“A Rogue Cancer Patient Gets Better Outcomes” (Ari Akerstein) [#109]

Ari Akerstein and Brad Power
August 14, 2024

“A crisis is a terrible thing to waste.” – Winston Churchill

“It became clear to me that I was going to be fighting this system, just from that very first entry point.” – Ari Akerstein

“I felt the burden of ownership for caring for my own health. In a way, it was a little bit like what I do at work day-to-day.” – Ari Akerstein

“There's two parts: How do you do it on the bleeding edge, to push the standard of care as far as can be, and then how do you bring up the base and give that to the broadest set of people in an automated platform delivery fashion?” – Ari Akerstein

Meeting Summary

In 2018 Ari Akerstein, a software Product Manager in Silicon Valley (at places like Facebook/Meta and @Walmartlabs, IncludedHealth), was diagnosed with an aggressive blood cancer (Diffuse Large B-cell Lymphoma, DLBCL), which can be lethal within 6-12 months. Over the course of several months he had to go from being the healthy dad of three young kids to navigating his healthcare decisions and making complex treatment decisions.

Many patients who are diagnosed face a similar “bolt out of the blue”. Some react with denial that there is a problem. Some trust their care to their doctors and the medical system. A rare few engage actively in their care decisions.

Ari is a leading example and role model for the engaged patient. He took an aggressive "rogue" approach to navigate his care, leveraging the problem-solving approaches he had learned as an entrepreneur and product builder.

Attitudes, Behaviors, Strategy

- Questioning, challenging, thinking for himself, from the bottom up, from first principles, about what was happening, combined with a distrust of the medical system; diving deep into the details to understand his disease, reading the research papers and not being scared of the jargon; bridging between molecular biology, molecular pathology, and clinical oncology
- Finding treatments he didn't like, and being scrappy and inventing one (e.g., laparoscopic surgery)
- Focusing on a positive attitude
- Becoming much more intentional about good diet and exercise

Tactics, Decision-Making Approaches

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- Developing and implementing deliberate decision-making frameworks to navigate his care and drive better outcomes for himself, such as the distinction between “two-way doors” (reversible decisions which you can make quickly) and “one-way doors” (most medical decisions, which are irreversible)
- Leveraging his friend and expert network to help him make decisions, especially “smart generalists” – people who don’t know anything about healthcare, but they make a lot of decisions under uncertainty, and have a track record of doing that well
- Getting the right treating physician, including pulling through a physician social network and shifting from an excellent community hospital setting to an academic research cancer center
- Finding his therapy, including pushing back on recommendations, in some cases from the leading institutions/Centers of Excellence, by doing research and getting “second opinions”

Tips, Tricks, Hacks

- Converting hard things, like getting chemotherapy, into events
- Sending out an email to everybody in his network, then launching a blog
- Ensuring that the surgeon collected extra tissue from a biopsy to be able to run more tests
- Pushing to get more diagnostic tests, e.g., liquid biopsies

What were the results of his approach?

- Complete remission
- Avoided stem cell transplant OR Clinical Trial OR more chemotherapy - all were recommendations from leading doctors at academic centers
- Modified a surgical protocol in collaboration with his surgeon, resulting in a much less invasive approach
- Made beautiful connections and memories
- Top fundraiser for the Leukemia and Lymphoma Society in the San Francisco Bay area post treatment due to sharing his story widely

How is Ari sharing what he learned?

- Compiled his journey into an ebook - (free) download at Chemolog
- Blogging at Rogue Patient https://ariakerstein.substack.com/
- Building the CancerHacker Lab/Accelerator
- Developing a company to help with diagnostics navigation
- Consulting informally to cancer patients

What can you learn from Ari’s story?

- Active/empowered patients get better results.
- You have more agency than you think.
- Many of the industry's problems are man-made and result from system failures.
- Discover frameworks anyone can use to become a more deliberate decision-maker.

What can you do to learn more?

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- See other examples of engaged patients, such as Mark Taylor, Robb Owen, and Brian McCloskey.
- Join the discussion at our Cancer Patient Lab discussion hub here.
- Read Ari’s blog at Rogue Patient https://ariakerstein.substack.com/

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Meeting Notes

KEYWORDS

people, decisions, brad, pathology report, outcomes, ari, question, kaiser, felt, oncologist, work, clinical trial, ucsf, care, bit, ended, diagnostics, system, doctor, patients

SPEAKERS

Ari Akerstein (70%), Brad Power (9%), Chris Apfel (7%), Allen Morris (7%), Rick Davis (3%), Bill Paseman (2%), Brian McCloskey (1%), Roger Royse (1%)

CHAT CONTRIBUTORS

Allen Morris, Alexander Lalov, Ryan Moon, Rick Davis, Noel Resch

SUMMARY

The conversation revolved around Ari Akerstein’s personal experiences with cancer diagnosis and treatment, with a focus on the importance of patient-led communities and personalized medicine. Ari shared his experience with non-Hodgkin's lymphoma and the lessons he learned. The speakers discussed challenges and opportunities in scaling innovation in healthcare, emphasizing the need for navigation and integration of multiple tests and interventions from a patient's perspective. They also highlighted the importance of informed and engaged patients in achieving better outcomes, and the potential solutions for implementing personalized medicine in clinical practice.

OUTLINE

Ari Akerstein introduction and his story in navigating the healthcare system.

- Ari Akerstein shares his experience with aggressive blood cancer and lessons learned.
- He was diagnosed with non-Hodgkin's lymphoma.
- A nurse navigator at Kaiser Permanente scheduled his chemotherapy session without properly orienting him.
- His initial reaction to his cancer diagnosis was feeling resigned but determined to fight the system.
- He prioritized keeping his network updated on his health journey, sending an uncomfortable email to his contacts.

Managing health crises through email updates, blogging, and a positive attitude.

- Ari Akerstein received support from friends and strangers after sharing his cancer diagnosis through email updates and a blog.
- The support he received helped him process his thoughts, make difficult decisions, and feel motivated by the goodness coming from the universe.

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- He focused on mental game, positive attitude, and decision-making during cancer treatment.
- He drew a napkin sketch to help him approach decisions intentionally and deliberately.

Decision-making strategies for cancer treatment.

- Ari Akerstein reflects on his family's medical history and the importance of making informed decisions when facing cancer diagnosis. Some decisions are “one-way doors,” some are “two-way doors”.
- He uses a pyramid analogy to describe how he triangulated information from various sources, including oncologists and trusted friends, to make decisions.
- He sought advice from "smart generalists" to help make medical decisions.
- He used a decision tree to evaluate potential outcomes of treatment and work. He considered the role of regret in checking decisions he made.

Cancer treatment options and surgeon selection.

- Ari Akerstein struggled with self-injections and found ways to cope with the treatment.
- He flipped his chemotherapy experience into a series of memorable events, inviting friends and colleagues to join him and creating a window into the process for them.
- He negotiated with a surgeon and found a laparoscopic option (with an open surgery path), reducing risk and improving recovery.
- He sought a better treatment approach after a biopsy revealed residual cancer activity after completing first-line treatment.

Cancer treatment options with conflicting opinions from doctors.

- He sought second opinions (4 total) on his pathology report after doubts raised by doctors. One of the keys to his successful outcome was getting new data: he had a lab run another pathology report on the same biopsy tissue as the original lab.
- He sought advice from smart laypeople and experts on treatment options for his rare blood disorder. The key was laying out the situation and assessing areas of converging vs. diverging perspectives.

Cancer treatment options and lifestyle changes.

- Ari Akerstein emphasizes the importance of getting a second opinion (sometimes multiple such opinions), and using a deliberate decision-making process when faced with a medical diagnosis.
- He suspected misinterpretation of pathology results due to differences in opinion among pathologists.
- He shares his experience with a pescatarian diet and exercise, noting the intentionality of his lifestyle changes, and that it’s impossible to attribute positive results to these changes. For example, he questions the effectiveness of green tea steeping for more than 10 minutes, citing scant evidence but acknowledging a possible placebo effect.
- He built up his strength, understanding the cumulative damage multiple rounds of chemotherapy would incur on his body.

Kaiser Permanente's healthcare quality and accessibility.

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- Kaiser Permanente's flexibility and convenience may come with limitations in care quality.
- Ari Akerstein and Rick Davis share experiences of being blocked and sabotaged by medical professionals.
- Akerstein found a way to get access to treatment through a former colleague at Stanford.

Using technology to improve healthcare outcomes.

- Ari Akerstein shares his unconventional background in fitness and product management, from starting a small equipment company to pursuing graduate degrees in molecular biology and math research.
- He shares his personal journey in healthcare, from bench research to product management roles at big companies.
- He reflects on the access gaps he experienced during cancer treatment, motivating him to help fix disparities in healthcare.
- Ari Akerstein and Brad Power discuss the challenges of building technology to improve healthcare, with a focus on diagnostics and enabling founders to deliver better care.
- Akerstein shares his experience in health tech and the importance of working closer to a consumer model, with a focus on enabling an ecosystem of innovation.

Personalized medicine, patient engagement, and healthcare quality.

- Brad Power and Chris Apfel discuss the challenges of navigating multiple cancer tests and integrating results.
- Chris Apfel praises community health care providers for their cost-effectiveness and quality of care.
- Apfel questions the effectiveness of enrolling patients in clinical trials for better outcomes.

Empowering patients through informed decision-making in healthcare.

- Chris Apfel believes patient engagement leads to better outcomes, and suggests collaborating on a publication or podcast.
- Ari Akerstein presents on accelerators and takes questions from the group.
- Bill Paseman, a rare kidney cancer survivor and engineer, takes a DIY approach to informing himself about his care.
- Ari Akerstein and Brad Power suggest automating the process to reach a broader scale of people, including those with limited education or access to Centers of Excellence.

Cancer treatment processes and language barriers.

- Allen Morris characterizes Ari Akerstein and Brad Power as "systems thinkers" who try to solve cancer problems through decision processes.
- Allen Morris believes that the lack of communication among medical professionals with different specialties is a significant issue in cancer treatment, likening it to the Tower of Babel.This is especially evident in regards to molecular tumor boards.
- Allen Morris and Ari Akerstein discuss the challenges of communication in medicine, including language barriers and biases.

- They suggest the need for a universal language and a more collaborative approach to decision-making in medicine.

Personalized medicine, diagnostics, and AI in cancer treatment.

