



Erica Aitken

# Reflection

**By Jacob Mandel**

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“Her eyes never opened,” Ms. Williams humbly proclaimed. Paradoxically, my eyes opened more than they ever had before. Destiny, an infant who had been crippled

by the force of nature, lay before me nearly flaccid in her mother’s arms.

Her heart would never know the soul of the mesmerizing island of which she is native. Her toes would never sink into the sand of the endless beaches of her homeland. In this boundless universe of infinite possibility she is destined to be locked in a form that renders her

human experience finite, impossible.

Destiny is two-years-old, and suffers from trisomy 18—Edward’s syndrome, caused by a presence of all, or part, of a third copy of chromosome 18. Babies with Edward’s syndrome are not expected to live past the first few weeks of life, let alone the first few years.

I had only encountered Edward’s syndrome in my studies, never in reality. With shame, I stood before her, only recollecting a mere glimpse of my previous course notes with which I was able to associate her suffering—rocker bottom feet, microcephaly. I recalled learning these terms for class, but would the brevity of my knowledge ever appreciably encompass the depth of complexity this disease entailed?

I feebly attempted to identify with her presumed anguish. As if it were not enough that every one of Destiny’s breaths possessed the risk of life-threatening aspiration, her mother’s most herculean efforts would never successfully negate the will of genetics.

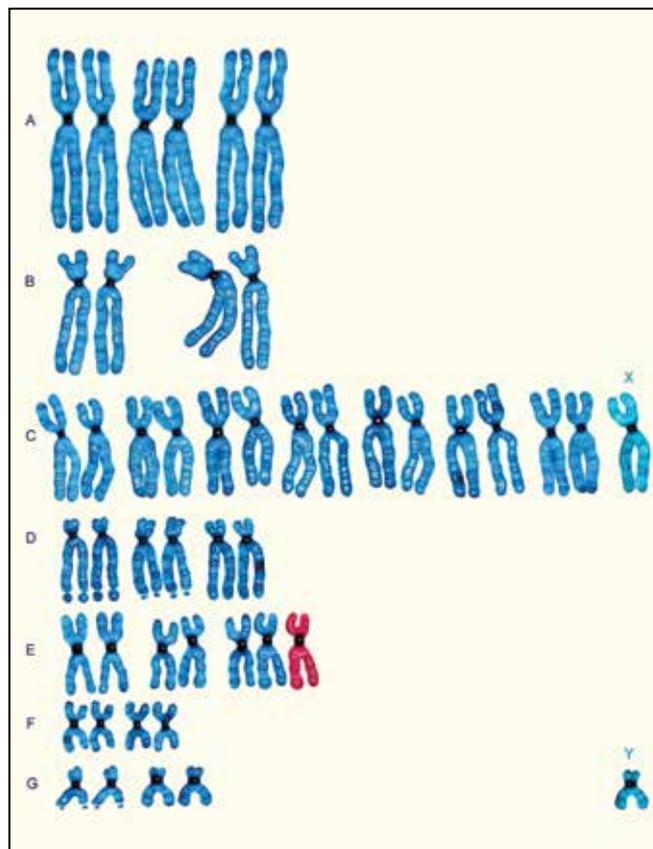
As Destiny squirmed restlessly, drool dripped down her face and onto Ms. Williams’ lap, but Ms. Williams remained unscathed. I recalled how, not hours before I whined about the inconvenience that the weather would have on my ability to make it into the hospital without soaking my white coat. I couldn’t help but wonder what Ms. Williams would give to watch her daughter jump in a puddle.

Did Ms. Williams feel aggravated that she sought help from the hospital, her daughter in distress, only to be pestered by students who cannot directly help her? Did she think we immediately typified Destiny, reducing her to a scientific specimen? Do the words “get well soon” resonate to a mother who loses more of her baby as every passing moment drifts away?

As most medical students would, my peers and I went through the motions, asking “What brings you in today?” “Was there anything significant about your pregnancy?” Yet, asking the question that we have unceasingly been taught to ask seemed to be the most arduous task of all, “How has giving birth to Destiny affected your life?” Would she be reluctant to respond? Would she welcome the question, as responding may be a potential outlet for her to drain her modestly kept sorrow? Must we remind her of the hand she was dealt?

For the first time in my minimal clinical experience, I was frozen.

The interview continued and then ceased, as all things do; the day went on just as any other. Still, an unshakeable residual aura lingered among the background noise.



Trisomy 18, set of severe congenital malformations, supernumerary human chromosome at the level of the 18th pair. Photo By BSIP/UiG via Getty Images

How long does Ms. Williams have before she loses her daughter?

A profound sense of admiration for Ms. Williams began to stir inside me. Against all odds, she fights for her daughter who cannot fight for herself. I also admire the physicians who, knowing the chances of her survival, continue to support and care for Destiny with enthusiasm. How their dedication must seem in the mind of a mother who probably feels as though she is losing everything.

It perplexes me to consider the meaning that my presence will carry in the lives of those individuals that I have yet to encounter. Who am I to become in the years ahead?

A concrete reflection of the significance of this experience and the impact that it has had on my life has been difficult to grasp. The lone tangible aspect of my feelings on the matter is manifest in my knowing that if I remain faithfully absorbed in my work, that if I channel my effort to best preparing myself for any of the countless scenarios that may present, then I may, one day, possess the ability to help someone surmount the apparently insurmountable.

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