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THE POWER PLAYERS

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and all the inspiration anyone needs.

— *I Have A Voice*, Gigi's Playhouse



☆☆☆

BY BRIAN MELTON PHOTOGRAPHY BY MARC PISCOTTY

the girl with stars in her eyes

ONE FAMILY'S VISION AND GENEROSITY — ALONG WITH A LITTLE GIRL'S TENACITY AND COURAGE — IS HELPING TO CHANGE THE WORLD.

"Mommy! Mommy! Mommy!" Sophia yells when she sees her mother Michelle hiding behind the Laughing Butterflies classroom door. This isn't a typical Friday morning at Fisher Early Learning Center; Mommy's busy schedule rarely affords her the chance to stop by the school.

Sophia's nose is a little runny, and as the two embrace, Michelle takes the opportunity to wipe it with a tissue. Looking up at me from her crouched position, Michelle says, "She's a little under the weather today," almost apologetically.

"No I'm not," says Sophia. "The weather's nice, Mom!"

I had heard about Sophia's wit and charm and had even briefly seen it firsthand as she exchanged high fives with the legendary Quincy Jones at a press announcement for the Linda Crnic Institute. But I'm not prepared for this level of wordplay from a five-year-old, and I let out a hearty cackle.

As the hallway fills with laughter, Sophia's eyes sparkle until she realizes that, while she's cracking jokes, her friends are playing outside without her. She wiggles out of her mother's embrace. This little girl has things to do.

She takes us into her classroom — your everyday, normal preschool setting. Books, puzzles and games adorn the shelves. There is a reading area and a smaller play section where Teacher Max keeps dress-up clothes. We sit on tiny blue plastic chairs at a tiny table in the center of it all. At 6'3", I feel like Gulliver, my travels leading me to Fisher Early Learning Center, a nondescript building on Evans Avenue where I will soon come to realize that everything I've ever thought about children with special needs — Sophia is the first person I've ever met with Down syndrome — is completely and utterly wrong.

"When you woke up this morning, you were singing a bunch of songs," Michelle says to Sophia who is headed, marker in hand, to a sign-in sheet near the door. "Do you want to sing one for our new friend Brian?"

"No," Sophia says.

"No, thank you," Michelle quickly corrects as Sophia begins writing her name.

BUT ... IF YOU SPEND YOUR LIFE MOURNING THE FACT THAT YOU DIDN'T GET TO ITALY, YOU MAY NEVER BE FREE TO ENJOY THE VERY SPECIAL, THE VERY LOVELY THINGS ... ABOUT HOLLAND.

— WELCOME TO HOLLAND, EMILY PERL KINGSLEY, 1987

Sophia Kay Whitten was born June 9, 2003, four weeks premature. Her mother, Michelle Sie Whitten, was undergoing a routine checkup when her doctor gave her the surprising news. “The nutrition through the umbilical cord is sluggish,” he said. “We’re taking the baby out today by cesarean.”

For Michelle — a warm, friendly and wonderfully articulate first generation American of Italian and Chinese descent — this was another complication in a long line of prenatal nightmares leading up to Sophia’s birth. When Michelle was 17 weeks pregnant, the results of a maternal serum screening, which measures the levels of protein in a mother’s blood, showed she had a one in nine chance of her newborn having Down syndrome. Two weeks later, the results of her amniocentesis confirmed her worst fear: the baby growing inside of her had Trisomy 21.

Normal reproductive cells contain 23 pairs of chromosomes. In children with Trisomy 21, there are three copies of the 21st chromosome due to an error that occurs during cell division known as nondisjunction. As the fertilized egg develops, the triple chromosome is replicated in every cell of the growing fetus. The extra genetic information is expressed in characteristics collectively known as Down syndrome, an occurrence seen in one out of every 733 births.

Heart abnormalities affect nearly 45 percent of all children with Down syndrome, and Sophia was no exception. “At 32 weeks, the specialists said, ‘We don’t know how we missed this, but your child has a complete atrioventricular defect and will need open-heart surgery at about three or four

months,’” says Michelle. “So that was another curveball.”

But the Whittens’ story begins before the Down syndrome diagnosis, before the premature birth and the open-heart surgery. It begins at a wedding in China nearly 12 years ago, where British-born Tom Whitten, a contemporary Chinese art consultant, met the powerful and well-established Michelle Sie, soon-to-be president and CEO of Encore International, the sister company of her father’s Colorado-based Starz Entertainment Group. The two married in Naples, Italy, in 1999 before settling down in Denver the following year. Six years ago, Michelle and Tom found out they were pregnant and were overjoyed with the news.

