

"A Marketing Analytics Expert's Journey Through Testicular Cancer Treatment" (Scott Petinga) [#123]

Brad Power
December 4, 2024

"We all have time when we're diagnosed. Doctors want to scare us into making an immediate decision. They told me I had to make a decision within 24 hours, and I was scared shitless that I had to make a decision in 24 hours." – Scott Petinga

"Not only did he lie to me; he withheld information from me so I could clearly make the decisions that I needed to make." – Scott Petinga

"Medicine is not a dictatorship. It's a partnership. It's collaboration. Yes, you went to school. You're just an educated asshole with an opinion. I have thoughts. I have opinions. I've done my research, as we all have. Sit down. Listen to me. Respect me. Just because I never went to college, and I've never studied medicine, doesn't mean I don't know about my disease, about the treatment. I've done my homework. I've talked to your peers. I know what I'm talking about." – Scott Petinga

"I'm going to do whatever it takes for myself or my family to get the best standard of care. I don't care who I piss off along the way or who I upset. I don't care if I hurt your feelings." – Scott Petinga

"Think about how much time as consumers we spend trying to find a car, trying to figure out what toaster to buy, or what piece of apparel to buy. Imagine if we put that same effort in earnest into finding a doctor." – Scott Petinga

Meeting Summary

When Scott Petinga was first diagnosed with cancer, he approached the situation like most people—trusting that the experts had all the answers and would guide him through the process. He was naive, relying on their knowledge and expertise to address the care he needed. Looking back, he now realizes that was the biggest mistake of his life. While healthcare professionals are invaluable, blindly accepting their recommendations without question left him unprepared for the challenges ahead and missed opportunities to take a more active role in his own treatment.

That experience was a turning point for Scott. He began to refuse to accept things at face value, questioning every step of his care. He started to dig deeper, research alternatives, and ensure that he had a clear understanding of what was being recommended and why. No longer satisfied with the traditional path, he sought out second opinions, explored new treatments, and even funded his own research when the answers simply weren't there. This shift in mindset empowered him to take control of his care, leading to better outcomes and a greater sense of confidence in his health journey.

How can you shift from passive patient to active advocate?

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- Take time when you're diagnosed. Doctors want to scare you into making an immediate decision.
- Get the scientific information to make your decisions.
 - Always seek a second opinion
 - Increase your understanding of your condition by doing research (e.g., the Journal of American Medical Association, the New England Journal of Medicine, Medline, Google Scholar)
 - Seek out an "angel" with experience in your situation for one-on-one support, e.g., at [Imerman Angels](#)
 - Know your most effective treatment options (e.g., National Institutes of Health, American Society of Clinical Oncology, Biotech Innovation Organization)
- Understand the economics of medicine, particularly in the cancer world, where 50% of surgeons are getting paid from pharmaceutical companies in some way. You should know everybody who's giving your doctor money, anyone who's sponsoring them, anyone who's influencing their decision, so you can make the best decision for you.

What are the right questions to ask which challenge assumptions, and make informed decisions that are aligned with your personal needs?

- Ask your doctor: Have you done this before? How often have you done it? If not, can you make a referral?
- Find all the individuals who are posting research and are going to conferences about your specific disease to create your network of the best doctors.

How can you learn more about your disease and testing and treatment options from less well known sources?

- [RefSeek](#): A web search engine for students and researchers that aims to make academic information easily accessible to everyone. Searches more than five billion documents: web pages, books, encyclopedias, journals, and newspapers. Comprehensive subject coverage without the information overload of a general search engine—increasing the visibility of academic information and compelling ideas that are often lost in a muddle of sponsored links and commercial results.
- [WorldCat](#): A resource for locating unique, trustworthy materials that you often can't find anywhere except in a library. By connecting thousands of libraries' collections in one place, WorldCat.org makes it easy for you to browse the world's libraries from one search box.
- [SpringerLink](#): Access to the depth and breadth of Springer's online collection of journals, eBooks, reference works and protocols across a vast range of subject disciplines.
- [Bioline International](#): A not-for-profit scholarly publishing cooperative committed to providing open access to quality research journals published in developing countries.
- [RePEc](#): (Research Papers in Economics) seeks to enhance the dissemination of research in economics and related areas. Volunteers from 102 countries have collected almost 4 million publications on economics and related science.

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- [Science.gov](#): Access to millions of authoritative scientific research results from U.S. federal agencies. 2200+ scientific sites. More than 200 million articles are indexed.
- [BASE](#) (Bielefeld Academic Search Engine): One of the world's most voluminous search engines especially for academic web resources. The index contains more than 400 million records from more than 11,000 content providers.

What can you do to find answers to your issues, share your knowledge, and help change standard medical practices?

- Share your story and knowledge with others through social media, patient advocacy groups, and media outlets.
- If you have money, you can fund research on issues important to you, such as the long-term effects of different treatment regimens.

The information and opinions expressed on this website or platform, or during discussions and presentations (both verbal and written) are not intended as health care recommendations or medical advice by Cancer Patient Lab, its principals, presenters, participants, or representatives for any medical treatment, product, or course of action. You should always consult a doctor about your specific situation before pursuing any health care program, treatment, product or other course of action that might affect your health.

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Meeting Notes

KEYWORDS

cancer survivor, caregiver story, marketing analytics, testicular cancer, radiation treatment, infertility issues, in vitro fertilization, medical misinformation, hormonal issues, executive physical, concierge care, integrative oncology, second opinions, patient advocacy, healthcare system

SPEAKERS

Scott Petinga (71%), Chris Apfel (13%), Brad Power (8%), Bill Paseman (7%), David Plunkett (1%), Chad Magnussen (1%)

CHAT CONTRIBUTORS

Bill Paseman, Noel Resch, Chris Apfel, David Plunkett, Chad Magnussen, Helen

SUMMARY

Scott Petinga, a cancer survivor and caregiver, shared his journey and insights on navigating the healthcare system. Diagnosed with stage 1 testicular cancer at 31, he faced challenges with his treatment, including infertility and long-term side effects. Scott emphasized the importance of being informed, seeking second opinions, and advocating for oneself. He highlighted the need for patients to understand their condition, treatment options, and the economic interests of medical professionals. Scott also discussed funding his own research and the significance of integrative oncology and alternative treatments. He stressed the importance of being proactive and knowledgeable in managing one's health.

OUTLINE

Scott Petinga's Background and Initial Cancer Diagnosis

- Scott Petinga introduces himself as a marketing analytics professional who transitioned to a caregiver after his cancer diagnosis.
- He describes his career before cancer, working with major brands and developing marketing strategies based on clinical trials.
- Scott shares his cancer journey, starting with a stage one testicular cancer diagnosis at age 31, followed by surgery and radiation treatments.
- He discusses the impact of his cancer treatment on his fertility and career, leading him to start his own company to afford in vitro fertilization.

Challenges with Medical Care and Advocacy

- Scott recounted his experiences with medical professionals who withheld information and provided misleading advice.

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- He shares his daughter's and nephew's similar experiences with medical care, emphasizing the importance of being informed and advocating for oneself.
- He described the long-term health issues he faced due to his cancer treatment, including hormonal imbalances and physical ailments.
- Patients need to seek second opinions and be aware of the economic interests of medical professionals.

Funding Research and Seeking Answers

- Scott explained his decision to fund his own research to understand the long-term effects of hormone suppression and cancer treatments.
- He described his partnership with the University of Southern California and the University of Minnesota to conduct long-term studies on hormone suppression and cancer treatment efficacy.
- He emphasized the importance of understanding the economics of medicine and the influence of pharmaceutical companies on standard care.
- He shared his experiences with alternative treatments and the importance of being proactive in one's health care.

Advocacy and Sharing Knowledge

- Scott discussed his approach to sharing his story and knowledge with others through social media, patient advocacy groups, and media outlets.
- He highlighted the importance of telling one's story and being an advocate for better health care.
- He emphasized the need for patients to be informed and proactive in their care, seeking out the best medical professionals and treatments.
- He shared his experiences with integrative oncology and alternative treatments, and the importance of being informed about all available options.

Q&A Session: Integrative Oncology and Informed Consent

- Chad Magnussen asked about Scott's sources for information on integrative oncology and naturopathic treatments.
- Scott explained that he relies on AI and online resources to find information on alternative treatments.
- David Plunkett asked about the withholding of information by doctors, and Scott shared his experiences and the importance of seeking second opinions.
- Chris Apfel discussed the legal requirements for informed consent and the importance of patients being informed and proactive in their care.

Responsibility and Self-Advocacy in Healthcare

- Bill Paseman emphasized the importance of patients taking responsibility for their own healthcare and being their own advocates.
- Scott agreed and shared his experiences with the complexities of the healthcare system and the need for better education and awareness.
- He discussed the importance of understanding the system, being informed about treatment options, and being proactive in seeking the best care.

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Final Thoughts and Encouragement

- Scott encouraged patients to be informed and proactive in their care, emphasizing the importance of understanding the healthcare system and being their own advocates.
- He shared his vision for better education and awareness about healthcare and the importance of being informed about all available options.
- Patients need to be aware of their environment and the impact of factors like nutrition, alcohol, and pollution on their health.
- Being informed, proactive, and advocating for oneself in the healthcare system is important.

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TRANSCRIPT

Brad Power

This is the Cancer Patient Lab.

We're honored to have Scott Petinga with us today. Scott is a cancer survivor and also a caregiver for his daughter, and he's going to tell us about the approaches that he's taken to deal with his cancer and his family's cancers.

This is for information purposes only. This is not medical advice. We try to arm patients with information they can take to their medical team.

We are a volunteer-led nonprofit, so we would appreciate any contributions you could make, which you can do through our website, at cancerpatientlab.org, and we have a donate button there.

Scott Petinga 1:28

I'm excited to tell my story.