- Allen Morris highlights the importance of bridging basic molecular biology and molecular pathology in cancer treatment.
- Bill Paseman discusses using LLMs in tumor boards to address scalability and rare capabilities, such as molecular pathology.
- Ari Akerstein shares his personal experience with limited diagnostic options for prostate cancer.

Advanced diagnostics for cancer detection and personalized medicine.

- Ari Akerstein wants a diagnostic platform that provides personalized test recommendations and data analysis to optimize cancer treatment.
- He desires a platform that integrates with the medical system to minimize interface and provide actionable insights.
- Optimize costs, outcomes, and health with emerging tech, leveling the playing field for most people.
- Participants in the accelerator could help stress test ideas and provide insights based on their own knowledge and expertise.

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TRANSCRIPT

Brad Power
This is the Cancer Patient Lab.

Before we get started with Ari Akerstein telling his story of the rogue patient, and how he's solved his own problems, and wants to bring it to other people, we will do a quick bit of housekeeping.

This is not medical advice. This is information that you can take to your medical team to help you in making decisions.

The Cancer Patient Lab is a patient-led community, all volunteers, and we would appreciate any donations that you might make, which you can do through our website.

Ari and I were introduced by a mutual friend, an innovative doctor, and I learned that he is a lymphoma survivor as I am, and as he will explain. Like many of us, as a cancer survivor, Ari has witnessed the problems in the way that patients experience our healthcare system, firsthand, intensely. He is also by background a product manager from Silicon Valley. He has the Silicon Valley software perspective on developing apps and entrepreneurship. He has combined those two things to talk about some ideas that might be useful to people. We've been collaborating to develop this notion, both for him and his startup ideas, as well as the idea of creating an accelerator of like-minded founders who have similar needs.

Ari Akerstein 2:13
Let me just start off by saying it's really nice to see you all. Allen, I know we're on many threads, so good to put a face to a name. I hope this will be useful to this group. From the few sessions I've sat in on, this is really like the top 1% group of patient citizen scientists. I have been nothing but impressed, and so it’s a little bit intimidating to be here, but a privilege nonetheless.

I want to make sure that this is as valuable as it possibly can be to this group.
I will go through two key areas:

1. I will go through my own personal journey, how I got here, some of the lessons that I experienced and some of the approaches that I took in dealing with my own large B cell lymphoma, an aggressive blood cancer. When you ask the mandatory question to doctors; what's the likely outcome in the “do nothing case”? The answer: you have six to 12 months. This is a very, very aggressive situation. I'll talk about some of the lessons and approaches that I took that worked for me. I hope that you find them useful and also very open to hearing about your approaches and if they diverge from the things that I've done.
2. And then, as Brad alluded to, we'll talk a little bit about the accelerator that Brad and I are kicking off. We're in the initial stages, and so we'll give a little primer on what we’re doing and the approach we’re taking.

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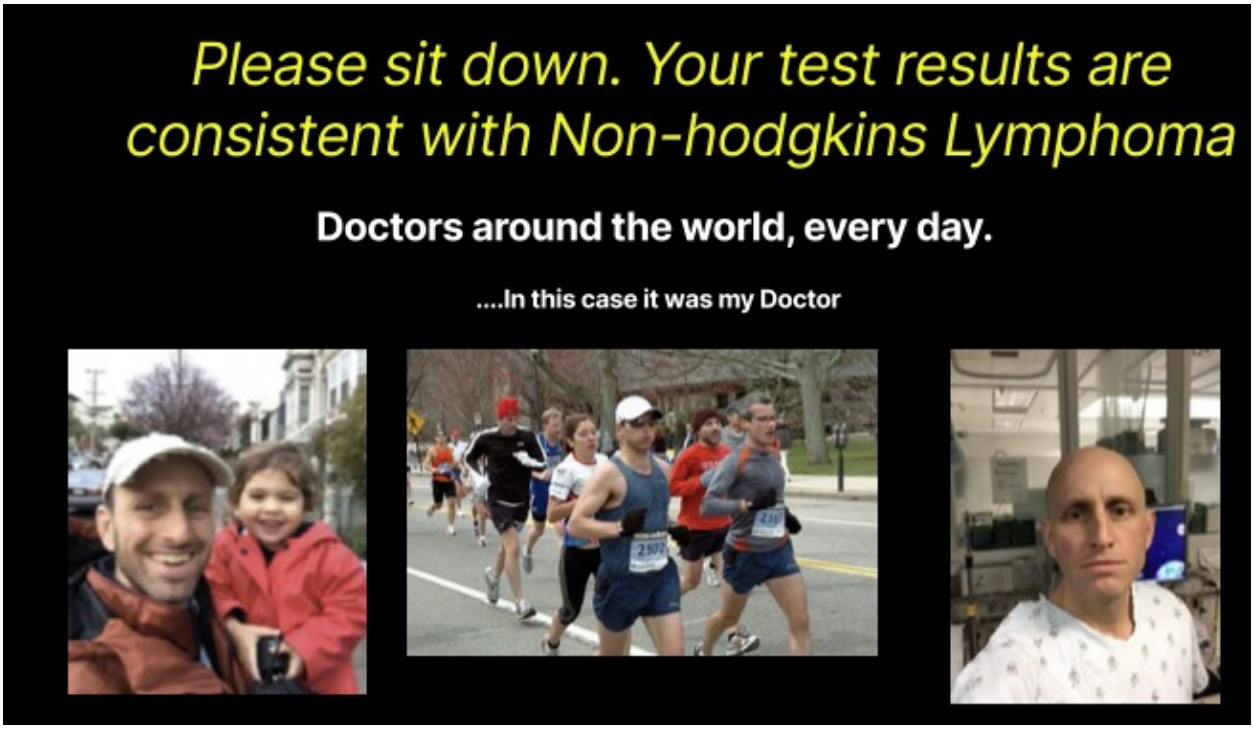
It’s always dangerous to start with a quote, because it's probably Mark Twain or Lincoln or somebody said it. In this case, it's Churchill, apparently. But I definitely believe in this one: “A crisis is a terrible thing to waste.”

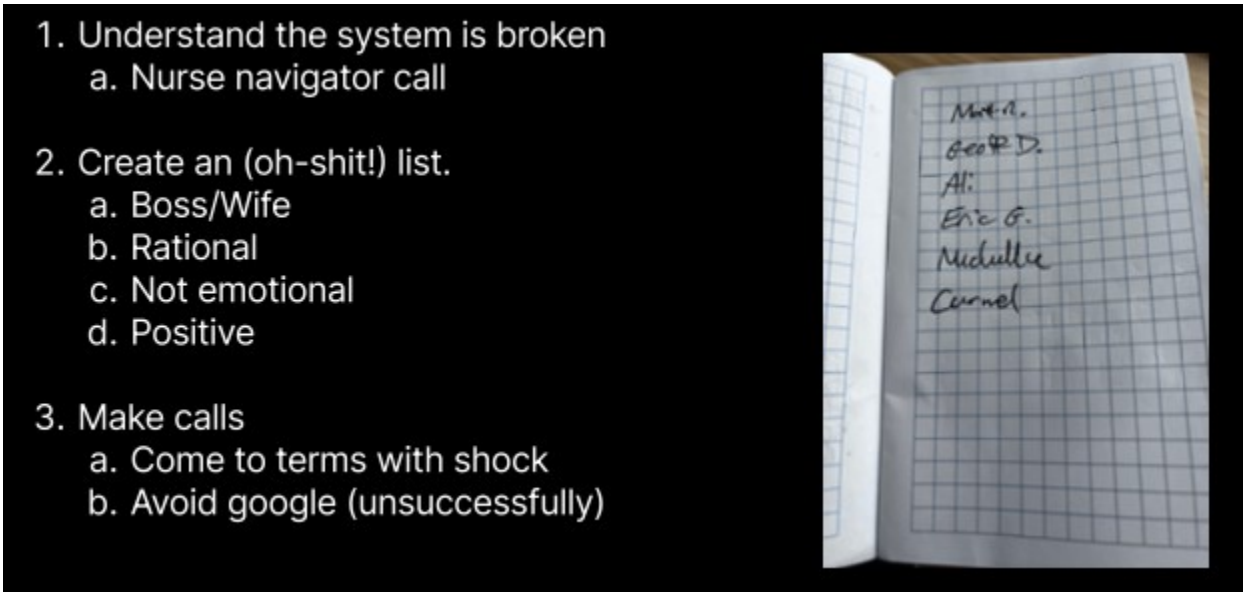


The context for me was I had just turned 40. I was a new dad living in San Francisco. I was working in Silicon Valley at places like Walmart Labs and Facebook and startups and doing that whole thing. The lead up was me feeling some kind of small thing in my abdomen, not knowing very much, I had crazy questions like “can things get trapped in your intestines?” “What could cause a lump that felt like a small nerf football?} “What the heck is this?” I was avoiding going to the doctor, thinking it was nothing, it would pass, and relying on the knowledge that I was generally healthy. Then my wife probably saved me by saying, “You're being a very typical guy. You should go and swallow your ego and go get it checked out.” There’s no heroics in that!

After a month or so of tests, I got some hard news, which was, “You have gobbledygook.” I'm like, “I don't know how to even make sense of what you're saying.” I remember very distinctly I was biking to work in San Francisco in the South of Market area. I saw my doctor’s number pop up, so I dropped into a happening coffee shop. He told me the news, and I was just in utter disbelief, shock, not really understanding, like what was up and what was down. I felt myself separating from the rest of the buzz that I’d normally be a part of, just isolated, sinking and feeling very heavy as if the gravity dial just got turned way up. From a chronological standpoint, I got this test result that I did not understand from my PCP, which just goes to show how naive I was.

I didn't even know the words that he was telling me: non-Hodgkin's lymphoma, B cell, diffuse, blah, blah, blah. I'm like, uh, I heard “oma”, so that means cancer, like, like, what is this that

you're talking about? He told me to just take a few moments. There are good treatments and the oncologist will call me shortly.



I was expecting a call from the oncologist to help orient me to figure it out like, the PCP hangs up. Okay, you'll have a call in five minutes from the oncologist. Instead, I got a call from a nurse navigator, which I don't know what a nurse navigator is from Kaiser, which is where I was going, and she literally launched into operations mode: *let's schedule your chemotherapy session*. And you know, a bunch of other logistical matters when I don't even know what's going on.

