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## Brief Candle

Reviewed by Roland Merullo

### ***BREATHING FOR A LIVING: A Memoir***

**By Laura Rothenberg**

**Hyperion. 237 pp. \$22.95**

Given that cystic fibrosis is the leading genetic killer of children and young adults in America today, and that one out of every 28 Americans is a symptomless carrier of the CF gene, it is strange that the affliction has such a relatively low public profile. No former presidents, movie stars or professional athletes suffer from CF. Thousands of communities hold fund-raising walks, and Washington is home to the well-respected Cystic Fibrosis Foundation, but there is nothing equivalent to the Jerry Lewis Labor Day telethon for Muscular Dystrophy. And while some celebrities have given generously of their time (the former NFL star Boomer Esiason, for instance, father of a child with CF), no one with a household name has made it his or her life's purpose to raise awareness of the disease in the national consciousness.

Perhaps the late Laura Rothenberg, whose "CF Radio Diary" was heard by millions on NPR last summer, had all this in mind when she started putting into words the wrenching story of her last two years with cystic fibrosis. As the memoir begins, she is a sophomore at Brown University who writes: "I am having a midlife crisis. Tomorrow I will be nineteen." The crisis she faces is typical of neither a college student's existential questioning nor a 50-year-old's yearning for a fresh start: She is wondering if this is the moment to put her name on a list for a double lung transplant.

Breathing for a Living tells the story of Rothenberg's fears and hopes as she waits for new lungs, and her discouragement, suffering and flashes of joy once she has received them. Woven among the descriptions of medical procedures and the inspiring, imperfect love of friends and family, an immense courage is on display here, a marvelous and rare courage.

Like many CF sufferers—there are 30,000 in the United States—Rothenberg was diagnosed shortly after birth. By the time she was three days old, she'd had the first in a long list of invasive procedures, in this case surgery for an abdominal obstruction common to infants with cystic fibrosis. The ancient disease has a simple cause: a defective gene that makes for abnormal movement of salt and water in and out of cells. As a result, mucous becomes dehydrated and thickens, and because mucous plays a role in the functioning of most organs—lungs and pancreas especially -- a person with cystic

fibrosis usually suffers from an encyclopedia of respiratory infections and digestive troubles.

It is common for CF children to “fail to thrive” because the lack of pancreatic enzymes in the intestines keeps nutrients from being absorbed. Certain types of ambient and otherwise harmless bacteria such as *B. cepacia* and *Pseudomonas aeruginosa* luxuriate in the environment of a CF patient’s lungs, forming colonies there that resist even the most powerful antibiotics. Over time, these colonies do irreparable damage, and the patient—sometimes only in his or her teens—is faced with the choice of a year of slow suffocation or a problematic life extension courtesy of some generous donor’s lungs. Though always fatal, the disease varies widely from patient to patient. Average life expectancy for a person with CF has now been raised to 33 years, and some of those years, like the ones Rothenberg describes in this memoir, are a hell of bronchoscopies, intestinal surgeries, drugs, side effects, repeated hospitalizations, sinus irrigations, insulin injections, coughing, gasping and on and on.

Not exactly easy material to write or read about. But Rothenberg speckles her tale with anecdote and humor and with wonderful short sections written by her parents and friends. She doesn’t pretend she is the only person on the planet with troubles (“Life goes up and down, down and up, up and down. For everyone. And I don’t want any of them to be down, ever”) or that she is fearless in the face of death (“Anyone who thinks I’m in this waiting room without hours I’m not proud of thinks too highly of me”). What she wants more than anything, what any disabled person wants, is a normal life. But even going out to a movie theater with a chronic, noninfectious cough turns into an exercise in facing down the arrogance of the able-bodied. People stare, clear their throats sarcastically, make ugly remarks, until Laura’s friend announces to a nearby couple, “in a polite New York tone, that I was going to cough throughout the movie so if they had a problem with it they should just move now.”

Her prolonged wait for new lungs creates a page-turning tension in first third of the book. What really holds this memoir together, however, and what will make it stand proudly in the library of the literature of illness, is the author’s almost superhuman resilience in the face of a suffering that Job himself would not have been able to endure. She died this past March at 22 from chronic rejection of the new lungs.

Those in the grasp of a fatal illness will recognize themselves here— the loneliness, the pain and hope—as will family members and friends.

The rest of us, so often oblivious to our good luck, might be moved to set the book down between chapters and put our complaints in perspective. No one who reads this powerful memoir, though, will ever again fail to feel a cold knock in the spine at the sound of the words cystic fibrosis. •

Roland Merullo’s most recent novel, “In Revere, In Those Days,” will be published in paperback in the fall.