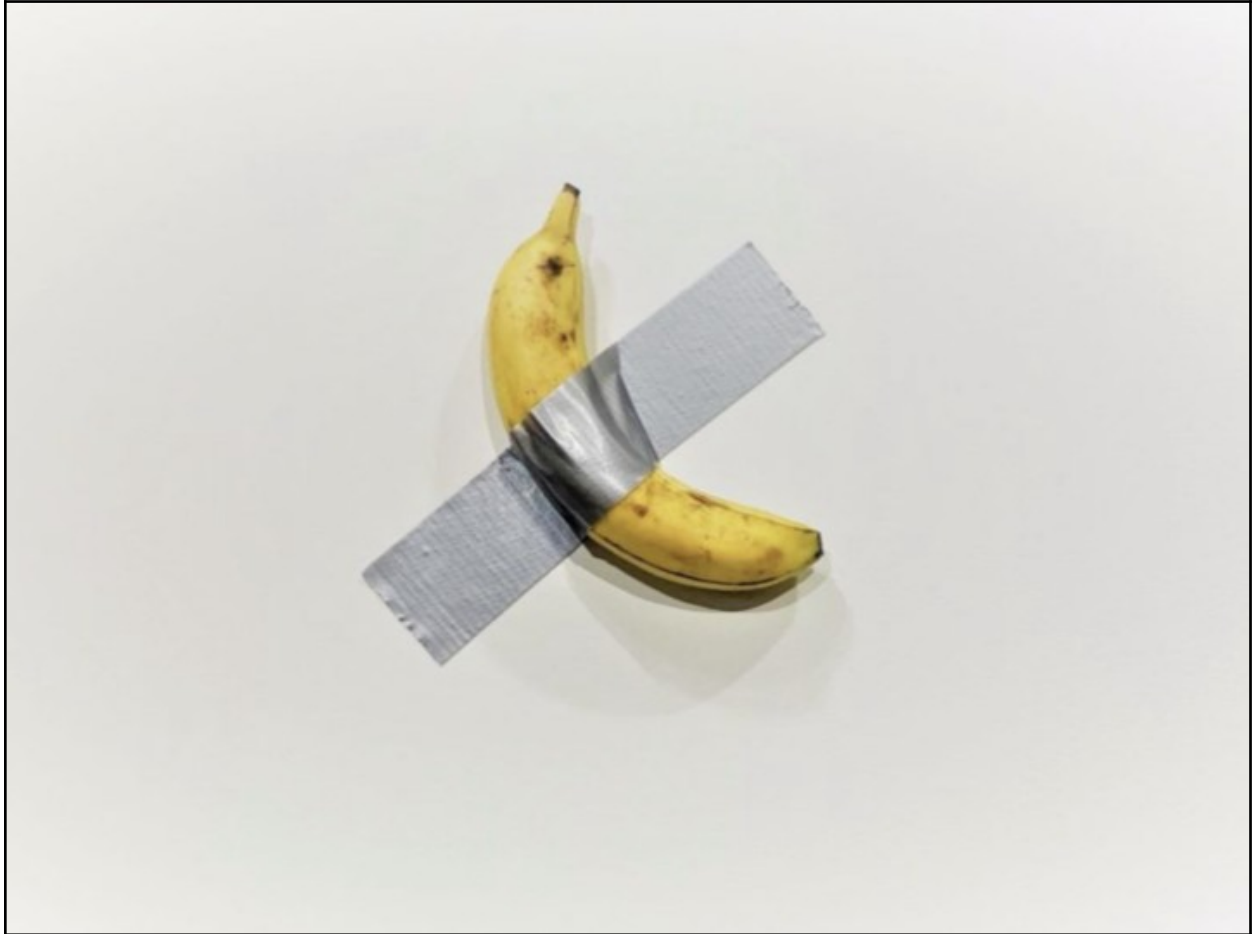
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I'm essentially a marketing analytics guy. But there is an interesting point to this.



There's two parts of me, before cancer and after cancer.

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Before cancer, I was an artist, not this type,

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but this type.

I did a lot of marketing for a lot of big Fortune 500 companies.

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I'd always present to ginormous boardrooms, lots of opinions, lots of egos.

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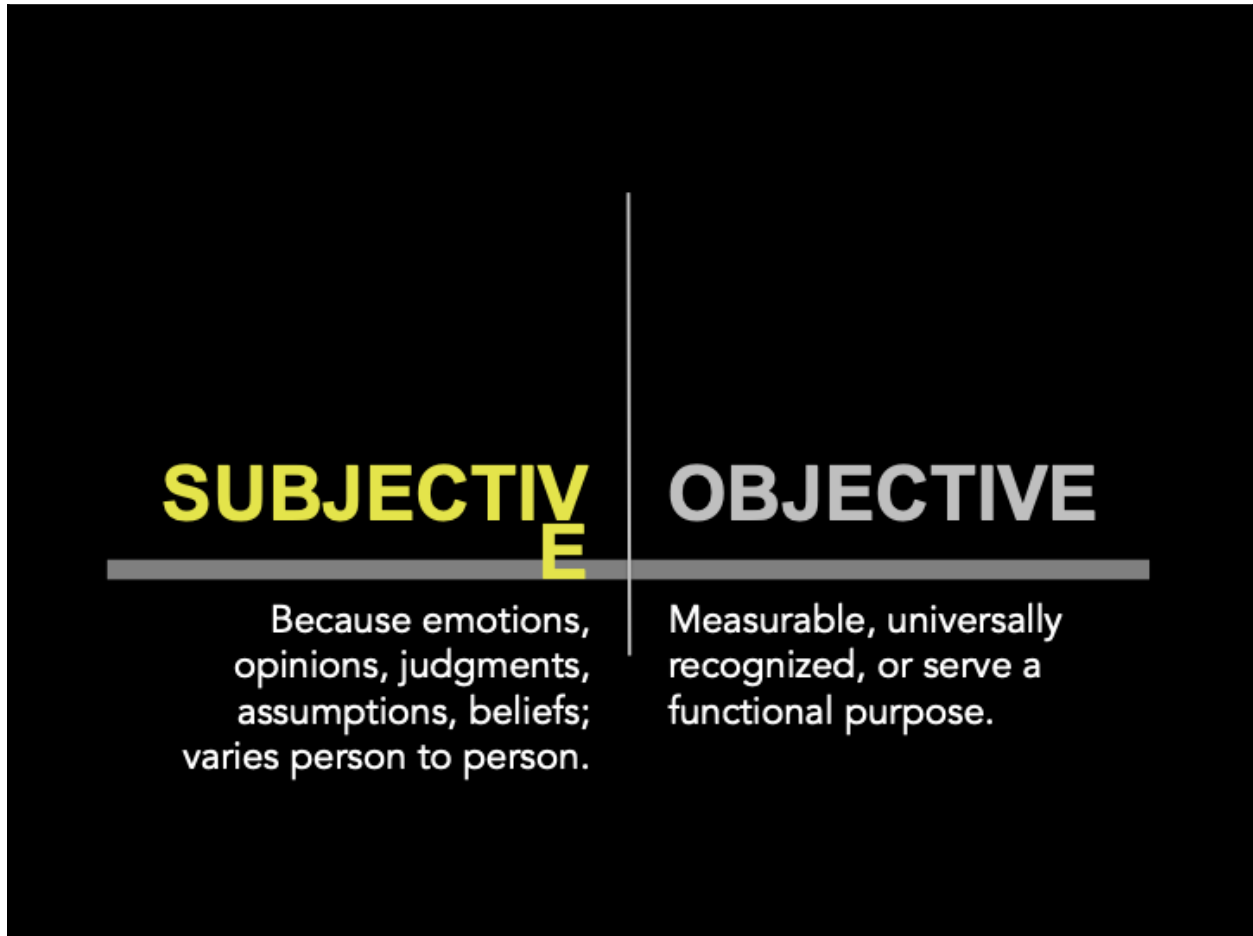
I believe all these people lived in their ivory towers. They didn't understand who their consumers were, what their consumers wanted.

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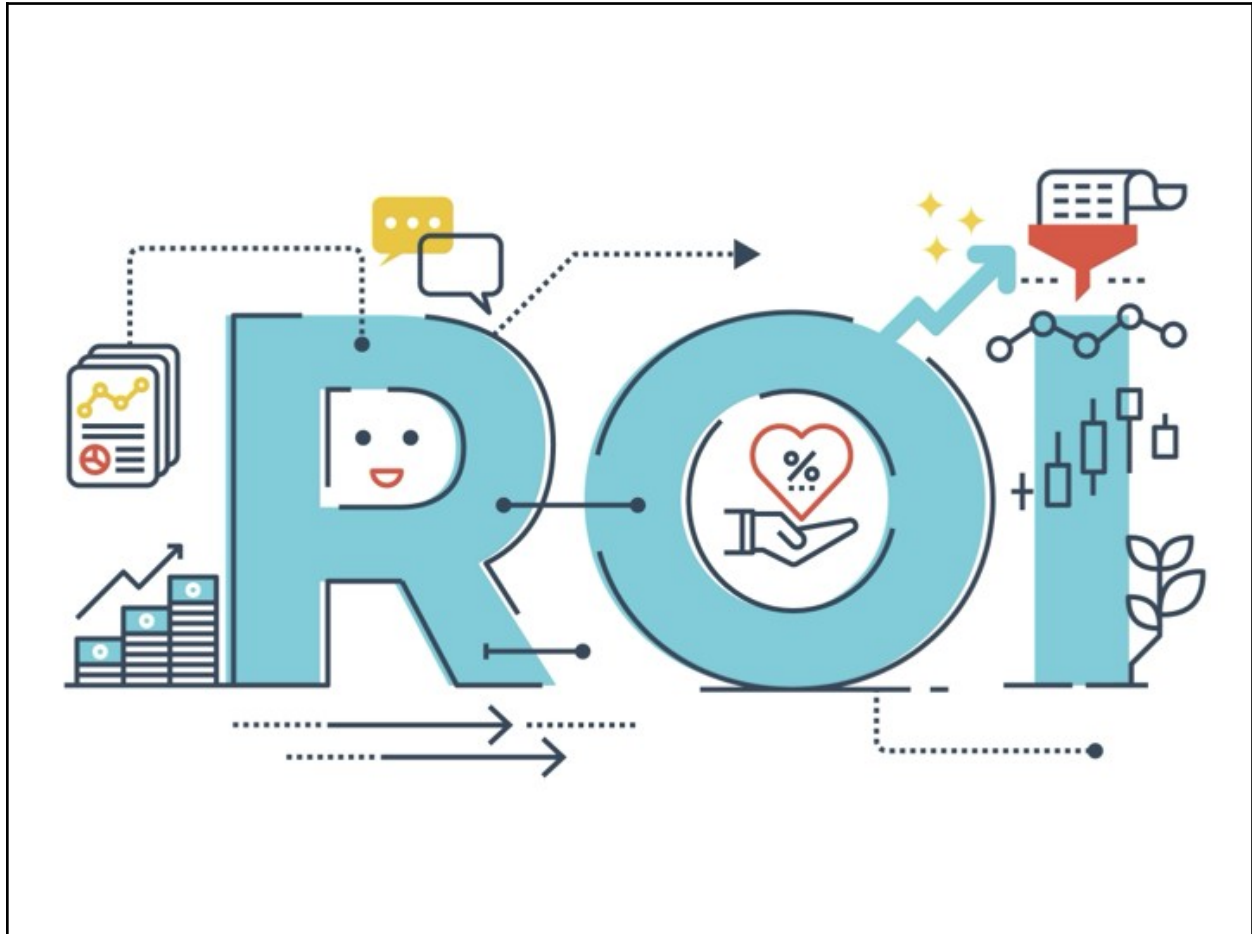
Unfortunately, because I was an artist, and I couldn't get consensus among a lot of the people in the boardroom, I essentially was a starving artist.