I very abruptly told her that I was going to hang up now. Get the oncologist, or whoever it is, to give me a call and help me sort out where I even am, but this is not appropriate to start jumping into treatment scheduling. Like, this is ridiculous.

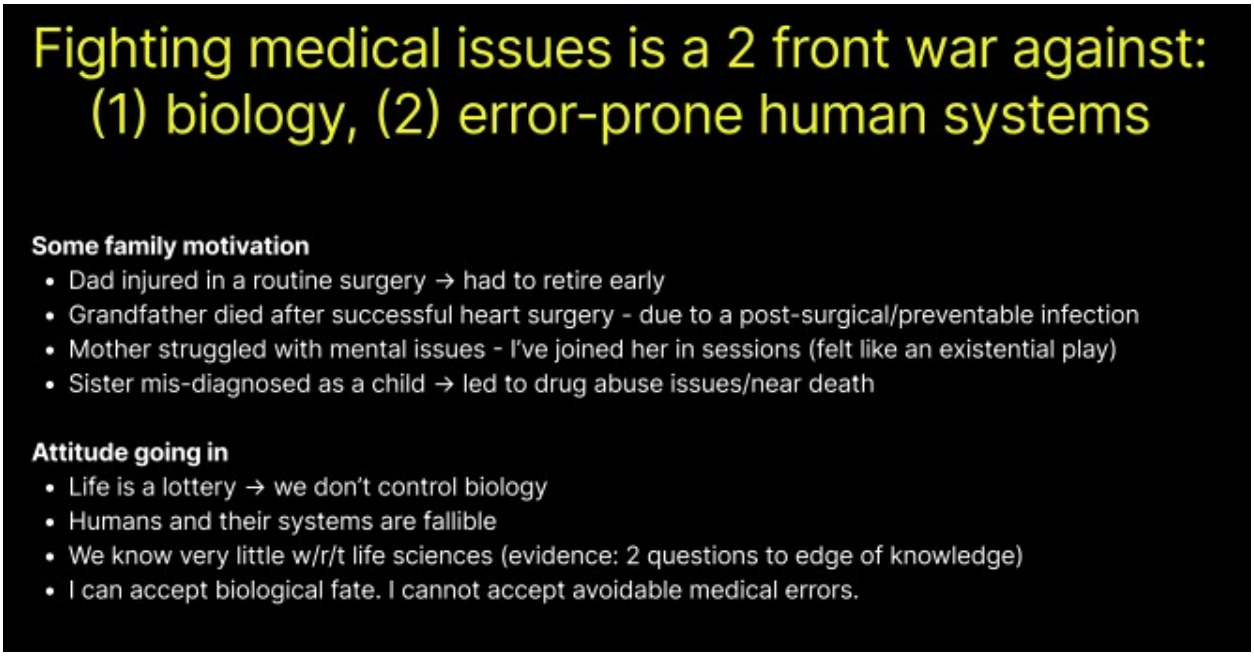
So this was my nurse navigator, who was supposed to help me with this. I ended up creating what I call the “oh shit list”, not “the shit list”, but the “oh shit list”.

I called up the CEO at my company, who I was working for, and I'm like, “Hey, I don't know what's going on here, but I'm totally out of sorts and not coming.” I called my wife and said, “I don't know what's going on, but those test results came in, and I have very bad news that I have to sort out.” Then I wrote down a list of five or six people that fit a very specific set of constraints, which was, they're rational, not super emotional, and their emotional valence tends to be positive, and I felt like that was what I needed.

It was very clear that this was a much bigger thing than me, and I needed to process it with some friends. Thank God I had friends that fit those criteria. I felt so blessed that I had a short-list like that. Really.
I spent probably the next two hours, which is literally two hours that I was waiting for this oncologist to call. I thought it was going to be a few minutes, which is what the nurse told me. I

made those calls and brought my shock levels down from whatever, 100 to 80 or something. It became clear to me also that I was going to be fighting this system, just from that very first entry point. I'm going to be fighting this system. This won't be easy.

A little bit of background for me is some of the approach that I had mentally around this was, look, you have biological systems. I studied molecular biology in grad school, so I knew I knew enough to know about how much we don't know, and that systems are always broken and fallible.



I saw this firsthand with my own family, and so I had this at least initial awareness that things don't go well often, particularly if you're unprepared. And so part of the way that I thought about this was I saw family members who are not very vigilant or questioning dealing with the system, and I saw how that produced really poor outcomes for them. My attitude going in was very much like, “Hey, life is a lottery.” I was actually fairly okay with: if this is my time and this is what it is, life is a gift, and if it's going to go that way, fine. The thing I could not accept, though, was that some idiotic human decision or fallibility or poor system design was the thing that was going to do me in, and so I took that really to heart.

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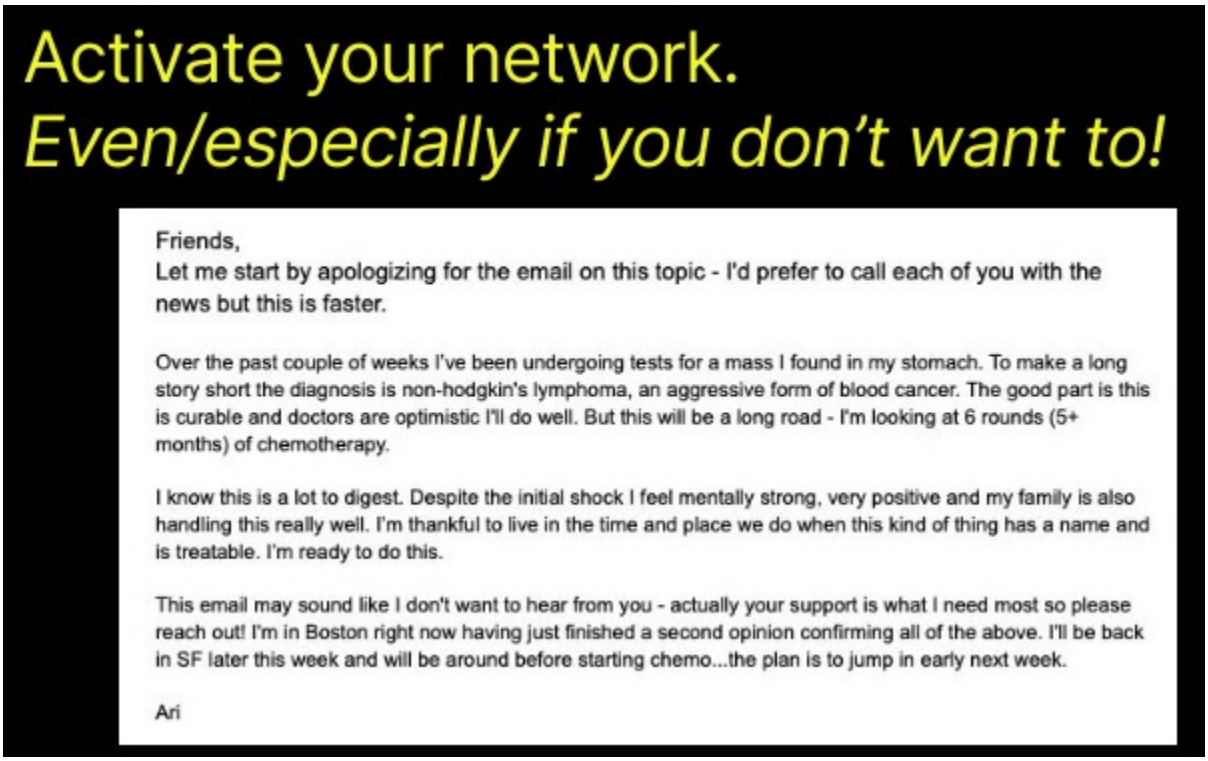

Time is precious - especially when battling a medical situation.

On a tactical level, it became quickly apparent that I was having a lot of phone calls, and that was not going to scale with respect to keeping people updated about what was happening. One of the first decisions that I made was I sent out an email to my network - everybody.
That's a really uncomfortable thing. I don't know about you. For me, that was like, “Wow, this is really uncomfortable to send out something like this.” I forced myself to do it.

And this is probably one of the more high leverage emails that I had ever sent out. And I mean, right off the bat, I got friends started, like, they generated like, $10,000 GoFundMe like to just deal with life and my family, just out of the blue, like crazy to see that energy, advice, connections and friendship. I got food delivered to my house, like, more than I could eat. And it really turned into, like, a large embrace from people that I hadn't heard from in a very long time.

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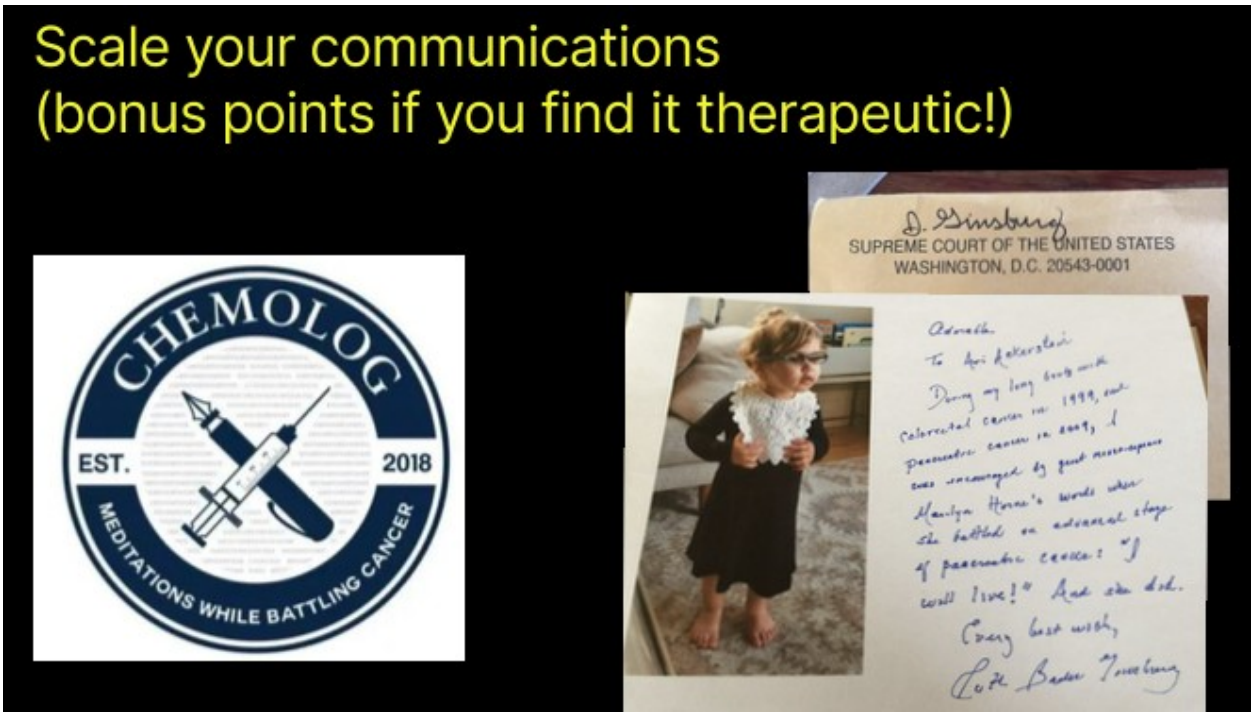

