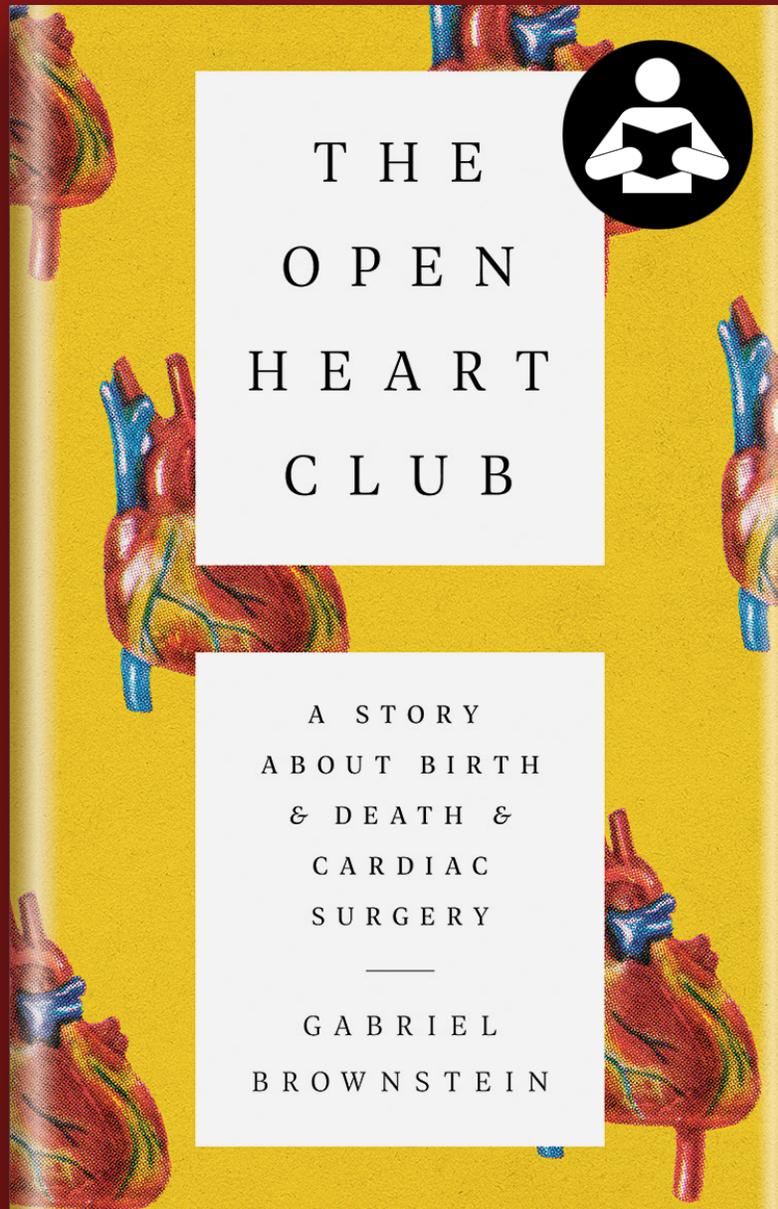
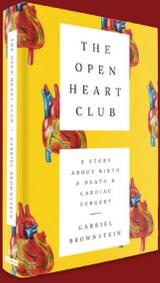

Reading Group Guide



Published by **PUBLICAFFAIRS**



Discussion Questions

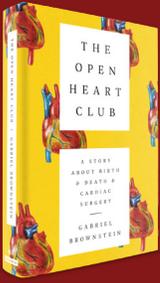
The Open Heart Club by Gabriel Brownstein, Published by PublicAffairs

