

Williams Syndrome ? A Rare Genetic Disorder ? Creates Challenges in Some Children Far Beyond the Norm for Williams Syndrome

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In the spring of 1988, the Cincinnati Center for Developmental Disorders diagnosed three-year-old Michelle with Williams syndrome, a genetic disorder that most physicians had not heard of at the time of her diagnosis. Now, almost 30 years later, most doctors are somewhat familiar with Williams syndrome and the medical challenges that often accompany it, but few are aware of the struggles that haunt the parents when their child is atypical (not conforming to the usual type or expected pattern).

ANOTHER DAY, ANOTHER CHALLENGE, written by Marjorie Strebe, chronicles Michelle?s story from birth, through her diagnosis and delayed development, and the challenges her mother faced one after another.

From the doctors, who wouldn?t listen to Strebe?s concerns but blamed her for the baby?s failure to thrive, to the school faculty, who refused to learn about Williams Syndrome, so they weren?t equipped to meet Michelle?s educational or emotional needs, to Michelle herself? Between the child?s fascination with 911 and her love for the telephone, Michelle incurred exorbitant long distance charges, constant emergency room visits, complaints from the fire department, and chronic visits from the police department at all hours of the

day and night.

ANOTHER DAY, ANOTHER CHALLENGE mentions the distinguishing characteristics of the syndrome, and

it describes the unusual and difficult circumstances that the parents faced as Michelle led her family through

medical battles, social dilemmas, and obsessions galore. These unique challenges caused a special needs

child to fall through the cracks of every service designed to support her needs. It clearly showed where the

system failed, yet a conscientious doctor or teacher could have improved the situation.

Williams syndrome affects different people in different ways. And while these children deal with

developmental delays and learning disabilities, they often talk intelligently and are usually gifted in music. Yet

most people can?t see past their intelligence to identify and work with their learning disability.

?That was one of the biggest challenges I faced with family, friends, and the school system,? said Strebe.

?That is also one of the main reasons I wrote the book. I want to educate people on a syndrome few know

nothing about and help others recognize the best ways to offer much-needed support to the family.?

Dr. Marilee Martens, Williams syndrome specialist, added, ?While every parent?s experience with a special

needs child is unique, ANOTHER DAY, ANOTHER CHALLENGE shows that persistence and faith are

important when you?re doing your best to care for the child you love.?

Marjorie Strebe is a mother, grandmother, and author. You can find out more about her at

http://marjiestrebe.com and book aet her at

https://www.tatepublishing.com/bookstore/book.php?w=978-1-68028-543-7.

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