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11 Best New Cystic Fibrosis Books To Read In 2022

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1



Little Matches

A Memoir of Grief and Light

Maryanne O'Hara (You?) | Apr 19, 2021

| ★★★★★ 4.25

“Gripping and true in all ways. This fine, affecting memoir will stay with me for a very long time.”—Meg Wolitzer, author of *The Female Persuasion* “In this vividly written memoir novelist O’Hara shares a painful but ultimately beautiful account of her daughter Caitlin’s life with cystic fibrosis. . . . Her compelling story will resonate with anyone seeking a light in the darkest depths of grief. [...more](#)

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See also: [Grief](#), [Memoir](#)

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2



Scars Tell Stories

From a Cystic Fibrosis and Heart/Double Lung Transplant Patient

Dan Lagasse, Doug Lagasse (You?)

| Sep 24, 2020 | ★★★★★ 4.08

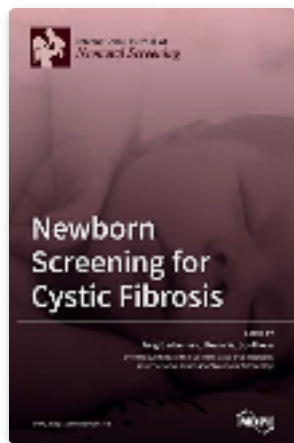
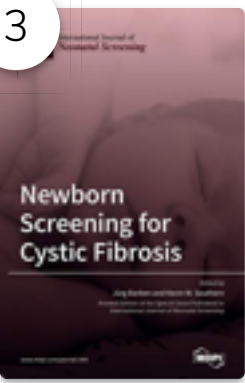
Inspiring stories of courage in the face of illness and of hope when all looks bleak. Dan tells his personal journey fighting cystic fibrosis, receiving a heart/double lung transplant and his battle with a litany of other illnesses - in nine different countries! Discover how our scars can become trophies of victory. Be encouraged with deeper truths about life and death, that give promise and not despair. Live! [...more](#)

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3



Newborn Screening for Cystic Fibrosis

Jürg Barben, Kevin W Southern (You?)

| Sep 13, 2020 | ★★★★★ 4.13

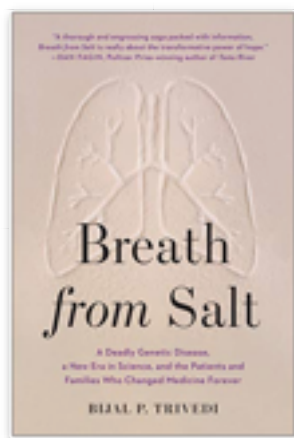
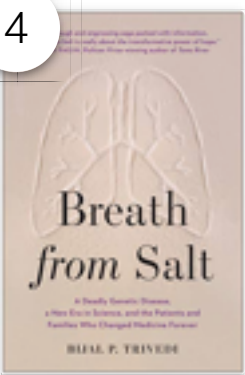
The introduction and widespread implementation of newborn bloodspot screening (NBS) for cystic fibrosis (CF) has offered earlier diagnosis and better outcomes for children with CF in many countries of the world. It represents a paradigm shift in the diagnostic pathway for these families. In contrast to a clinical diagnosis, infants are now referred for diagnostic testing after a positive NBS result. The introduction of NBS has enabled the provision of early appropriate treatment to prevent the manifestations of the disease. [...more](#)

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Breath from Salt

A Deadly Genetic Disease, a New Era in Science, and the Patients and Families Who Changed Medicine Forever

Bijal P. Trivedi (You?) | Sep 7, 2020 |

★★★★★ 4.26

"Elaborating on the science as well as the business behind the fight against cystic fibrosis, Trivedi captures the emotions of the families, doctors, and scientists involved in the clinical trials and their 'weeping with joy' as new drugs are approved, and shows how cystic fibrosis, once a 'death sentence,' became, for many, a manageable condition. This is a rewarding and challenging work."

