Cinderella but even truer for all children like her. *"Impossible things are happening every day."*

COUNTING A LITTLE BLESSING

June 14, 2009

Blessed is a word I find myself saying a lot lately. How blessed I am. How blessed my family is. How blessed we are to have Lucy.

Six years ago, I didn't feel blessed. Lucy, my first grandchild, my daughter's child, was 12 hours old when we learned she had Down syndrome. We wept. Three days later, we were told she had holes in her heart and would need surgery. We took her home and fed her and held her and rocked her and sang to her. And we prayed.

Fear consumed us then. We worried about her health. Were her lips blue? Was she sweating from exertion or was the room too warm? We worried about her future. Would she walk? Would she talk? We worried about our future. Would the stress of all this worry pull our family apart?

Heart surgery. And we almost lost her. Then more heart surgery and, again, a crisis. Blessed? The word never crossed my mind.

Then slowly things got better.

If only life were like a book and you could peek ahead. Lucy turned six on Saturday. If only,



when she was new and we were scared, we could have had a glimpse of Lucy now.

When she was little, two, three, maybe even four, she used to practice talking in her room. Away from everyone, she would chatter, naming things, her stuffed animals, the toys in her room, the people in her books and in her life. Over and over, she'd say Mommy, Daddy, Adam, Mimi, cow, duck, cat, and every other word she knew.

She was quieter in front of people, shy until she got a word right.

It took time, but she got them right. This is Lucy. Give her time and she'll amaze you.

These are the things about her now that I never could have imagined then: that her favorite movie would be *Gone With the Wind*. That she would know all the characters, except Suellen. ("Who's that?" she asks every time Scarlett's sister appears on-screen. Poor Suellen — forgettable even to a child.)

That she would always race to the door to greet her mom and dad, dropping whatever it is she is doing to hug them, to tell them with her smile and her open arms — even if they've been gone just ten minutes — how glad she is to see them.

That she would love the "Peace be with you" moment in church. That she would say "peace," reach for hand after hand, look into a stranger's eyes and smile. And that even the most reluctant handshaker would smile back.

And that she would love our neighbor Al, and seek him out in his yard, in his house, in my house. “Al! Al!” Katherine, his wife, the one who makes her favorite cookies, but Al the one who has her heart.

It’s not all roses of course, with Lucy. She doesn’t understand that the street is dangerous and that you can’t sit down when you’re an outfielder and that the DVD player sometimes sticks and whining doesn’t unstick it. In these ways she is a lot like a typical six-year-old. But she is not typical.

It takes her longer to learn and longer to understand. But when she does? It’s like the circus has come to town. She says a whole sentence “I want to have a banana, please.” She puts together a puzzle. She matches colors and shapes. She climbs to the top of the slide, sits, and glides down. She stands at the window and reenacts a scene from *The Little Princess*. The Flying Wallendas doing headstands on a tightrope couldn’t thrill us more.

Sometimes when I watch children her age do things effortlessly, my heart aches a little. But then Lucy will saunter by, climb on my lap, or say “hi” and keep on walking, and I will be bowled over by her presence, by the amazing gift of her.

How blessed I am. How lucky to be loving her. And how easy she is to love.

SEEN THROUGH LOVING EYES

September 20, 2009

My granddaughter Lucy is six-years-old and is part of a class of people that is quietly being eliminated in my country. She has Down syndrome, a genetic condition that frightens so many women that the majority of those who learn they are carrying babies with it choose to abort.



Dr. Brian Skotko* suspects the number of terminations will rise.

Prenatal tests like amniocentesis, are invasive, carry a risk to the fetus, and are given in the second trimester, so many women choose not to have them. But a simple new and non-invasive blood test, to be given early in a woman's pregnancy, might change all this. "As new tests become available, will babies with Down syndrome slowly disappear?" Skotko ponders in a soon-to-be-published article in the Archives of Disease in Childhood, (a British medical journal) available online now.

It's easy to understand why parents fear a diagnosis of Down syndrome. You Google definitions of it, and even now archaic words and misinformation pop up. It's the same in doctors' offices. Pregnant women are told only the negatives. Old stereotypes linger.

My granddaughter cannot do all the things that typical kids

can. She doesn't come home from school full of stories. They may be in her head, but we can't see in there. She speaks and sometimes we don't understand. She can't make a teddy bear with paper and glue, not without help. She can't understand why her grandfather would rather watch baseball than Shirley Temple. She does not have the same skills and abilities that her five-year-old cousin Adam has.

But Adam doesn't have the skills and abilities she has. He doesn't always enter a room and greet everyone with a big smile. He doesn't always leap to his feet and race to his father when he comes home from work. He can't sit for hours in a fancy restaurant or through a long movie. And he doesn't know instinctively when someone is sad and needs a hug.

He can field a ball and she can work a room. He sings a whole John Denver song, and she sits and applauds. This is what doctors don't tell mothers having babies with Down syndrome, that you will see in your child amazing things that you won't see in ordinary children.

Of course, parents want healthy kids. And some get them. But children get sick. They get in accidents. They lose limbs. They suddenly stop talking one day.

Children in wheelchairs, on ventilators and crutches? Children hooked up to IVs getting chemotherapy? People on waiting lists for transplants? People with chronic diseases. Soldiers changed by war. Civilians changed by an accident.

They weren't born this way. But if there were a test that showed their future - that showed diabetes and cancer and autism and muscular dystrophy and mental illness and depression and alcoholism - would women take it? And seeing what would be, would they choose to abort?

Last week we took Lucy to Davis' Farmland in Sterling, where we played with the animals. Then we went to a wine tasting at Nashoba Valley, where Lucy drank juice and shared our cheese and crackers and enjoyed the day.

