A Review of
*Grateful Guilt: Living In The Shadow of My Heart* (2019)
Author: Steven G. Taibbi

Reviewed by Jim Gleason, heart recipient ‘94

Of the over 200 transplant books I’ve reviewed, Grateful Guilt is unique in that it is a first-hand story of the author’s lifetime heart experiences, from shortly after birth in 1953, not expected to live past ten years old, through heart transplants, in 2001 and his second in 2016, still living a full life now in 2022. These detailed recollections of hospitalizations and surgeries, from his first open-heart surgery at age five and then too many more in the years that followed when children were not included in medical discussions, seemingly ignored, make for scary reading. Steven shares how even in those youthful years when as a child he was protectively not talked to, non-verbal communication was very obvious to him those things were dire, both for himself and in seeing children around him who didn’t come back from failed treatments. Imagine being given the church’s Last Rites as a young child?

I was deeply drawn into his harrowing experiences, feeling very uncomfortable despite knowing (hoping) that things are much different many decades later in today’s pediatric medical treatments. His loving parents tried to raise him as being ‘normal’ but with so much medical attention, it naturally caused sibling jealousy, complicating his already overly complex life.

The book, could be viewed in three distinct parts: 1st as his story up to about age 12, a 2nd through teen/young adulthood, and a 3rd following adult challenges that led to two heart transplants. Each ‘phase’ is well described in words that both educate and convey the feelings/emotions that come with each experience, making the reader feel those as one follows his stories. Another feature of his writing is the way he explains in very layman terms any technical language he uses, making this a reading fit for anyone’s medical background, lay or professional. Eighty short chapters, many only 2 and 3 pages long, make for fast reading in continuing from one chapter to the next, knowing there is only a few more pages in that next chapter. Another facet that makes this book my favorite is how the author includes humor throughout harrowing life experiences, low key but inspiring.

In sharing many self-taught survival lessons, I especially liked his self-taught ‘bulling my heart’ method of pushing through when heart symptoms appeared, often scary life-threatening ones. In another major life-changing milestone, he decides to discover how he is, in short order, moving from that always bullied failing person, as he describes it: “Who was I? Or more importantly, how was I perceived? He discovers that “everything in my life was my fault and, worse than that, all those things happened to me because I deserved it”. With that insight, he decides to turn life around a full 180 degrees, leading to moments like this. Several quotes from this book caused me to pause my reading to write them down for later revisits/reflections. As an often-bullied teen, after winning a summer camp canoe race, he wrote: “I was stronger than I thought, including the fact that I was still alive in spite of the fact that I was past my ‘due date’.” Have you ever thought about your own ‘due date’? Having survived so many lifesaving surgeries, those are insightful words for a young man. And thus is born a new person, carrying out that resolve in all aspects of his life, a joy to read as he shares those moments of growth. On page 54 we find another powerful quote: “Part of my new strategy
was to dare death and spit him in the eye and act like he wasn’t there, even though I knew he was.” Still later he reinforces that with how he overcomes his fear of death in writing: “I don’t fear you (‘death’). You won’t have me cowering in a closet. I’M GOING TO LIVE WHILE I HAVE MY LIFE AND I’M GOING TO DIE ON MY OWN TERMS.” He continues: “But that was only possible because I’d made peace with the fact that I was going to die. HAVE YOU, DEAR READER? Embrace your death and you will have the freedom to live.”

While highly fascinating, his ‘out of body’ experiences found on pages 190 through 195 are beyond my writing skills to describe without doing injustice to his own description, so I leave it up to your reading to enjoy and take in as to its reality. Left it to be said, I do believe his story and wonder, as he does even today, what his God-given life is still meant to fulfill. Similarly, but not to the same extreme, I leave it to you to read his ‘biofeedback’ experiences on page 206 and judge the reality of that power within each of us when life is under threat.

But life challenges continue even through age 46, facing the placement of a pacemaker, praying the Lord’s prayer, he has another beautiful moment of peace and acceptance, eventually going on to survive two heart transplants, first in 2001, then with a second 16 years later, sharing now his amazing life in this book! A year after that second transplant, sadly, his loving mother dies. That touches my own heart in a shared story where my mother, a 74 year old nurse who nursed me through my heart transplant, also died one year later. As I said, his book touches my heart and life like none other.

I highly recommend this book, sharing a lifetime of medical challenges by a gifted writer describing, for example, with remarkable prose like this: “...I waved to them from the ward window and felt that geologic shift beneath my feet, that earthquake whose faultline became a chasm no family member could cross.” To which I say “Wow!” What beautiful phrasing.

Grateful Guilt is available in Kindle and paperback formats from the author or Amazon.com and other book sales sites.

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Brief bio:
Jim Gleason, receiving his own heart transplant Oct. ’94, retired after 37 years with Unisys Corporation in 2005, is a volunteer with The Gift of Life Donor Program, UNOS, president of TRIO as well as a nationally recognized speaker and author. His own book, A Gift from the Heart, is offered free in thanks to his donor family and can be viewed on-line at https://www.rjwitte.com/changeofheart/GiftFromTheHeart/.