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A Roxbury Sisters' Tale

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Alicia and her mom. Photograph by Walter

Rachel Crossley has a story to tell, and it's about her younger sister Alicia. Children's book author Nancy Tupper Ling also has a story to tell, and it, too, is about Rachel.

Both versions relate a touching tale about the loving, caring and sometimes challenging relationship between a big sister and her special needs kid sister. That dynamic is captured in the thoughtfully written and beautifully illustrated "My Sister, Alicia May," a recently released book by Ms. Tupper Ling that is told through Rachel's voice. The author will be signing copies Saturday at the Borders bookstore in Southbury.

"In some ways, my sister is like any 6-year-old girl. She likes dogs and horses," Rachel narrates, as colorful illustrations portray Alicia admiring such animals near her home on Judd's Bridge Road in Roxbury.

"She likes to paint her toenails with polka dots, and she loves bugs," the story continues, embellished by corresponding depictions of Alicia. "She peers long and hard at crickets and June bugs and dragonflies. She watches ladybugs warm themselves on our red door."

Given these interests, Rachel is correct in saying that her sister is like any 6-year-old girl. (The book was drafted three years ago; Alicia is now 9 and Rachel is 11.) Indeed, other than the fact that Alicia has Down syndrome, there is seemingly little difference between her and her Booth Free School peers.

As she sat recently in the family room of the Crossleys' farmhouse, Alicia flipped through her collection of Disney DVDs (she's a fan of "High School Musical" and "Hannah Montana"), declared ownership of a toy her 6-year-old sister Taryn was monopolizing and showed off her own invention-a toy compass she tied to a string. She then picked up a copy of her book, flipped to her favorite part-herself at the zoo, staring at a skunk-and began to read aloud.

"Hi-ya, stinky butt," Alicia read, quoting herself, before adding her own commentary: "That's funny."

Her mother, Cheri Crossley, was equally amused by the caption, noting that it was based on an actual zoo trip, which was just one of many outings the kids enjoy with their mother and father, Brian Crossley.

"We went on a three-mile hike at Steep Rock park yesterday," Ms. Crossley said, almost marveling at how well Alicia handled the excursion. "She's such a strong little girl."

Strong indeed, as Alicia was also born with a hole in her heart and a defective heart valve, a condition for which she underwent open-chest surgery as an infant. And she has had nine inner-ear surgeries since then.

Still, she remains extraordinarily outgoing, flashing her Cheshire Cat grin at every person she meets-even though, Ms. Crossley laments, not everybody reciprocates. "She's a friendly girl. Sometimes she smiles at people and she gets a warm reception, but sometimes they won't smile back," said Ms. Crossley, attributing the

seemingly indifferent response to awkward confusion on the part of others. "I hope this book will change that."

Ms. Tupper Ling began drafting the book three years ago, but the seed was planted shortly after Alicia's birth.

The Massachusetts-based writer and Ms. Crossley have been friends since nursery school. When Ms. Tupper Ling, a mother of two, learned that her friend had a daughter born with complications, she wrote baby Alicia a poignant poem entitled "Our Fragile Emissary."

"With such stinging receptions how we long to shelter you, surround you, keep your gentle smile to ourselves," reads the final stanza. "Instead, we hold you up, for others to see, let you, our fragile emissary, speak to an imperfect world."

That piece, tender as it is, gained national attention, and in 2005 earned Ms. Tupper Ling the Writer's Digest Grand Prize Award. With that, she pitched an idea for a children's book about Alicia's story to her editor. In July 2006, Ms. Tupper Ling spent some time in Roxbury, learning more about her subject's history, gathering anecdotes and observing life with a special needs child.

But after watching the sibling dynamic, Ms. Tupper Ling began to reconsider the story's trajectory. This wasn't a tale just about Alicia but also one about the unsung hero, Alicia's protector and guardian, her older sister Rachel.

"At first, it was going to be all about Alicia, but the more I looked into it, it was really more like Rachel's story," said Ms. Tupper Ling. "If you look, the story never mentions the words 'Down syndrome,' because I really wanted it to be a story about two sisters."

Without a disorder or handicap specified, the book becomes more universal, so families with any special needs or otherwise challenged child can enjoy this story of adaptation. For example, as Alicia also suffers from asthma, there is a page that has Rachel assisting her sister with her nighttime breathing machine.

"Have you ever seen a nebulizer in a storybook?" Ms. Crossley asked in wonderment. "Lots of kids have asthma, and this gives them a way to relate to another child. It's a neat thing, because it will touch a lot of children."

As accurate as most of it is, "My Sister, Alicia May" is technically fiction. Some creative liberties are taken, perhaps a character or two has been added, but Ms. Crossley still deems it "three-quarters true." Such as the moment at the zoo, or when Rachel and her friend Katie go bike riding, only to be met with Alicia's open arms upon return.

The story does have trying, even upsetting, moments.

As is illustrated, there was a time when boys on the school bus teased Alicia for three straight days, telling her to stand upon order and yell upon command. Rachel was embarrassed by the situation, though Ms. Crossley wasn't aware of it until informed by Rachel's friend. But the scene in the book resolves happily, as Rachel stands up to her sister's bullies, and is in turn hugged by a much-appreciative Alicia. Children taunting other children is not uncommon, but prejudices can be expressed by people of all ages, and those present the biggest challenges for the Crossley family. But Ms. Crossley hopes this book will help others overcome any preconceived notions.

"I'm hoping the outcome will be to help sensitize children and their parents about people that look and act differently," said Ms. Crossley. "Whatever the awkwardness is, when I take her places, so many people just don't know how to interact with her." One person that had no problem interacting with Alicia was the book's illustrator, Shennen Bersani, who has a younger sister with Down syndrome, for whom she is the legal guardian.

"When first asked to illustrate this book, my editor, Jean Cochran, had no idea of my background," Ms. Bersani explained in the foreword. "I agreed to illustrate the book, but with one condition: I wanted to meet the actual sisters about whom the book was based."

So she traveled to Roxbury to spend some time taking pictures, both candid and posed, of the family. By the end of the visit, Ms. Bersani snapped about 600 pictures, and left feeling a very real connection to the family, particularly to Rachel, whose story is so similar to hers.

This is a story similar to countless families, as one in every 800 children is born with a superfluous chromosome, the culprit of Down syndrome. And for those whose families aren't affected, "My Sister, Alicia May," serves as a welcoming conduit into a very special world.

Ms. Tupper Ling will be signing copies of "My Sister, Alicia May" at 2 p.m. Saturday, July 25 at the Borders bookstore in Southbury Plaza. For more information, call the store at 203-262-9419. Ms. Tupper Ling has a Web site at www.nancytupperling.com.