I think my tendency, which I was fighting, was to kind of go it alone and maybe in a lower key way. I'm really glad that I ended up doing this, because that set the trajectory for a lot of the things that ended up happening,

I also realized that I was doing email updates, and those email updates also wouldn't scale, and so I ended up starting a blog, really just to keep people kind of updated, very utilitarian communication kind of thing. And that ended up taking a life of its own, in several important ways. First, I found that this ended up being therapeutic for me. I would get up at 5:30 in the morning and just write because I had so much on my mind, you know, from emotional to like, What the hell did the doctor just say? I don't even understand it. Second, this practice really helped me process my own thoughts. Third, this really helped activate other people to help me in a time of need, and that was incredibly useful, and it helped me think through, like a lot of hard decisions that I'll talk about in a little bit.

And I realized also that it ended up growing in a way that I did not expect, beyond the utilitarian communications, like RBG wrote me a note, and it was just like, wow, the amount of goodness coming back is just crazy. And so that was quite amazing to me, and also just motivating to get a little bit of like, nuggets of goodness coming from the universe. I also focused on the mental game quite a lot, and I like to think of it as focus, your focus.

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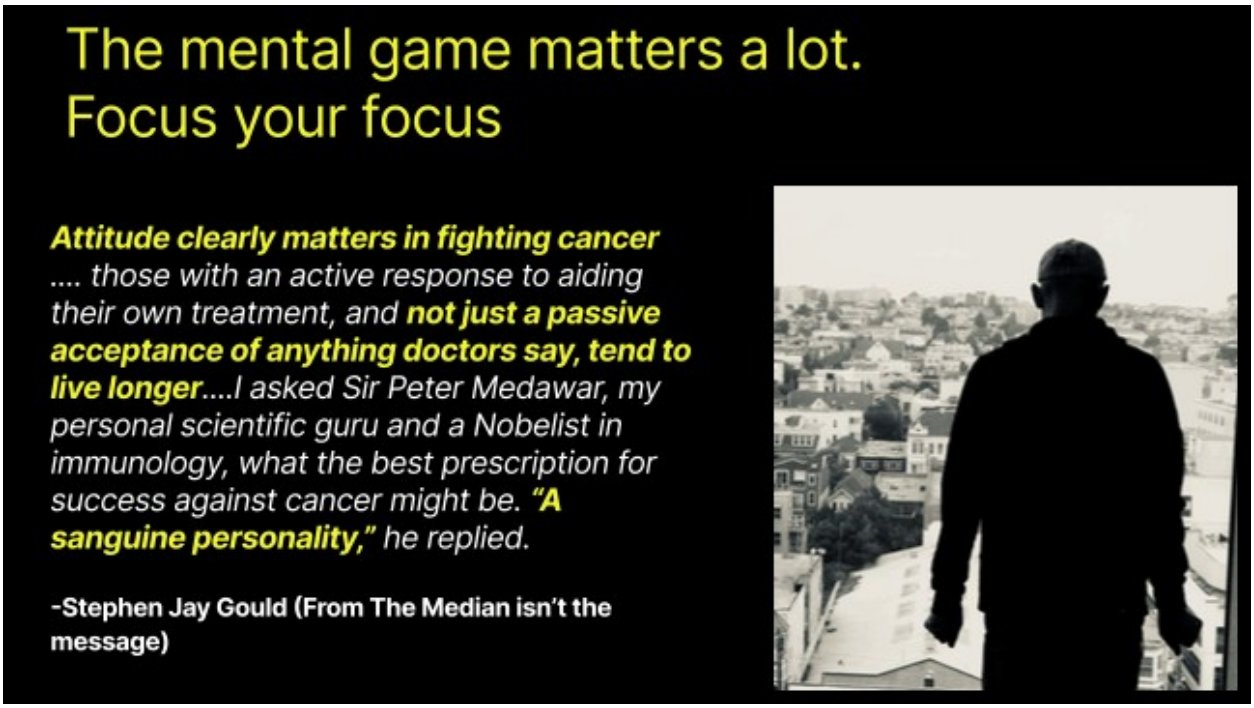

I like Stephen J Gould, and I thought that this fit my anecdotal perceptions, which is that one’s attitude really matters a lot. Does it impact the immune system? There's enough anecdotal evidence supporting this, though I don't know mechanistically how it works. I tried to be clear with myself about where I would focus my sort of low resources and energy on making smart decisions being as present as I possibly could, which for me, is not easy.

I'm like a person who lives in his head quite a lot, and, you know, won't notice things around me. And so I really tried to be present as much as I could, because I knew I had to have a clear head to kind of go from emotional to putting on Spock hat and making decisions, which I really did need to do quite a lot throughout this journey, and tamp down on the anxiety that I felt like I was feeling.

My wife took this image of me. I used to have a pre-chemo ritual where I’d do some stretches and mentally prepare for the session. It was like what I used to do before races or games. I was in SF, this image was from the top of Geary Street. I’d look over the city and just mentally rehearse and visualize the cancerous cells dying. I could not imagine just walking into a chemo session without that level of preparedness. It may sound weird. Honestly it even sounds weird to me now as I don’t really do this in my day-to-day, but I took this really seriously.

The corollary here is also to say what I was not focused on. In particular I was not going to think about the outcomes. How is this thing going to go on the end of it, things that are not inside my perimeter of control?

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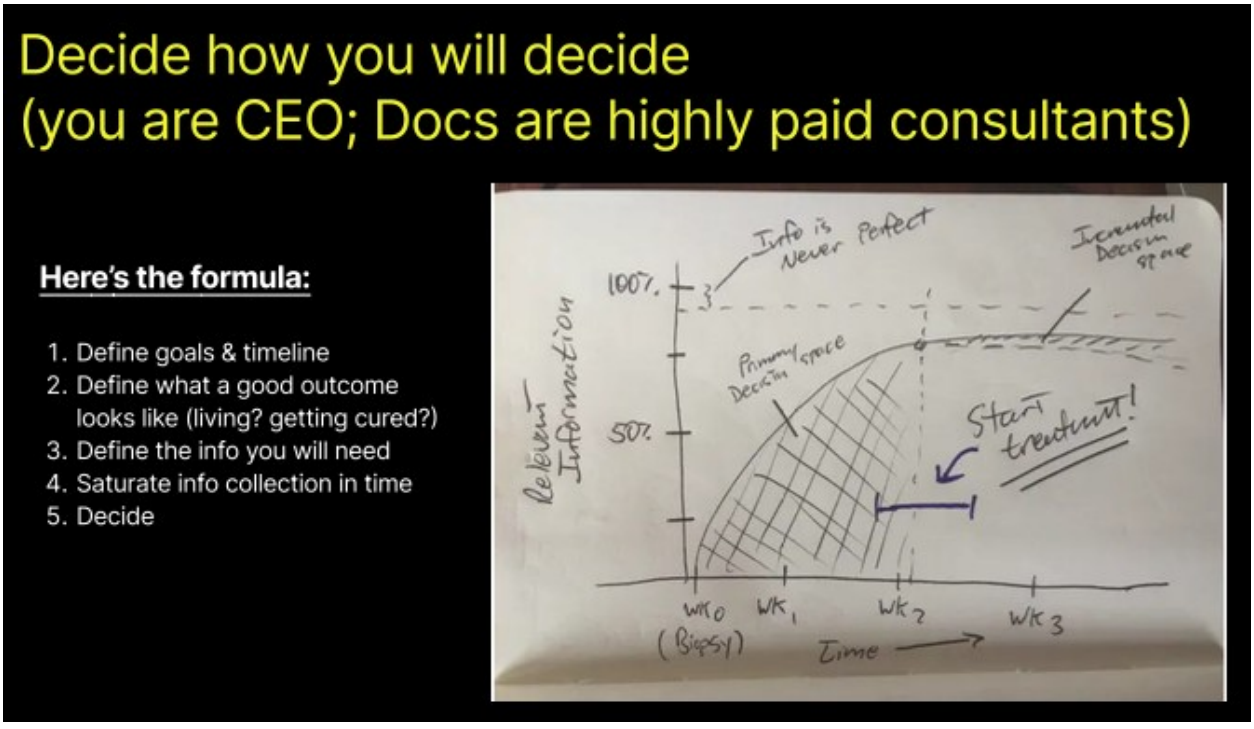
I thought about, how can I step inside the perimeter of what I do control and not focus on those outcomes? Because I do not control them. All I control is the inputs going into the decisions that will lead to outcomes. I felt like that was very important.

I also felt like it was important to be deliberate about deciding how I will decide and how I will approach the myriad decisions that I will probably need to make, not knowing the fog that I'm stepping into.

I drew up this napkin sketch, and I ended up going back to it quite a lot through the course of treatment.



I'll talk a little bit more about how it helped me later. The key for now is that just having an intentional framework about how one will go through decisions is really important, particularly when they pertain to your health.

Potentially, they carry incredible amounts of leverage. And so in a way, I felt the burden of ownership for caring for my own health. In a way, it was a little bit like what I do at work day to day. In terms of the space that I was traversing in making decisions I would ask, “Okay, what's the timeline that I have, for example, between my diagnosis and jumping into chemotherapy?” I had two weeks. My oncologist literally told me I could not wait more than two weeks. So my approach was, “ok, then I have two weeks, and I'll do what I need to do inside of that.” I think about this as saturating the amount of information that I get inside of that, that two-week period, which is the dotted line here. It’s unrealistic to think you’ll get to 100% perfect. Don't aspire to it, just get as much as you possibly can. You probably can't read my scrawl - but after a while, you get diminishing returns on the amount of information that's useful that you'll actually get, and then make a decision and move on and be good with it (so-called Pareto’s law or 80/20).