—Publishers Weekly Cystic fibrosis was once a mysterious disease that killed infants and children. [more](#)

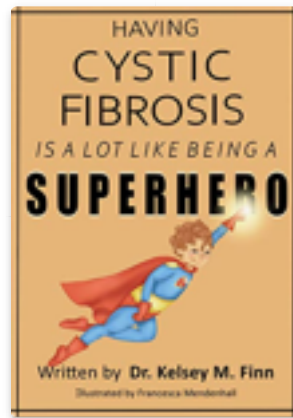
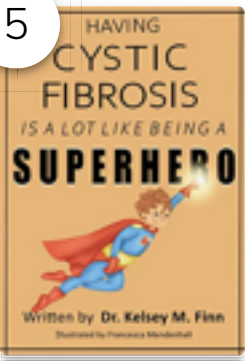
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See also: [Genetics](#)

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Having Cystic Fibrosis Is A Lot Like Being A Super Hero

Dr. Kelsey M. Finn, Francesca Mendenhall (You?) | Jul 23, 2020 |

★★★★☆ 4.11

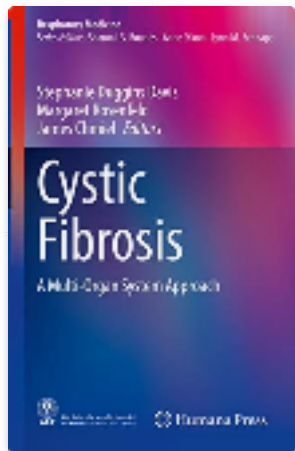
This book tells the story of Jack, a boy who has CF, and his CF Superpowers. This book is intended to serve as a way to communicate with children about CF, to embrace and foster acceptance of the human condition, and help children understand what Cystic Fibrosis means for themselves or someone they know who is affected by Cystic Fibrosis. The book also contains a section for parents of tips of how best to communicate with kids about CF. The tips in this section are based on empirical, peer-reviewed research. [...more](#)

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6



Cystic Fibrosis

A Multi-Organ System Approach

Stephanie Duggins Davis, Margaret Rosenfeld, James Chmiel

(You?) | May 21, 2020 |

★★★★☆ 4.13

This book provides a comprehensive overview of the multisystem disease, cystic fibrosis, for both pediatric and adult patients.

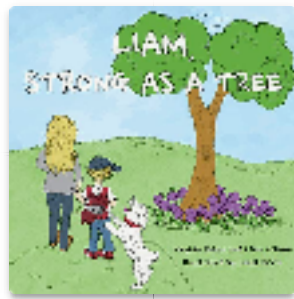
Written by experts in the field, the text outlines the progressive nature of CF as well as the impact of this autosomal recessive disease on the respiratory, gastrointestinal, endocrine, rheumatologic, and renal systems, as well as the patient's mental health. The book begins with a chapter describing the history of cystic fibrosis and how the face of this life-shortening disease has changed over the past several decades. [...more](#)

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Liam, Strong as a Tree

Meghan Behse, Liam Wilson, Leesa Ervin

(You?) | May 4, 2020 |

★★★★☆ 4.38

Liam couldn't be happier. He's off to kindergarten, where he's going to make a million new friends and learn a billion new things! Mom is worried about Liam going to school, but Liam knows he'll be fine. He has his oxygen mask and his medication for lunch and snack time. Plus, he knows he's strong as a tree. You see, Liam has a great big tree in his backyard. Mom says trees need lots of oxygen from the air, just like his lungs. And they need food from the ground, just like his tummy. Sometimes, their tree gets sick, sicker than the other trees. [...more](#)

