## The Center for Medical Humanities, Compassionate Care and Bioethics

# **GRAND ROUNDS**

## Thursday, November 14, 2019

RSVP <u>here</u> or to

bioethics@stonybrookmedicine.edu

HSC, Level 3, LH 6 (<u>directions</u>) 4:00pm- 5:30pm

# Grateful Guilt: Living in the Shadow of My Heart

### Steven G. Taibbi

Steven G. Taibbi has been operated on his entire life. He was born with two "holes in the heart", the colloquial term for atrial septal defect or ASD. On April 26, 1953, the day he was born, he had his first three surgeries. He had his first open heart surgery for ASD repair in 1958, when he was five, and his second in 1959, which made him the first person to live through two open hearts for ASD repair. He almost died on

his 17th birthday from a heart block incident, and was later told by the doctors that they didn't expect him to live past his 20's. By the time he was 34, the doctors told him he had beaten his heart troubles and that he should, "Go out and live." But things started to change in his early 40s and at age 45 he was diagnosed with end-stage heart failure caused by Idiopathic Cardiomyopathy. This had nothing to do with his previous heart troubles. In 2001, Steven had his first heart transplant at Columbia-Presbyterian. That heart lasted almost 15 years to the day, when he lost it to transplant coronary artery disease, a chronic form of rejection. Three years ago, he received his second heart transplant at Cedars Sinai, in California.

The one constant that Steven credits with his still being alive is that, even at the age of five, and lasting to this day, he has been devising strategies that would keep him alive. Mr. Taibbi's arsenal of strategies included everything from disassociation, gratitude, being his own advocate, being as much a part of the team as his caregivers, how he would prepare for a hospitalization and what he would wear in the hospital, among others. But the most important arrow in his quiver of strategies was creating an environment so that doctors and nurses *wanted* to come into his room and help him. He accomplished this not just by being extraordinary polite, courteous and welcoming to all who came into his room, but he accompanied this with a large dose of humor. Everyone who came into his room—from the head of cardiology to housekeeping staff—got this treatment. In his upcoming talk, Steven Taibbi will offer a detailed discussion of how, to a large degree, he saved his own life with these behaviors, the specific types of humor he used, as well as what the responsibilities are for every patient to become "part of the team."

#### More about Mr. Taibbi

After graduating college, with honors, he started his own television production company, Steven G. Taibbi Productions and went on to become a multi-award winner Director of Photography. He was also a writer of radio and television scripts, a producer and director. He worked on commercials, industrials and network and cable TV. He also became a Contributing Editor at Videography Magazine and wrote for other magazines as well as being part of a song writing team. Against his doctor's orders, he became a glider pilot as well.

When he was 34 he was told he had beaten his heart problems. A few years later he got married, started a marketing company and became a national marketing and motivational speaker. Shortly after his first heart transplant, he became a transplant advocate, serving as vice-president of Transplant Speakers, Int., Inc with offices in New Jersey and an adjunct in London. Mr. Taibbi's donated heart started to reject in 2014 and he received his second heart transplant in March of 2016, at Cedars Sinai in Beverly Hills, Ca.

Steven G. Taibbi is the author of Grateful Guilt: Living in the Shadow of My Heart, and is currently a public speaker and organ donation advocate, as well as a professional photographer.