Related to decision-making, this was another way that I thought about this, which is that Jeff Bezos has a really great way that he likes to describe decision-making, which is one-way and two-way doors. Maybe you've heard this, and he writes about it in his annual letters. The two-way doors are reversible decisions, and so you can make those quickly. There's really not a lot of penalty in making the wrong choice. However, for medical decisions, I feel like the leverage is so high.

As I mentioned at the beginning, I saw this go down really not great paths for my family. For example, my grandfather died from a preventable infection on a tube in his throat - a classic medical error. My father had to retire early, as an engineer due to the slip of a surgeon’s knife during a routine outpatient procedure. I think of all these as non-reversible decisions in practice (the theory doesn’t matter so much because the world is messy).

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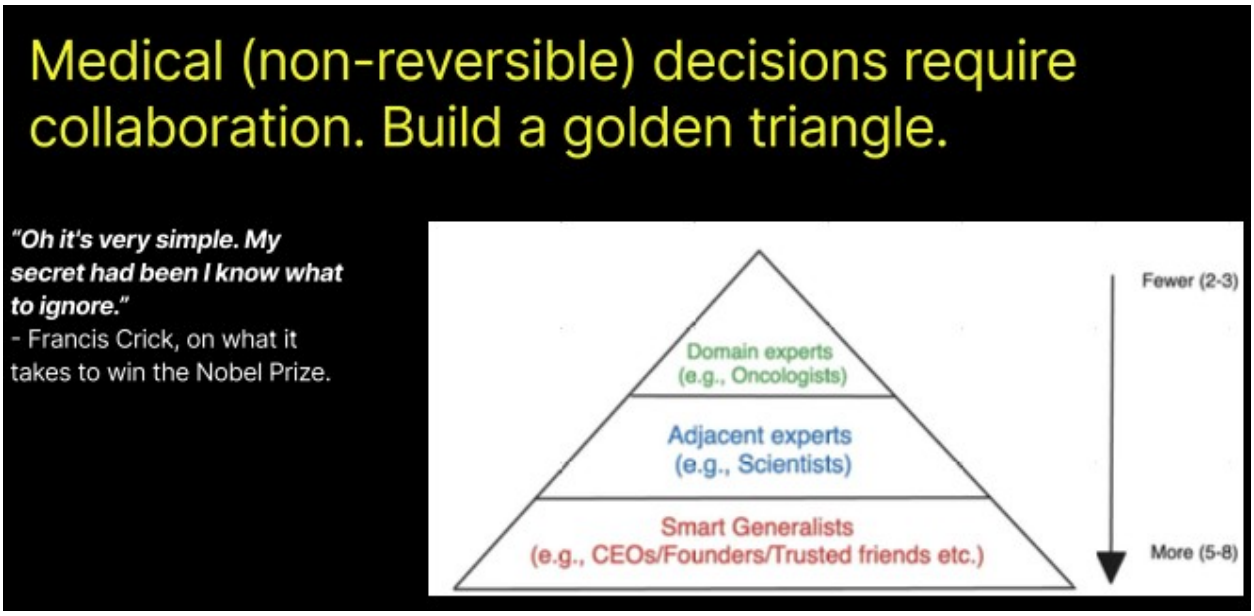
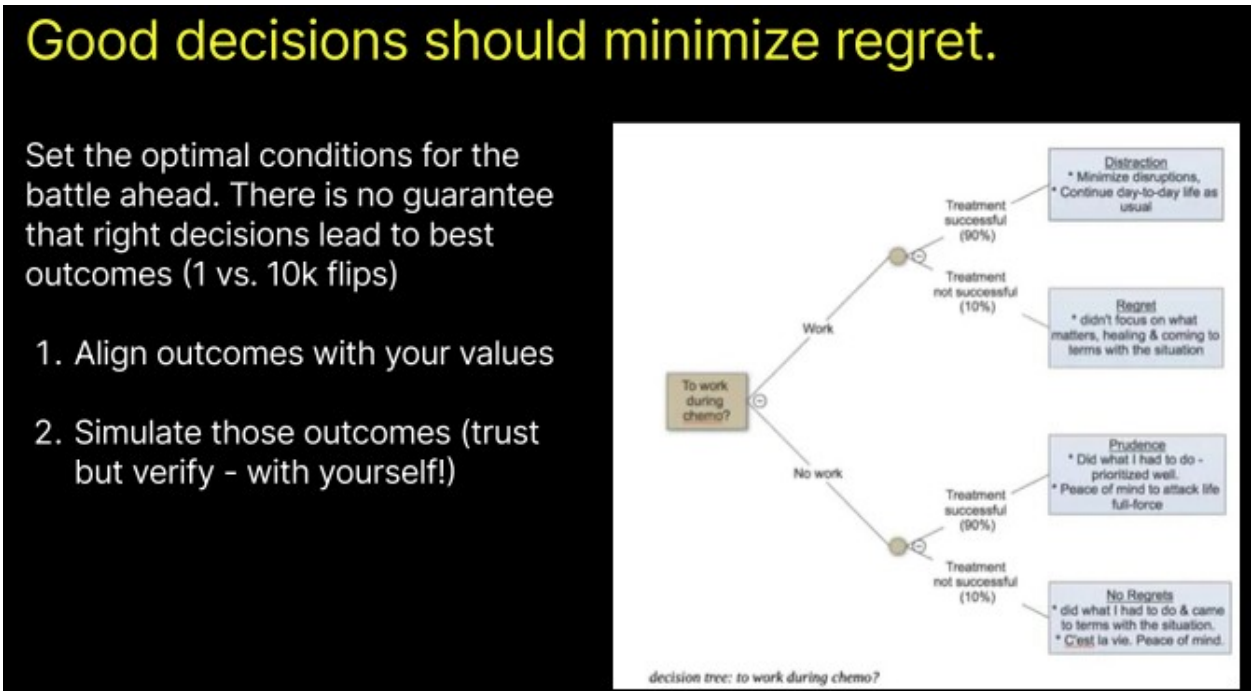


When you are not a domain expert, which I certainly was not in cancer, I felt like I needed to triangulate opinions to converge on the right decisions. So I constructed this imaginary pyramid, if you will, where at the top I had my oncologist and the super specialized experts. At the bottom, I had groups of friends that I trust their judgment, because they deal with just uncertainty all the time. Maybe they don't know anything about health care or whatever, but they make a lot of decisions under uncertainty, and have a track record of doing that well. These are Founders/CEOs, Data Scientists, Engineers and so on. In the middle, what I call adjacent experts, is people that are maybe more less life-sciences oriented - they have an understanding about molecular biology, mechanics, and how some of these things work.

We were talking about TNF (Tumor Necrosis Factor) before. Tell me about P-53. Can I create a mouse model with my tumor type? Are check-point inhibitors relevant to my situation? Is there a supplementary drug I could take that targets an expressing receptor on my tumor? How can I think about Car-T in my particular situation, and so on. Help me understand some of the things that are related, maybe at the more foundational research level, but maybe not a clinical expert. Gaining a window into how the landscape of what's possible may be evolving, like is there a new treatment coming down the pipes in the next year that my doctor wouldn't tell me about, that sort of thing? Fewer to most, from the top of the pyramid to the bottom. I found myself really leaning on the smart generalists, quite a lot, to help me out with decisions.

“A Rogue Cancer Patient Gets Better Outcomes” (Ari Akerstein) [#109]



The other thing that I noticed myself dealing with wasn't specifically medical decisions per se, but kind of setting the conditions for the battle that I was going to go into. So I remember doing this even before starting treatment, which was to ask: what's a regretful kind of place to wind up, what's the not acceptable outcome? Because it could be that nothing works and I die, right? So how do I minimize regret? So to speak on this. And so I kind of drew out a little tree for myself about whether I was going to work. I mean, that was the first question, like, should I work, or should I quit and deal with this, or not quit, but go on disability and kind of put everything on life on hold and just deal with this.

I don't know if y'all can read this, but I assigned the same odds of the treatment being successful or not, because, I don't know what impact working or not would actually have, and I don't know how to change those odds related to that. What I did notice, however, was that if you look at the treatment not successful, 10% let's just say, I was making up these numbers a bit, but if I worked and the treatment was not successful, I knew I would have regret, and I would have these what ifs, and maybe I shouldn't have and maybe it was stress, and maybe this, and maybe that, and I felt like that wasn't going to be acceptable to me.

So this was very useful for me to actually simulate the outcomes. It was not just the numbers, but the more important aspect turned out to be the gut check with myself. I was able to assess how I felt about these decisions as they actually played out in the various scenarios. And I found this useful. This helped me decide to not work, and, never mind the money, I just can't deal with not knowing whether the stress of work, which you know, I was a little bit stressed at work. Deep down I wondered whether some cumulative stress had actually somehow contributed to my disease.

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Some of the things that I additionally needed to do was to deal with hard things that weren't expected. So I don't know if any of you do self injections. I was using, I think Zarxio for neutropenia, and I could not get over that. And I really needed to call a few friends and kind of, like, hack my psyche in a way. I could not do it. I literally could not do it. And it took me days to actually be able to puncture my own skin. It was really embarrassing and ridiculous, but when I got on the other side of that, through a lot of help here I'm, like, with my brother and I called over a nurse to help me. I couldn't do it myself, but every time it felt like a win on the other side of it when I could do it. So that felt like progress.

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Related to the experience of chemo itself, I was terrified of chemotherapy. I had no experience with it. My mental model was really, like, I had seen Breaking Bad (which is really depressing). I really didn't have a reference point, because nobody, really in my family, had dealt with this.

I decided to flip the script and make this my own/do it my way. I was looking at six rounds of our chop, which is a chemotherapy that I was prescribed with three week intervals. I tried to make every round into a memorable event. And so I would invite some friends and colleagues and people like that. And what would have been a really hard and isolating event for me ended up turning into, like a really great set of memories, and I found that really useful and motivating for myself.

I think my friends got value out of it as well, and seeing the other side of it and kind of getting a window into what that process looks like. Going through cancer is kind of an abstract thought many of us have. I hoped to make it more concrete for people that I loved so they could get a window into what this is, maybe take the edge off the fear for them too.