1. Brownstein writes that nearly all the pioneers of cardiac surgery were women. Why do you think this is true? What might the consequences of a gender split like this be?
2. A major theme of the book is the idea of dual citizenship in what Susan Sontag described as “the kingdom of the sick” and “the kingdom of the well.” Who do you think belongs to each kingdom, and what might it mean to be a member of both?
3. In Part One, Chapter 4, Brownstein writes that his mother never mentioned his congenital heart defect to her friends because she felt it was taboo. What effect do you think this silence had on his mother, and how does silence about health problems impact our cultural understanding of them? Are there medical taboos in our contemporary world that we’d be better off lifting?
4. Numerous stories in this book illustrate that heart surgery is a fierce and painful business: organs placed into handbags, patients getting repeated electric shocks, people dying on operating tables. Did this surprise you? Did you expect it to be more controlled? Were there stories that stuck with you especially?
5. On p. 280, Brownstein notes that adult congenital cardiology was not an established field as recently as 1995; in many ways, the field is still in its infancy. Why do you think it has taken so long to develop? Do other, more established disciplines suggest what might be possible in the coming years?
6. Has this book changed the way you feel about health care generally? How so?

Additional Reading

Illness as a Metaphor by Susan Sontag





Interview with the Author

The Open Heart Club by Gabriel Brownstein, Published by PublicAffairs

Q: *What is the “open heart club”?*

A: My first heart surgeon, Dr. James Malm, was the doctor who made the real breakthrough in saving kids like me, kids with tetralogy of Fallot. He figured out how to fix this defect about three years before I was born, and he went on to fix (amazingly) most every heart he treated. (In speaking with him for the book, he told me that “no one was allowed to die.”) In the early 1970s there was a big party to celebrate his first decade of success. All these kids with hearts he had repaired were there, and they called us the “Open Heart Club.”

Q: *How does living with congenital heart disease continue to affect your everyday life?*

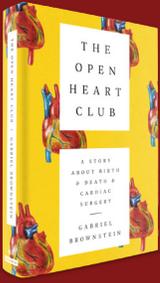
A: I don't always know when it's affecting me. Most of the time, I feel fine. But that doesn't mean I am fine. I've climbed mountains and weeks later been told I need a new heart valve. I've ignored life-threatening arrhythmias even as they happened. But I'm not alone.

One doctor I spoke to said that people with congenital heart disease don't really know what “healthy” is. We've never been exactly healthy, and we tend to think the way that we feel is more or less normal. So, we are inclined to ignore it when we're in danger. In researching this book, I met more than one patient who went around pretending they were fine right up until the point their doctor told them they needed a heart transplant. This is typical. Of people living with surgically corrected heart defects—people with moderate to severe heart defects—approximately 90% do not see the appropriate physician. There are lots of reasons for this. But a lot of it is denial.

Q: *What is your own personal history with the intervention of medicine?*

A: I've had many interventions: open heart surgery in 1971 and 1999, an implanted cardiac defibrillator put in in 2001 and replaced three times thereafter. Three catheter ablations to treat cardiac arrhythmias, all between 2012 and 2015. (That's where they stick a wire in your heart and burn the interior to break up the arrhythmia.) And a valve replacement surgery via catheter in 2017, during the writing of this book. My implanted defibrillator will need to be replaced within the next few years, and my new heart valve has to be monitored: the life of a valve can run anywhere from six months to twenty years.





Interview with the Author

The Open Heart Club by Gabriel Brownstein, Published by PublicAffairs

Q: *When we think of heart surgery we tend to associate it as being exclusive to adults and particularly the elderly. Why is that, and why is it important to change this perception?*

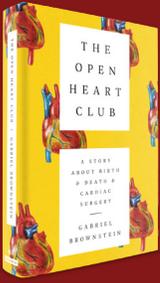
A: There are a number of factors, but the problem I emphasize most in my book is that people do not talk about congenital heart disease. It's largely unknown, and even people like me often don't know that they need a specialized doctor. We frequently fall through the cracks. What's even more surprising is that the US invented heart surgery. And heart surgery, bypass surgery, was invented to treat kids like me. Walt Lillehei and John Kirklin, the two Minnesota surgeons who pioneered open-heart surgery in the 1950s, worked exclusively on kids. But as a country, we've done a terrible job keeping track of those kids.

