

have vaccines. It would have been so ... different.”

I am suddenly ashamed of how terrifically spoiled I've become. In the office, I tick off the tetanus boosters and flu vaccines on the never-ending list of health maintenance items to keep up to date on my patients. I get irritated when the vaccines are out of stock. I never spend an iota of time wondering what would happen if those vaccines didn't exist.

And in my own life, I take vaccinations for granted too, dragging the kids to the pediatrician for another set of shots, dreading the fevers and crabbiness that occasionally follows. I would have had an aunt if these modern annoyances existed seventy years ago.

An hour later, our interview is over, but my sleeve is damp because the vision of a tiny, dark-haired girl lying alone and lifeless in an empty room refuses to leave my mind.

Days later, I call my father to ask what my aunt's name was.

“I cannot remember. Our family did not allow us to speak of her. It was too painful. I'll look it up in our genealogy records.”

A short time later, he emails back.

*Hyang-dong. Depending on how you look at the Chinese translation, it could mean “beautiful fragrance that comes from the east.” Or, “a beautiful beginning.”*

Her name makes me catch my breath for a moment. I start to type out a thank-you in response. Something shoves my legs away from the table where my computer rests.

“Mama, *off.*” It's Phoebe, her bright, dark eyes telling me to turn off the computer and play with her. I smile, and close my laptop.

**Lydia Kang MD**

General Internal Medicine  
University of Nebraska Medical Center  
Omaha, Neb.

This is a true account. Consent from the author's father was obtained.

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## CREATIVE WORKS

### Déjà vu

Two nights ago, I was working at my desk when a wave of déjà vu hit me and didn't leave. I felt like all this was familiar: the precise sentence that I wrote was identical to some perceived memory, the song that was playing was the same, I sat at my desk in the same position in the same room under the same circumstances as “before.” But the feeling didn't go away. I continued to live some already-lived memory, all my movements and sensations just as they were the last time. And I thought to myself, “How nice!” I am only 22 years old, and yet I am already 22 years old. How many things will I never experience again? How many landmarks have I passed forever, never to return? The intensity of the feeling of déjà vu washed those feelings away. For a moment, I was certain that every place and time I visited, I would one day return to. For a moment, living a good life wasn't just a goal of being happy and proud of good decisions for now, but for the next time around, for the happiness and pride of a future me. The song changed, the moment was lost, the feeling drifted away, leaving



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only traces, memory, confusion, awe, and a silent resolve.

Yesterday, I visited a dying man. He was in the palliative care unit, dying of a prostate cancer that wouldn't leave him alone. Its latest injustice, only months ago, was perpetrated on his spinal cord. He is now paraplegic, confined to a wheelchair. He revisited his life for me and some classmates of mine. Sixty-two years he has lived. Thirteen of those years he has had cancer. But he has no regrets, a loving wife and daughters, a passion for life. His youngest daughter is pregnant with his first grandchild, a girl. Her due date is July 23, six months and nine days from today. His modest yet ambitious goal is

to be alive to hold his granddaughter. He doesn't consider himself dying. But he also doesn't know if he'll make it. He doesn't ever expect to return home.

He spends his days reading and entertaining visitors. His family visits whenever they can. The hardest thing to deal with is the difficulty his condition has placed on his family. The second hardest thing to deal with is his sudden immobility. He can't walk, he can't take care of himself, he can't change position in his bed on his own. He hates depending on others. He used to travel often. He stayed at his job as a manager of an international company until three years ago. Now he lives to make it to July 23.

A few months ago, he had an MRI. As he lay with his face inches away from the off-white plastic, with the machine's gears grinding loudly, he drifted off, and relived his trip to the island of Santorini, in Greece. In his mind, as he relived it all, he could walk. He lived without fear, and walked with his wife, who he could hold, and be free with, and make love to. In that moment, he captured *déjà vu*, and used it to live forever, for a small while.

**Ariel Lefkowitz BA BSc**  
Class of 2013  
McGill University  
Montréal, Que.

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## BOOKS

# Searching for the value of the imperfect

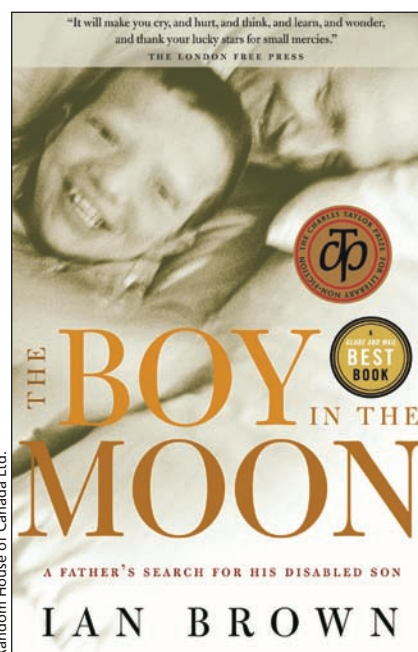
## The Boy In The Moon: A Father's Search for his Disabled Son

Ian Brown

Random House of Canada Ltd.; 2009.

Walker Henry Schneller Brown is a child of modern medical science. Born with the rare genetic condition, cardiofaciocutaneous syndrome, he is medically complex and fragile and would not have survived his first months of life had nature been left to take its course. Now, at 13 years of age, Walker functions like an 18 to 24 month old. *The Boy in the Moon*, written by Walker's father, *Globe and Mail* journalist Ian Brown is the deeply moving account of a father's search for his disabled son. Brown likens Walker to the man in the moon "you see the face of the man in the moon, yet you know there's actually no man there. But if Walker is so insubstantial, why does he feel so important?" His search is one "for the value of a life ... lived in the twilight and often in pain and ... the cost of his life to those around him?"

Brown treats readers to an enlightened account of human potential and worth. While conveying the gravity of Walker's life and life with him could overwhelm a reader, in the gifted hands



Random House of Canada Ltd.

of Brown the reader feels, but does not suffer his anguish. Through juxtaposing accounts of his despair with quirky, sometimes black humour and poignant moments between father and son, Brown lifts us and in so doing draws us deeper into his search for the value of an imperfect life. Brown's style is exemplified in the following account: A neuroradiologist shows Brown an MRI contrasting a normal corpus callosum to Walker's;

Walker's was just a fraction of the normal width. Brown is devastated, "Its hard to describe how quickly it crushed me ... " Continuing, the physician explains, "So that means there's a lack of connectivity in your son's brain." Recognizing that ... "the corpus callosum is the information highway of the brain," Brown concludes that "... Walker's brain subscribed to a crappy Internet service that constantly broke down and misdelivered messages ... " The MRI revealed nothing about Walker that Brown had not already known, but through this offbeat account Brown ponders the profound: "Without a knowable brain, was Walker a knowable boy? If he wasn't what was his value?"

Many of the physicians Brown encountered were confounded by Walker's case and distanced themselves from him and their inability to offer a cure. Others like Paul Wang a developmental pediatrician and cardiofaciocutaneous syndrome researcher from Philadelphia's Children's Hospital, admitted the limitations of medicine, and engaged in Brown's search for meaning. Wang delivers the devastating diagnosis of significant developmental delay and the necessity for life-long support, but doesn't conclude the interview, instead he asks for questions.