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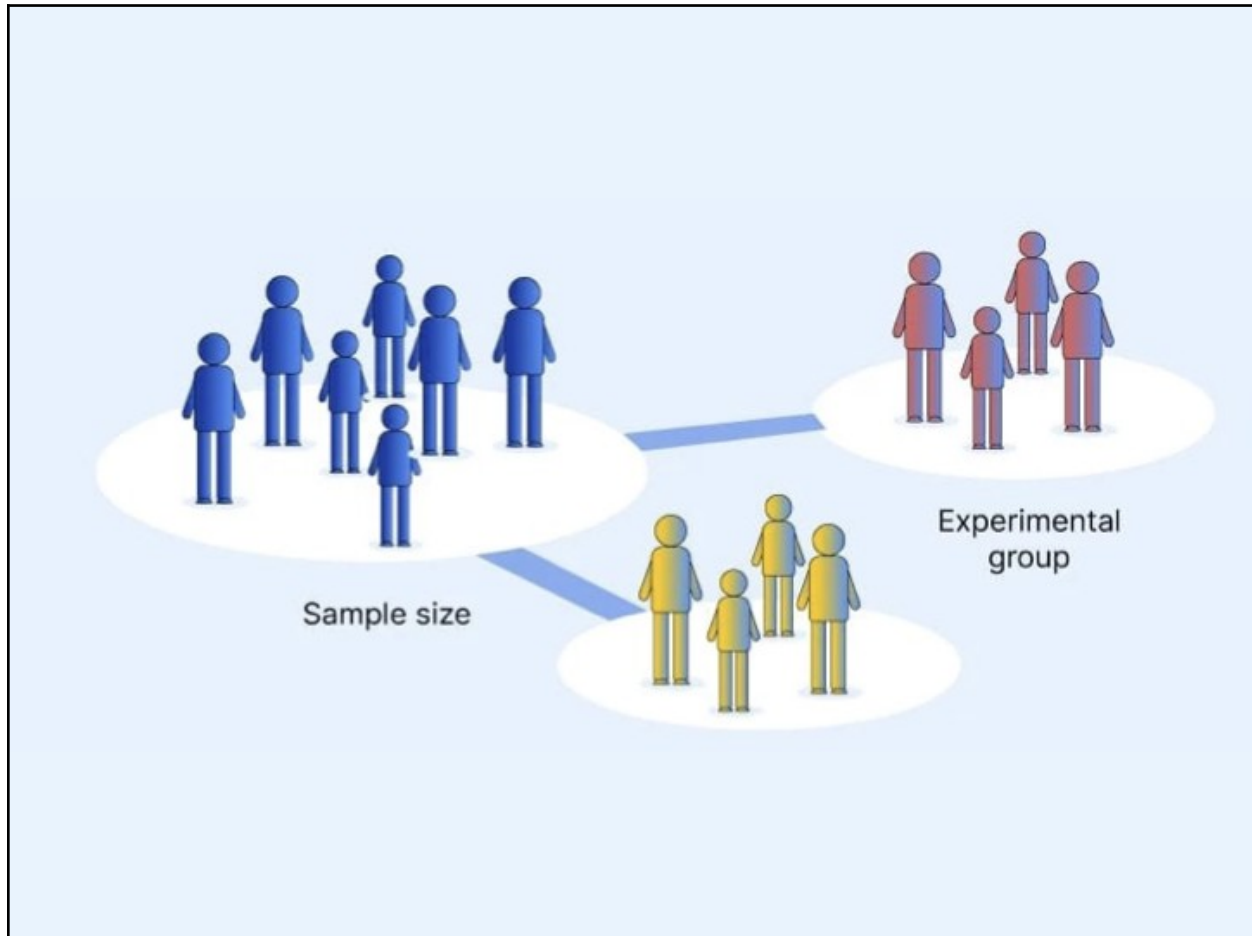
I realized art, like everything, is subjective. Tons of emotions, opinions, judgments, assumptions, personal beliefs. It all varies based on us individually. But I wanted my art to be more objective, measurable.

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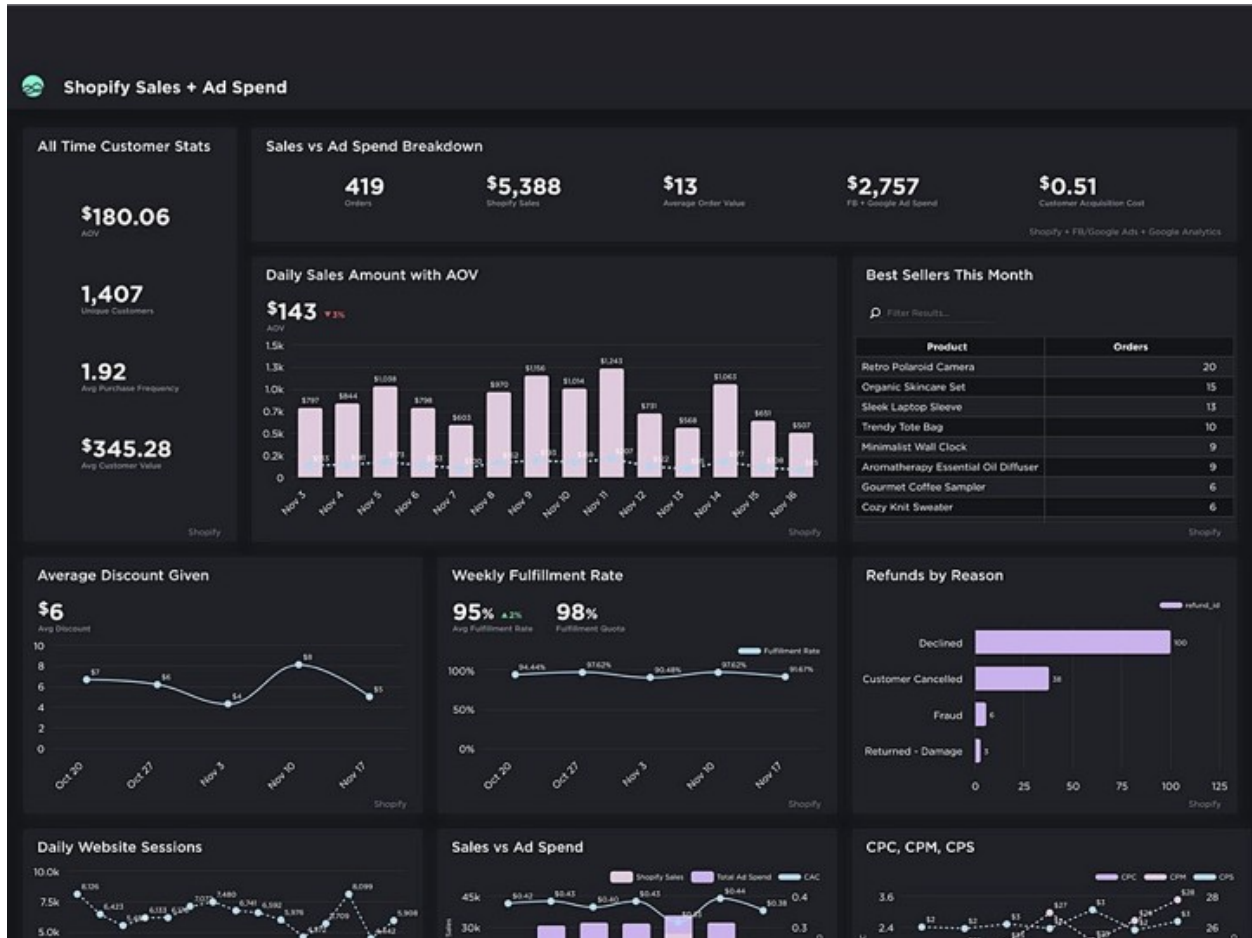
When you're creating an advertising campaign, whether it's a Super Bowl commercial or just a piece of direct mail. My thing is, like, I don't give a shit about your opinions. Does it work or doesn't it work?

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I decided to create marketing that was devised and developed almost like a clinical trial that we're all familiar with. I would have a sample size. I would break people up into two different groups. One would get treated with marketing stimuli. One would be the placebo group or the control group who wouldn't get treated. The idea was to understand the efficacy of the marketing program in place.

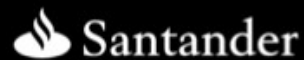
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It was truly about that. Did it work? Did it drive sales? Did it do what it was supposed to do?

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**DATA DRIVEN. MASSIVE IMPACT.
NO BULL\$#!T!**



I worked for some of the most prestigious brands in the world, truly global brands, from Puma to Bentley, Pfizer, Ford Motor Company. What I did moved the needle.

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At that time, I lived in Chicago, got married and fell happily in love, and literally, within 28 days, I was diagnosed with stage one testicular cancer.

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I was working the nine to five.

