

Run to the Light

By Laura King Edwards

Laura has it all: a great job, a loving family, a new husband, and a house in her hometown, where she can watch her sister, Taylor, grow up. But one month after her wedding, Laura and her family receive shocking news: Taylor has Batten disease. A rare, fatal disease that will cause Taylor to go blind, suffer seizures, and lose the ability to walk and talk. There is no cure. Laura thought she'd get to watch her baby sister grow up, but instead she'll have to watch her die.

Unwilling to take no cure for an answer, Laura founds a charity with family and friends, Taylor's Tale, to save children with the disease. Meanwhile, Taylor starts running, completing her first race blind. Inspired, Laura, a lifelong runner, begins running in half marathons to raise money and awareness. And also to run away from the pain.

Taylor's Tale becomes a world leader in the fight against Batten disease, but not quickly enough to save Taylor. Stripped of her faith, Laura falls into a dark despair. But Taylor's unwavering courage in the face of certain death gives Laura a renewed sense of purpose to turn her family's tragedy into an opportunity — to ensure others won't have to suffer as her sister has suffered.

A Conversation with the Author

1. Why should people read *Run to the Light*?

Run to the Light is a fascinating narrative about a family faced with a heart-wrenching, traumatic situation.

Stories of others' unfortunate situations broaden our perspective of our own personal traumas. They help us find hope even in a situation where there is no clear solution. Some readers also like to know about bad situations that could happen, so they're more prepared in case one does.

The medical and science side of the story will intrigue some readers as well. Others might be runners who also use running as a way to deal with stress and pain and to work out problems and have achievements they might not otherwise have in other areas of life.

There are of course a variety of reasons a reader comes to a book, and this book hits on a half-dozen different possibilities.

2. Running plays a role in your story. What does *Run to the Light* have to offer to people who don't run?

This is a story of family, of facing incredible odds, and of how to deal with a negative outcome. We see so many uplifting stories of overcoming staggering odds, but most people facing their own horrific diagnosis or that of a loved one have a hard time even finding information on how to deal with life if the miracle cure doesn't come. How do you keep fighting? Where do you find the strength to go on? In our lives, even if we don't face a fatal medical diagnosis, we all at some point face some uphill struggle, and sometimes one that feels insurmountable. *Run to the Light* is an encouraging example of what can happen when we're determined to find a path forward through the darkness.

3. Talk about your inspiration for writing the book.

I wrote hundreds of short stories before I studied fiction writing in college, but I never planned to write a memoir. In 2006, I was a recent college graduate working on a young adult novel when my seven-year-old sister, Taylor, was diagnosed with a rare, fatal genetic condition called Batten disease. The news changed everything for Taylor, our family, and me. *Run to the Light* was born out of my own decade-long experience fighting a battle more difficult than anything I could have imagined.

My family's fight against Batten disease has never been easy, but I wrote *Run to the Light* after going through a particularly tough time, during which I nearly lost my will to move forward or my ability to believe in anything good. Before I could see the path forward, I had to be blinded by the pain of watching someone I love suffer. Yet Taylor has never faced her illness with anything less than courage. People think I'm brave, but I wish I could be half as brave as my little sister.

Run to the Light isn't really about Batten disease. It isn't really about running. Instead, *Run to the Light* is about finding the good in each day. It's about having the will to believe, even if "believe" doesn't mean what you once thought. It's about turning a loss into a legacy.

I wrote this book as a love letter to my sister and to raise awareness of Batten disease. But I hope it also serves as a testament to the strength of the human spirit, and I hope it helps readers find the courage to face whatever they're fighting.

Readers' Group Guide

1. How do you think Laura's family's advocacy for Taylor helped them cope with Taylor's diagnosis?
2. Some members of the family, like Laura and her mom, jumped into activism and research. However, others, such as Laura's father and her brother, weren't as involved. Are you more of an active fighter, sidelines cheerleader, or passive bystander in a difficult situation? Can you see roles for all three types of people in fighting a health problem?
3. Do you wish Laura had discussed her feelings more? What do you think she was feeling at different points? How do you think you would have reacted in this situation?

4. Do you have an escape for stress like Laura has running? What is it? How did Laura's running help her understand and come to terms with Taylor's condition?
5. Have you ever participated in a charity race? How did it make you feel?
6. If your family carried a potentially serious gene mutation, would you want to know if you were a carrier? What would that knowledge change about the way you live your life? How would it change your relationship with your family?
7. What is the meaning of the title?
8. Given the large age gap between Laura and Taylor, are you surprised by the bond between them? Are you closer to your siblings who are close to you in age or far apart? What roles do children in a family typically assume? How do those roles play out in the King family?