

Waking Up the Nation,
One Reader at a Time...

PUBLIC HEALTH ALERT

Over the Edge by Brandilyn Collins: A Must-Read



by **Linnette R Mullin**
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Over the Edge is a must-read. Brandilyn Collins expertly weaves a story representing the life of Lyme patients with precision and empathy. Though an issue-based novel, the story doesn't feel issue-based. It feels like mystery, suspense, intrigue, and for us Lymies, *real life*. What a great way to show the world how Lyme sufferers live!

Brandilyn Collins is a best-selling author known for her trademark Seatbelt Suspense®. Her crime thrillers earned her the tagline "Don't forget to breathe..."® Her first book, *A Question of Innocence*, was a true crime published by Avon in 1995. Its promotion landed her on local and national TV and radio -

including the *Phil Donahue* and *Leeza* talk shows. Her author awards include the ACFW Book of the Year (three times), Inspirational Readers' Choice, and Romantic Times Reviewers' Choice.

Brandilyn is also known for her unique book on fiction-writing techniques, *Getting Into Character: Seven Secrets a Novelist Can Learn From Actors* (John Wiley & Sons). *The Writer* magazine named *Getting into Character* one of the best books on writing published in 2002.

When she's not writing, Brandilyn spends time teaching the craft of fiction at writers' conferences. She and her family divide their time between homes in the California Bay Area and northern Idaho.

Now, for more about her latest novel, *Over the Edge*:

1) Why did you write *Over the Edge*?

I wrote *Over the Edge* to tell a good suspense story. But beyond mere entertainment, I wanted to help shed light on the difficult struggles of thousands of Lyme patients in this country. I hope the novel helps individuals out there. Perhaps you. Perhaps someone you love.

2) Does any of the story reflect your personal experience?

I haven't just studied Lyme. I've lived it.

Remember Jannie McNeil's fall in her kitchen, and her inability to get up? That's straight out of my own life. When Lyme hit me, it came fast and hard. Until that day I had been a healthy, fit, five-miles-a-day runner. Fortunately I had a friend who recognized the symptoms and insisted I go for testing. From there I linked up with a Lyme-literate doctor. Most fortunate of all, God chose to miraculously heal me from the disease months later. But not before I'd lived the nightmare of Lyme. Six years later in 2009 I was re-infected and conquered it after six months of antibiotic treatment.

I remember slumping in the waiting room of my doctor in 2003, so sick I could not remain sitting in the chair. (They had to move me to the doctor's personal padded armchair with footrest in a private office.) Hanging on the waiting-room wall was a framed newspaper article summarizing the 2001 findings written in *The New England Journal of Medicine*. (While Brock McNeil's part in writing those findings is fictional, the find-

ings themselves are very real.) The newspaper article explained how researchers had once again proved that Lyme was never chronic and was, in fact, very easy to treat with a short-term round of antibiotics. People claiming months or years of crippling symptoms from the disease were just wrong.

What those know-it-alls need, I thought with an admittedly un-Christian attitude, is a real good case of Lyme.

And so the idea for this novel was born. It would take another seven years before I was ready to write it.*

3) How much of your novel is true to life and how much of the Lyme wars are real?

In *Over the Edge* the background information about Lyme disease and the Lyme wars is straight out of my research. To this day many Lyme patients have to fight for diagnosis and treatment. But beyond that, this book is a work of fiction. The characters are in no way real. Brock McNeil does not represent any one doctor. Rather, he arose from my own imagination as a combination of researchers who still deny the existence of chronic Lyme as an active infection. In placing

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him at the Stanford School of Medicine I'm casting no aspersions on that respected institution. It simply provided a setting for my story.

One other fictional point to note: In *Over the Edge*, Jannie's test results from the Lyme lab were available within about six hours. I wrote it that way to keep my story moving. In reality, results could not be ready that quickly.

Fiction aside, the Lyme wars go back a number of decades. It's a complex war with complex arguments, but simplified it comes down to these two sides: Lyme-literate doctors-working in the trenches with very sick patients-who believe long-term antibiotic treatment is effective, vs. doctors aligned with such powerful entities as the Centers for Disease Control (CDC) and the Infectious Diseases Society of America (IDSA), who deny the existence of chronic Lyme as an active infection. The latter group of doctors insist that long-term patients suffer from a post-Lyme treatment syndrome-some form of autoimmune disease as yet unknown and undefined. This "syndrome" should only be treated symptomatically, they say, and not with antibiotics.

As *Over the Edge* depicts, the Lyme wars arise from these four factors, which form a vicious circle:

First, **Ineffective testing**. The CDC criteria for administering and interpreting tests have been controversial since they were approved in 1994. The CDC insists on a two-tier form of testing, starting with the ELISA test, then proceeding to the Western blot only when the ELISA is positive. Unfortunately all too often a negative ELISA is a

false negative because of the test's poor sensitivity. (Although the CDC insists the test is sensitive.) So many patients are lost right there.

Second, **Lack of education among doctors**. Lyme-literate docs are few and far between. The rest simply don't know enough about the disease, relying on outdated information as to where Lyme is found and what its symptoms are.

Third, **Doctors' fear of treating chronic Lyme**. Many of the doctors who treat Lyme with long-term antibiotics are taking a great risk. Some Lyme-literate docs have had their licenses pulled. They've been sued by insurance companies, who didn't want to cover the expensive drugs. Even a reputable doctor who recognizes a case of Lyme may refuse to admit it because he simply does not want to get caught in the Lyme war crossfire.