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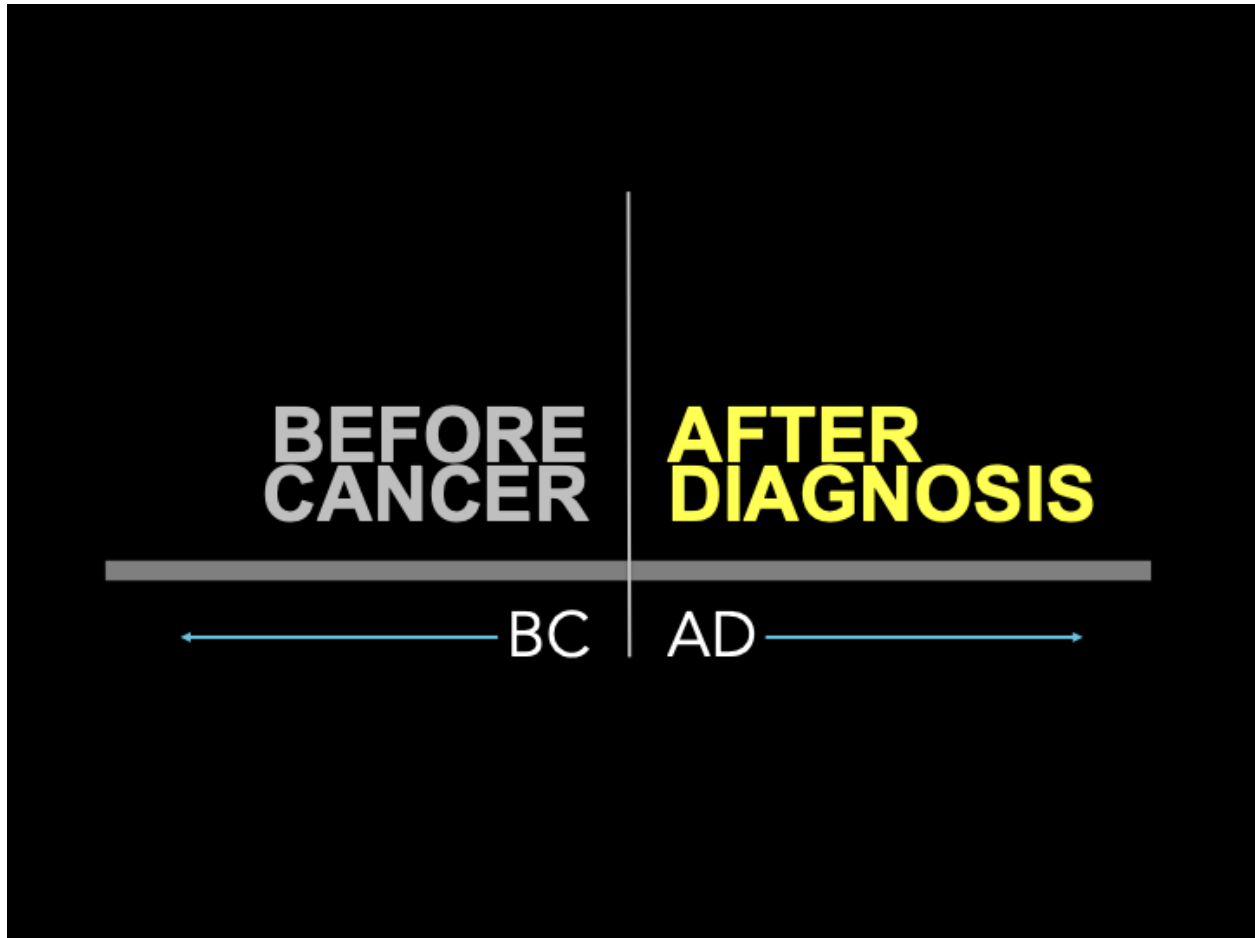
I thought I was invincible.

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Then I got diagnosed with cancer.

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I was 31. I never used any type of medical care in my life. I'm living in a small little town called Reading, Pennsylvania, which is about an hour and 45 minutes outside of Philly.

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I didn't know any better, so I had surgery.

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I had tremendous amounts of radiation – 10 rounds of photon beam radiation.

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Of course, like all superheroes, I was exposed to radiation. I got my spidey sense, my superpowers,

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but I also worked for a Fortune 200 company at the time, where I thought I had amazing benefits, where I thought I could take some time off, and they wouldn't let me. I literally had to work through the entire cancer treatment. That truly changed my world. That truly changed how I viewed benefits, both from an employee standpoint as well as an employer.

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My fertility gone, being 31, getting recently married, the only thing I ever wanted to do was be a dad. And yet, the tremendous amount of radiation along with the orchiectomy (a surgical procedure to remove one or both testicles) prevented me from having kids.

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**HAPPINESS
IS BEING A
DADDY**

I was infertile, and the only thing that truly mattered to me was being a dad.

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I quit my job at that Fortune 500 to start my own company.

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That's my first office in my spare bedroom.

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It was all in the means to go through in vitro in order to have a baby. I knew I had to go through in vitro. That was my only hope, my only chance. And it worked. I was able to have two kids via IVF.

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INITIAL APPROACH

But to go back to the beginning.

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We all walk into a doctor's office. They have a lot of pieces of paper on the wall. When I walked into the Reading, Pennsylvania, urology office, the guy was old, so I assumed he knew what he was doing. He had a ton of paperwork on the wall. Ivy League educated. I assumed, because he was old, he was Ivy League educated, that he was the guy.

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But unfortunately, he wasn't. **Not only did he lie to me, he withheld information from me so I could clearly make the total decisions that I needed to have.**

That's not just my care. My nephew is 26 years old. He just got diagnosed this summer with stage one testicular cancer as well, in South Jersey. Same thing: the doctor withheld information from him.

My daughter was diagnosed in September with an acoustic tumor. Doctors withheld information. They are presenting information to guide you down and pick the answer that they want you to pick, not necessarily providing you all the information that we need as patients, to pick fairly, to pick where we want to go.

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THE TURNING POINT

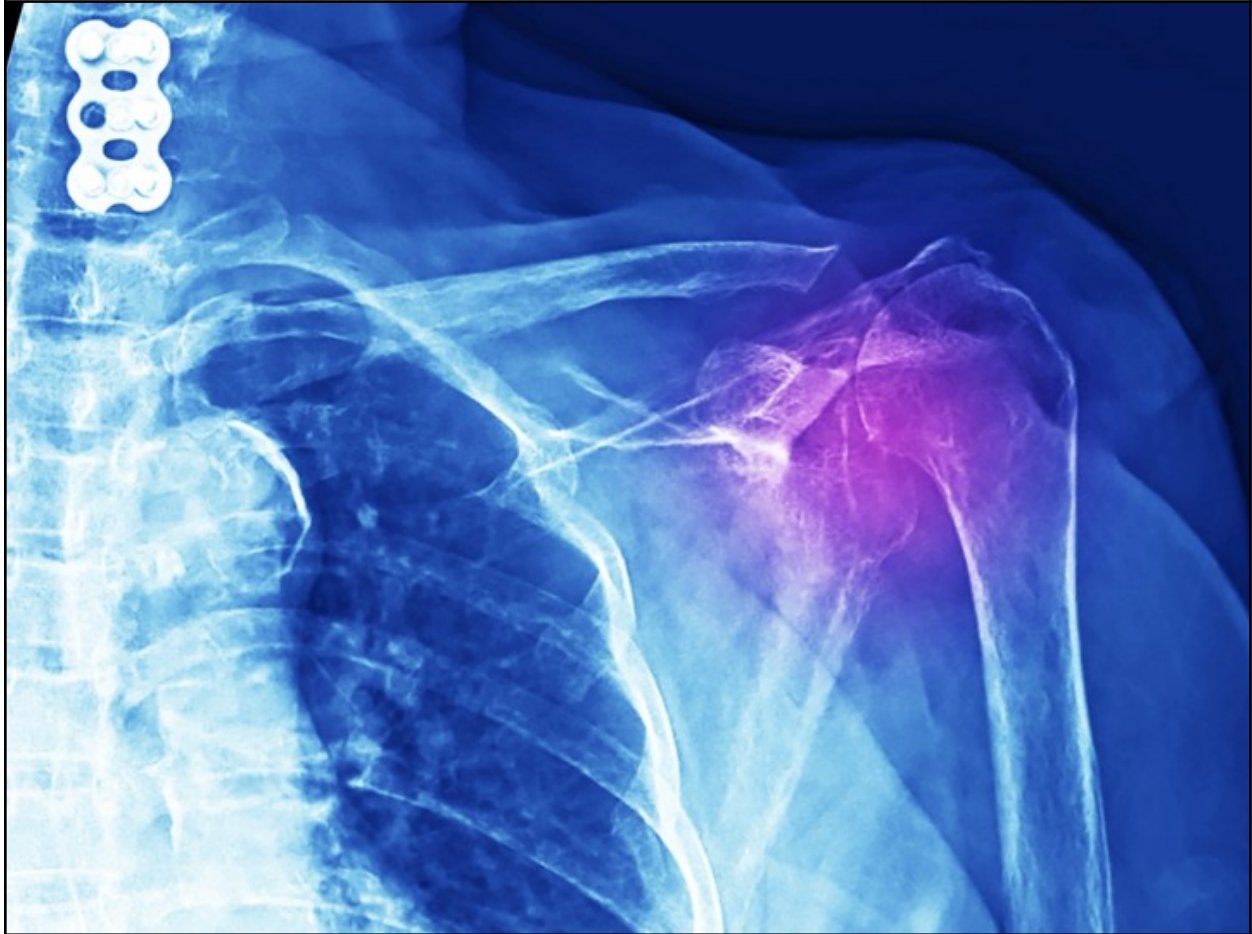
The turning point for me was

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I lost a testicle, and the other one got damaged during the process, which means, as a man, I have no working testicles, so I started to become incredibly hormonal. At this point, I'm in my late 30s. I'm experiencing hot flashes. I'm experiencing signs of dementia and Alzheimer's. I seek treatment at Mayo.

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My body's literally starting to break down. My tendons are snapping. My chest is collapsing from all the radiation. It's becoming incredibly problematic. I moved to Minnesota so I could follow up at the Mayo.

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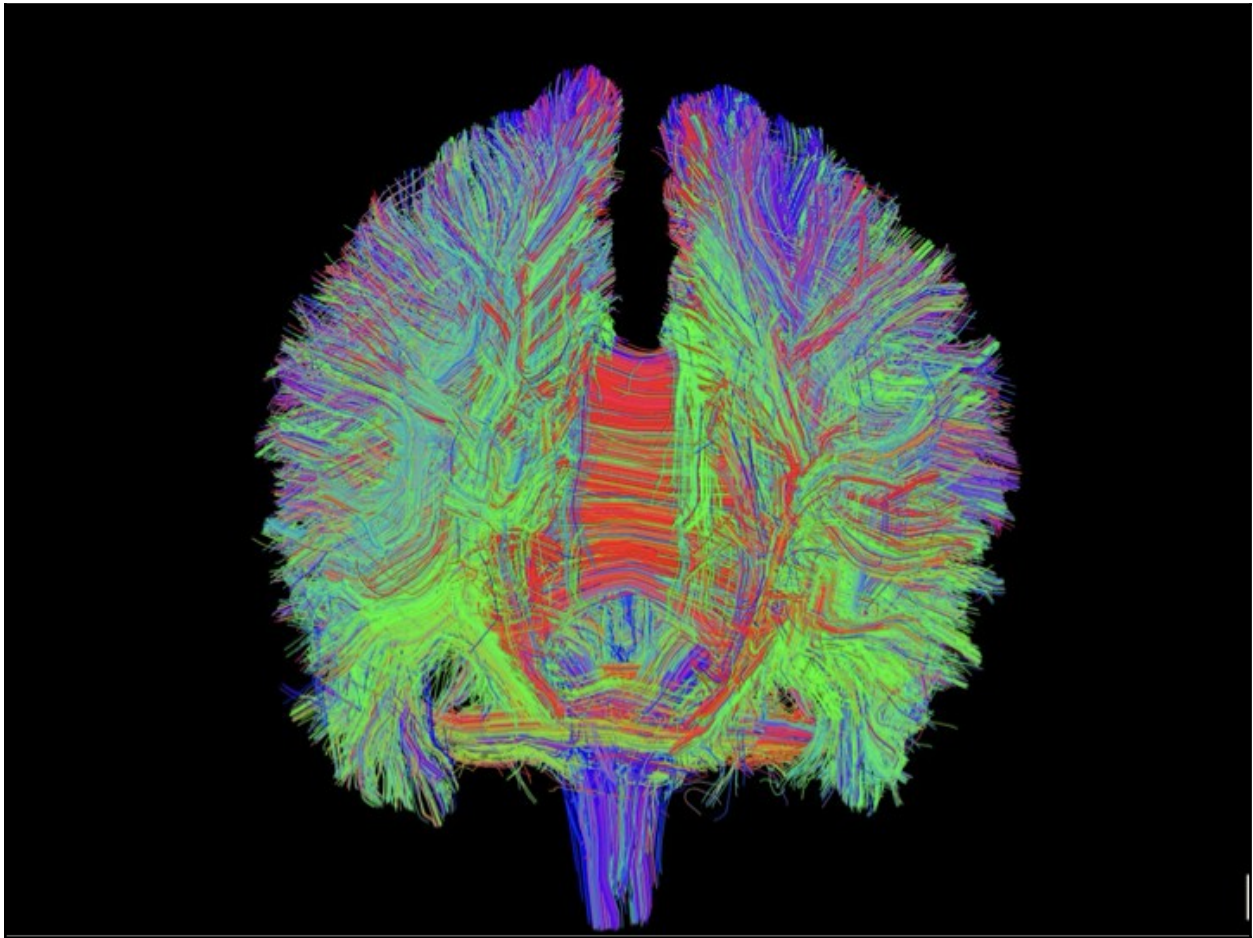