All kids with Down syndrome are not like this. But this is Lucy. She makes me notice the ordinariness of people who don't have it.

In the play "Cabaret," set in Berlin as the Nazis rise to power, a man loves a woman he's not supposed to because he's Christian and she's Jewish. He tries to explain his love to his friends. And because "Cabaret" is a musical, his explanation is a song.

"If you could see her through my eyes, you wouldn't wonder at all. If you could see her through my eyes, I guarantee you would fall, like I did. . ."

Like I did. Like Lucy's mother and father did. Like all the people who know Lucy and people like her did. Like the world would, too, if only given the chance.

**At the time this column was written, Dr. Brian Skotko was a genetics fellow at Boston's Children's Hospital. He is now, in 2024, Emma Campbell Endowed Chair on Down Syndrome, Massachusetts General Hospital, Associate Professor, Harvard Medical School.*

A GIRL WHO'S RIGHT WHERE SHE BELONGS

April 10, 2011

Sometimes I think it's as simple as this: Lucy was born on the wrong planet. There was a mix-up in Paradise and she got on the wrong shuttle and ended up here on Earth instead of in some galaxy a trillion miles away where everyone is like her.

Because in the world she was meant for, Lucy is perfect. Perfect size. Perfect student. Perfect child. She lands in the middle of every performance chart that doctors and schools so revere. She reaches all her milestones exactly when her peers do. She smiles and rolls over and crawls and talks and walks right on schedule.



In the world she was meant for, she remains on schedule. She climbs as high as everyone else on the jungle gym, runs as fast, plays as hard. In class she knows as much as the boy in front of her and is a little bit better at sequencing than the girl beside her. At lunch, she talks to the kids across the table and they talk back. She gets invited to playdates all the time, has lots of friends, sings and dances, and plays along with everyone else. And every afternoon when she comes home from school, her mother holds up her artwork and spelling and arithmetic papers and smiles.

In the world she was meant for, even strangers look at Lucy and think, I wish I had a little girl just like her, because in the world she was meant for, Lucy epitomizes childhood. But by some geographical glitch she landed here on Earth instead of in the place where she would shine. She landed in the hinterlands of evolution, where innocence is meant to be grown out of and where the tongue does all the talking, not the heart.

On the afternoons I pick up Lucy from first grade, I watch all the children racing across the school yard, yelling and whooping and smiling, so many children, all the same. And then comes Lucy, holding her aide's hand, taking it slow, beaming when she sees me.

And I think, if we were the only family on Earth, we wouldn't know that Lucy should be adding and subtracting and reading chapter books and running across a school yard eager to go home and play Wii. We wouldn't equate Down syndrome with limitations. We would instead think, isn't she amazing? Look at how she loves us. Look at how happy she is.

Lucy needs extra help with things. She depends on extra help because it takes her longer to learn what typical kids pick up without trying: How to clap in rhythm. How to pump on a swing. How to say a whole sentence. How to add and subtract. How to write her name.

But she tries and she tries and she tries and she tries. And when she gets it right, she is all joy.

Here on planet Earth, we all depend on wheels. We don't have wings. We can't fly. This is our disability. We accommodate this disability by using bikes and cars and trains and planes and, yes, these are clumsy, cumbersome things and, yes, we'd get places a lot faster if we could just spread our wings and fly. But we don't beat ourselves up over this. We don't think of ourselves as imperfect because we can't take flight.

But we would if everyone else could fly.

Lucy cries when someone else cries. A child she doesn't know starts bawling on the playground and Lucy's lip quivers and the next thing you know she is crying, too. But soundlessly. This is Lucy's heart talking.

Was she sent here by mistake? Is she on the wrong planet? Or did she one day gaze out at the universe and see us here, on this flawed, messed-up earth, and think, this is where I want to be. This is where I choose to be, with that family. With this mother and that father. In that little room with the tilted ceiling.

Because this is where I am wanted. Because this is where I'll be loved.

WHO WOULDN'T WANT THIS CHILD?

JUNE 4, 2012

She was born nine years ago on June 20, and it was the best of times and the worst of times.

Lucy's being here was what we had prayed for, what we had begged for. But not exactly. Because she was not the child we had imagined.



At first she was. Ten fingers, ten toes. Blond hair. Blue eyes. "Isn't she perfect, Mom?" my daughter said, cradling her new daughter. She is, I agreed. We were all smiles.

It was the best of times. My daughter was happy. Life was good.

Minutes later, everything changed. Trisomy 21, a doctor said. Down syndrome. And Paradise was lost.

We had been in the Garden of Eden a mere 12 hours. Now we were in deep woods imagining quicksand and quagmires and animals ready to attack, our joy obliterated by fear. Where do we go? What do we do? How do we get out of here? though not a single thing had changed.

But we had changed. We now saw with different eyes. We saw what we were told to see.

This was the worst of times.

Nobody picked up Lucy and said, “Look at the miracle she is. Look at those fingers and toes. See how she stares at you. Watch how she kicks and coos. She will be fine. Your family will be fine.”

Nobody knew what to say. Friends hugged us. Nurses looked at us with sad eyes. The doctor unswaddled Lucy’s blanket and pointed out the space between her big toe and her other toes, the single line on her palm, the skin folds near her eyes. All indicative of Down syndrome, he said.

And where we had seen only perfection minutes before, we now saw only flaws.

People with Down syndrome have low muscle tone, heart problems, hearing problems, digestive problems, and a higher incidence of childhood leukemia, he continued. When he finally left the room, we cried.

Lucy did have heart problems. When she was two months old, she had surgery. Two months later, she was back in the hospital.