“The first thing I want you to know,” says Michelle as we take a seat in one of Fisher’s second floor observation rooms, “is that I happen to personally be pro-choice. When Tom and I found out Sophia was diagnosed, I went into the experience not knowing what my decision would be. I talked to my ob-gyn, and he felt that getting an amnio would make me better prepared.”

Due to the risk of miscarriage attached to the amniocentesis procedure, Tom and Michelle selected a well-known physician who had an excellent record of accuracy. They wanted to be sure their unborn baby was in the best hands. “Statistics are fine,” Michelle says, “unless you’re on the small end of them.”

The rest plays out like a modern-day medical horror story. Before Tom and Michelle were allowed to meet the amnio doctor, they were given a video to watch. “It was bizarre because the video felt homemade,” says Michelle. “When it was over, the genetic counselor came back into the room with a tissue and said, ‘Mrs. Whitten, please don’t cry. You know, 80 to 90 percent of all people terminate. If you want to terminate, you can, too.’”

Upon finally meeting the doctor, it is Michelle’s belief that he himself had



FROM LEFT TO RIGHT: PATRICK, MICHELLE, TOM AND SOPHIA WHITTEN

provided the narration for the video, and after doing her own research, she realized most of the information consisted of outdated statistics. "My first reaction after meeting with the amnio doctor was more like anger," says Michelle. "What most people don't realize is that in the 1980s, the normal lifespan for a child with Down syndrome was around 20+ years. Today, because more people are choosing to keep their children with Down syndrome, it's closer to 60. I felt like all the information we were given was wrong."

A week after her amnio, Michelle received a matter-of-fact call. "The voice on the other end said, 'Mrs. Whitten, you've tested positive. Your baby has Down syndrome,' just like that," Michelle says. "I had to lock myself in the bathroom, and Tom had to pick me up off the floor."

Tom and Michelle gave themselves two weeks following the diagnosis to make their decision. They contacted the Mile High Down Syndrome Association, met with two families with Down syndrome children, and after reading what they felt were more accurate statistics, the couple decided to go through with the pregnancy. "We thought, 'OK, we can do this,' and we never looked back."

"It was going to be a new journey," says Tom, "but then again, so was parenting. She was our first. It was going to be all the same issues any parent would deal with — I suppose a little more on the medical side of things — but once she came out yelling and kicking, it was clear that she was just another baby." ☆ ☆ ☆

I HAVE A DAUGHTER WHO IS SIX YEARS OLD. IT TAKES HER MORE TIME, IT'S TRUE, TO MASTER NEW THINGS. BUT SHE HAS LEARNED TO DO EVERYTHING ANY OTHER CHILD LEARNS TO DO: TO CRAWL AND WALK AND TALK AND USE THE BATHROOM, TO DRESS HERSELF, WHICH SHE DID THIS MORNING. WHAT I SEE IS A LITTLE GIRL WHO WANTS TO LEARN, AND WHO LOVES EVERYONE SHE SEES.

— THE MEMORY KEEPER'S DAUGHTER, KIM EDWARDS, 2005

On a Saturday morning in the Whitten household, the sun is barely creeping through the window when Tom and Michelle hear the familiar slam of a bedroom door. Moments later, Sophia is standing at Michelle's side of the bed with a secret to tell.

Within the hour, Tom, Sophia and Patrick — the Whittens' typically developed two-year-old son — are preparing a breakfast of pancakes. Sophia has pulled over a stool, put on her apron and is mixing batter in a large silver bowl. "Recently, she's really taken to helping me get meals ready," says Tom, who does most of the cooking. "She's become my mushroom cutter before dinner. I give her a little knife, nothing too sharp, and she'll very happily cut her mushrooms. Of course, now Patrick is putting on his apron and wants to help too, which can cause some problems."

The relative flexibility of Tom's job as an art consultant gave him the opportunity to spend the first two years with Sophia as she began to explore the world around her. According to Tom, the two spent time doing what any father and daughter would do. From the family's Bonnie Brae home, they made trips to nearby Washington Park an everyday activity. Visits to the zoo were always a treat, and occasionally, little Sophia would accompany her father to the art museum or to afternoon meetings.

"She was great and very responsive to every kind of stimulating environment as long as it wasn't really noisy," says Tom. "I tried to take her to a soccer game, but that was really too loud for her."

The rest of Saturday is spent in much the same way, a loving family of four enjoying some rare time together. Tom takes Patrick to the grocery store while Michelle and Sophia practice writing. At 10:30, the family heads to Wash Park for a play date with Sophia's friend Gretchen and her family with a stop at Bonnie Brae Tavern for pizza. By the time the Whittens make the walk back to the house, Sophia and Patrick are exhausted and ready for a nap, giving Tom and Michelle some time to meet with me.