If you're not familiar with the Mayo, the Mayo has a program called an executive physical, where you pay a lot of money out of pocket. You get concierge care. It's about 10,000 bucks, and you get a slew of tests every single year, and they run you through the gamut. Executives from all over the world come here, get it done. The problem was, they didn't care about why I was there. I'm symptomatic. I can barely get out of bed. I can barely function. I don't know how to get home on certain days of the week because my memory is shot. They just blamed it on me being exhausted, on me being a serial entrepreneur and being too busy and not focused. They blamed it on me having newborn children and being a dad. No one cared about all the things that were happening to me as a result of the cancer, which were a result of the residual treatment.

This is America. There are all these lines of "concierge doctors" now that they're being called. There are all these nurse practitioners. There are all these individuals who have the ability to write prescriptions, and a lot of them are "pay to play". So I flew to Vegas, found a concierge doctor, gave the doctor \$2,000 a month, and that doctor allowed me to play doctor on myself. I wanted to inject myself with testosterone. I wanted to do it in a clinical trial setting. I wanted to measure what happened to me from a hormonal panel, from a blood panel, from a CBC

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(complete blood count, a blood test that measures the number and size of different cells in your blood), from brain functionality.



I did that for about nine months, and I felt dirty. I felt like I was doing something that shouldn't have been done and wasn't under necessarily total guidance. I decided to partner with the University of Southern California. I had this hypothesis that, depending on how much testosterone was in my body, determined how my brain functioned. This was 10 years ago, where there was no machine learning, there was no AI and computing power to do a functional MRI. It just didn't really exist. But they took 10,000 images of my brain with hormones and without hormones, and it took over a year-and-a-half to process all the images. They found that there was a difference in my brain.

They're like, "but you're just an individual, one person. This is a sample size of one. There's nothing we can do."

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**EMPOWERMENT
THROUGH
ACCURATE INFORMATION**

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I needed to seek answers.

That wasn't good enough for me. "You're just one person. It's anecdotal. Who gives a shit."

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I wanted to seek answers. I went out. I talked to the best of the best endocrinologists. Interesting enough, endocrinologists will not treat a male with hormonal issues. Mind blowing. An endocrinologist, we all think, is a hormonal specialist. They are, but not for men, and particularly not when it comes to testosterone. When you have testosterone issues, which are impacting your hormones, you have to see a urologist. As somebody who hasn't been in medicine a long time, it was just mind blowing. It's almost like thinking of it from a perspective of your home: If you're having an electrical issue, which neurology is, they're telling you to call in a plumber. That makes no fucking sense at the end of the day outside of the medical world, but that's how the medical world works.

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RESOURCES

<http://www.refseek.com> - Academic Resource Search. More than a billion sources: encyclopedia, monographies, magazines.

<http://www.worldcat.org> - a search for the contents of 20 thousand worldwide libraries. Find out where lies the nearest rare book you need.

<https://link.springer.com> - access to more than 10 million scientific documents: books, articles, research protocols.

<http://www.bioline.org.br> is a library of scientific bioscience journals published in developing countries.

<http://repec.org> - volunteers from 102 countries have collected almost 4 million publications on economics and related science.

<https://www.science.gov> is an American state search engine on 2200+ scientific sites. More than 200 million articles are indexed.

<https://www.base-search.net> is one of the most powerful researches on academic studies texts. More than 100 million scientific documents, 70% of them are free.

I decided to do something about it. I decided to literally scour the internet. We'll share this with everybody. These are resources most people are unaware of that I found can prove completely fruitful for finding information that doesn't exist anywhere else, not even on the NIH. I've used this for myself over the years. I've used this as a patient advocate to help other patients. I've used it for my nephew's care. I've used it for my daughter's care. Highly informative, definitely sourced, and not necessarily tainted by pharmaceutical companies funding research.

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**GOING BEYOND
THE STANDARD**

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\$.5 Million To Spark Innovation In Cancer Treatment

The Th!nk Different Foundation awarded a \$500,000 grant to the University of Southern California (USC) Norris Comprehensive Cancer Center to support two comprehensive programs:

At the end of the day, what I realized is, in order for me to get the answers I want, I had to fund my own research. At that point, as a serial entrepreneur, I had made a decent amount of money, so I funded two studies, one at the University of Southern California, USC Norris, for half a million bucks.

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And then, not only did I do it once, I did it twice, here at University of Minnesota – long term studies on the impact of hormone suppression. The main one is when it comes to brain functionality. The other one is realizing that testicular cancer, particularly the lower stages, stage 1 and stage 2, the treatments were antiquated and not based on real science. They were based on studies that were done literally 50 years ago by [Einhorn](#) in Indiana. They were outdated, irrelevant, and unfortunately the standard of care in America. It was different in Europe, which is still problematic. Right now, if you have early stage testicular cancer, and if you do need chemo, the standard rounds in the US is three rounds of BEP (bleomycin sulfate, etoposide phosphate, and cisplatin, a chemotherapy combination that treats various types of cancer, including testicular). In Europe, it's only two rounds. The toxicity of that additional round is problematic: hearing loss and a tremendous amount of other side effects.

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LESSONS LEARNED

The lessons that I've learned, more importantly,

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is that we all have time when we're diagnosed. Doctors want to scare us into making an immediate decision. They told me I had to make a decision within 24 hours, and I was scared shitless that I had to make a decision in 24 hours. I didn't know any better.

My nephew, who got diagnosed 20 years later, was the same thing. They told him he had to make a decision in haste. I'm like, "You don't. You have time."

My daughter was the same way. They wanted to have her on the table within hours of her being diagnosed with a tumor. We actually waited six weeks. We can get the information to make a decision, a decision that was based on science.

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We have to truly understand the economics of medicine. Particularly in the cancer world, 50% of the surgeons are getting paid from pharmaceutical companies in some regards. That's a stat that can be found all across the internet. It's just not me. I'm always joking around. When I walk into a doctor's office, a surgeon's office, his jacket should look like a NASCAR jacket. Or a car. I want to know everybody who's giving you money, anyone who's sponsoring you, anyone who's influencing your decision, so I can make the best decision for me.

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Medicine is not a dictatorship. It's a partnership. It's collaboration. All you are is a doctor, basically an asshole with an opinion. That's all you are. Yes, you went to school. You're just an educated asshole with an opinion. I have thoughts. I have opinions. I've done my research, as we all have. Sit down, listen to me, respect me. Just because I never went to college, I've never studied medicine, doesn't mean I don't know about my disease, about the treatment. I've done my homework. I've talked to your peers. I know what I'm talking about.

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A FRAMEWORK FOR ADVOCACY

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ACTIONABLE STEPS

Increase your understanding of the condition

- Journal of American Medical Assoc.*
- New England Journal of Medicine*
- Medline and Google Scholar*

Seek out an Angel for one-on-one support

www.imermanangels.org

Know the most effective treatment options

- NIH
- ASCO (American Society of Clinical Oncology)
- BIO (Biotech Innovation Organization)

Always seek a second opinion

Just to recap:

Know your condition. There's a tremendous amount of resources out there.

If you haven't heard of Imerman Angels, it's an incredibly important resource. It's a matchmaking service that matches you with somebody who has your same stage for the same age. They can't offer medical advice, but it's a great sounding board. I'm an angel myself, so people call me who are in their 30s or stage 1 testicular cancer in the Midwest. It's highly valuable. I had my nephew reach out when he was diagnosed.

Know the most effective treatment options. Just because your doctor's recommending something doesn't mean the efficacy of the treatment is there. There's the NIH.? There's ASCO. There's BIO.

Most importantly, seek a second opinion. I've done a lot of research on second opinions. In breast cancer, about a third of breast cancer patients are receiving the wrong diagnosis. That diagnosis is more severe than the actual disease. 50% of overall cancers are misdiagnosed. If

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you go to an NIH facility to get your second opinion, that second opinion will be less severe when it comes to treatment, when it comes to the disease as well.

If you don't have the ability to get to an NIH, the great thing about telehealth now, it gives us that access.

BIOHACKING TO A BETTER RECOVERY

The art and science of changing the environment
AROUND YOU AND INSIDE YOU
so that you have full control over your own biology.

One thing which is incredibly important too, is what I call biohacking, understanding the ability to manipulate your environment. When I say, "manipulate your environment", it's like my daughter. I found out that with my daughter's condition, if we gave her fish oil pre-surgery and then post-surgery, it had the ability to lessen the risk of facial paralysis. I didn't know that going in. When we first met about my daughter's condition, we were told she only had a 1% chance of having facial paralysis. That fact, that statistic, is not true. It's not a fact. It's a fact when you look at overall conditions. But my daughter had a five centimeter tumor. It is one of the biggest tumors for this disease. On that size tumor, it's almost probable that she would have facial paralysis. We weren't told that. So after the 12-hour surgery, the doctor comes back. He's like, "I got good news. Her tumor is 100% removed. The bad news is she's paralyzed." We're like, "What the fuck! No one ever talked about paralyzation. It was 1%. How did we not get the 99% card?" After the fact, after we found that she was paralyzed, we started looking into what we could do

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to prevent her from being permanently paralyzed. Then I came across this study that was done at the Mayo, a clinical trial that was terminated for not having enough patients participate. But the Mayo was looking into the efficacy of fish oil on paralysis. We were never told that. The doctor never put her on fish oil before he did the surgery. It could have helped. But immediately afterwards, I reached out to the clinician who was working on this omega 3 study, who's no longer at the Mayo. We had a chat. There's research out of Asia that's promising. So we immediately did that.



