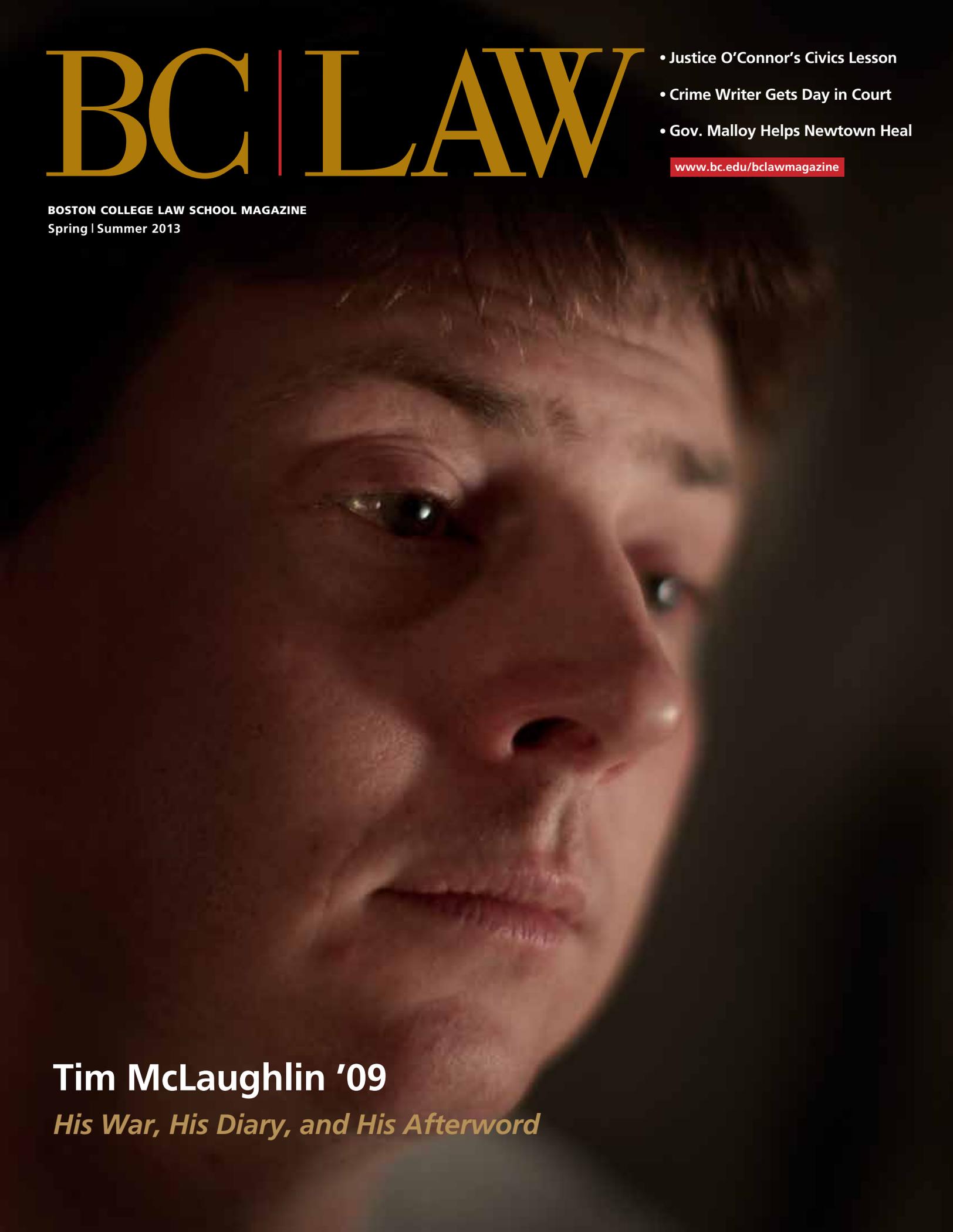


BC | LAW

- Justice O'Connor's Civics Lesson
- Crime Writer Gets Day in Court
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Tim McLaughlin '09

His War, His Diary, and His Afterword

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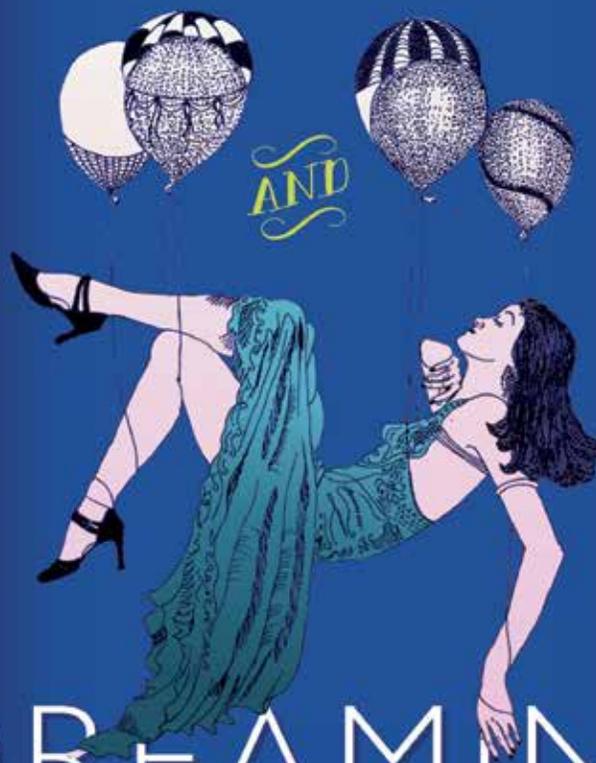
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COVER: Photo of Timothy McLaughlin '09 by Gary Knight