Another issue is that those of us with CHD have a different set of problems than people with adult onset heart disease. The valve that needs constant replacing in my heart is the pulmonary valve. But adult on-set heart disease patients very rarely have problems with their pulmonary valves. So replacement valves aren't really developed so much for the pulmonary position. (Not enough customers to make it worth the manufacturer's efforts.) In my last valve replacement surgery, the FDA hadn't approved the valve my doctor wanted to use for the pulmonary valve. So we had to do it off label. Which worked out but was risky.

There's also trouble—I hear—getting doctors to train to be adult congenital cardiologists—the kind of doctor who sees patients like me. We're a fairly recent population, and the specialty is pretty new. The first board-certifying exam in adult congenital cardiology was given in 2015. Those doctors have to go through an incredibly rigorous training, and they go to a frankly less lucrative field than your average adult cardiologist. These CHD doctors are, I hasten to add, an extraordinary set of people. Smart, sensitive, kind, cooperative—an amazing group.

Q: *We tend to think of “health care” and “medicine” as synonymous. You acknowledge that we need to make the distinction between the two clearer. Please explain.*

A: We owe our health and our loved ones' health to the advances of medicine. “Medicine” shouldn't be a scary word that politicians avoid. We shouldn't soft pedal it and say “health care.” We should all be able to say and hear the word medicine and think about it. I believe that if we could talk about medicine more honestly, and if we could be honest about medicine's place in our lives, we might be able to better address the problems with our



Interview with the Author

The Open Heart Club by Gabriel Brownstein, Published by PublicAffairs

medical system, and its inefficiencies and inequalities and profiteering.

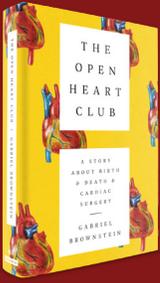
Q: *Why did you decide to write this book?*

A: I was trying to finish a novel that needed one more rewrite, and I was just in an awful period, health-wise. I was having cardiac arrhythmias all the time. My heart was going crazy every night, and it kind of wrestled me to the ground after a while. My heart was the thing I was constantly thinking about. And as I got better, I felt compelled, engrossed really, in telling this story. It was the only story I wanted to tell. I started meeting other people whose lives were like mine, and talking to doctors, and the writing of the book became very important to me, trying to figure out how our stories were interconnected.

Q: *What was the most challenging part about telling this story, aside from the fact that it's so personal?*

A: The scope of the book is wide and necessarily so. I tell the stories of patients and doctors in modern times but also of the important, and often overlooked, trailblazers from the very beginning of heart surgery. It was a real responsibility to tell the stories of so many lives and relay the impact of their work. People like Maude Abbott in Montreal and Helen Taussig in Baltimore who were among the first doctors to treat kids with heart defects yet were not considered real doctors by their male peers. People like Vivien Thomas, Taussig's colleague at Johns Hopkins, who was the first person to develop a real set of surgical tools to treat these kids; yet because he was an African American technician had to go through a separate segregated entryway to get into the hospital where he worked. And not to mention their patients—the kids with deformed hearts—who were not considered real patients by other doctors but rather curiosities, at best, and certainly beyond the reach of medicine. These people whose stories I tell are barrier-breakers and visionaries. I had to get it right.

Q: *You've published fiction previously with *The Curious Case of Benjamin Button*, *Apt 3W*, which won the PEN/Hemingway Award, and *The Man from Beyond*. What was it like writing a nonfiction book?*



Interview with the Author

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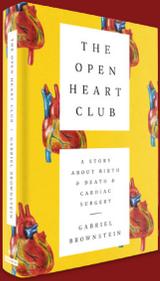
A: In some ways, my background writing fiction was my great strength and my great weakness. Writing fiction is all about imaginative sympathy—trying to imagine how someone felt in a particular moment. So I was always trying to do that. But fiction is also all about letting your imagination run away with you—and in this book that wasn't allowed.

