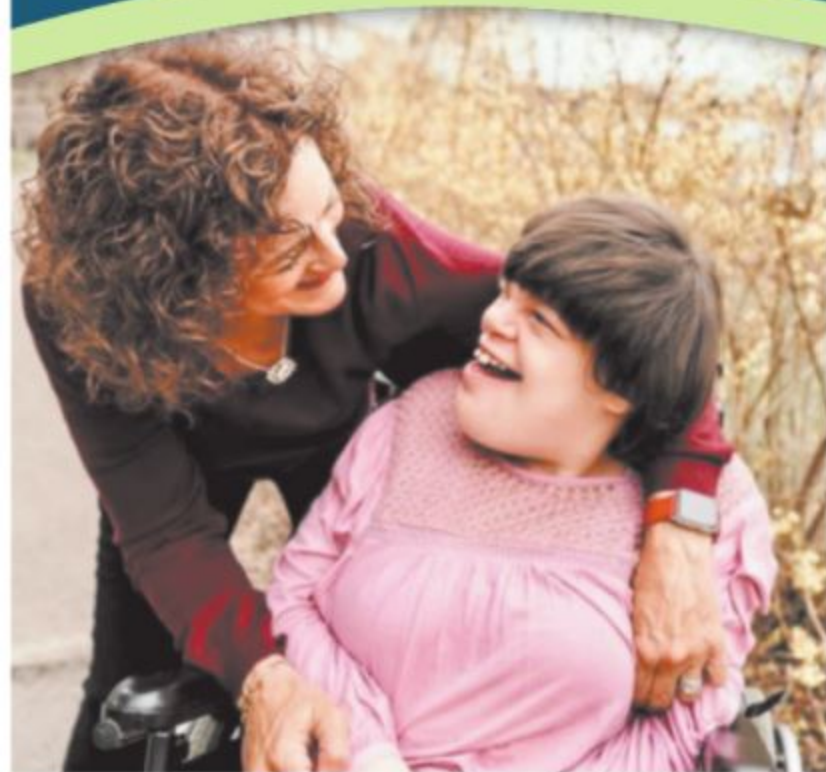


RUBIN  
WRITES INSPIRING  
STORY ABOUT

# 'Raising Jess'



couraged her to start writing.

Despite a lifetime of keeping notes, Rubin said she was still overwhelmed and unsure of how to turn it all into a book.

"I didn't want the book to be, 'I woke up on this morning and gave medicine at 8 o'clock,'" she said. "I wanted it to be a little bit humorous, but be real and authentic about what it was like."

Rubin said Carly had given her Jean-Dominique Bauby's memoir, "The Diving Bell and the Butterfly," in which he wrote about how a stroke turned him into a quadriplegic. The book is written as a series of essays, which is how Rubin said she likes to write. So for the next four and a half years, she wrote every day until the book was completed.

Rubin's mother developed Alzheimer's shortly after Rubin started writing and since her mother had inspired her so much, Rubin wanted not only to get the book published but also to make sure her mother read it. So after she finished each chapter, she sent it to her father, who would read it to her mother.

Jessica was not correctly diagnosed as having a deletion in the long arm of her first chromosome until her 20s; however, Rubin and her husband, Mitch, made sure she was able to have a full life, as her family adopted the motto, "We're going to do everything; it's just going to take longer."

to convince her doctors that her daughter needed a developmental evaluation, finally getting the evaluation and other stories through the book's July 2021 publication.

"It's a hopeful book and it's a positive book," Rubin said. "It's about the transformation of a family finding out we have a child with a very severe disability and how our family embraced Jessica for who she is."

Rubin said her mother had been encouraging her to write a book for years about her experience raising Jessica. But Rubin always told her that between work and raising three kids she didn't have any time. After Rubin retired, her other two children, Alex and Carly, bought her a thesaurus, dictionary, journal and pens and en-

Rubin recounts both the highs and lows of Jessica's life and their family and marriage struggles, including the stories of Jessica making her Bat Mitzvah and when she received Williamsville East High School's "Principal's Award."

Jessica, who will turn 40 on April 11, lives in a group home where her mother says that though families are very much involved, Jessica is still extremely independent. While unable to attend as many programs and events as she could prior to the pandemic, Jessica still attends speech therapy through Zoom and physical therapy on a weekly basis.

The author said she thinks her book has a message for everyone, whether or not they have family members with special needs.

"What I hope is that people who have a child with a disability see they can have a beautiful, rewarding life," she said. "There's a lot of hard stuff, but there's also a lot of hope and a lot of beauty."



The book can be purchased online at Amazon.com and barnesandnoble.com, as well as at Barnes & Noble stores.