The other thing I looked at was red light therapy. Red light therapy works for facial paralysis. It's one of the key treatments for Bell's palsy (a neurological disorder that causes temporary weakness or paralysis of the muscles on one side of the face) nowadays, particularly in Europe and Asia. I can't put her on red light therapy yet because she's still on steroids, and they counteract with one another, but next week, when she's off of her steroids, I will immediately put her in red light therapy to try to make the paralysis temporary and not permanent.

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I've seen it with myself in my care and others that they've done a tremendous amount of research on meditation. When you're in the right mind, your body can essentially heal itself. Stress is horrible when you have cancer. It makes it spread.

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Calorie restriction. There's a doctor out of USC. His name is Dr. Longo. He focuses on ketosis and cancer and cancer treatment. It's proven. It works. I'm probably in the best shape of my life now due to calorie restriction and being on a very low processed food diet, very low sugar diet, and high protein, but good proteins and vegetables.

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Cold water therapy. I do this as well, and I don't have an ice bath. I don't jump outside in a bed of water. I turn my shower from hot to cold. I do that for a small period of time. I believe that works, particularly keeping me thin with low body fat.

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Heat exposure as well. Sauna, steam room. All proven to work in different components.

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Most importantly, supplements. Like I just talked about the Omega 3s. When I was having a lot of brain issues, I studied supplementation and the brain. There's an amazing doctor out of Austin. He's a neurologist. His name is [Perlmutter](#). A phenomenal individual. He talks about how genetically some people are predisposed to have dementia and Alzheimer's, depending on your ApoE, depending on some other things. Amazing book. He talks about how supplementation is so important for brain health.

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WORDS TO LIVE BY

"Real-life has no signs, and no straight lines. There's just a maze of infinite options."

-Oliver Emberton

"It is not the strongest of species that survive; nor the most intelligent that survives. It is the most adaptable to change."

-Charles Darwin

Two things that got me by, that made me focus:

"Real life has no signs, no straight lines. There's just a maze of infinite options." Same with healthcare. There's no right answer. There's no wrong answer.

The same thing with Charles Darwin. "It's not the strongest of species that survive; nor the most intelligent, it's the most adaptable."

We're probably not the most intelligent, but we are some of the smartest, and we are willing to adapt, we are willing to change, we are willing to get better.

Brad Power 22:05

How have you multiplied your impact? You've just shared this with us. What is your approach, given your marketing background, in particular, to sharing what you've seen and learned and making it more accessible to other people who might be interested?

Scott Petinga 22:59

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I share my story on social media. Social media has a tremendous amount of opportunity. LinkedIn for one – connecting to doctors, to people in the pharmaceutical world, to clinicians. That's one thing: telling my story, telling my daughter's story, my nephew's story. Telling as many stories as I possibly can, and how we have options.

My biggest thing has been after care. The whole survivorship side. What pisses me off, for example, was the doctor at the Mayo who removed the tumor. He's like, "I'm done". I'm like, "What about her facial paralysis?" And he made it sound like, 'I did my job. My job was to remove the tumor. Her facial paralysis is not my problem.'

The great thing about the Mayo is how tremendous the talent is under one roof. My daughter's mom and I just started looking for stuff. She works in the neuro unit, so she asked her doctor what we could do. We uncovered this thing called "facial reanimation". And the Mayo has a specialty about facial reanimation, but the doctor didn't know about it, which is crazy, because he caused the paralysis. My thing was like, "I need to talk to the doctor in the morning." They were like, "Oh no, you can't." My thing is that you have to fight your battles. I raised Holy hell that I better see the doctor before the morning comes. Sure enough, the doctor was there, because I raised the stink. My daughter, who's sick, Brooklyn, she calls me "a Karen", and I am. **I'm going to do whatever it takes for myself or my family to get the best standard of care. I don't care who I piss off along the way or who I upset. I don't care if I hurt your feelings.**

I'm trying to get the best and minimize those long-term side effects, because 20 years later, I'm still battling. Yes, I'm cured from cancer. I'm in remission, but I have a collapsed chest. My ribs aren't connected. My lungs are impacted. My heart's impacted. I've had 50 surgical procedures just to get hormones in my body, two wrists replaced, two rotator cuffs, both hips replaced. I don't care if you did your job. I'm trying to make life easier in the long run for me and everybody else, particularly as we get diagnosed younger. My daughter, 15. My nephew, 26. I was 31. We have 20, 30, 40, 50 years ahead of us. Hopefully, knock on wood. But that's the thing. Tell your story. Tell it often.

Secondly, the more knowledge we uncover on our own, it's up to us to share it, to be part of Imerman Angels. When someone's in our same trajectory, we can give them everything we've learned, we've experienced, so they don't have to walk the difficult challenges that we've had. To go into some of these groups on Facebook. Facebook is a tremendous area, because there are groups for almost every single disease out there. Going there, telling your story, imparting your wisdom, is tremendously key.

Because I'm a marketer, I've also used my story to get major press. I've been in Entrepreneur Magazine. I've been in Forbes. I've been in Vogue telling my story, even Playboy, because that's where young men are. We all need to go out there and tell our story, because without those stories being told, the only information we're forced to see is the information that's being feeded to us by the practitioners, by the pharmaceutical companies, by the medical device companies, and that's not the world we want to be in.

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Chad Magnussen 27:07

You talked a lot about things like integrative oncology, red light therapy, all of that.

Where are you finding your information? Is it from an integrative oncologist or or a naturopath doctor? Or are you finding it through AI?

Scott Petinga 27:22

All through AI; all through those sources that I listed in my resource page. Unfortunately, even when I talked to the doctor for my daughter with red light therapy, they had no idea. When I talked about supplementation, and how I saw all this promise from omega 3, she was like, "Well, it can't hurt." But they haven't read the research. They don't know about alternative treatments, particularly post-surgical treatments. For example, silicone gel for scars. That's why I first started using red light therapy. I have keloids, and I scar incredibly, horrifically. I was looking for a means to not having so many grotesque scars all over my body. I started using back in the day, before AI, search engine results looking for options, and I found the silicone-based gel. It's not cheap. It's about 60 bucks a tube, but it's miraculous what it does to scar and healing.

David Plunkett 28:35

You mentioned that your doctor and your nephew's doctor withheld information. Can you say a little bit more about that? What was withheld, and how did you determine that it had been?

Scott Petinga 28:46

They didn't give me all the options. In my particular case, the doctor is like, "You need an orchiectomy" (which is removal of the testes), "and you need radiation". That was the only plan. There was no other plan. Same with my nephew. It was, "You need an orchiectomy, and you need 3 rounds of chemo." There was no other plan. Surveillance wasn't a plan. To my nephew, I'm like, "Wait. You got time." The doctor scared him into getting chemo, saying, "If you don't, it's going to spread. If it spreads, you're going to die." I'm like, "No. You listen to me. This is my world. This is what I fucking do. Particularly testicular cancer. Wait. I funded research on your exact disease, on the exact stage. Time is on your hands. Wait three months. Wait six months." The doctor scared him so much that he got three rounds of chemo (over 9 weeks). Then I even presented my nephew with the European research, where it's like, "Hey. The European Research says you don't need three rounds. You only need two." Then the doctor's like, "That's Europe." I was like, "What's that have to do with anything? People are people." I was like, "My nephew is genetically European." Saying you have to go three rounds doesn't make any sense. He's like, "Well, that's standard of care in America." And I was like, "Well, this is standard of care in Europe, and Asia too." He scared my nephew into having three rounds. Then I told my nephew right when he was having chemo, I was like, "Your tumor markers are normal, so essentially you have no signs of cancer.

He's like, "Yeah, but there's a small, little two centimeter node in my chest." I'm like, "It could be benign, so you can wait to see if it actually even grows." Long story short, he had nine weeks of chemo, three rounds. After all that, the node was still there. After that, the doctor's like, "Now we need to go in and surgically remove the node." I was like, "You don't. It's benign. Let's wait." The

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doctor scared him into having surgery to remove it; cut from here (pointing to chest) past his belly button. I know the surgeon. I've known him for 10 years. Over the years of my funding of testicular cancer research. After he removed the node, and the biopsy came back, my nephew reached out. My nephew was like, "I'm so happy I'm cancer free." And I was like, "You've been cancer free for a long time." I reached out to the doctor, and I was like, "Do me a professional courtesy. What did the biopsy say? It was fucking benign, wasn't it?" And the doctor, no shit, was like, "It was benign-like." I was like, "There is no such thing as benign-like." He's like, "Well, it was benign, but it could get bigger. So we removed it." And I was like, "Yes, it could get bigger, or it could stay the same. That's why you do surveillance, and you don't remove it immediately." So again, those are decisions, where I'm saying doctors are adamantly lying, or they're not necessarily giving him options or talking to the patient in a certain way where you're scaring them, you're giving them anxiety, you're giving them a false sense of success if they don't go down the path that you want them to go down. I was showing my nephew, and my nephew's 26, and he's still got a kid brain.

I'm talking to his mom, my sister-in-law, and I showed her how much money the University of Pennsylvania made off of pharmaceutical companies last year, \$750 million. So you can't tell me that does not impact the standard of care in America when all around the world, it's less drugs and the efficacy is the same. That's what I'm trying to educate people about. Here are the facts. There's a website out there that shows every single penny hospitals make and doctors make from pharmaceutical companies. It's there. It's available. Nobody knows about it. I'm just sharing the information. Here's how much your doctor made. Here's how much the medical facility made. You make the decision. Here's the standard of care outside the US. Here's the standard of care in the US. You make the decision.

Brad Power 33:28

You represent a role model. You're a citizen scientist. You're a super advocate. A rogue advocate, like a crazy, maniac advocate. You're advocating that others should do it as well. Here at the Cancer Patient Lab we believe that engaged patients get better outcomes. So you must have dealt with this. Let's just stay with testicular cancer, or it could be prostate cancer, men are often too macho to talk about their disease. They don't share publicly, as you are, their journey, and what they're feeling, and their choices. They're hesitant. They might even be avoiding getting the tests, getting the treatments, having the conversations, doing the research that you're doing.

What in your experience can help people? I'm thinking of it as some kind of a pyramid, and you're trying to get them to move up to levels of advocacy for themselves. What has been your experience in getting people to be better advocates for themselves?