Fourth, **Misdiagnosis**. Since the patients are really sick and Lyme is ruled out through misuse of the CDC criteria and poor testing-well, they must have something. That "something" often is misdiagnosed as Chronic Fatigue Syndrome, Fibromyalgia, Multiple Sclerosis, Parkinson's, Rheumatoid Arthritis, and other diseases. Either that or the symptoms are just "all in their head." (Which some doctors have been known to claim.) The problem with misdiagnosis isn't just the lack of right treatment, but the introduction of wrong treatment. For example, CFS patients are often given steroids to combat their swollen, painful joints. The problem is, steroids suppress the immune system and therefore are never given when a doctor knows a

patient has an active infection of any kind. Bacteria are left to thrive in an immune-suppressed body. The Lyme patient gets worse.

For more detail, see my author's note at the back of the book or on my website. You will also find stories of real people suffering as a result of the Lyme wars.

In 2009 a national hearing was held, during which physicians and scientists on both sides of the debate presented their research data regarding Lyme to the review panel. Some of the presentations arguing against the IDSA guidelines are included in my author's note, as well.

I will say, however, that all findings from the hearing which proved that *Borrelia burgdorferi* exist after the IDSA-recommended two to four weeks of antibiotics were completely discounted.

In my novel, *Over the Edge*, Jannie reads an abstract of research that proves *Borrelia* continue to exist in mice after the recommended four weeks of treatment. This was taken from the article "Persistence of *Borrelia burgdorferi* following Antibiotic Treatment in Mice" by Emir Hodzic, Sunlian Feng, Kevin Holden, Kimberly J. Freet, and Stephen W. Barthold. from the University of California at Davis. The full paper can be found online at: <http://aac.asm.org/cgi/content/abstract/52/5/1728>. *

4) What advice would you give someone who thinks they may have Lyme Disease?

If you are experiencing muscle weakness, joint pain, confused thinking, or other symptoms mentioned in

this story, you owe it to yourself to be properly tested for Lyme. Don't allow doctors in your area to dissuade you from tests by claiming it doesn't exist in your state. And to ensure results are as accurate as possible, have your blood sent to a lab dedicated to testing for Lyme. There are numerous organizations and online sites that can help with information.

5) Which resources do you recommend?

There are a dozen resources listed in the author's note at the back of my book and on my website, but here are a few:

a. **Lyme Disease Research Database**. Covering "Lyme disease symptoms, treatment, diagnosis, prevention, and research." Members receive access to the large database of LDRD resources. (<http://www.lymedisease-research-database.com>)

b. **Lyme-Aware**. This organization was formed to "create a unity among all of the [Lyme] organizations, websites, blogs, authors, etc." (www.lyme-aware.org)

c. **Advanced Topics in Lyme Disease** by Dr. Joseph J. Burrascano. This is an in-depth medical abstract about the symptoms and treatment of the disease. The symptom checklist is particularly helpful if you are experiencing symptoms that might be caused by Lyme. (<http://www.lymenet.org/BurrGuide200810.pdf>)

d. **Under Our Skin**, an award-winning documentary that follows the stories of numerous

Lyme patients and includes interviews with doctors on both sides of the Lyme wars. *Under Our Skin* is well worth watching. It is both heart-breaking and hopeful. You can see firsthand what the symptoms of Lyme look like. And you'll be amazed at certain doctors' attitudes against recognizing the chronic form of the disease. You can order a DVD of the documentary from its web site at <http://underourskin.com>.

e. **Cure Unknown**, by scientific journalist Pamela Weintraub. This book is a highly researched and fascinating look into the Lyme wars, from their beginning history to present day. Weintraub and her entire family were infected with Lyme disease after moving to an idyllic setting in Connecticut. Her ensuing years of discovery about the disease and its controversy within the medical community make for a richly detailed and often horrifying picture of the patients and doctors embroiled in the battle.

f. **My own web sites** contain answers to questions about Lyme disease and links to helpful organizations. See www.brandilyncollins.com and www.seatbeltsuspense.com. On my Lyme-Over the Edge blog are many incredible stories of Lyme patients and their struggles, including my own. Read these stories, and you'll understand how they suffer, and why they continue to cry out for proper testing and treatment. (www.lymeovertheedge.blogspot.com)

6) How can our readers get a

hold of you?

I always love to hear from you. You can contact me from my web site. I am also on Facebook: www.facebook.com/brandilyncollinsseatbeltsuspense and Twitter: www.twitter.com/brandilyn.

7) **Just for fun, most writers have a favorite beverage they enjoy sipping on while writing. What's yours?**

My morning mocha, made by moi at home on my handy-dandy espresso machine.

Brandilyn, thank you for all your research and the time you put into this novel. As a fellow writer, I know the emotional battles waged when writing a book. This could not have been an easy book to write. A Lyme sufferer myself, it was difficult to read. Not because it was poorly written, but because it was written so well. The entire story is very true to life and I admire the way you ended the book - realistic to Lymies and yet allowing for some closure. You did an amazing job! Thank you for sharing our story with the world through this work of fiction!

"God's blessings and health to all of you." ~Brandilyn Collins

*Due to the length and detail of Brandilyn's answers along with her busy schedule, much of her answers are excerpted from her author notes and published with her blessing.

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