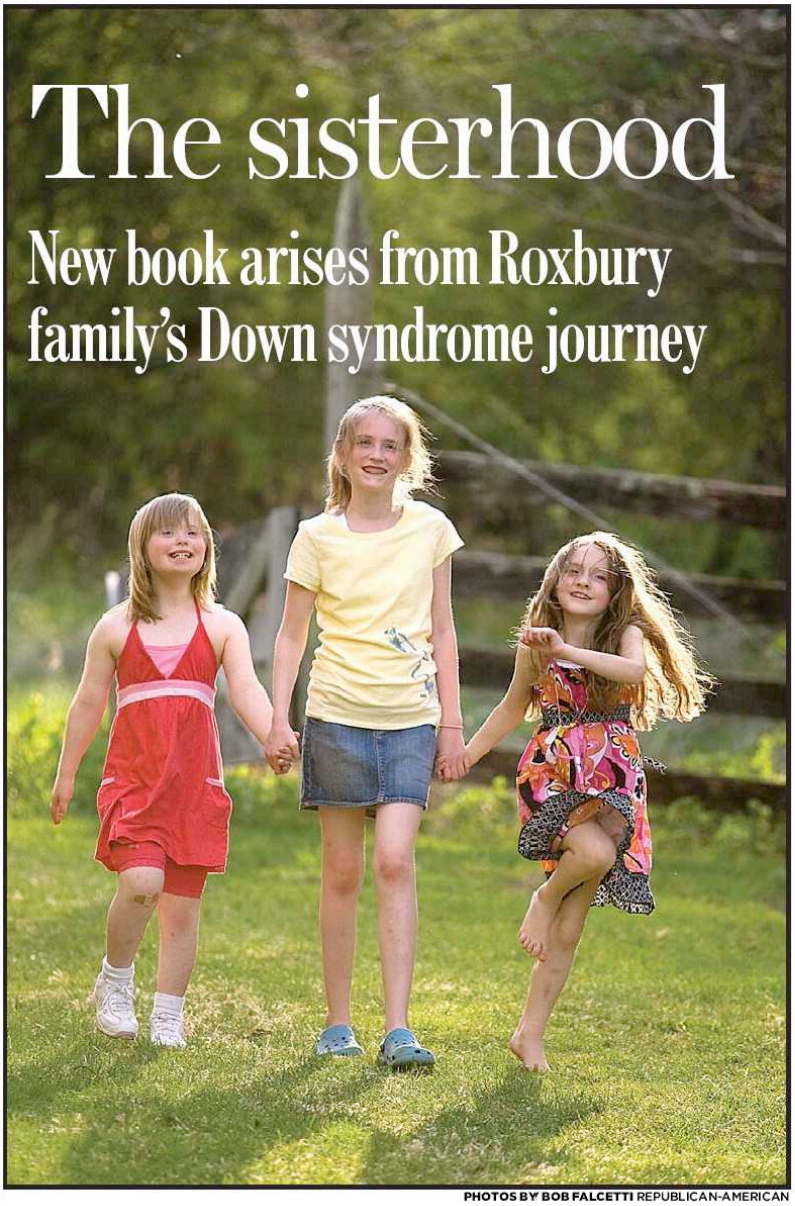
The sisterhood

New book arises from Roxbury family's Down syndrome journey



PHOTOS BY BOB FALCETTI REPUBLICAN-AMERICAN

Above from left, Alicia May Crossley, 9, enjoys an afternoon with her sisters Rachel, 11, and Taryn, 6, at home in Roxbury. A children's picture book, 'My Sister, Alicia May,' is based on Alicia, who has Down syndrome, and her sister Rachel.

Cheri Crossley, center, jokes with author Nancy Tupper Ling, right, and illustrator Shennen Bersani at her home in Roxbury. The three collaborated on a children's picture book about Crossley's daughter, Alicia May.

BY TRACEY O'SHAUGHNESSY
REPUBLICAN-AMERICAN

She recoils from certain pictures. Still. Cheri Crossley doesn't cry much any more. Not in front of the girls, and certainly not in front of Alicia. But midway through the children's book, "My Sister, Alicia May," based on two of her three daughters, one of whom has Down syndrome, she can't stop a tear.