The structure was tricky, too. There were these big pieces of story—of my life, of other patients' lives, of the doctors' lives, of history—and I had to fit them together. It felt like building a bridge or a highway system. It felt architectural. I had to figure out how to fit the pieces together so they would work. I couldn't really change the basic structure of any of the pieces. They were what they were.

Q: *What do you hope people take away from reading The Open Heart Club?*

A: When I was writing this book, people asked what it was about, and they'd seem baffled when I answered. I don't think I'd have gotten that same confused response if I had said, I'm writing about cancer, or headaches, or anxiety. Or even heart attacks. This subject scares people: babies having heart surgery! And it shouldn't. It should be a really happy thing. This is one of our great inheritances—that we can bring sick children back to life. Give them long lives. It's cause for celebration. So I hope that I can make the condition a little more familiar to the world. And make people appreciate the medicine that saved me. In a bigger way, I want people to see how wonderful medicine is.

My book is about my good fortune, and it's a kind of good fortune I share with everyone who might read the book—the good fortune to be born in the world of medicine. We're all very lucky.



History of Advancements in Heart Surgery

The Open Heart Club by Gabriel Brownstein, Published by PublicAffairs

“Surgery of the heart has probably reached the limit set by Nature to all surgery: no new method, and no new discovery can overcome the natural difficulties that attend a heart wound.”

—STEPHEN PAGET, revered British surgeon (1855–1926)

Late 1800s : Heart surgery is proven to be possible.



Daniel Hale Williams III

In 1893, Daniel Hale Williams III, an African-American doctor working at a small black-owned hospital in Chicago, stitches up a knife wound to the pericardium, the tough three-layered sack that surrounds the heart. And in 1896, in Germany, Ludwig Rehn sutures a wound to the heart muscle itself and publishes the results proving that heart surgery is possible.

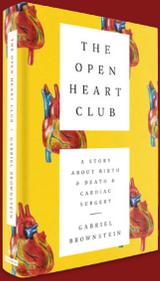
During this time, devices such as the stethoscope are transformed from a long wooden tube to the two-eared device we know today, and diagnostic machines are invented, including the x-ray, the electrocardiogram, and devices to measure blood pressure.

1920s : Maude Abbott and Helen Taussig found pediatric cardiology.

In the male-dominated medical profession, many female doctors (or “hen-medics” as they were called) were not given the opportunity to work on adult patients. But babies and young children with heart deformities were thought to be unsavable and not worth the male doctors’ time. Abbott, working in Montreal, catalogues and defines all the various deformities of the heart, and Taussig, working in Baltimore, begins to diagnose babies and to think about how to treat them. Their work lays the foundation for all future heart surgery.



Maude Abbott



History of Advancements in Heart Surgery

The Open Heart Club by Gabriel Brownstein, Published by PublicAffairs

1930s : The first successful pediatric surgery is conducted.

At Massachusetts General Hospital, Robert Gross performs the first operation to save a child born with a defect in the cardio-pulmonary system. Later that same decade, Maude Abbott publishes her *Atlas of Congenital Cardiac Disease*, the first book to describe the pathology of congenital heart defects. The study of congenital heart disease begins.

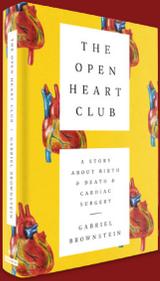
1940s : World War II drives an intense investment in medicine and pushes forward developments in surgery and cardiology.

The development of inexpensive mass-production of penicillin and cheap antibiotics allows for safer surgeries. In New York, federal grant money supports the work of Andre Cournand and Dickerson Richards, who develop practical uses for the cardiac catheter, measuring blood oxygenation and producing vivid images of blood flow in the heart.