Scott Petinga 34:41

I was a Marine. My cancer is from Camp Lejeune. I'm sure we're all aware of it: Camp Lejeune, toxic drinking water. I was stationed there. I'm one of the statistics. Me being a Marine, me being a man. Super macho. Everybody could tell you, before cancer, I had a stone cold heart. I didn't have emotions. Somebody asked me recently, if I were to change any part of my life,

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would I? Even cancer? And I said, "Absolutely not." I even tell my kids I am where I am because of where I've been. Cancer truly is my superpower. It's weird. As I reflected so much because I've been sick so much, and every time I go on the table for a surgery, I believe I might not wake up. My legacy has been the most important thing for us. I would ask everybody here, whether you have kids or not, I'm looking at it from the standpoint of, what do you want your legacy to be? I admit that I cry. My daughter sees me cry. I'm highly emotional now, but my biggest thing is I put my ego aside because I want my legacy to be known as the guy who would do anything to help mankind. That's my thing. We all have a story. We all have a story that can help so many people to stay alive.

Men do not go to doctors. That is a fact. Most men wait way too long. That's why a lot of men don't get diagnosed until the later stages, because there have been problems. We always blame it on something else, or we don't have time. I don't care if you have a sore wrist.

My daughter for nine months was complaining of headaches. Nine fucking months. Her mom, who works in a neuro unit, was brushing it off: the hormones. Her pediatrician was brushing it off: the 14-year-old girl hormones. Then she's vomiting, and she's losing weight, and it's like, "Oh. Not only is she hormonal, she has an eating disorder." Everything was being blamed, but at no point did anyone ever look at an MRI, look at an x-ray. Everybody missed the basics. By the time I got involved, I literally took her in for a psych eval, because she just wasn't acting herself. Behaviorally, she changed 180. So I took her in for a psych eval. We were in the emergency room waiting for a psych eval, and I asked the attending to do me a favor and let me have a CT scan. She got a CT scan. It came back with fluid on the brain. The doctor's like, "It's just fluid on the brain. She's fine." I'm like, "Fuck, no. I want an MRI." I demanded an MRI. I raised hell to get an MRI. This was like, two o'clock in the morning on a Saturday night. They did an MRI. It came back with a five centimeter tumor in her brain. Even there, I had to fight with everybody, with pediatricians, with doctors, because as we all know, practitioners no longer have time. They're in, they're out. You go. She doesn't have the same pediatrician all the time. It's always somebody different. No one's looking at the totality of everything that happened to her all the time. She came in for all these different symptoms that when you look at it, you're like, "Holy shit. How come no one ran any imaging?" And I think, "We just need to keep on it. We just need the heart. We need to see doctors, often, occasionally for annual exams. If we have any type of problem, if we're not feeling well, if we're getting sick, if we're having headaches, go in."

It takes 30 minutes. Oftentimes nowadays, it's amazing. With technology, you don't even have to wait in line for urgent care anymore. I can pick up my app, and I can make a reservation so I don't have to go there and sit there for two or three hours. At least in Minnesota, I can log in. I can check all the urgent cares around my city, and pick the one that has availability, and pick a time so I don't have to wait.

We all need to suck up the manliness. I was as manly, if not more manly than most people. Get those annual exams.

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Think about how much time as consumers we spend trying to find a car, trying to figure out what toaster to buy, or what piece of apparel to buy. Imagine if we put that same effort in earnest into finding a doctor. It's mind blowing. I was the same way. I was guilty right at 31. I'm like, "There's a urologist near me. Oh shit. There's one right here, five blocks away. That's where I'm going." I didn't research.

We're undermined by insurance. What insurance do we have? What insurance don't we have? Where do those insurances allow us to go? Does it even allow us to go outside of the network or a different tier, like the Mayo.

For a long time I've been calling it the "hub and spoke" model. As a data scientist, I did research into testicular cancer. I looked at all testicular cancer patients that were diagnosed and treated over a 10 year period. I plotted them on a map. I created two nonprofits in the testicular cancer space, because when I got testicular cancer, I just went to the guy down the street.

What I've realized about diseases is they're specific. When my daughter got diagnosed with brain cancer, I didn't realize there are 140 different types of brain cancer. 140. She had one type. I don't care if you've done brain cancer. Have you done her type? Have you done it a lot?

Same thing that I've realized about testicular cancer is that only 10,000 guys in the US actually get the disease every year, which means the guy that I went to – I learned this after the fact – never treated testicular cancer. I was his first treatment. I didn't know he had never done the surgery before. He had never treated it. I was patient number one. I never asked them, "Hey. Have you done this before?" I just assumed. I never asked him, "When was the last time you've done this?" I just assumed he did it all the time. I was almost hoping that he would tell me, "Hey. Guess what? I've never done this before, and you're my number one." Because I would have been like, "Shit." I would have left, but because I didn't ask, he didn't tell. For a lot of us, as we start seeking care, ask the doctor, do you do this? Do you do this often? If not, can you make a referral?

What I've realized over the years is that knowledge is power. With my daughter, I went on LinkedIn. I found out all the individuals who are posting all their research, who are talking about vestibular schwannomas, who are going to conferences about that specific disease. I created my network of the best of the best. What's amazing too is everybody is willing to talk, particularly if you have a sick child. Everyone sat down with me. 99% of the doctors talked to me for free. They didn't care about what insurance I had. I had a sick kid. They wanted to help.

Harvard was going to be our number two facility that we were adamantly seeking treatment at. We did that legitimately on the record under the insurance as a second opinion. But it was amazing how many times people would talk to me, and set my daughter's labs. Sat down, talked to me for a half hour, an hour, and walked play by play. For everybody who's seeking treatment, that's what you want. You want to know, play by play, from the time they wheel you in to the time they put you in the ICU. You want the details. I want to know how you're going to close the skull. I want to know how you're going to suture. I want to know how big the wound is going to

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be. I want to know everything from point A to point B, and we're not going to miss all the plays. A lot of times we just go in. We don't care how things are going to happen. But that's where I see things become problematic, when you're unaware, as a patient, of the steps they are going to take.

Same with me when I woke up from my testicular cancer surgery. I had a C section. I didn't even think that they would remove my testicle from my belly. As a guy, I just assumed it was in my scrotum. They were going to remove it from the scrotum. I woke up, and I was cut wide open. I'm like, "What the fuck." And they're like, "Yeah. We had to remove all the tubing." He didn't tell me. I didn't ask. I didn't know to ask, and he didn't provide that information. I see this time and time again, talking to patients, either pre-surgery or post-surgery. No one's talking about the details, and we all need the details.

Chris Apfel 44:46

Informed consent is legally required for any physician when he's treating you. Informed consent is only valid if it explains the proposed treatment, pros and cons, and also explains the alternative, and also has an obligation to ensure that the patient really understands it, and that the patient voluntarily agrees to it. It can't be done under coercion or or under duress, or something like that.

The reality here in the United States, apparently, and what you experienced sounds, unfortunately, a little bit different, but from a legal perspective, that's relatively clear. The reality is different. You are a prime example of that, where you went in with a lot of trust and confidence that the doctors will know, and you had a rude awakening and are now more on the other extreme, on, "Oh. He certainly knows what he is doing." A middle ground is probably good there, but the key is really to speak up for yourself and ask questions and educate yourself.

I've mentioned this on this channel before about [Archelle Georgiou](#). She has a book called "Healthcare Choices" and a podcast that's called "Speak up for your health." If you really want superior outcomes, you can't just go with standard of care. You need to ask questions, educate yourself. Unfortunately, the way our healthcare system works here is physicians get reimbursed, and hospitals, by procedure and not by the quality. The quality that we are looking for as patients is not something that is properly documented and cannot be logically. Therefore, it's really important to speak up for your health. I wouldn't go that far and say, "How do you close the wound?" But in a way, I would like to have a really good understanding of what the procedure entails, and that's important.

Brad Power 47:32

Ari Akerstein, a member of this community, tells a story about how he was going to be cut from one end of his chest to the other to do a biopsy or surgery, and they said it couldn't be done laparoscopically. The first surgeon said, "No." The second surgeon said, "No." The third surgeon said, "No." A fourth surgeon that he knew said, "Well, maybe you could talk to this guy over here. He might consider it." He then talked to that surgeon, and the surgeon said, "No." Then Ari said, "Well, what about if we did it laparoscopically, and then if there's a problem, you can cut

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me open." They did it laparoscopically. It saved him from being hospitalized for about three weeks.

To counter your point, Chris, even the way that they're going to cut you open can be on the table for discussion.

Scott Petinga 48:15

What's crazy too, is surgeons aren't necessarily plastic surgeons. My cuts are not straight lines. Sometimes you're like, "What were you doing?" They're jagged, they're sharp. They're problematic post cancer care.

Same with my nephew. I see a lot of surgeries and a lot of pictures, and you look at some of these, and there's no way that was done carefully. Thinking about the long term, with any finesse. Even my daughter. The doctor was like, "Oh. Who cares? It's in her hairline." Really?

Chris Apfel 48:51

I was made in Germany over half a century ago, and I had proper training as an MD and anesthesiologist. We usually take care of our patients, and we keep patients alive despite a surgeon. I'm also an intensivist and clinical researcher, and now have a cancer diagnostics lab. When I moved here to the US, there were a few things that I learned in this US healthcare system. As an anesthesiologist, you're not on par with the surgeon. The surgeon decides what anesthesia you give. In Germany it would be illegal to mess in the other's procedures. I, as an anesthesiologist, wouldn't say to the surgeon, "Oh. Please do this laparoscopically. Don't do this open." That's not my prerogative. I feel offended even today, if a surgeon would tell me how I should do my anesthesia. But isn't that quite interesting? Why can't the surgeon do this? Because the surgeon owns the patient. What do you mean, "owns the patient"? There are two types of physicians in hospitals. There are referring physicians. They bring in the money. Patients come to that person, and as a result, they have the leverage and the power to make decisions. So if you have an aneurysm that could probably be coiled with an interventional radiologist, if you see the neurosurgeon, the neurosurgeon makes a decision whether he wants to operate on you and open the skull, or whether he lets the interventional radiologist do the procedure. It's interesting what the hierarchy is.

It's also very interesting how the U.S. healthcare system is optimized for profit maximization. In many procedures, we have for cost reasons (time is money) physician assistants. Physician assistants in this country have the right to do everything that the physician believes is acceptable for doing. For certain procedures, opening, let's say, back procedures, opening the skin and removing some of the musculature, or closing the skin, can be done by a physician assistant. It's interesting how much in the United States can be delegated to the sufficiently educated or trained person to minimize cost and maximize profits, just as a sideline, and one is not aware of that.

Scott Petinga 51:38

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When you're in a training facility, it's times 10. There's a whole slew of hierarchy in there, who are observers, learning, touching.

Chris Apfel 51:51

One thing in regards to a training facility. I have trained many residents and vice versa. If you're in a training facility, in general, you get better care because the residents are supervised. There is a sense of responsibility to show how it's done right. There is very close supervision in training. In the US in that regard, I have seen in private practice when people have been in practice for 20 years, and not worked with supervision anymore, that it's more the wild wild west. Even if you have a resident or a fellow being involved in the care, I am more comfortable than with an individual private practice guy.

