‘Rare Mamas’ Helps Parents Raising Special-Needs Kids

BY ALICIA VENTER

When Nikki McIntosh’s son, Miles, was diagnosed with spinal muscular atrophy at 18 months old, a journey began.

It was a journey of self-discovery and learning, one that she and her husband had to largely navigate on their own. It was 2013, and she was having to learn how to take care of both herself and her family. Quickly, she learned it was a lofty ask, especially without any guidelines or tips on parenting. Since nothing like that seemed to easily exist on its own, she decided to make it herself.

Over the next decade, McIntosh shared her journey with others, first through just speaking with mothers at doctor appointments and later through a podcast and public speaking. Building on her mission, the San Clemente resident has released “Rare Mamas,” a book that serves as a lifeline for parents trying to learn how to raise a child with a rare diagnosis such as spinal muscular atrophy.

“I was immersed in the world of rare disease and became aware of the glaring gaps of information and resources for rare disease patients and families,” she said. “We found that it was really devastatingly difficult to figure out how to navigate all of the different systems: the health care systems, the educational systems and the financial system that support patients. Going through our journey, it took me some time to figure them out — I hit a lot of roadblocks. There were a lot of obstacles, and it was very time-consuming.”

Around one in 10 Americans has a rare disease, and about half of them are children, according to the Ann & Robert H. Lurie Children’s Hospital of Chicago. Of those rare diseases, McIntosh said, only half have a patient advocacy group. Among the biggest challenges parents and children diagnosed with a rare disease face are misdiagnosis, treatment inequity and isolation. Without a support system, families are left to fend for themselves.

“I hope that this book can save a parent time, so that mother knows that she’s not alone,” McIntosh said. “There are others like her on this journey, and there are tools and systems and tips and things that can help her along the way. I hope this can meet and fill that critical gap in the market of information, strategies and emotional support, and really empower her to take care of her amazing child.”

The book includes tips and daily tools for how a mother can take care of herself while also taking care of her child. She also details some of these tips on her podcast, “Rare Mamas Rising,” each episode featuring honest conversations with mothers navigating parenting a child with a rare disease. McIntosh also travels to rare disease conferences, biotech events and patient advocacy meetings to further raise awareness for the challenges these mothers face.

“I give some really practical and concrete ways to create a plan for our own care,” McIntosh said. “I think coming from another peer, that peer-to-peer support from someone who’s lived it, can be really, really helpful.”

McIntosh calls “Rare Mamas” the book she felt called to write. She has been the mother receiving devastating news about her son’s diagnosis and has seen how difficult it is to find information. Now, she wants to make sure no other mother has to do it alone.

“Any diagnosis is difficult to navigate,” McIntosh said. “You put the word ‘rare’ on top of it, and it exacerbates the fear surrounding it, because so much of it feels unknown. I want this book to allow these mothers to see that there is a community out there who understands, and I think that community can really strengthen that mother. I hope she knows that we’re here, we’re rooting for her, and that this community is really a great source of support for getting everything that she needs to move forward.”

“Rare Mamas” was released on Sept. 23 and is available at Amazon, Bookshop.org, Barnes & Noble, Books-a-Million and various Indie booksellers. Learn more at raremamas.com.