"I think the most eye-opening aspect of Down syndrome for me, once Patrick was born, was to see that, in many ways, he is much more of a handful than Sophia is," says Tom. "Really she is just a kid with the same periods when she's on, when she's off. We do a bit more running around in terms of medical stuff, but essentially she's just a little girl."

"We do have a son who is typical, so it's frustrating when Sophia has to work so hard," says Michelle. "She'll watch herself in the mirror sometimes, and she'll say the words to a rhyme, and you can just tell she has to work so hard for that. It's painful for a mother. But she's a great communicator. If she wants something, she might not use a very long sentence, but she'll tell you that she wants it. And she'll say 'please.'"

It's 4:45 pm, and Sophia has just come in from outside, her clothes and hair a bit mussed from play. As we're standing in the living room, it's Sophia's politeness that really catches me as I help her with the last few teeth of her coat zipper. I offer to lay the jacket on a nearby couch for her. "No, thank you," she says to me, not because she is being difficult, but because, as Michelle explains, the coats go on a particular chair in a particular way.

"Would you like to show me your playroom?" I ask.

"Yes, please," she says, as she smiles and runs through the kitchen. ☆ ☆ ☆

As Michelle and I walk the halls of Fisher Early Learning Center, it is evident this is no ordinary preschool. There is a calm that hovers like a dewy morning fog, an air of positivity that I certainly don't recall in mine. These children are so well behaved. The normal piercing screams coming from the young disgruntled masses is absent. A twenty-something with dreadlocks happily walks by, an acoustic guitar strapped to his back. I think I hear him humming to himself. Humming? In a preschool?

This is Sophia's last year at Fisher. In order to prepare her for the jump to kindergarten, the Whittens increased Sophia's school schedule from three to five days last September. Sophia's morning begins at 9 am. Fisher is a play-based preschool that focuses its curriculum around the *Read, Play, Learn* model of teaching developed by Dr. Toni Linder, an education professor at the University of Denver. Throughout her day, Sophia and her peers learn problem solving, communication, literacy and social interaction through the use of storybooks.

Every morning, Sophia and her classmates begin by reading a book and learn math, art, science and vocabulary that are related to the story. The class stays focused on the book for two weeks, which helps solidify early reading skills. The *Read, Play, Learn* concept has proven to work well for students with special needs because of its individualized nature. If Sophia needs to work on pronouncing her Rs, her speech therapist talks with Sophia's teachers and gives examples of rhyming games the entire class can play that will improve her ability to pronounce the letter.

The Donne and Sue Fisher Early Learning Center, in conjunction with the University of Denver, opened in October 2000 as one of the few preschools that practices full student inclusion. "Instead of Sophia being pulled out of class to work on her articulation," says Lenita Hartman, the

associate director at Fisher, "she has the power of her peers as models. Her class may focus on articulation in the morning, during snacks, just before naptime or whenever. What research is telling us is that there is more success when it's implemented into a child's natural learning environment, rather than pulling that child out of class."

Of the 200 students who are currently enrolled in Fisher this year, 20 percent have been identified with special needs. Students like Sophia learn and interact with typical children of all ability levels throughout the day. Average learners are in classes with gifted and talented students. Socially shy students are encouraged to interact with more affable children. Fisher also uses the multi-age classroom model as well. Children who are three are integrated into classrooms with five-year-olds.

"The value of inclusion is that it mirrors life," says Hartman. "We live in a diverse world, and inclusion helps children at a very young age build positive social relationships. My hope is that the children growing up right now will have a whole different level of understanding about what it means to be a person in this world."

"People think inclusion means a program for kids with special needs," says Michelle. "But it's a whole philosophy of teaching. It appears to me, as a mother who is somewhat educated, that preschools are really into early intervention and inclusion. When Sophia goes to kindergarten, it will be more of a throwback to non-inclusive pullout styles."

Over the past year, the Whittens have looked at 13 public and private schools in the area. Tom thinks they have it narrowed down to three, two public and one private. "DPS (Denver Public Schools) is not considered to be the best-regarded school district for special needs although it certainly varies from school to school," he says. "The tricky thing is to find a school that understands that inclusion is inclusion. Not just for the nonacademic aspects of school, but for math and reading as well."



In 1975, Congress passed the Education for All Handicapped Children Act — now the Individuals with Disabilities Education Act (IDEA) — because research concluded that nearly four million students with disabilities were not receiving appropriate educational services. The law was amended in 1997 and again in 2004.