Okay, so I went through six rounds. And for those of you who may be familiar, maybe Brad, you are, but if you fail the first line treatment for diffuse large B cell, that's really bad, and your odds start dropping very quickly on a curative treatment. When I got the news it was also obvious that bedside manner was not my primary oncologist's strong suit. I mean, he literally is, like, I have devastating news for you, and I dropped my phone and just like no bedside manner.

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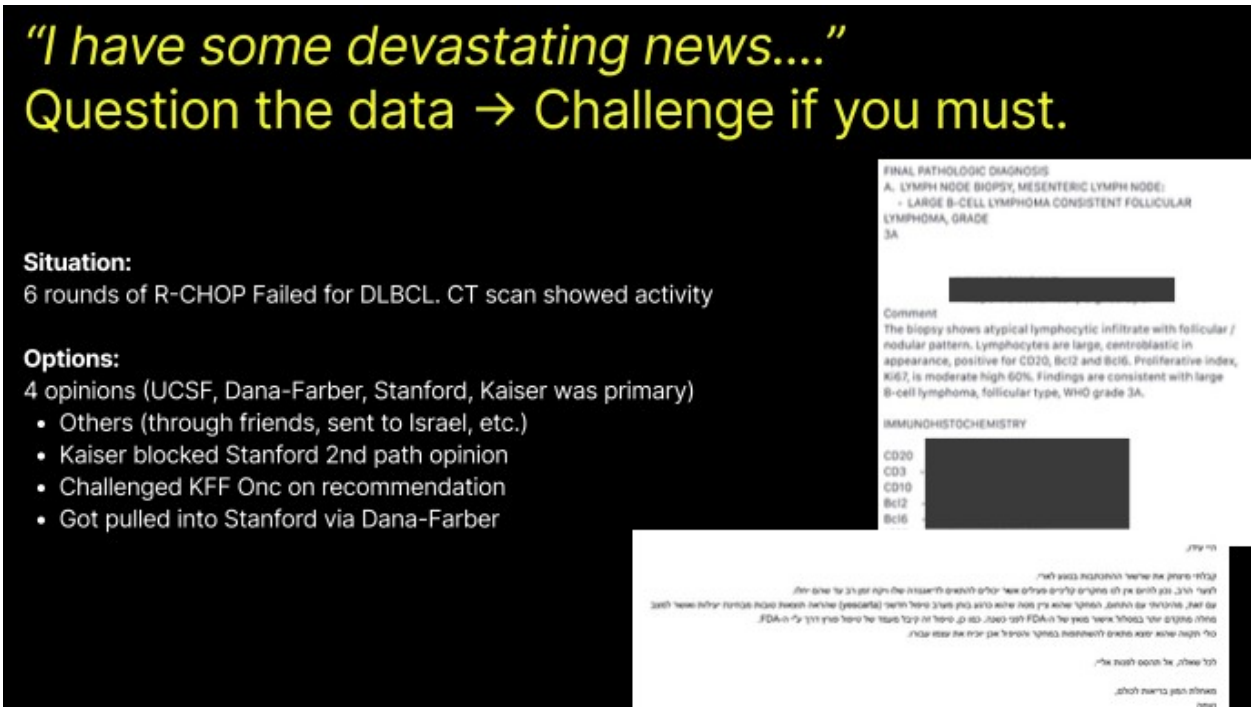

What happened was the CT or the PET scan showed residual activity, which is very bad. So there was residual activity. I needed to get a biopsy.
I thought of a biopsy as just like a little needle thing, and outpatient. It turned out that the cancer was growing behind the bowels on something called the mesentery. That's a pretty dangerous spot for doing a surgical procedure.

So I talked with the surgeon.

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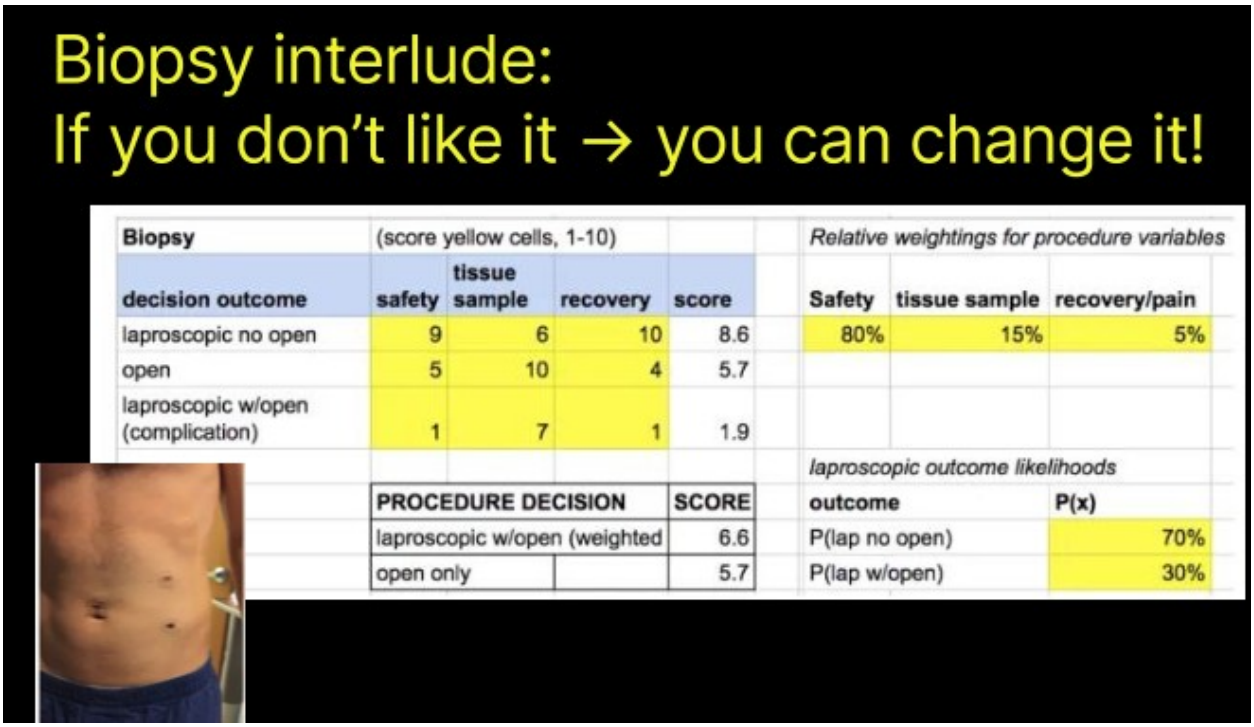


He literally said, I'm going to slice you open like a fish and go in the old fashioned way. This was not an image that sat well. I then also realized that I had no idea how to actually assess whether a surgeon is good or not. Maybe you've had this challenge. But how do you know - like, there isn't, like, a rating scale out there?
And so ended up doing some maybe underhanded things and asking the front desk person: I’m curious, who do the other doctors send their family to? Amazingly, her eyes lit up and she had a confident answer - that was good enough for me!
So I said that I wanted to talk to the other surgeon she suggested.
We set up a time to talk. I wanted to know if there was an alternative way of doing this surgery besides the fish route.

One of my motivations was that I have a wife and three kids who are very young, and I felt like I'm going to be useless for the next six weeks. I wanted to pick them up and all that. So I tried to see if I could change that, asking a bunch of naive questions, which I specialize in, which is like, “Well, could you do this laparoscopically, less damage?” “No, can't do it - it’s too hard.”
But I wasn’t quite satisfied with that. I actually thought my kids seeing me in bed for 6 weeks vs. up and about mattered a lot.

I called up a friend whose wife is a trauma surgeon. I asked her if it’s possible to do a thing like this laparoscopically. She said, “Yeah, but you need some skill.”

I thought about it a bit more. Then I built a simple model examining an alternative path, and to myself about this idea. I evaluated the key parameters that I thought mattered (safety, getting the actual tissue sample, recovery). I didn’t know the right numbers but I felt that I could fairly well approximate them.

I called my friend again, ran the model by her - she thought it was reasonable. I then organized a 3-way call with her and my surgeon. To his credit he was very open to this! The idea was to start this laparoscopically, and then revert to the original plan if things proved complex or safety was an issue etc.

And the surgeon agreed! YES!

In the end, what I showed here was sort of my triumph, which was not a gigantic slice down the middle, but just a couple of stab wounds. That really was helpful, not only for me, for the recovery, but because I could help my wife with like kids for six weeks, which would have been yet more burden.

I will actually talk about this in one of the following slides. But as part of this procedure I ensured the surgeon collected additional tissue samples to run another pathology report on. I wanted enough in case I had to do this.

This proved incredibly important, and was actually one of the keys to my overall outcome as I’ll explain later.

After the pathology report came back, I remember my Dana Farber Second Opinion told me that she wasn't convinced by the pathology report. The verbiage was kind of suspect - was hand wavy. It was not very convincing, one way or the other.

As a result of that, I was left in a bit of a conundrum, which was that I had a bunch of scenarios with the activity from the CT and the PET scan showing residual activity. R-chop failed.
First line had failed. Now I need to take some action.

I got similar signal when I when I actually shopped this around back to the triangle, kind of the the middle tier, talking with people who know something about these pathology reports, staining, staining approaches, things like this, screenshot from Israel, where I sent to a friend of mine who was a doctor there working on some cancer.

I had enough doubt about the pathology report to desire a new pathology report on the tissue sample I had the surgeon put aside. To make a long story short, my Dana-Farber connection was able to connect me with Stanford and have them run another pathology report (we decided to do it there since I was already in CA).

