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Celebrating Life with Down Syndrome

Brian Skotko denies that he is the coauthor of a book. There is his name, right on the cover, but the 23-year-old medical student says the "true authors" are the individuals with Down syndrome whose tales of triumph fill the pages of *Common Threads: Celebrating Life with Down Syndrome*. "We are just privileged to be their voices," he explains.

Skotko, a first-year student at Harvard Medical School, wrote a series of profiles and research summaries for the glossy coffee-table book while he was an undergraduate at Duke University, where he participated in an HHMI-supported undergraduate program in neurobiology and research. Coauthor Cynthia Kidder's Band of Angels Press published the book, which is available through the publisher's Web site (www.bandofangels.com) or at Barnes and Noble bookstores. Some of the profits will go to the Ralph E. Waltenbaugh Scholarship Fund, which helps young people with Down syndrome attend college, trade school or job training.

Skotko's sister, Kristin, has Down syndrome, a genetic condition caused by an extra copy of chromosome 21. So does Kidder's son, Jordan. The college student and the Michigan publisher discovered each other through Kidder's sister, who was Skotko's high school chemistry teacher in Cleveland, Ohio. A freshman research project on Down syndrome families, which Skotko did for a cultural anthropology class at Duke, showed him that there were primarily two kinds of books about Down syndrome: how-to manuals for parents and caregivers and scientific treatises on mutations of chromosome 21. "Both serve a purpose, but they are missing the inspirational thread, the stories of people with Down syndrome who succeed despite their limitations and the low expectations of the world around them," says Skotko.

When the university freshman proposed writing that inspirational book, Kidder, who had been wanting to publish a book about Down syndrome, immediately agreed. Did her coauthor's age—19 at the time—give her pause? "Not a bit," she says. "Brian is the most mature young man I've ever met. I heard the dedication in his voice as he talked about his sister and her

accomplishments, and it was clear that he understood the science too."

For the next four years, while he majored in biological anthropology and anatomy and minored in mathematics, conducted electrophysiology and neurobiology research, wrote a senior thesis on the anatomical development of the mammalian tongue, and earned a certificate in neuroscience, Skotko somehow found time to conduct dozens of phone interviews and write profiles highlighting the accomplishments of more than 60 people with Down syndrome. He also researched and wrote summaries of the latest Down syndrome research. Working with photographer Kendra Dew, Kidder filled the book with captivating photos of people with Down syndrome at work and play.

Graduating from Duke with honors, Skotko entered Harvard Medical School, which he describes as "a dream come true." Once he finishes his M.D., Skotko plans to earn a degree in public policy too. "I want to treat people with disabilities, and I want to become a policymaker representing them," he says. "I love doing research, but bench research just isn't as much of a passion for me as working with whole people. The essence of research—the rigors and the methodological approaches I learned at Duke—will always be part of my life."