The image of her daughter Alicia standing in the middle of the school bus, open-faced and tender, while a group of children taunt her, is an picture swimming in the Popsicle-bright colors and clumsy cruelty of childhood. It is a picture that breaks Crossley's heart no matter how many times she looks at it. And the Roxbury mother has looked at it thousands of times. It is not only the vulnerability of an ingenuous 9-year-old girl who responds to the goading with a good-natured laughter, it is the mortified look of Alicia's sister, Rachel, 11, who shields her eye with her left hand, wishing all of this — the teasing, the mocking — and maybe Alicia herself, would all just disappear.

"My Sister, Alicia May," is, at its core, a story of sisterhood and concessions embedded in the love between two very different sisters. Written by Crossley's childhood friend, Nancy Tupper Ling, the book is not so much a story about Down syndrome (the word is never mentioned) as it is about the anguish of misunderstood children, the longing to be typical and the "pity beyond all telling," as W.B. Yeats called it, that is "hid in the heart of love."

Pity is not a word one would associate with Crossley, a slim, athletic 42-year-old with a fresh-scrubbed face that scarcely masks a steely maternal will. Pity is not what she sought when Ling suggested a book about Alicia May, the golden-haired, affectionate girl who clambers onto Rachel's back, riding piggy back toward the blooming magnolia on the family's farm. It is not what she expected nine years ago in New Milford Hospital, aglow with the ecstasy of delivering her second daughter. As her tired husband showered in the bathroom nearby, a doctor walked into Crossley's room and abruptly asked, "How familiar are you with Down syndrome?"

"I felt like I had been hit by a Mack truck," Crossley said. "One of the most painful moments of my life was when my husband walked out of the shower and I had to break his

See **BOOK**, *Page* **2D**

BOOK: Mother's childhood friend in author

Continued from 1D

heart," Crossley says, her voice catching. "I had to be the one to tell my husband. I had to be the one."

In a small town that houses a large prison, just southeast of Boston, Ling heard of Alicia's birth and began immediately to pen a poem that would encapsulate her friend's emotions. She sent it south — a gesture Crossley credits as being the first draft of "My Sister Alicia."

With such stinging receptions
How we long to shelter you,
Surround you; keep your
Gentle smiles to ourselves.
Instead we hold you up, for others to see;
Let you, our fragile emissary
Speak to an imperfect world.

"I think it was God's plan for me to have Alicia and I think it was God's plan for me not to know," says Crossley, a teacher at Waterbury's Arts Magnet School. "I've always been a very sensitive person. Even as a child, I felt other people's pain. I think part of the reason I'm here is to bring a child like Alicia into the world and to help the world understand her."

In the summer of 2006, on a visit to the Crossley's farm, Ling, a children's book writer, broached the subject of writing about Alicia, a process that would be charged with coincidence, astringent truths and acts of profound grace. For Crossley, Ling's friendship made the decision simple. "If [the request] came from a stranger, it would have seemed like an imposition." Crossley made only one stipulation: Don't demean her.

As Ling began to write, and the story began to shape as a story not about a disease, but about two sisters, Pleasant Street Press Co-owner Jean Cochran phoned an illustrator in Weymouth, Mass., whose photo-realistic drawings Cochran believed would enhance Ling's book.

Bersani, a successful illustrator whose first four books combined had sold more than a million copies, was busy working on her sixth book and dismissive of Cochran's initial query. "She told me, 'It's a book about two sisters, one of whom has Down syndrome.'" Bersani, a Brockton, Mass., native with a broad face, strong jaw and piercing caramel eyes, even now catches her breath when she recalls the moment.

"She couldn't have known," Bersani says. "She couldn't have known."

Bersani, 47, grew up with a sister afflicted with Down syndrome. When Cochran requested her illustrations, Bersani, now the mother of four, said her mind spun in a whorl of recrimination, guilt, regret, shame and mostly, overwhelming love.