Vivien Thomas

In 1944, at Johns Hopkins in Baltimore, Helen Taussig makes the first important breakthrough in helping children born with heart defects. With the surgeon Alfred Blalock and medical technician Vivien Thomas, she develops a technique to relieve the suffering of children with tetralogy of Fallot, the most common complex congenital heart defect. This surgery extended patients' lives by years, even decades, and makes headlines across the world.



History of Advancements in Heart Surgery

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1950s : The race to develop a heart–lung machine is on.

At the University of Minnesota, C. Walt Lillehei succeeds in open–heart surgery by using his patients’ parents to oxygenate the children’s bodies during surgery—a parent on one gurney, a child on the other, a machine between them pumping blood from one to the other so that the parent’s heart and lungs supported the child’s body during surgery. In Philadelphia, John Gibbon works with IBM to design and build the first successful heart–lung machine. John Kirklin, at the Mayo Clinic, builds a new heart lung machine of his own devising. He operates on children with simple defects reducing surgical mortality rates from 50% to 25%.

Still, at the end of the decade, congenital heart disease is among the top ten causes of death in the United States. Most kids with heart defects face stark odds of long–term survival.

1960s : Newer, simpler, and safer heart–lung machines mean more complex corrections become possible.

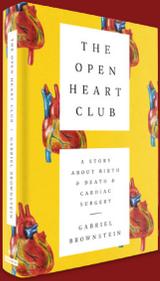
At the beginning of the sixties, open–heart surgery is almost exclusively performed on children, but by decade’s end doctors are busily replacing diseased valves in adults and performing coronary by–pass surgery.

In Toronto, Dr. William Mustard develops techniques to repair hearts in which the placement of the great arteries is reversed. In New York, Dr. James Malm demonstrates a repeatable technique for safely correcting tetralogy of Fallot, patching holes, and opening valves, and letting his patients live long lives.



Christian Barnard performing Heart surgery.tt

And in South Africa, Christiaan Barnard performs the first heart transplant surgery.



History of Advancements in Heart Surgery

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1970s : Doctors can safely operate on infants.

By the mid-1970s doctors no longer had to wait until children were older to operate, reducing mortality rates considerably. But patients operated on in the 1960s are beginning to grow to adulthood. Dr. Jane Somerville, in England, proposes that a new medical field is necessary to treat these patients—adult congenital cardiology.

1980s and 1990s : New diagnostic technology, like the echocardiograph, allow doctors to follow the aging hearts of their congenital heart disease patients.

MRI technology allows for more precise measurement of the chambers of failing hearts, follow up surgeries become more routine in adult congenital heart disease (ACHD) patients, valve replacement surgery become increasingly commonplace in ACHD patients, and heart transplants more effective.

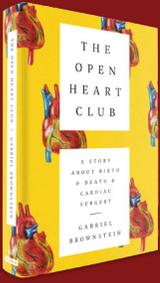


Television host Jimmy Kimmel with his son, Billy, who was diagnosed with tetralogy of Fallot.

But as the number of ACHD patients increases, pediatric cardiologists realize their former patients aren't under the care of an appropriate doctor. As a result, Dr. Joseph Perloff, at UCLA, opens the first Adult Congenital Heart Disease (ACHD) clinic in the US.

2000 to 2018 : Adult Congenital Cardiology becomes a recognized subspecialty.