She had a rough start.

There have been other rough patches, not medically, yet hard, still, very hard, because it isn’t easy being different. It takes Lucy a long time to learn. Her cousin, Charlotte, mastered doing a cartwheel last week in just one hour. It will take Lucy lots of hours.

But she will do it.

She's been singing "It's a Hard Knock Life" since she was four. This year she sang it in a drama class. Last week she sang and acted it out on a stage with a group of children at a packed recital.

Lucy does what she sets her mind on doing.

It's hard to watch her work so hard at things that most kids learn by osmosis. But she plugs along, trying and trying, and succeeds just when we're about ready to give up, when we think she is never going to sip from this cup, say a full sentence, engage in a real conversation.

And then she does.

Lucy wakes up smiling every day. She always has. On long car trips, she sings away the miles. She knows when someone needs a hug. And when someone cries, she cries, too. If a child falls at a playground and wails in pain, Lucy sobs whether the child is a friend or a stranger. She is pure empathy.

Who wouldn't want a child like this?

Nine years ago, we shed a lot of tears worrying about the future. Now it is that future. And it is not a deep, dark, scary woods. Not always, anyway. Sometimes it's pink balloons and pink plates and pink napkins and a pink tablecloth and even pink frosting because it's Lucy's birthday and Lucy wants pink.

Everybody's life has challenges. Lucy's has a few more. But what Lucy's life is is not a tragedy. What Lucy's life is is not a burden. What Lucy's life is is not what we were led to believe it would be: sad and joyless and not worth living.

Her life is full of joy. Lucy is a happy child. She makes our lives worth living.

She is not the child we imagined. Nine years ago we cried over this. Sometime we still cry. But not because Lucy isn't who we want. She is exactly who we want.

We cry because Lucy is sweet and good and imaginative and kind and funny and caring, and so much of the world doesn't see any of this. It sees only a little girl with Down syndrome. We cry now, not because of Lucy, but because of the world.

CAMERA CAN'T CAPTURE INNER REALITIES

January 27, 2013

The pictures are ordinary. There's Lucy in front of Cinderella's castle. There's Lucy on the Dumbo ride. There's Lucy standing next to Prince Charming.

These are shots that everyone takes. "Stop. Look at me. Say 'cheese!' "

Even the best of the photos, the candid, the ones where she isn't posing, where she is laughing, clapping, gazing up in wonder, where she is dancing, swimming, running, eating a chocolate doughnut, don't begin to capture all that was.



Lucy is my granddaughter and she is nine and has Down syndrome. Last week a friend and I took her to Orlando and to Disney's Magic Kingdom. And it was magic, every minute of it. We took hundreds of pictures that should show this. But none does. Just like the fairy dust that a cast member sprinkled on us the first day, the magic was temporary. Walk away, leave the park, get on a plane, go home. And it's gone. Illusion. Sleight of hand. Was that all it was? If what we saw is not in the pictures, does it not exist?

Back here in the world far away from the Magic Kingdom, Lucy's days consist of school and little children talking to each other and playing games, third-grade games, that are challenges for Lucy. Every day in the world far away from the Magic Kingdom, there are constant reminders of all that Lucy cannot do.

Walt Disney World was the other side of the coin.

Lucy was the model child there, the one all parents would beg for. The child bedazzled by everything. The child who loved every ride, every character, every parade, every hamburger and chicken finger and ice cream, never mind whether it was vanilla or chocolate or in a cone or in a cup.

Lucy never went into a store and pouted because she couldn't have something. She looked at all princess dresses and shoes and crowns and gloves and magic wands and princess dolls and gasped and said they were beautiful. But she left them there and went on to the next store and the next and the next, eventually choosing just a necklace.

Lucy didn't want to get her hair done at the Bibbidi Bobbidi Boutique. "No thank you," she said. But she walked around and told all the little girls who were getting their hair styled how pretty they looked.

She wanted to do the hula hoop like everyone else, but didn't have a meltdown when she couldn't figure out how. She tried for a while, then handed the hoop to another girl. She didn't throw a fit when we told her the line was too

long at “Enchanted Tales with Belle” and that we would go on “Ariel’s Undersea Adventure” instead. She said, “OK,” and away we went. And she didn’t complain, not even once, when we told her at the end of each day that it was time to go.

Most kids say, “But I want to sit here!” or “I want to go first” or “I want to sit on this horse, not that one.”

Not Lucy.

To an elderly woman in a wheelchair, she asked, “What happened, Grandma? Are you all right?” To a boy who was crying, she said, “It’s OK.” And to me as I screamed on the “Tower of Terror,” she took my hand and said, “Don’t be scared, Mimi.”

“I wouldn’t change a hair on her head,” I heard a mother of a child with Down syndrome say when Lucy was four or five. And I thought, back then, I would. I would take away her Down syndrome in an instant because it would make Lucy’s life easier.

But what I’ve learned is this isn’t true. It would make our lives easier her parents’ and family’s and teachers’. But Lucy is fine with her life. It’s not without problems, but whose life is? Lucy is who she is because she has Down syndrome. Taking it away would change her. Her spirit, her love of people, her innate, unselfish goodness. They’re on that extra chromosome. Not illusion, not sleight of hand, not things a camera can capture, but real.

WOULD A CURE CHANGE THE LOVE?

August 4, 2013

It was the middle of the heat wave and we were inside sitting on the floor, Lucy using my iPad, looking at Disney characters on YouTube. “Not that. Not that. Not that. This one, Mimi!”



Then she clicked and Mulan sang.