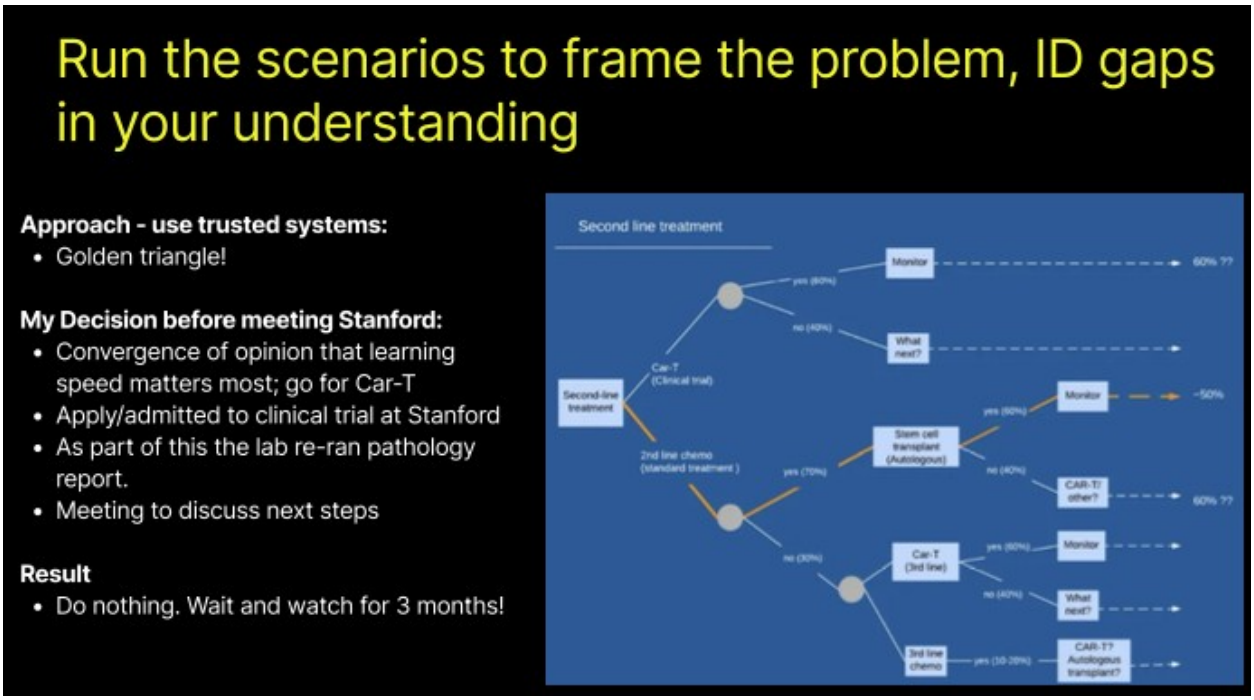
That left me in a weird space where I had Kaiser, who I didn't fully trust for quite a few reasons, telling me that I should do a low probability second line chemotherapy or an autologous stem cell transplant. This was a few years ago where CAR-T was just starting out, and so I could potentially get onto CAR-T through a clinical trial. This left me in a “I have no idea what the right approach to take here is.” I don't really trust Kaiser. I have a few other second opinions through UCSF and Dana Farber. But what I did in going through this golden triangle approach was I was

talking with many of the smart generalists and kind of that middle tier, and realized that speed from getting CAR-T, which brings with it a set of risks, assuming I could get into the clinical trial, brings a set of risks, like cytokine storm and other things that were still a bit earlier depending on which version of the CAR-T there were, like three of them, which is just yet more complexity.

What was useful, though, was to put side-by-side the CAR-T in a clinical trial, assuming I could get onto the trial arm of the clinical trial, which is like a blind thing, and so you don't really control that, but you would enter anyway to with the chance of doing that versus the stem cell transplant.

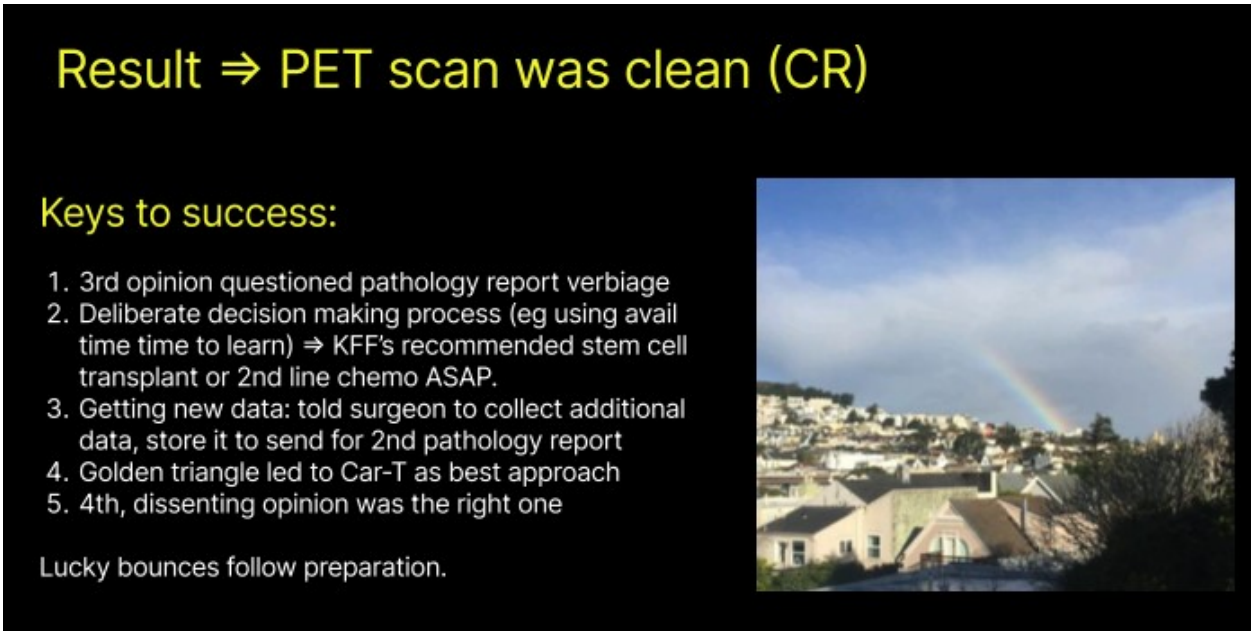
What I ended up doing, really, was going through the kind of probability tree like to poke holes in my own understanding and be able to socialize this with friends. I remember having a bunch of conversations with CEOs and other people like this that were really good at decision-making under uncertainty. What was fascinating was seeing a convergence on the speed of learning as the most important thing for me to get, whereas stem cell transplant would take months. CAR-T I would know fairly quickly whether it was effective or not, and seeing that convergence of opinion from smart lay people, was really validating to go down this path.

Ari Akerstein 30:14



I buried the lede a bit here. In making that decision, I then had a meeting with Stanford, and from those three options, none of which were appealing, actually, they were all scary as hell. I remember bringing my daughter into Stanford, and this is the head of the hematology lab. It was amazing, and he literally pulled up my new pathology report that he had run in order to verify my eligibility for the stem cell, or rather, for the clinical trial, and said, You have a beautiful daughter.

Let's, let's do nothing, and let's just wait and scan you again in three months. And the result was complete remission, like, don't do anything. And it was, I mean, it was remarkable because I had spent the last like, three weeks really, like, agonizing over what to actually do. Here, some of the keys for me when I reflected on this was that getting a second opinion is mandatory. But in my case, it was a third and a fourth opinion, and it was the fourth that actually dissented and had me not doing anything except watching, wait, and, you know, and convincing me that I wouldn't die if that happened, which was also divergent from what Kaiser had led me to believe, which is just shocking.



Using a deliberate decision-making process for me was just, I mean, it sounds almost corny when I say it, but that really was essential to take the amount of time that I needed to learn as much as I could in the allotted time, and not jump right into getting it done, and doing what the doctor said was absolutely essential, getting the new data, so doing that second pathology report, specifically at standard at Stanford. Incidentally, they had invented the staining technique that was being used by Kaiser, and so they felt like they had more confidence in their ability to interpret those types of reports than Kaiser did. And triangulating those opinions with my network, let's say, was really useful as well. And Yeah, lucky bounces definitely follow the prepared mind. So I'll stop there with that part of it, before jumping into some of the work that Brad and I are doing. But any questions or anything to dwell on there before moving on.

Roger Royse 33:00
Did you have a spontaneous remission? Was there anything you were doing?

Ari Akerstein
I did a whole lot of other things that are impossible to attribute, like doing a pescatarian diet and drinking green tea and working out like I have no I have no way to know whether those things were useful or not. In fact, I had a slide with all those things, and I just deleted it because it's too

anecdotal for me. I think it was useful. But who the hell knows, and I have no evidence from it. What I think it was, there's small evidence that you could have spontaneous remission. When I read the papers, it was in the sub 5% on that so I don't know. I think the more likelier, the likelier situation is that they may be tested early and there was a residual activity from the chemotherapy drugs, maybe lingering and killing certain populations, because it's not a homogenous population, necessarily, of these types of diffuse, large B cells, as I understand it. But you could have follicular, indolent type of cells mixed in, and maybe the composition of cell types changed. It could be the pathology misinterpretation. It could be

Roger Royse 34:19
You said there was some difference of opinion over that?

Ari Akerstein 34:25
The challenge is that I had two pathology opinions. The first one was run by Kaiser, and then everybody at UCSF, by everybody, I mean, UCSF, Kaiser and Dana Farber, all were reading the same. They weren't running their own pathologies. They were taking the pathology report generated by Kaiser and using that as the data to ascertain the truth and what the treatment path ought to be.

The tip off was that Dana Farber, my doc there, Karen Jacobson, who's fantastic, if any of you know her, she thought the verbiage wasn't actually looking at the staining technique itself. She thought the verbiage around the description of what was going on suggested a second rate pathologist. It was in passing, it was just like a thing that, like my eyebrows perked up a little bit when she said that. I was like, “Huh, do you maybe not trust this?” Maybe I should get a second pathology opinion. And she's like, “No, that wouldn't hurt. Okay, just go for it.” That was quite telling.

Roger Royse 35:47
That last slide of yours really caught me. These lifestyle changes you made, the pescatarian diet, the exercise, etc., is that way different from what you were doing before?

Ari Akerstein 36:04
It was much more intentional. Gosh, I wish I didn't delete that slide. After we go through this, I'll see if I have it in another deck. I could probably pull it up and share it with you. I basically had like, three, two or three buckets. I had mental, physical, nutrition. There were the three buckets, and then there were a dozen in each one or something.

This is a tangent. It is fascinating that whenever you get advice that is 180 degrees opposite from one another, that should make you tingle really hard. Like, should I be a carnivore and just eat only meat for inflammation? Or should I be like, vegan, Ayurvedic? These two things are not the same. That should make you suspect any of this. Well, green tea. If I steep my green tea for more than 10 minutes, for the ECG, GC, or whatever the acronym is release. It looks like no harm, no foul, although the evidence is pretty scant from when I read it, so I'm like, “All right. I'll do it. Not going to hurt anything.” And maybe there's a placebo effect which, to be honest, if

there's anything I could point to, it's probably that, like all these things, are summing to some kind of placebo effect which is known to have some weight, but I'll share it with you.