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Loving Someone Who Is Dying

Choose Your Attitude Create Your Life

Nicholas Strand (You?) | Apr 6, 2020
 | ★★★★★ 4.54

A story of inspiration and hope. Heartbreak and reality. A quiet lesson in grace and acceptance from a young woman who saw life as an opportunity even when she was given a medical death sentence. Diagnosed with Cystic Fibrosis at age three, Brianna Oas Strand was told she wouldn't live past thirteen. A tragically short life spent in and out of hospitals, ruthless infections, medical trials and treatments, and no promises. But with a superhuman spirit and the support of her family and community, Brianna fought for not only each breath but to put life into each breath. ...more

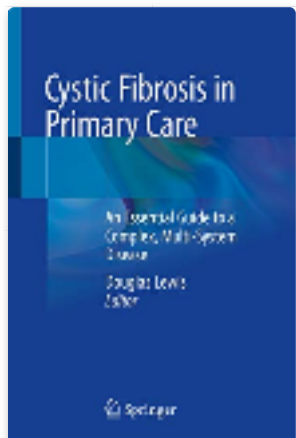
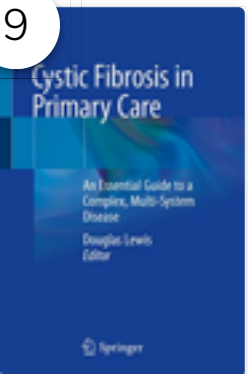
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See also: [Dying](#)

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9



Cystic Fibrosis in Primary Care

An Essential Guide to a Complex, Multi-System Disease

Douglas Lewis MD FAAFP (You?)
 | Jan 28, 2020 | ★★★★★ 4.13

Cystic fibrosis is a disease that affects the entire body. It tends to be thought of as primarily a pulmonary disease since pulmonary decline is the main factor in early mortality. Because of the multi-system nature of the disease, a better understanding of cystic fibrosis expands the family physician's understanding of subjects

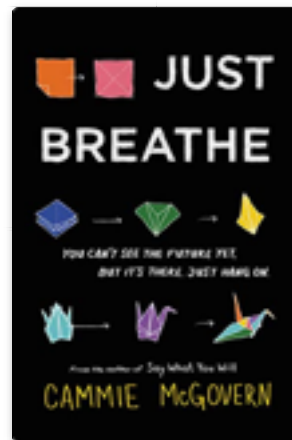
ranging from genetics to pulmonary function to nutrition to colon transport to hydration to electrolyte management. The primary care philosophy is unique in that it always considers how a narrow problem can affect an individual globally. [...more](#)

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Just Breathe

Cammie McGovern (You?) | Jan 6, 2020

|  4.14

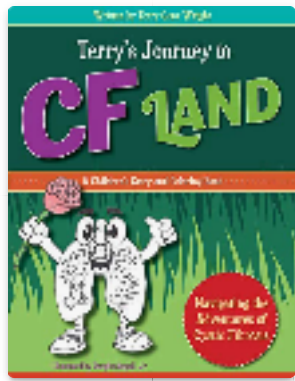
From the critically acclaimed author of *Say What You Will* and *A Step Toward Falling* comes a deeply emotional new novel, perfect for fans of *Five Feet Apart* and *The Fault in Our Stars*. David Scheinman is the popular president of his senior class, battling cystic fibrosis. Jamie Turner is a quiet sophomore, struggling with depression. The pair soon realizes that they're able to be more themselves with each other than they can be with anyone else, and their unlikely friendship starts to turn into something so much more. [...more](#)

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TERRY'S JOURNEY TO CF LAND

Navigating the Adventures of Cystic Fibrosis

Terry Gene Wright (You?) | Jan 4, 2020

| ★★★★★ 4.13

TERRY'S JOURNEY TO CF LAND: Navigating the Adventures of Cystic Fibrosis is a children's story coloring book that follows and depicts the surreal journey of Terry Wright, a 58-year old African American male Cystic Fibrosis (CF) patient (born August 1962) who is not diagnosed until the age of 54, although he has been hospitalized, seen by an array of healthcare practitioners, and unknowingly dealing with the devastating consequences of CF throughout his entire life. [...more](#)

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