*“Who is that girl I see
Staring straight back at me?
When will my reflection show
Who I am inside?”*

Then she clicked on “Pocahontas.”
*“You think the only people who are people
Are the people who look and think like you.
But if you walk the footsteps of a stranger
You’ll learn things you never knew you never knew.”*

Then she chose a clip from the Disney movie “Tarzan.” A mother ape walks out of the woods holding a human baby and the other apes gasp and the dialogue went like this: *“Freaky looking.”*

“What the heck is it anyway?”

“He’s a baby,” the mother explained. And the other apes looked again and said, *“You know*

he's not so bad, once you get used to him."

And I looked at Lucy and thought, as I have since the day my granddaughter was born, there is so much going on inside this child.

She turned 10 in June. Double digits. "You're a big girl now," we told her. And she is.

But she is not like most girls her age.

Lucy has Down syndrome and that makes her different. She was born with an extra chromosome that's in each cell of her body. We human beings have 100 trillion cells. With that one extra chromosome present in all those cells, there's a lot more substance to Lucy than to most people.

But substance is not what people see.

Lucy was born with a heart problem that required surgery. People saw this. She walked and talked later than typical kids. They saw this, too. She has trouble forming sentences. She has to work hard to speak clearly. She has low muscle tone. And she is intellectually delayed. These are the things that most people see.

Her essence?

Lucy wanting me to hear words that have meaning to her. Lucy, knowing when someone needs a hug. Lucy, walking up to an elderly woman in a wheelchair, leaning close and asking, "Are you OK, Grandma?"
People don't see these things.

When Mason, my goddaughter's son, was born in the spring, Lucy, her mom, and I raced to the hospital to meet him. Lucy took off her shoes and climbed onto the bed and plunked herself between Sarah and her husband, Kyle. And draping one arm over Sarah's shoulder and the other over Kyle's she declared with a huge smile, "My family."

Lucy knows things.

Her extra chromosome gets a rap for all of her disabilities. But could it be responsible for this, too, for her ability to love and empathize, for her insight, her honesty, and her genuine goodness?

Last month, Jeanne Lawrence, a researcher at University of Massachusetts Medical School, wrote in the science journal *Nature* that she and her team had figured out a way to switch off the extra chromosome linked to Down syndrome in human cells in a laboratory. This is a huge discovery, a potential cure for Down syndrome. But what does cure mean? What more, besides medical and intellectual issues, is that one extra chromosome responsible for?

Lucy tries so hard. When she was a baby, we would watch her practicing her words, holding her toy mirror and studying the shape of her mouth. She still practices words and phrases. "How are you?" "May I please have?" Is this Down syndrome? Or did she get this doggedness from my father? He couldn't spell. But he never stopped trying. Lucy likes musicals and show tunes. Is this Down syndrome? Or does she like them because her mother

and aunt and I do?

The other day she sang a duet with me. She was brushing her teeth and I was beside her and she put down her toothbrush, brought her head close to mine, and grinning in the mirror, began.

*“Together at last. Together forever.
We’re tying a knot, they never can sever!
I don’t need sunshine now, to turn my skies to blue.
I don’t need anything but you!”*

Is this Down syndrome? Maybe. Maybe not. But if it is, why would we ever want to change it?

LEARNING TO APPRECIATE THE MOMENT

January 18, 2015

There is such joy in Lucy. I don't always see it. Sometimes I'm too focused on improving her, reminding her to stand up straight, to look a person in the eye when she's saying hello and goodbye, to slow down her words when she talks. "Can you say that again, Lucy?" "Where are your shoes?" "Did you brush your teeth?" "Do you have your seat belt buckled?" Always on her case but for her own good, right?

Lucy, my first-born grandchild, is 11. I worried so about her when she was born. I still do. She has Down syndrome. There are plenty of reasons for worry.

But I worry about my other grandkids, too. You love someone and you want to protect them. And you can't. So you worry.

In the beginning, I worried most about Lucy's health. She had a heart problem. That colored everything. But I worried, too, about her life. What would it be like? Would she have friends? Would she go to school? Would she be happy? She was a brand new, pure soul in my arms, and I was worried about the whole rest of her life. I wish I had stayed in the moment and focused on the sheer wonder of her.



Lucy is in the fifth grade at the John F. Kennedy School in Canton now. In a typical classroom with typical kids. She has an aide, and the classwork is modified for her. But there she is, with all the other fifth-graders, at her desk, out on the playground, in the lunchroom, in the gym.

All of Canton's elementary schools had their annual winter concerts last week. I went to the Hansen School concert Monday morning for my grandsons, Adam and Matt, and to the Kennedy school concert Tuesday morning, for Lucy. I'm a sucker for little kids standing up on a stage doing anything. But dress them up in white shirts and black pants, comb their hair, give them a few songs to sing, add a music teacher plunking out some notes on a piano, and it's the Ziegfeld Follies to me.

Fifth grade. The toothless grins are gone, replaced with teeth now that are a little too big for children who have yet to grow into them. Some wear braces to keep these teeth in place and when they open their mouths to sing, their braces sparkle.

The children stand in place, too, braced by age, habit, a budding maturity? There's less fidgeting this year, a reserve to them that wasn't there in first or second grade or even last year.

You can almost see, in the tilt of their heads, in their frowns, in the way they smile, a glimpse of the adults they will be. I watch Lucy singing and smiling, keeping beat to the rhythm of the music, standing in the front row next to her friends and her classmates, part of it all, just another kid up on a school stage.

And I am so grateful for the moment, grateful that she was born in this country, at this time, into a culture that not only accepts her but nurtures her. Grateful for all the people who have come into our lives because of her. Grateful for her teachers in and out of school, who go the extra mile for her, who include her and applaud her and love her. Grateful that there she is up on the stage with all the other fifth-graders, singing and smiling.