Bill Paseman 52:58

It kind of relates to Agile programming, and a little bit to the tumor board. Generally, if you have two people looking at each other, talking about stuff, recognizing that their opinions are being scanned by the other person, it makes them sharper. They have no desire to be embarrassed in front of a peer, or definitely in front of a superior, in terms of any particular decision that they make. They have a tendency to be more careful. That doesn't reflect on anything about the ethics or about the guides. It's what it is to be human. That is, if you go on and have a person that wants to go on and get approval. You can use that, in fact, in the creation of these processes.

That's why I like the tumor board stuff a lot. A lot of times, I do it in two stages. First off, these guys don't get to talk to each other. Then secondly, they do. Now, it turns out, do you get a different answer as a result of doing each of these approaches?

The other thing I want to bring up, which has not been brought up at all, especially interested in Scott's point of view and in Dr. Apfel's point of view. If you go on and look at the United States health care in particular, and I've also lived in Germany, so I've got a little bit about that too: It's a paternalistic system. The idea is that there's this person. They have an obligation. They're going to take care of you and so on. I know as a father of three kids, that I can pay more attention to one kid than I can pay to three. If I wind up pushing to have just N patients, I'm going to take care of, I can't take care of N patients nearly as well as I can take care of N over two patients and so on. Ultimately, then, what do you do?

The answer is, in particular, for a guy that's been a marine, and I used to work on drilling rigs, you're responsible for yourself. Ultimately, what's going to happen if you get in a bad situation, there's not going to be somebody else taking care of you. There's somebody out there maybe taking care of themselves. You can watch. That's about as good as it gets. You have to be taught early on that you're responsible for your own health. No one loves you as much as you do. You need to pay very careful attention to every decision that's being made on your behalf, not necessarily because these people are evil, not because there's bad intent. They might just be busy, and it might also be that it's a bad day. There might be any variety of reasons, all of which you get to do, but the concept of a paternalistic system versus a system where you're

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self-sufficient, you're required to be self-sufficient. You have to take responsibility for your own care. You need to understand all of the options that are available to you. You're the one that's going to suffer the result. Ultimately, you're the one that's going to have to go on and make it. That's the direction I'd like to go. But unfortunately, we're very far away from that in the United States, and I would argue, in Europe too.

I'd be interested in particular, first off, Dr. Apfel in your opinion on that, and Scott, your opinion as well.

Chris Apfel 56:02

I would agree that it's a paternalistic system. The challenge is that it is also a system. We should be very careful to be too tough on our physicians, because the challenge is in this healthcare system. This is a unique setup, because we have the payer, usually the insurance companies, when it comes to who is the customer, and then we have the patient with the beneficiary. We have the physician who has decision authority, and then we have also the hospital system, and other factors as well. And then we have the legal system in terms of liability on what is considered standard of care. Oncologists sometimes feel themselves in shackles. There are the NCCN guidelines. This is the way you have to practice. If you practice outside of the guidelines, that could be completely legal. If the patient asked for something, you can prescribe a drug that is off label. It's not illegal to prescribe an off label drug, but you may have a hospital that says we want you to practice within the NCCN guidelines. If you prescribe a drug off label, you will be fired. And so so there are so there are many things that actually keep also physicians, besides their workload, also in line, and restrict them in the way that they are often restricted not to be able to treat patients how they would like them to, how they would like them, to treat them and what they probably originally envisioned.

Bill Paseman 57:41

Let me preach your point. One of the reasons you practice standard of care is to reduce your legal liability, and especially if you work inside of a system that has to be taken into account. And as a result, standard of care is what you get, regardless of what the doctor thinks is the best thing to do. Is that what you said?

Chris Apfel 58:01

Yes. I had oncologists who wouldn't refer their patients to me, but if they know one of their relatives is affected, they will send them.

Bill Paseman 58:16

That's exactly what happened to me. When I had to choose a physician, I asked for a referral from my wife's brother, because if I died under the knife, he'd have to deal with her for the rest of his life. I'm very, very serious about this. Having the appropriate referral at the point that your life is on the line, figuring out those appropriate emotional levers is helpful.

Scott, the idea of pushing patients to be their own advocates, it's their problem. It's not the doctor's problem. It's not the problem of the medical system. You've danced around this in a lot

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of your presentation, but effectively that's what you're doing. Addressing it from that point of view, head on, what do you think? Do you agree? And then secondly, if that's the case, how do you get people to be Marines, to be responsible for their own welfare going forward and pound in them to recognize that they are responsible for themselves, and that's the primary thing they have to depend on?

Scott Petinga 59:31

I wholeheartedly agree with you both. The way I visualize it is, we are consumers of healthcare. Just like we're consumers of everything else. It is a product that we're purchasing, and therefore we have to do the same due diligence. So take a step back further. Nowhere in life do we learn about finance. Do we learn about healthcare. I never was taught anything about healthcare, how it worked, how it didn't work. We start our first job. We're on our parents' plan until we're 26, and then all of a sudden, we become adults, and then we have a work plan. We don't even know what the work plan is a lot of times.

We just realized that for 2025 because my kid's mom works for a health care system, it's a lot cheaper for us to get benefits from her employer than mine. She and I are adults. We're both in the system. It took us two hours to try to go through all the different options of what they meant. As educated we are in the healthcare world, it is still incredibly complicated.

I'm the caregiver to my parents, who are on Medicare, Medicaid. They're seniors, even more complicated. That's the problem. Oftentimes, we don't know what we're buying. We don't know what we're eligible for, what we're not eligible for, and that's age dependent. I'm going to get older, and I'm going to need Medicare, Medicaid. I know a little bit about that based off of having to deal with my parents, and my dad's also a veteran on top of that. Unfortunately, as the doctor said, it's a system. It's an incredibly complex system, so that's part of it.

One of my younger daughters is 13. She wants to be president of the United States. I'm always joking around with her, saying, "When you're President, I want to be in a cabinet position, and I want to be in charge of education so I can create a curriculum to teach people how the healthcare system works, on how supplements work, about how nutrition works. We're part of the system, but that system is not just medical and or pharmaceutical. It's nutrition. A lot of our problems deal with the fact that what we eat, processed foods, high amounts of sugar, and I hate to say it, I've seen a lot of studies, alcohol. I believe alcohol is part of the reason why we have an increase in cancer. It's a poison. Once we see CBD and marijuana coming pretty much in every state. Just because things are legal doesn't necessarily mean they're good for us. That's a whole other thing we have to look at. Is the water we're drinking, the micro plastics we're consuming? I just saw an open heart surgery where they thought the individual had plaque. It wasn't plaque, it was micro plastics. We're tremendously exposed to dirty air, polluted water, and food that's not good for us. It's all of it. We have to understand our environment shapes us, so we need to do better.

Then if something does happen to us, where we do need medical intervention, and we do need to partake in the system, how the system works, how the system incentivizes, and how do we

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get the best outcomes at the end of the day? And that's us participating, having a voice, challenging the status quo or the standard of care, so we get the best outcome at the end of the day. When I say outcome, it's just not are we alive, it's we minimize those residual side effects.

Brad Power 1:03:37

In the chat from Helen is a message regarding brain cancer: "Can I please ask for a way to understand the difference between brain mets, for example, from ovarian cancer and from primary brain cancer? As you said, there are over 140 different types of brain cancer. Are treatments the same? How should patients with brain mets approach researching this in relation to the treatments proposed, such as radiation and immunotherapy.

Scott Petinga 1:04:10

The doctor might be better at that. I know from my research my daughter's brain tumor was outside the brain. It's an acoustical tumor. It sat right outside the ear canal and didn't penetrate the brain, so it was benign. That's one thing. They had to go in and take it out. The reason her face is paralyzed is at that portion, just geographically, anatomically, there are 12 facial nerves, and they all control different things. All the facial nerves were wrapped around the tumor like a spider web. In order to get the tumor out, they had to move everything around. Because her specific tumor was probably inside of her head, growing for 10 years, think about it like a rubber band. Right! When you stretch a rubber band and it just is elongated for a long period of time, and then you let it go. Of course, it's not going to have that elasticity anymore. Part of her paralysis is probably due to the fact that for a long period of time, those nerves were just elongated, and now the tumor is gone, and they're just floating around. We have to wait for them to condense.

Based on what I've seen, because at first we didn't know what type of tumor it was, we were researching a tremendous amount of tumors. They're all different, and the doctor can probably say more on that. The treatments are different. Some are surgical interventions. With her tumor, if it was smaller, they could have gone in and used an GKRS Knife (Gamma Knife Radiosurgery) in order to reduce the size of it. There are options based on the size, based on the type of tumor, based on whether it's malignant or benign.

Chris Apfel 1:06:24

That's a deep question. There is a blood brain barrier question, and then there is also the question of the primary tissue type, and what are the different treatment options?

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CHAT DISCUSSION

00:22:19 Bill Paseman: Don't think so. Likely an NF2 mutation, since both are implicated in p1RCC and meningiomas

00:22:32 David Plunkett: Reacted to "Don't think so. Like..." with 👍

00:22:46 Bill Paseman: Last talk: <https://rarekidneycancer.org/blog/using-ai-traverse-path-clinical-trials-personalized-medicine>

00:45:15 helen: Thank you for your extremely interesting presentation. What did you say the Austin, Texas dr's name was? And you said he wrote a book on supplements?

00:54:18 chad magnussen: Dr. Stacy DeAndre is an integrated oncologist at Mayo Rochester. She recommended many alternatives therapies to me. Something you could share with Mayo patients!

00:58:33 David Plunkett: "Rationalization is not just a river in Egypt."

01:00:31 Noel Resch: This is spot on!!!

01:00:43 Dr. Chris Apfel: David and Scott, I asked Chat GPT: Yes, physicians have an ethical and legal obligation to provide patients with informed consent, which includes:
Explanation of the Proposed Treatment: Details on the treatment's purpose, benefits, and risks.
Pros and Cons: Clear discussion of the advantages and disadvantages of the proposed approach.

Alternatives: Information about reasonable alternative treatments, including no treatment, and the risks and benefits of those options.

Patient Understanding: Ensuring the patient understands the information provided and is able to make an autonomous, informed decision.

Voluntariness: The patient's decision must be made without coercion or undue influence.

This process aligns with ethical standards (e.g., Principles of Autonomy and Beneficence) and legal frameworks to protect the patient's right to participate in their care decisions. Failure to provide this information could lead to claims of negligence or battery.

01:06:11 helen: Regarding brain cancer, can I please ask for a way to understand the difference between brain mets, for example from ovarian cancer and primary brain cancer - as you said there are over 140 diff types of brain cancer.' Are treatments the same? How should patients with brain mets approach research this in relation to the treatments proposed such as radiation and immunotherapy.

01:28:29 helen: Thank you.