At the time Bersani's sister, Holly, was born, many parents institutionalized babies with Down syndrome. The practice was recommended by Dr. Benjamin Spock, whose influential "Baby and Child Care," advised, "If the infant exists at a level that is hardly human, it is much better for the other children and parents to have him cared for elsewhere."

Bersani's mother didn't institutionalize Holly. But she couldn't tolerate caring for her either. Her mother took a full-time job, leaving Bersani to care for her sister, a practice she continued while she was a student at the Art Institute of Boston.

There, when a fellow student learned of Bersani's obligations to Holly, she dismissed them, saying, "Oh, my mother had one of those, but she got rid of him," a revelation that horrified Bersani. Eighteen years ago, Bersani's father left the country, leaving her legal guardian of her sister Holly, now 42.

"Even if I say I had all these frustrations of having to go home and watch my sister, I loved her," says Bersani, who has brought Holly to Roxbury to meet Alicia. "She's always a ray of sunshine. I could've been a teenager, just waking up in the morning, covered in zits with my hair looking like a rat's nest and she'd say, 'Oh, Shenni, I love you. You're so pretty. You look so beautiful, honey.'"

Nationally, an estimated 90 percent of women abort when they discover their fetus has Down syndrome. No, Crossley wouldn't have done so. Yes, people have asked. Asked her reaction to the 90 percent figure, Crossley sets her jaw and says only, "Outrage."

"My Sister, Alicia May," is not a biography, nor is it completely fiction. But the characters bear a striking similarity to Alicia and Rachel. And the incidents — like one in which the older sister turns away, maddened by her clinging "special" sister, seem as much drawn from Rachel's and Alicia's life as they do from Bersani's. Rachel is taciturn about the book's publication. Although affectionate and indulgent with Alicia, she nods silently when asked if Alicia can annoy her sometimes.

"Alicia's potential — emotionally, conversationally, socially — has yet to be tapped," says Crossley. "It's very hard for me to look far ahead and wonder what their relationship is going to be."

Neither Ling nor Crossley said they intended "My Sister, Alicia" to be a mother-daughter book, nor a book about Down syndrome.

"This book is for everyone," said Crossley.

"Being part of the creation process brought out a lot of emotions— some good and some painful," Crossley says. "I'm glad I put it out there because it's real. I mean how must it feel to be the older sister of someone who others are making fun of?"

As a teacher, she said, "Having my own child with learning difficulties makes me that much more aware of the needs that other children may have and the worries their parents may face. It makes me that much more tuned into the feelings involved, because I experience these feelings myself.... I'm hoping that the book is going to change their perspective and make them more aware, more compassionate."

———

"My Sister, Alicia May," published by Pleasant St. Press, is available through Southbury Borders Books & Music, ipgbooks.com, Barns & Noble, Borders and Baker & Taylor. For details, e-mail info@pleasantpress.com.

What is Down syndrome?

Down syndrome is a set of mental and physical symptoms that result from having an extra copy of Chromosome 21.

Most of us have 23 chromosomes. Having an extra copy of Chromosome 21 changes the body's and brain's normal development. Down Syndrome, which occurs in about one in every 800 live births, can range from mild to severe. Usually, mental development and physical development are slower in people with Down syndrome than in those without the condition, according to the National Institute of Child Health and Human Development.

More than 400,000 people live with Down syndrome in the United States. People with Down syndrome have an increased risk for certain medical conditions, such as congenital heart defects, respiratory and hearing problems, Alzheimer's disease, childhood leukemia, and thyroid conditions, the National Down Syndrome Society reports. Because many of these conditions are now treatable, most people with Down syndrome lead healthy lives. In the past 25 years, life expectancy for people with Down syndrome has increased dramatically — from 25 in 1983 to 60 today, according to the society.

About 90 percent of pregnant women who are given a Down syndrome diagnosis have aborted the fetus.

For details, visit:
www.ndss.org
www.down-syndrome.org
www.nichd.nih.gov/health/topics/Down_Syndrome.cfm


My Sister, Alicia May