It's such an ordinary thing, a school concert. Except when it isn't. Children like Lucy were denied this for so long. I watched my granddaughter sing. I watched her spy me in the audience and wave.

And as I waved back, I had to try not to cry.

LEARNING TO LOOK A LITTLE DEEPER

September 24, 2017

‘You plant black-eyed peas, that’s what you git,’ my daughter’s friend says in an Oklahoma drawl she exaggerates whenever she wants to make a point. I laughed when I first heard this phrase some 20 years ago, but it’s a saying our family quickly adopted.



I found myself thinking these words while listening to my granddaughter Lucy belt out the score from “Gypsy” on our drive home from seeing the play last week.

Fourteen years ago when my granddaughter was born, we were certain there were no black-eyed peas in store for us, no family traits that would be passed on to her. We believed that Lucy would not resemble any of us in any way because she was born with Down syndrome.

We knew so little about Down syndrome back then. We were ambushed. Unprepared. People said, “Sorry.” Friends said it with their words. Strangers said it with their eyes. We said it with our tears.

We were scared and worried and ignorant.

Someone gave us the book “When Bad Things Happen to

Good People” and we didn’t howl and say, “Lucy isn’t a bad thing!” What did we know? Everything seemed bad. What she had was bad. What we were going through was bad. Jump ahead, and the future looked bad.

“You plant black-eyed peas, that’s what you git.” Not one person said this to us.

Who is Lucy today? She is a black-eyed pea. She’s a girl who loves musicals because her mother loves musicals. “Gypsy,” “Grease,” “Hairspray,” “Hamilton,” “Annie” — she knows every score. She’s a girl who loves movies, not just the ones made for kids, but adult movies, too: “The Goodbye Girl” and “Gone with the Wind” and “The Way We Were,” because her mother loves movies. She’s a girl who binge-watches “The Miracle Worker” because she learned about Helen Keller at school. She’s a girl who loves books because we all love books and we read them to her and read them to her still. Her hair curls on humid days just like her mother’s. And on days when her mother’s not in earshot, she listens with her father to opera because he loves opera.

Because her parents take her to fancy restaurants, she likes oysters. “Want to try this?” they ask, and she always says yes. She’s not afraid to try new things. She also tries very hard. She’s like her father in that way, too. She never gives up.

We were at a party last month. There was a ring-and-hook game. It’s a game that requires patience. Attached to a long string is a ring that, to win, has to land on the hook.

Think ring toss at a carnival, only much more difficult. Everyone was playing it, cursing and laughing.

Lucy tried again and again and again. She realigned. Gave it her best. Kept missing. Kept trying. And when she got it? When the ring landed on the hook? She whooped with joy. She whooped for everyone else, too. She always does. She is empathy incarnate. Someone cries and she cries. A friend falls and twists an ankle at cheerleading and Lucy limps off the field with her.

Lucy's 10-year-old cousin, Charlotte, sang the national anthem at a fund-raiser last Sunday. Charlotte has a beautiful voice. Lucy stood next to me as Charlotte sang, and I watched her watch her cousin without a molecule of envy, with only pure love.

No one ever said to her mother or father when Lucy was born, "I promise you that someday your daughter is going to dazzle you by simply being who she is." But this is what I would say to someone whose baby isn't Grade A perfect: You will be proud. Your child will dazzle you. One day, when you least expect, you will feel your heart stretch. And you will discover within yourself, a kind of love you never knew you had.

LOVED BY FAMILY AND FRIENDS

July 1, 2018

I wasn't there. Only the parents had tickets. Schools aren't big enough to accommodate all the grandparents and aunts and uncles and friends who would like to be present at an eighth-grade graduation. So we get pictures and sound bites and video clips instead, which is almost like being there.

The video clip of Lucy, my just-turned 15-year-old granddaughter, walking across the makeshift stage in the gym of the Galvin Middle School in Canton two weeks ago, is a gift. My husband and I have watched it a dozen times and every time it brings us both to tears.

There's Lucy in line waiting for her name to be called. There she is accepting her diploma. And there she is walking to her seat, applause propelling her, applause that goes on and on and on. Students. Teachers. Other children's parents hoot and whistle. And those sounds, all that affirmation and affection, fill us with joy.



School is not easy for Lucy. She has Down syndrome. Nothing is easy for Lucy. But her life is her life and she loves it. She loves her little room with its slanted ceiling and her big bed with its down comforter.

She loves the beads she picks out and wears every day. She loves her iPad and the swing in her backyard. She loves her parents, who take her to fancy restaurants and movies and almost everywhere they go. She loves her grandparents, her cousins and her aunts and uncles and teachers and friends. Lucy loves. And she is loved. And isn't that everything?

That's what the applause assures us.

When she was born, a doctor told us all the things that Lucy would never do. And then he told us all the bad things that statistically might happen, could happen. He never mentioned that she would, every day of her life, in some way, change people's hearts.

She opens hearts. I've seen it. I've watched hearts grow because of her. I've seen wariness, standoffishness, turn to curiosity, turn to wonder, turn to respect because of her. I've seen young people major in special education because of her. I've seen grumpy old men smile because of her. I've seen her fill hearts, mend hearts.

Lucy has a sixth sense. She knows when people need a smile. And she gives them a smile. She's 15, a full-fledged teenager, and she is still smiling.

She also scowls, of course. But she doesn't scowl for long. A few weeks ago she was doing some reading and got stuck on a sentence and very frustrated. But the frustration passed as quickly as it came. A friend who was working with her read her the sentence correctly, then

Lucy read it back, then the friend said, “Good job, Lucy” and there she was, her sunny self again.

