

JP Top Reads for Cancer Advocates

I highly recommend any and all of these books to cancer advocates, especially those interested in research. Many focus on cancer, but some address health and science more broadly. All, with one possible exception (the Rettig book), are highly readable and accessible, with most directed at a lay audience. They cover a variety of topics and include some science stories in the tradition of Watson and Crick's "Double Helix" (c.f., Bazell, Cooke, Rettig, and Shreeve), a survivor story (c.f., Schneider), in-depth discussion of important patient issues (c.f., Holland, and Hewitt), history/philosophy of science (c.f., Kuhn, and Salsburg), and public health policy (c.f., Angell, Brownlee, and Welch), among other topics. The list is idiosyncratic, but each volume was included because I found it especially informative, provocative, enjoyable, and memorable. I present the list in alphabetical order, and recommend that advocates pick and choose according to their own interests. The books are all available and discounted at amazon.com. Many of the books might not be available at your local library, but they all probably can be ordered through inter-library loan. Enjoy and please pass along your own recommendations (janep@gemini-grp.com)

Author	Title	Year	Pages	Paper	Audience
Angell, Marcia	The Truth About the Drug Companies: How They Deceive Us and What to do About it	2004	319	Yes	Lay
	This book has been referred to as the "Fast Food Nation" of the drug industry. Angell clearly lays out many of the issues that are concern to advocates about undue influence in both research and clinician prescribing by drug companies. She also clarifies how these practices negatively impact the progress and costs of treatments. She provides both a framework and specifics that can help advocates be sensitive to these issues. In my opinion, the last chapter which proposes potential remedies, is the only chapter that does not achieve its goals. However, informing the public about these difficult problems, is a first step remedying them.				
Bazell, Robert	Her1: The Making of Herceptin: A Revolutionary Treatment for Breast Cancer	1998	240	Yes	Lay
	This book is science journalism. It helps the reader relive the drama associated with the development of Herceptin, from early research on targeted therapies to the development and testing of a specific drug. It helps readers better understand the politics of science and the interplay between achieving positive results and funding. It is also presents an example of how advocates can make a difference in moving promising therapies through the pipeline.				

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Author	Title	Year	Pages	Paper	Audience
Brownlee, Shannon	Overtreated: Why Too Much Medicine is Making Us Sicker and Poorer	2007	368	Yes	Lay
	<p>Most Americans believe that more and newer is better when it comes to healthcare. Americans' healthcare is by far the most expensive in the world, and while the newest and best technologies are available, we are far from the healthiest. Brownlee convincingly argues that this pattern is due to a misallocation of resources, with some Americans being overtreated and others undertreated. In this book she provides many specific examples of the downside of overtreatment. Some of the overtreatment is driven by marketing (to both consumers and clinicians) and conflicts of interest. This leads to more, newer, and more expensive drugs and procedures being prescribed, even when there is no evidence that they are better than older ones for which there is more data. Another driver is defensive medicine which will lead clinicians to over order tests that often lead to unnecessary further procedures to rule out highly unlikely conditions.</p>				
Cooke, Robert	Dr. Folkman's War: Angiogenesis and the Struggle to Defeat Cancer	2000	392	Yes	Lay
	<p>This book is another story of an important development against significant odds. In particular, this book conveys Judah Folkman's multi-decade crusade to prove the importance of angiogenesis in the natural history of cancer, and the potential of disrupting this growth of blood vessels to destroy cancer. It gives the reader a close look of this very special scientist and makes one wonder how much personality influences the scientific progress.</p>				
Dresser, Rebecca	When Science Offers Salvation: Patient Advocacy and Research Ethics	2001	232	No	Academic
	<p>This book is one I recommend all research advocates read. It raises many issues about which advocates should ponder and discuss. It also provides a nice summary of many of the ways advocates have influenced research and research policy, and points to opportunities for additional influence. Dresser discusses the role of advocates in five contexts: 1) on research teams; 2) in activities surrounding expanded access; 3) in allocating government research funding; 4) in ethical oversight, especially IRBs; and 5) in influencing and interpreting research reporting. She argues that advocates have played a large role and have had a significant impact in the first three contexts, but that there is untapped opportunity/need in the last two. A number of key themes arise from this discussion. The final chapter presents several overarching ethical imperatives for advocates and discusses future areas that are likely to profit from their consideration.</p>				

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Author	Title	Year	Pages	Paper	Audience
Hewit, Maria	From Cancer Patient to Cancer Survivor -- Lost in Transition: An American Society of Clinical Oncology and Institute of Medicine Symposium	2005	536	No	Academic
	<p>This volume summarizes the work of an Institute of Medicine (IOM) study of the issues that face the ten million and increasing cancer survivors alive in the U.S. at the beginning of the twenty first century. The committee took advantage of a plethora of available, but not necessarily integrated, sources of data. The resulting book is a valuable reference. Several chapters present descriptive data about cancer survivors, and the ways in which their lives are affected by a cancer diagnosis and its treatment. This coverage is quite broad, including discussion of physical, psychosocial, vocational, spiritual, and economic issues. Several other chapters focus on defining optimal care for cancer survivors—both medical and psychosocial—as well as describing models for delivery. Ten recommendations are presented that are heavily influencing current research and clinical care of cancer survivors. A shorter, synopsis of this volume is available in paperback.</p>				
Holland, Jimmie	The Human Side of Cancer: Living With Hope, Coping with Uncertainty	2000	368	Yes	Both
	<p>Jimmie Holland is often referred to the matriarch of psycho-oncology, having pretty much established the field. In this book she provides clear and sensible advise for people living with cancer, and those supporting them. Her approach is holistic and individualistic. She is more concerned with the well-being of the patient, than with the cure of the cancer. She emphasizes the individual differences among the issues people face as well as their different coping styles. Although numerous self-help books are now available, this one is special.</p>				
Kuhn, Thomas	The Structure of Scientific Revolution	1962	226	Yes	Both
	<p>This book is a true classic that will surely change your thinking about the process of science. Kuhn introduced the concept of "paradigm shift" in the early 1960s to capture the natural history of science. According to Kuhn, scientific progress includes long periods of what he refers to as "normal science" where many mundane experiments lead to an accumulation of data, some of which do not fit well into the generally accepted conceptual framework. As more and more "problematic data" accumulate, a short spurt of rapid change occurs that lead to new ways of thinking about the area that accommodate the incongruent data occurs. These periods of "paradigm shift" occur infrequently, and on unpredictable schedules. This view underscores the fact that science is a process of refining our understanding of nature, rather than seeking "absolute truth." Although many of the subtleties of Kuhn's ideas have been highly debated and may no longer be accepted, the his overall framework is still useful. Indeed, the concept of "paradigm shift" is now commonly used for all sorts of phenomena.</p>				