WIDE AWAKE



DREAMING

Julie Flygare

A MEMOIR *of* NARCOLEPSY

COVER DESIGN: CECILIA SOROKHIN; ART: LUCY THILLENBRAND

Flygare's new book chronicles a nightmare with a happy ending

AS A FIRST-YEAR STUDENT AT BC LAW SCHOOL, Julie Flygare '09 thought she was at the top of her game. At Brown University, she'd been captain of the varsity squash team and a good student of creative non-fiction and art history. She was a runner, a natural competitor, someone who was up to the law school challenge. Until she wasn't. Strange, embarrassing things began to happen: painful urges to sleep (sometimes in the classroom), extraordinary dreams, muscle weakness that caused her knees to buckle when she laughed or cried. The following excerpt is from her memoir, *Wide Awake and Dreaming*. It chronicles an early moment in Flygare's battle with narcolepsy and cataplexy, neurological disorders that made her life a living hell but over which she has ultimately triumphed, thanks in part to the mentoring of Professor Mary Ann Chirba and others at the Law School.



East Wing 115 was a stadium-style classroom in the basement of Boston College Law School, where my Property Law class was held. Instead of windows, only a few orange-tinted bulbs dimly lit the subterranean room. Silhouettes filed in from the hallway. The projector hummed softly, emanating a stream of blue and green flickers onto the large screen

at the front of the room.

Everything was state-of-the-art, from the wireless internet and electrical outlets at each seat to the rotating chalkboards, dry erase boards, and projection screens. My law school section, all eighty-five of us, settled along the various tiers of the underground coliseum, staring into glowing laptop screens—our only connection to the outside world.

At the front of the room, a quiet man in his forties, Professor Joseph Liu, stood looking into his own computer screen, preparing to start our class. A few students chatted softly with neighbors. I fanned through the 1,000-page textbook to find the cases assigned for the day.

At exactly 2 p.m., Professor Liu looked out at the students and everyone fell silent. He opened his mouth to inhale, and we placed our hands above our keyboards as if he were the conductor of a grand orchestra.

When he spoke, the clicking began, softly at first, in the front row with the especially eager students typing away. As he continued on past logistic announcements into course material, more students joined in the chorus, reaching a crescendo about twenty minutes into class, when Professor Liu made a particularly important point. At that time, the entire room fluttered with the pitter-patter of various electronic notes.

At this point, we were only a few weeks into our first semester and our note-taking was mostly

word-for-word lecture transcription. I was still learning to interpret the language of the law, so I followed along, typing almost every word that crossed Professor Liu's lips, afraid I might miss a nugget of wisdom that would be on the exam—the key point that would be the difference between an A and a B, the divide between getting the big, fancy job I wanted and being rejected.

Yet, this particular day my desire to record every second of class came up against another, equally strong desire—a dark and unwelcome compulsion to go to sleep.

About halfway through the class, a heaviness came over my head, with a weight sitting on my skull. Next, my shoulders and elbows began to ache and a wave of nausea crawled up my stomach. I shifted in my chair to find a more comfortable position and stretched my head to one side and then the other, hoping to dislodge the uneasiness swelling inside me.

Property class was an hour and twenty minutes long. I checked the clock on my computer; it was 2:52 p.m.—only twenty-eight more minutes to go. I returned to typing feverishly.



FLYGARE, left, credits Professor Chirba for giving her the courage to write a book.

PREVIOUS PAGE: jacket of Flygare's book.

Julie Flygare Dreams Anew

"Who's to say that dreams and nightmares aren't as real as the here and now?"—*John Lennon*

The exhaustion that Julie Flygare felt in law school was nothing like that of a typical student. Hers was a nearly catastrophic fatigue—mysterious at first, then frightening, and finally, life-altering. Her disease, a complex neurological condition known as narcolepsy with cataplexy, disrupted her studies, ruined some of her relationships, and tormented her physically and emotionally.

She entered BC Law in 2006 at the age of twenty-two. With an undergraduate degree from Brown University in art history, she aspired to become an arts and entertainment lawyer. Athletic, smart, and determined, Flygare fit the profile of someone who achieved her goals.