Not all kids with Down syndrome are sunny. But lucky for us, Lucy is.

She beamed clutching her diploma. She beamed a few days before at her birthday party, greeting everyone, reading every birthday card out loud, saying thank you for every gift. Liking every gift. She beams every time she gets up on a stage with a mic in her hand and sings a song.

We have these things on video, too — Lucy singing, Lucy smiling. But it’s the eighth-grade graduation that does us in. Inclusion is what Lucy’s parents chose for her. They chose to send her to Canton Public Schools instead of to a school for children with disabilities. They chose to have her included instead of segregated. They chose to fight for services that would make inclusion work. They chose what they hope is best for Lucy.

They’re still not sure what is best. Is anyone ever sure? High school looms and there are many more challenges. But what they know for certain is that it is because of inclusion that Lucy Rose Falcone is known and valued. And very much loved by people who know her best.

LOVE IS LIKE NIGHT VISION

June 30, 2019

I flew to California the day before her birthday. It was a big birthday, her 16th. And I was sad leaving her.

“I already miss you,” I moaned when I kissed her goodbye.

Lucy looked at me and smiled, cocked one eyebrow and said, “Save it for Farley,” which is Lucy teasing, Lucy pretending to like Farley (a favorite teacher) more than she likes me. It’s a game she invented, something she says when she wants to get a rise out of me, her words a joke.

Lucy makes jokes. She sees the humor in things. The doctor who told us she had Down syndrome didn’t tell us that she might be funny. She might not walk, talk, see, hear, read, write, he said.

Funny never came up.

Lucy is my oldest grandchild. We didn’t know for her first 12 hours that she had Down syndrome. “Isn’t she perfect,” we said to one another.

And then the world told us she wasn’t.

She had heart surgery when she was two months old. She



weighed seven pounds. Her heart was the size of a walnut. The surgeon clipped her aorta. Somehow she survived. Two months later she had more surgery to fix her aorta. Again, there were complications.

Other babies, babies without Down syndrome, were meeting their milestones, smiling right when the baby books predicted, rolling over, sitting up, walking. It took Lucy longer to do all these things. But when she did? We, her parents, grandparents, aunts, uncles, friends, her great, big, extended, supportive family, cheered. We took pictures. We celebrated. We poured champagne and toasted. What were we worried about, we wondered out loud. Look at her, walking, talking, amazing us.

But then there was the next thing. There was always a next thing. Because for every milestone Lucy reached there were always more milestones unreached. Tests. Performance charts, graphs and detailed reports routinely highlighted all that Lucy could not do.

From early intervention, through pre-school and grammar school and middle school into high school, every chart, every report, every evaluation, confirmed what the doctor first said: That Lucy is less than. That Lucy doesn't measure up. That Lucy is imperfect.

She isn't. It's the world that doesn't measure up.

I think sometimes that in order to see the real Lucy, the world needs a kind of night vision, glasses to put on so that what is hidden inside her is visible: her wit; her

kindness; her empathy; her generosity; her selflessness; her tenacity; her quiet strength; her memory of people and places and movies and songs; her great love of life and of family and friends. All that Lucy is, all that she thinks and feels and believes and wishes for, all that she has learned, all that she remembers, are inside her in a place we human beings cannot see.

And so her attributes go unmeasured and undocumented. And her worth as a human being is diminished.

But she is like a bird in a forest on a dark, moonless night. We can't see her plumage, we can't see her colors, we can't see her wingspan and we can't see her soar. Why? Because we lack the ability. Our eyes cannot see in the dark. And this is our disability.

When Lucy was brand new, if I had been able to look into a crystal ball, if I had been able to see her at 16, I would have seen just her outside, too. I would have been struck by all that she isn't.

But love is like night vision. It gives us new eyes.

Lucy doesn't judge herself or judge anyone else. She does not compare. And she's happy, most of the time, unless someone else is sad and then she sits down next to that person and gets sad, too. She wishes she had curly hair. That's the one thing she would change about herself.

But I wouldn't change a hair on Lucy's head, not even to replace a few of them with curls, which would make me a hero. When Lucy was a baby, I would have. I would have

done anything to make Lucy's life better.

What I know now is that Lucy's life couldn't be any better. She is loved beyond measure. She walks into a room and people smile. She is 16 and still likes her parents so much that she wants to hang out with them. She is 16 and still likes hanging out with me. "You're 16, you're beautiful, and you're mine," I sing to her. And she grins, laughs out loud, and cocking one eyebrow, tells me, with perfect enunciation, "Save it for Farley."

CHEERS FOR UNSTOPPABLE LUCY

June 12, 2022

The words always come. That's what I tell myself when I can't find them. I sit. I think. And I wait. And when the words still won't come? I ask myself what it is that I am struggling so hard to say?

Maybe this time what I'm struggling to say is simply thank you. Thank you, world. Thank you, Canton High. Thank you, friends and relatives and neighbors and teachers and doctors and dance instructors and used-to-be strangers who have walked this road with us, sometimes many times, leading the way.

When my granddaughter Lucy was born with Down syndrome 19 summers ago, there were so many naysayers. I hear them in my head still. She'll never. Don't expect. She won't.

But she has and she did and she will. Because there were more optimists and believers saying she can than defeatists saying she can not.

Lucy graduated from Canton High School last Saturday morning. The ceremony was held outdoors under a blue sky with just enough clouds floating by to keep the temperature



perfect. Masks were not required so you could see all the smiling, beautiful, young faces. Lucy was just one of 255 young men and women to walk across the stage and accept her diploma.