When Sophia is ready to make the transition into public school, she, Michelle, Tom, Hartman and Sophia's service providers — such as a speech pathologist and an occupational therapist — will meet with a general education teacher, a special education teacher and a representative of the DPS in order to put together an individualized educational program (IEP). The IEP is then used to determine the least restrictive environment in which Sophia needs to learn. Factors such as a student's strengths, parental concerns, education enhancements and student evaluations are used to determine how much time she will spend with her peers.

"When we talk about IEP, the I is the core," says Sharon Hurst, the director of special education for Denver Public Schools. "All of our programming is based on inclusion practices and least restrictive environment. We meet annually to review a child's IEP to see if a child can be included more or less, depending on the individual child's needs."

"In a way, public schools are the easiest to incorporate inclusion into because they are legally bound to provide the least restrictive environment," says Hartman. "But what we're up against is how that's interpreted. What your interpretation is of 'least restrictive' and a family's are two different things."

Currently, there are approximately 94,000 students with IEPs in DPS and an operating budget of only \$50 million for the district's special education programs. Although 93 percent of that annual budget is allocated to salaries, many DPS service providers are assigned two or three schools among which they divide their time. Despite financial restraints, schools such as Bromwell Elementary in Cherry Creek —

a 2008 No Child Left Behind Blue Ribbon School — have had success with the inclusion model.

"Inclusion requires a lot of in-depth services at every school, and replicating intense special services at every elementary is just impossible," says Hurst. "But our department is always trying to give more support to schools to make sure they are practicing inclusion."

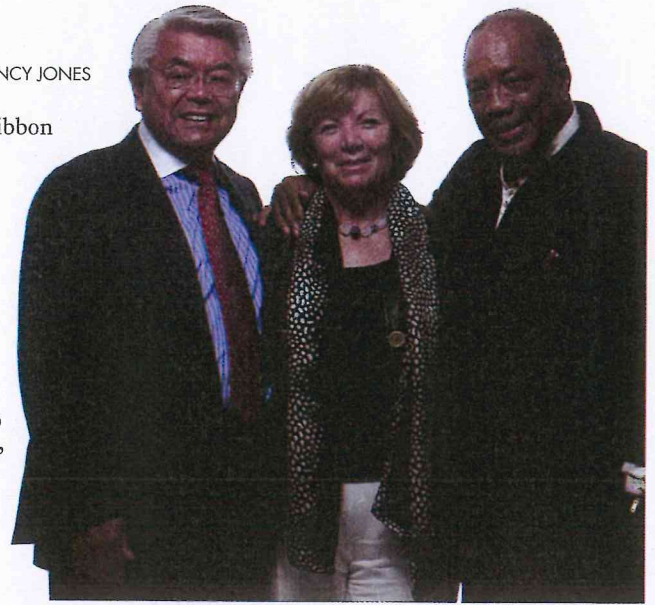
"It's much easier for a school like Fisher that has the support and affiliation of the University of Denver to be successful with the inclusion model," says Hartman. "Inclusion is very cost-prohibitive. It's expensive, and it's hard to do."

But to parents like the Whittens, the results far outweigh the effort. "The more people see that children with Down syndrome have potential, that they can be included, the better off we'll be," says Tom. "The average adult doesn't know how well a child with Down syndrome can do and how much fun they are to be around. Ultimately it's a civil rights issue, and as with all civil rights issues, there's going to be a bit of a learning curve." ☆ ☆ ☆

I KNOW I CAN
RUN WITHOUT STOP
HOLD HIGH MY DREAMS INTO
THE CLOUDS
AND FLY TO THE END OF THE SKY
THE PLACE WHERE I HAVE BEEN
IN MY DREAM

— I KNOW I CAN, QUINCY JONES, 2007

Long before Michelle and I wandered the halls of Fisher, long before Tom shared with me his awe-inducing collection of contemporary Chinese art and long before little Sophia had me down on all fours to retrieve her stuffed puppy on roller skates from under the kitchen table, I spent a September morning trying to find parking at the Children's Hospital.



As a guest of the Anna and John J. Sie Foundation, I was there to interview record producer Quincy Jones as he introduced the Linda Crnic Institute for Down Syndrome at the University of Colorado Denver's Anschutz Medical Campus.

John J. Sie arrived in the United States from China at the age of 14 and was raised in a Catholic orphanage in New York until his high school graduation. His wife, Anna M. Sie, emigrated from Italy in the 1950s and didn't speak a word of English. It was impressive when John accepted a job in Colorado with Tele-Communications, Inc., as senior vice president at what was then the largest cable operator in the nation. But when he founded Starz Entertainment Group in 1991 — home to 13 premium movie channels — that was something else entirely.