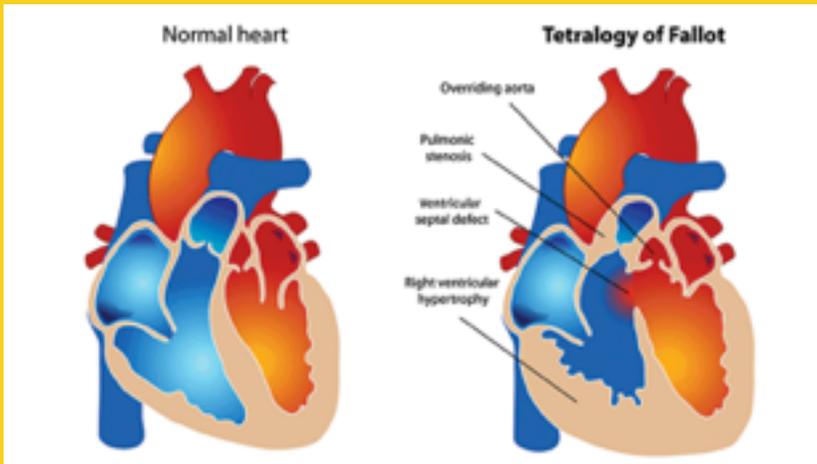
In 2015, the first board certifying exams is given to adult congenital cardiologists, and the number of ACHD patients continues to grow. By 2018, there are over two and half million congenital heart patients in the US, and adult patients for the first time outnumber pediatric CHD patients. As medical technology continues to develop, so does the gap between care and the people who need it.



History of Advancements in Heart Surgery

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2019 and beyond : Sustaining care.



In 2020, approximately 10,000 babies will have corrective heart surgery. Over 85% of them will survive to live long, potentially healthy lives.

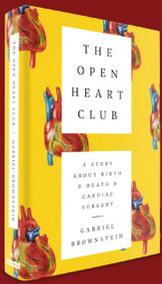
The achievements of pediatric cardiology and open-heart surgery rank among the greatest twentieth century American achievements. It's a proud part of our collective inheritance: because of the work of the generations that preceded us, we can bring children back from the dead. But we have failed to live up to this inheritance.

Families will continue to go bankrupt paying for children's surgeries, and most of the adult patients will not, over the course of their lives, get the follow up help they need. These people—either because they don't have insurance or because they do not understand the gravity of their conditions—often don't show up in doctors' offices until it's too late.

The next great advancement in heart surgery will be making it affordable to all who need it.

Gibbon works with IBM to design and build the first successful heart-lung machine. John Kirklin, at the Mayo Clinic, builds a new heart lung machine of his own devising. He operates on children with simple defects reducing surgical mortality rates from 50% to 25%.

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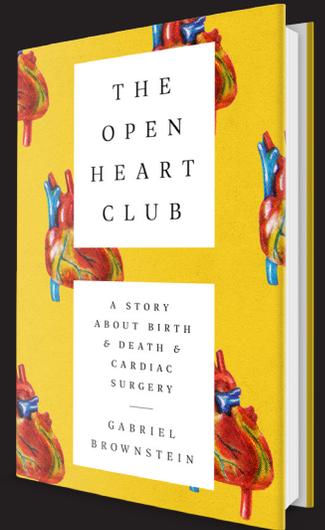
About the Book // About the Author

The Open Heart Club by Gabriel Brownstein, Published by PublicAffairs

This absorbing and poignant book is not merely the story of one writer's flawed heart. It is a history of cardiac medicine, a candid personal journey, and a profound reflection on mortality.

Born in 1966 with a congenital heart defect known as the tetralogy of Fallot, Gabriel Brownstein entered the world just as doctors were learning to operate on conditions like his. He received a life-saving surgery at five years old, and since then has ridden wave after wave of medical innovation, a series of interventions that have kept his heart beating.

The Open Heart Club is both a memoir of a life on the edge of medicine's reach and a history of the remarkable people who have made such a life possible. It begins with the visionary anatomists of the seventeenth century, tells the stories of the doctors (all women) who invented pediatric cardiology, and includes the lives of patients and physicians struggling to understand the complexities of the human heart. *The Open Heart Club* is a riveting work of compassionate storytelling, a journey into the dark hinterlands between sickness and health lit by bright moments of humor and inspiration.



GABRIEL BROWNSTEIN has published a novel, *The Man from Beyond*, and a book of stories, *The Curious Case of Benjamin Button, Apt. 3W*. For his short fiction, he has won a PEN/Hemingway Award and a Pushcart Prize. He teaches at St. John's University in Queens, New York, and lives in Brooklyn with his wife and two daughters.