Her father filmed the moment. Later that day, at home, I watched the video again and again and again. It captured Lucy in her cap and gown, strutting across the stage smiling and shaking hands with the principal and the school superintendent, accepting her diploma along with the rest of her peers, while the crowd whooped and clapped and cheered.

It's the cheers that moved me and the cheers that move me still. When Lucy was born in 2003, there were no cheers. There was no someone from MDSC (Massachusetts Down Syndrome Congress) showing up at the hospital with a gift package and a smile and assurances that Lucy and her family would have a supportive community behind them. That would come soon after. But not in time for us.

There was no easy access to other parents of children with Down syndrome either, the Internet and Google not what they are today. There were no models with Down syndrome posing for magazines back then, few current educational books about children with Down syndrome, no personal blogs, and though by law children with Down syndrome had to be included and integrated into public school classrooms starting with early intervention, the interpretation of this law varied from school to school and from year to year.

Since 2003, all this has changed. There has been progress, and Lucy is part of that progress. She is the first person with Down syndrome to graduate from Canton High School.

I remember the dentist who dismissed her when she was just four years old. I chose this dentist. “What does she need straight teeth for?” he asked me. I remember the eye doctor who told my daughter that she should wait to see if Lucy is “functional” before opting for eye muscle surgery. I remember the special education professional who snapped gum, yawned, and refused to make eye contact through every mandatory meeting she was forced to attend.

Every rebuff, every closed mind, every closed door hurt.

Now, looking back, I can see that there were open minds and open doors, too, and that we had more helpers than we realized.

We must have because look at Lucy now.

A week before she graduated, Lucy went to her senior prom. Her cousin Adam, who is also a 2022 graduate of Canton High, said that Lucy never left the dance floor, that she danced all night. Before her prom, Lucy was awarded Canton High School’s Drama Club Senior of the Year, not only for her participation in school plays but “for her joy of performing.” Someone videotaped that award, too. And, once again, all you hear are cheers.

I e-mailed the video of Lucy's graduation to her uncle, my son who lives in Scotland. "Makes me wish that somehow, someone could have shown Lauren and Dave this video 19 years ago when we were all afraid of the unknown," he texted back.

What we were most afraid of then — in addition to all the medical coulds and woulds — was how the world would treat Lucy. Would she have friends? Would she be appreciated? Would she be valued? Would she be loved?

Lucy is all these things because she wasn't cast aside, because she wasn't educated in a separate room, because she wasn't denied participation in the things she loves, theater and music and dance. It took a village. It will continue to take a village made up of family and friends and educators and strangers who become friends.

People talk about inclusion. This is what inclusion is. And this is why Lucy thrives.

ACKNOWLEDGMENTS

In musical theater, which Lucy so loves, there is a song from Andrew Lloyd Webber's musical "Aspects of Love" that has played in my head since the day she was born.

*Love,
Love changes everything:
Hands and faces,
Earth and sky,
Love,
Love changes everything:
How you live and
How you die.*

Thank you for the love. This is what I want to say to everyone who has been a part of my granddaughter's life. Our love for Lucy changed my family, for sure. It propelled us. It changed not just the way we see Down syndrome. It changed the way we see the world. Love has sustained us, too, the love of family and friends and strangers who became friends.

Many of the early helpers we met when Lucy was small have moved on or moved away because this is what human beings do. But in their leaving they made room for other strangers who became friends, other people who met Lucy and loved Lucy and learned to see not just Down syndrome, but the person Lucy is.

Which leads me to now and to this book and to this constantly evolving community of new and old friends

who have helped me put together what has been a labor of love, this compilation of Lucy's life.

All of these columns have appeared in print before. Those dated prior to September, 2005 were first published in the Boston Herald, those after in the Boston Globe. Over the years I have written many columns about Lucy. The challenge has been what to include in this book and what to leave out.

I did not do the choosing or the designing or the formatting or the double and triple checking alone.

Like Lucy, I sometimes need help. To these helpers, my deepest thanks. It's to you all I dedicate this book.

Thank you, Liz Lennon, whom I texted out of the blue. Can you do me a favor and design a book cover, I asked? And she said yes, and created a work of art.

Thank you, Leslie Anderson, not just for being my editor at the Boston Globe where many of these columns first appeared, but for reading them again, in their entirety, at home, when you could have been doing a million other things.

Thank you, Maureen Palermo, for reading all the Lucy columns and searching through hundreds of Lucy pictures to help me cull twenty-one of each.

Thank you, Lisa Tuite, for finding columns I never thought to save.

Thank you, Frank and Carolyn Lane and Jen Laun and Lane Printing & Advertising for your instant and magnanimous generosity of time and resources in printing this book.

Thank you, Dr. Brian Skotko, not just for checking my work but for being one of the few doctors who has always valued people with Down syndrome, who talks about capabilities, not limitations.

Thank you, Sarah Cullen, for starting MDSC's First Call program, which reaches out to expectant parents and new parents whose child has been diagnosed with Down syndrome. Thank you for advocating for this program nationwide and for being a bright light wherever you go. I wish First Call had existed when Lucy was born.

Thank you, Maureen Gallagher, for being a tireless and relentless supporter of and advocate for children and adults with Down syndrome. As executive director of MDSC, you are the force behind legislation that has helped families all over Massachusetts. If I were a Marvel comic book writer, I would make a superhero of you.

Thank you, Barry Cohen, for your always generous heart. You have supported MDSC and me since the beginning. It's because of you, this book is in the hands of not just a few but many.

Thank you, Anne Jackson, who also read over these columns and to my husband, Bruce Beckham who found every spelling mistake and misplaced comma and should be a copy editor.

Thank you, Lucy's friends, her parents' friends, my friends, and Lucy's teachers who have and continue to include her and celebrate her.