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Author	Title	Year	Pages	Paper	Audience
Rettig, Richard	False Hope: Bone Marrow Transplantation for Breast Cancer This book is tough going, but worth the effort. The story of using unproven, high dose chemotherapy with bone marrow transplants outside of clinical trials in patients with breast cancer is now familiar to many advocates . However, this book provides details and raises issues that go beyond the simple lesson of supporting clinical trials, rather than extensive expanded access for unproven treatments. We see many well meaning, true believers who think they are acting in the best interests of desperate patients. But we also see many who are placing their own financial and/or professional interests ahead of patients.	2007	368	No	Academic
Meyers, Morton	Accidents: Serendipity in Modern Medical Breakthroughs This book provides many interesting examples of medical breakthroughs that resulted from surprises and accidents in the lab. While the author stresses the role of serendipity, his examples point out the importance of having a prepared and curious mind notice the surprise and then devote the time and energy required to follow-up on it. The book will make advocates wonder how one can predict where breakthroughs will be made and what can be done to foster the type of mind that will capitalize on serendipity.	2007	408	Yes	Lay
Salsburg, David	The Lady Tasting Tea: How Statistics Revolutionized Science in the Twentieth Century This book is a history of twentieth century statistics that is a good read, and will enrich advocates' understanding of some important statistical topics in a non-technical way. Reading it will also help advocates realize that accepted statistical dogma is often based on controversial fundamentals, like any other aspect of science.	2001	353	Yes	Lay
Schneider, Stephen	Patient From Hell: How I Worked With My Doctor to Get the Best of Modern Medicine & How You Can Too Schneider is a brilliant (MacArthur Genius Award winner) climate scientist who was diagnosed with a rare and lethal type of cancer--mantle cell lymphoma. He tells of the difficult treatment he went through. But more interesting and important is the story about how he applied his keen scientific mind to improve his treatment, ultimately save his life, and influence standard of care for his condition. While Schneider is clearly a very special person, he goes out of his way to indicate how all patients (and their loved ones) can and should be vigilant and strong advocates of their care.	2005	320	Yes	Lay

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Author	Title	Year	Pages	Paper	Audience
Shreeve, James	The Genome War: How Craig Venter Tried to Capture the Code of Life and Save the World	2004	416	Yes	Lay
	<p>This book traces a particular scientific project over a number of years and provides a view of the larger-than-life scientists (and their egos) often involved in major breakthroughs. In this case the story is about the Human Genome Project and how Craig Venter working in a corporate environment challenged, and eventually partnered with, the public/academic collaboration that was charged with mapping the genome. In addition to helping the reader understand the science and technology of the human genome project, it provides interesting insights into intellectual property and business issues that are becoming increasingly important to progress in cancer research.</p>				
Weinberg, Robert	One Renegade Cell	1998	176	Yes	Lay
	<p>This book is a good place for advocates to gain a better understanding of the biology of cancer. It is written for a lay audience and provides an accessible introduction to cancer as a genetic disease. It also provides a solid understanding of the mechanisms that are viewed as the "Hallmarks of Cancer"--those involved in the cell cycle, angiogenesis, apoptosis, and to a lesser extent invasion and metastasis. It will make advocates more comfortable listening and/or reading about molecular biology that continues to dominate much cancer research. While it would be nice to see an updated edition that discusses topics such as the roles of stem cells, epigenetics, the microenvironment, inflammation, and the immune system in cancer, the topics that are covered will continue to be the place to start achieving a solid understanding of the biology of cancer.</p>				
Welch, H. Gilbert	Should I be Tested for Cancer? Maybe Not and Here's Why	2006	234	Yes	Lay
	<p>This book is a nice complement to the Brownlee book. It also talks about the negative consequence of over use of medical procedures, but in this case is focused on cancer testing. The conventional wisdom is that there is minimal risk with most cancer tests, and early detection is key to cure. Welsh, however, provides convincing evidence to the contrary. The risks associated with testing have more to do with the path it often leads to than the real but minimal risk of most tests. In particular, tests often lead to additional tests to rule out false positives which are quite common. Even when a real cancer is detected and treated, there is considerable evidence that much of the treated disease is indolent cancer that would not have ever progressed to a life threatening condition, and treatments are always toxic. So many tests successfully identify cancer, but few actually extend life. This argument is not to say that there is no place for cancer testing; rather that given current technology, there are few tests ready for wide scale screening,</p>				