But her brain—and neurological system—had other plans for her, all of which are described in harrowing detail in her cathartic new book, *Wide Awake and Dreaming: A Memoir of Narcolepsy*.

Flygare's story has a happy ending. Moving to Washington, DC, after graduation, she became an effective advocate for narcolepsy research and policy and is founding a nonprofit to raise awareness about sleep health and disorders. She established an informative, upbeat blog, julieflygare.com/rem-runner-blog/, which has garnered the attention of fellow sufferers, the press, health experts, and policy makers. She led a successful campaign to have narcolepsy selected for the FDA's Patient-focused Drug Development Initiative, a dark horse victory that ensures official scrutiny of the often overlooked disease. Despite the risk of sudden muscle failure because of cataplexy, she ran the Boston Marathon in 2010 and the Mt. Washington Road Race in 2012.

First, though, she endured confusion, frustration, and sorrow as she saw the life she'd known, and the future she'd expected, slip away during her law school years.

"At first, I only saw what narcolepsy took away from me. I was angry and grieved for the 'stronger' person I'd been before," she wrote in the Spring 2012 issue of *Community* magazine, a publication of the Caring Voice Coalition. "Then, something shifted. I realized that 'health' was not a guaranteed, full-package ride. Narcolepsy woke me up to my life."

Helping along the way were people like Professor Mary Ann Chirba, who had Flygare in Health Law class. Chirba was so impressed by a paper that Flygare wrote about the Orphan Drug Act's efforts to incentivize big pharma to develop therapies for rare diseases like hers, that she urged her to take her writing seriously and pursue it professionally.

"I feel beyond lucky for Professor Chirba's support," says Flygare. "She gave a voice to my deepest dream of writing before I had the courage to admit that dream myself."
—*Vicki Sanders*

I tried to ignore the burning sensation at the back of my eyes but the harder I worked to keep my eyelids open, the more it felt like a ferocious fire blazing behind them. I glanced at the bottom of my computer, 2:53 p.m.

Soon, Professor Liu's voice faded. Some of his words echoed over and over while others went missing. I squinted to try to read the large font of his slideshow. My typing slowed to a lethargic pace. The lecture slipped like sand through my fingers.

Eyes open, Julie. Just keep your ...

Next, I opened my eyes and made direct eye contact with Professor Liu. I had no idea how long my eyes had been closed. Embarrassment flooded my body, and suddenly, I was freed from my struggle against sleep. The weight lifted off my skull and the flames died down behind my eyes.

All too soon, the heaviness returned and began seeping downward in my skull, sucking at my strength again. The time was now 3:03 p.m. I walked out into the hallway. Dizzy and only partially aware of my surroundings, I wandered toward the bathroom, as if through a fun-house wavy mirror maze.

I stumbled into a stall and sat down. My head collapsed over my arms and legs. I just needed to rest. Consciousness drifted from me and I started sliding off the toilet seat. I whipped back to attention. The bathroom was silent. Thankfully, no one else was there.

The heaviness still sat on my skull. My mind teetered between the bathroom and darkness. I tried pinching the skin of my forearms to wake up. I started slapping my face. With increasing intensity, I slapped myself again and again as hard as possible. These slaps were satisfying, not only because they woke me up, but also because they released a rage in me for not having the backbone and discipline to perform the simplest of tasks, of *just... staying... awake*. When I'd had enough, I jumped up and down a few times, like a boxer preparing to enter the ring.

Out of the stall, I looked in the mirror at the girl with glassed-over eyes. *What is your problem?* I splashed cold water on my face and patted a wet paper towel under my chin and against the back of my neck, hoping to refresh myself.

I took a few deep breaths and rearranged my hair to curve my bangs over my forehead. I straightened the collar of my pink dress shirt. On the outside, everything looked right.

The fog had lifted. I returned to class with eyes turned downward, hoping Professor Liu wouldn't notice me again, the same student whom he'd caught sleeping minutes earlier. The time was 3:13 p.m. I'd missed ten minutes of precious lecture time.

Placing my hands back on my keyboard, I scrolled up to review my notes. The top of the page was organized neatly in a variety of fonts and bullet points. Half way down, the order fell to pieces—with half-sentences, words standing alone, and even letters that formed no words at all. Legal terms co-mingled with random places and names from outside of law school. My stomach tightened. I'd interwoven the lecture with a dream in a nonsensical stream of consciousness.

Drawing my cursor over the scrambled words, I quickly erased the gibberish.

The last few minutes of class passed fairly smoothly, with only a few minor dips toward sleepiness. I closed down my computer after class, knowing there were major gaps in my notes, but I'd have to catch up later. What concerned me most was escaping the law school basement.

Excerpted from Wide Awake and Dreaming: A Memoir of Narcolepsy, Mill Pond Swan Publishing, Arlington, VA (2013), with permission of Julie Flygare. Copyright © 2013 by Julie Flygare. To obtain the book and learn more about Flygare's life and work, visit www.julieflygare.com.