Thank you, Dr. Robert Geggel, who way back in the beginning saved Lucy's life.

And finally, thank you to my children and grandchildren, who became Lucy's instant buddies. Thank you to Lucy's parents, my daughter Lauren and her husband Dave, for bringing Lucy into this world and allowing me from the beginning to tell her story. And most importantly, thank you Lucy Rose Falcone, for being you.

...in class she knows as much as the front of her and is a little bit better informed than the girl beside her. At the end of the year she gets the table top talk back. She gets invited to play all the time, has lots of friends, sings aces, and plays along with everyone in every afternoon. She comes from her mother holds up her k and spelling and arithmetic papers smiles.

...the world she was meant for, even if she just like her, because in the world is meant for. Lucy epilomizes of some geographical glitch she on Earth instead of in the plain and shine she landed in the bit out of and where the tongue of the heart.

...the afternoon I pick up Lucy I watch all the children race around the school yard, yelling and whooping so many children, all the sea then comes Lucy, holding her hands making it slow, beaming when she I think, if we were the only I wouldn't know that Lucy is and subtracting and reading and running across the school yard and play Wii. We wouldn't syndrome with limitations. Yes I think, isn't she amazing? Look up. Look at how happy she sometimes needs extra help to depends on extra help because her to learn what typical kid trying how to clap in rhythm on up on a song. How to me. How to add and subtract her name. But she tries and I and tries. And when she gets it is a joy.

...on planet Earth, we all de We don't have wings. We our disability. We accommodate by using bikes and cars and things, and yes, we'd get ter if we could just ourselves. But we don't beat ourselves up. We e don't think of ourselves as We we can't take flight. But we e don't think of fly.

...cries when someone else e doesn't know some starts bowll to cry. You know she is crying, less. This is Lucy's heart tall she sent here by mistake? she own planet? Or did she one the universe and see us here, messed-up earth, and thin want to be. This is where with that family. With this mo in this world. Why? Because this is where I am see this is where I'll be loved. a long time after my grandd was Down syndrome, was born and babies. They were every playground, cooing, smiling, sitting party-cake, walking, talking single developmental milestones. Their perfection a constant I's my inspiration.

...I's how I see my first grand an perfect. That's how most r. The doctors with their gll and studies my purred lips with Alexander all of us mourning who Luc ht have been.

...I't her first day, not because r. I was but I wanted to be a teen years later, I wish I could and tell that frightened me would be challenges and from dead and birds walk and stops. But that the high of the lows, the victories would eats, and most important e from Bikini. (My friend told me she has Down syndrome, but person she would grow to be. e's what gets lost in the word come." The individual. The e with Down syndrome are e and have almond-shaped ucle tone. But all people w come are not alike. They are e hundreds of ways all human e different.

...is that we didn't know wh n. That she would grow into e self. That she would be a e and dance and curly hair an looks and getting dressed up a and toasting to life and hang up and friends because she has been exposed to. When e turned 15 last month. Wh e, my daughter, turned 15, sh books and exaggerated sighs. Overh e to be loved and not to be my friend!" to barely tolerating me. I wrote m about 15. "A Trying Phase." That n got me a job at the Boston Herald. Ieas mothers of 15-year-olds ident e. I'm not sure if she's a restau e or by anyone. Lucy is kind and polite tutative and funny. Plus she shares. And e's not complain.

...to become a friend. Or about who would grow to become because of her. If I could go back in time, I would block my ears to the naysayers and ignore every developmental assessment that grades and degrades people. How is Lucy doing? Is she happy? Is she thriving? Is she going in the right direction? Is she doing better today than she did last month and last year? Does she have friends? Yes. Yes. Yes. I would trust this, what I saw, what I see. What Lucy shows me every day. Online, I found a definition of perfect that sums up Lucy: "Someone with few flaws."



...No, being a Mini could never compare with. And then Lucy was born. Children give gifts. Flowers picked from a neighbor's yard. The shape of their hands in plaster. Biggest gift in crayon. Toast in bread. Bugs in a jar. A ring from a church fair. But the largest gift is the love that they're born with.

...I said it didn't matter. It's what I thrived on. I said it didn't matter. It's what I thrived on.

...The beginning of everything is the hardest. When you have a baby with down syndrome, the beginning is extra hard. Doctors tell you all the medical issues that might arise with your perfectly beautiful newborn, and it's overwhelming. If every baby placed in a mother's arms came with a long list of life's tragedies that statistically might happen, women would stop having children. Eleven years later I'm aware that the journey has not been without challenges. Fear and

...I put it on sometimes. I can see my son as he was that day, so serious and sure that he would ever be about anything again. His eyes told me he thought I was perfect. And that he had found for the perfect mom the perfect thing.

...I celebrate the beauty of daisies growing wild on the side of a road, a hot-pink from door; a misty meadow at dawn, deer in that meadow, and a child who struggles so hard with speech, finally speaking in sentences. You see so much beauty when you're forced to slow down. You see magnificence in

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...I celebrate the beauty of daisies growing wild on the side of a road, a hot-pink from door; a misty meadow at dawn, deer in that meadow, and a child who struggles so hard with speech, finally speaking in sentences. You see so much beauty when you're forced to slow down. You see magnificence in

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...how the world would treat Lucy: Would she have friends? Would she be loved? Would she be valued? Would she be loved? Lucy is all these things because she wasn't cast aside, because she wasn't educated in a separate room, because she wasn't denied participation in the things she loves, theater and music and dance. It took a village. I will continue to take a village made up of family and friends and educators and strangers who become friends. People talk about inclusion. This is what inclusion is. And this is why Lucy thrived. I said it didn't matter. It's what I thrived on.