"My business career has always been about doing things people didn't think were possible and accomplishing them," says Sie. "People told me there were enough movie channels with HBO and Showtime, but we found a niche and created a multi-billion dollar enterprise. I think I take on the same characteristics with the Anna and John J. Sie Foundation and in taking on Down syndrome. The National Institute of Health's budget is \$26 billion, yet only \$13 million is spent on Down syndrome although it is the most common genetic disorder. A lot of effort has been spent on early detection and termination, rather than taking the time to

identify the positive aspects of Down syndrome that can be beneficial to society.”

“My parents decided to retire and create a foundation around the same time that Sophia was born in 2004,” says Michelle. “I don’t think it’s a coincidence that three neonatologists missed a huge hole in her heart. That may have influenced us down a different direction in choosing her. There was just so much serendipity surrounding Sophia’s birth.”

Through the largest private Down syndrome contribution in our nation’s history — a \$34 million commitment — the Anna and John J. Sie Foundation partnered with the University of Colorado (Boulder and Denver) and the Children’s Hospital to secure 10,000 square feet of research space at the Anschutz Medical Campus to establish the Linda Crnic Institute. The institute is named after family friend and University of Colorado professor of pediatrics and psychiatry Linda Crnic, who passed away in a bicycle accident in 2004. Under interim director Dr. Leslie Leinwand, the goal of the institute became clear: to completely eradicate the ill effects associated with Down syndrome in 10 years.

“The Linda Crnic Institute is meant to be a place where talented investigators work to define the problems people with Down syndrome have,” says Dr. William C. Mobley, the executive director of the institute. “In the short term, we will work to find the genes and figure out why they’re causing problems. In the long term, we will devise treatments that either turn down those genes or turn off the mechanisms that cause the problems.”

Quincy Jones stepped into the Sie picture during the 2007 Special Olympic Games in Shanghai. Jones, who has long been an advocate for global children’s issues, seemed the perfect fit as spokesman for the institute. “I had no hesitation in saying yes,” says Jones.

“He’s always been an icon, and we’re on the same wavelength of trying to do some good for society,” says Sie. “We’ve become good friends, and we’re very happy to have him as our spokesman for the institute and for Down syndrome on a national scale.”

Michelle left her position with Liberty Media Corporation (which had purchased Encore) in 2005 to become executive director of the foundation and has since become tireless in her dedication to Down syndrome-related issues. Last September’s Jet Set Fashion Show raised \$600,000 for Down syndrome research, and in November, her work led her to Saudi Arabia where she discussed Down syndrome issues with the country’s royalty.

“She has such a great vision and such a great ability to put that vision into practice,” says Tom. “This is such a fabulous area for Michelle to work in. I’ve ceased to be amazed at what she can do because the ability is there. She’s persuasive, and generally speaking, if it’s a good idea, people tend to come around.”

Under Michelle’s direction, the foundation created the Rocky Mountain Down Syndrome Educational Fund at the Denver Foundation and donated \$500,000, which was then matched by community donations. The fund also held an inaugural symposia series, headed by Nobel Laureate Tom Cech, which led to the creation of the Linda Crnic Institute. The foundation has been involved in providing numerous grants into scientific research and inclusion practices both at home and abroad.

“Our time is now,” says Michelle without a trace of hesitation. ☆ ☆ ☆

It’s a snowy December afternoon at the Whitten house. Tom is hurriedly cutting a rack of ribs — one of Sophia’s favorite foods — into individual pieces. Patrick sits on the living room floor playing with a tea set Michelle bought Sophia while in Saudi Arabia. Mother and daughter are in the other

room while Michelle gets ready for the Sies’ holiday party at their Cherry Hills home. We’re waiting on the babysitter, a teacher the Whittens have hired from Fisher, who is running a tad behind schedule. I decide, as we’re standing in the kitchen, to take the time to ask one last question.

“What would you say to a father whose child has just been diagnosed with Down syndrome?” It’s a self-serving query I admit. But it seems reasonable in case I ever find myself in Tom’s shoes.

“Hmmm...” he says, putting the scissors down. “I guess I’d tell him to enjoy himself. You’ve got to be patient, but that goes with any kid. You’ll be fairly sleep-deprived, but just enjoy those first few years. Enjoy seeing your child grow up. Time seems to go so quickly.”

And with that, Sophia bounces into the kitchen — apron around her neck — ready to help her daddy cut the mushrooms. □