[Update via email, adding here]

Mental

- Focus on mindfulness, meditation, being present. Still a work in progress but a big area of growth for me.
- Be positive. It’s a bit like that trick of biting the pencil to force a smile. It actually is shown to elevate mood though you’re getting there from the outside-in, mechanically so to speak. At no point did I feel despair. I worked hard to make this so.
- Mental toughness (I happen to think this is really important for me, so adding fwiw). I’ve run the Boston marathon 3 times. I was thinking about this yesterday as I’ve been getting stronger in anticipation of my next battle. Anyway my training has never been ideal for lack of time (NO lack of commitment!). For each one I offset this lack of training with mentally hard runs (unscientifically, foolishly). Weeks before the race I often would run to the top of twin peaks in SF just outside my house, at night in the cold fog with a headlamp. I avoided doing it for a long time because it was hard and not very appealing. Then I decided to make friends with it. It was pretty dumb and no substitute for preparedness. But I will say the mental hardship is something I can certainly carry forward into this situation. Really it’s not about physical though that seems to be what dominates the conversation. Anyway I just did that run for the first time yesterday since completing chemo. I’m gearing up for an even harder battle (car-T or stem cell transplant or whatever I decide), and the drugs will be more powerful. Today I went to the gym to test my strength and see where I’m at with my one-rep max to bodyweight ratio (my normalized standard of personal strength). I pulled off a 1.8 (meaning I can deadlift 1.8 times my bodyweight). That’s pretty good for me and where it was pre-chemo so I’m feeling physically strong now as I gear up for the next battle.

Nutrition

I should say at the outset that when it comes to nutrition, nobody really knows. There’s so many competing theories, and such a scarcity of compelling data to support most of it. Also, few folks ever bring up the obvious point that all nutritional advice may not be right for everyone. Taken together it seems likely that (at minimum) our divergent genetic, epigenetic and gut bacteria profiles play a significant role on our individual metabolic output. This is a separate post for sure. It’s worth bearing in mind that the placebo effect is strong and real. So nutrition may fall into that bucket. But the beauty is that it may not matter! Even if you knowingly take a sugar pill to help some ailment it still can work. I wouldn’t rule that out. Anyway, I’ve implemented some practices into my lifestyle that have at least a modicum of data supporting them (and that literally, pass the smell test), specifically:

- Intermittent/fasting until noon, and no eating after 8pm. The idea is to reduce the feeding window to 8 hours/day to limit supplies to the ‘cancer army’. Some rat models suggest this chemolog 191 has an anti-tumor effect. A less fancy way to say this is that I skip breakfast. I’ve fasted a few days for 24 hours but haven’t gotten carried away.

- Sip green tea (all day) – 5 cups minimum. Steep it ’til it’s bitter (8-10 min) to release all the catechins, especially the most potent one called EGCG. Note that other teas, (e.g., black) are less helpful due to effects of oxidiation.
- Lots of turmeric in food (sautee in olive oil, black pepper activates).
- Eat more vegetables. Lots of stir fry including cabbage, carrots, garlic, tomato. Lots of shredded cabbage-based salads.
- Eat less protein than usual. I think I require less than I did before. Following my body’s lead here. I mostly skip protein at meals if I don’t crave it. Used to think I should always have it in meals. Nonsense.
- Pescatarian diet and minimal dairy (if so, high quality cheese). Some studies positively link dairy consumption, meat with lymphoma. I’ve eaten a bit of meat if my body felt like it needed it, once a week if at all and mostly Friday night for Shabbat. No harm done.
- Consume minimal white/refined carbs and close to zero sugar. This one hardly seems controversial. I will buckle for butter croissants though.
- Overall I’ve been eating less. I don’t feel worse for it. In fact I feel better.

Physical*
- Workout every day – whatever modality. It’s just hygiene, like brushing teeth. Not worth over complicating it* with various fads.

Community/people
* I haven’t spoken enough about this. I’ve gotten so much positivity from all sides that it’s hard to believe all that energy didn’t help. If I had to pick one element only and point to that as the cause of this outcome this would be the one. It’s all about the people and the love. That’s what matters in the end. It’s unfortunate that it sometimes takes an event as horrible as cancer to deepen bonds between us. But it’s better than not having it happen at all. I feel blessed.

Tracking/monitoring:

Going into chemo I knew the drugs would cause a cumulative effect. I literally thought of chemo rounds as = fight rounds, in which I would need to draw more heavily on reserves. My plan was to Track the minimal set of metrics to make sure I wasn’t going off the rails entirely.

- Weight gain

  Tracked this by round vs. baseline. Fortunately my weight hasn’t really changed since college which made this rather easy. I tracked weight to see how things were shifting due to an unknown x-factor of chemo.

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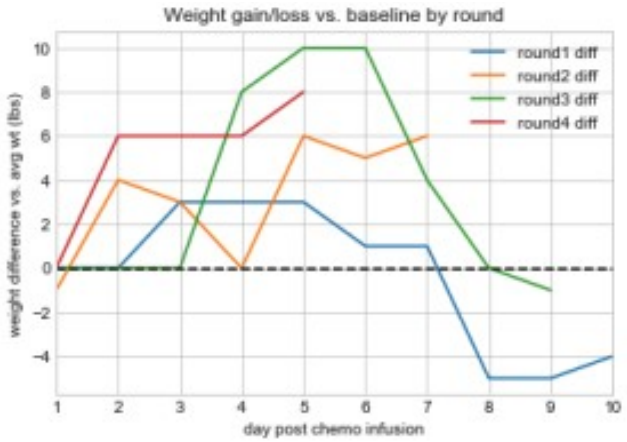

Weight gain on prednisone by round. My baseline weight is 144 (dashed black line). Hopefully round 3 was the worst of it.

> Try to at least maintain whatever I had. I would track one metric: deadlift (theoretical 1 rep max) as a multiple of my bodyweight. I felt this was 80/20 the most efficient lift to test strength loss over time. My baseline was ~1.8x bodyweight, so that’s what I had to work with. I used a theoretical 1RM vs. actual to minimize risk of injury.

Rick Davis 37:58
One thing that can be taken from this session, for anybody who listens to the future, is to be really leery of Kaiser.
You said KFF (Kaiser Family Foundation). I think you meant Kaiser Permanente.

Rick Davis 38:20
I personally have a lot of experience with Kaiser. I was very fortunate that at the time that I was diagnosed, they had a contract with UCSF, so I got a lot of my treatment at UCSF, and I made some lifelong contacts in doing that.

But Kaiser Permanente is a great system. It's flexible. It covers a lot, but it only covers to a community standard of practice. Most of the participants in this group are looking at bells and whistles that are way beyond the community standard of care and sometimes way beyond centers of excellence, standard of care to get uncovered here, as Brian will will attest. It's too late when you get diagnosed with a serious disease to switch your insurance, but it is really important to think about when you're choosing Kaiser Permanente. It can be great for a lot of people. It can be easy to get referrals. You can switch doctors incredibly easily. But as Ari has found out, as I found out, and as many people we navigate find out, it is really hard to get anything beyond standard of care. They give you that first line treatment. They push you on to a second line treatment, and then they're not interested. Then you have to fight and appeal and jump through hoops if you want anything more than that.

Ari Akerstein 40:03

I couldn't agree more. I had a new family. I was living in San Francisco. It was perfect for me. It was convenient. It was across the street from my office. It had everything that we needed. And on my radar was not that I might get diagnosed with cancer. To their credit I’ll also say that my PCP did all the right things in terms of getting me tested in the lead-up to the diagnosis.

But I would agree with your statement. I would maybe say it more strongly: that they actually did actively block excellent care, despite their mantra that they provide excellent care, or whatever it is, when it comes to like, I think they'll claim that they're providing, like an academic center of excellence level of care versus, say, the community level of care, as you described, and I felt actively blocked and sometimes even sabotaged, where they were pushing the wrong narrative around why they would do something.

For example, I asked them whether CAR-T would be an option - like you can say,”No”, and that's fine. Or he could have said, “We don't have a clinical trial here.”, or, “The evidence isn't there yet.” But to claim that the second line chemo, in my case, would be the better approach overall, when actually it came down to money, which is what it turned out it was, was just pretty underhanded and disingenuous.

Rick Davis 41:33
You're not alone. Don't feel they were picking on you.

Ari Akerstein 41:45
I don't take it personally.

Rick Davis 41:48
You shouldn't because this is exactly how they operate. It is really, really, really difficult to get. The only time I've seen them go out of their way is for some of them, their own very senior doctors, or any even not so senior doctors who fall sick, and then you'll see them stretch, and we've seen it.

Ari Akerstein 42:05
I'll give you a tip if you ever are in this, because I had some luck that got me out of there into Stanford, which was I was trying to push my way into Stanford by going through my primary oncologist. That proved unsuccessful. Because, again, he was pushing the narrative that they provide excellent care for my particular condition. What ended up happening, the way I got in, was my Dana Farber oncologist (for my 2nd opinions) was former colleagues with the head of the hematology lab. It turned out he was running the CAR-T study there, and she basically emailed him. She went silent when I was talking with her on the phone. I'm like, “Hey, are you still there?” “Yes, I'm emailing my former colleague over at Stanford.” What ended up happening was, instead of me pushing against Kaiser, he pulled me in. He essentially pulled rank on my oncologist, and got me in so, sometimes you have to go the hard way instead of the easy way with them.

Brad Power 43:11

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I want to go up to a meta level, based on a question from Alexander Lalov. You are a unique person to be questioning the system and challenging the system and getting better outcomes for yourself.

Who are you, and why are you wired that way? What was your background professionally? What is “the why" of how you were using problem solving techniques, etc.

Who am I?
I skipped over it because I thought it was dull. But I have a somewhat peculiar background.

After college, I ended up starting a little Fitness Equipment Company, making every possible mistake on my own dollar. I just like to exercise, and despite myself, ended up being successful. That entailed everything from, like doing user research, all the things that I ended up doing later in life as a product manager. I should explain what that is, essentially building products ultimately and delivering them to market in a commercially successful way. What I learned early on is that it’s pretty scary when you spend your own dollar. And so I got used to handling financial risk. For example, I’d have to decide to bring in a shipping container and spend a good percentage of my money to do it. I have to bet it on whatever this little website I built, and the demand will be there, and people will buy it, and I'll have margin and so forth. Despite many mistakes, I was able to make that work.

At that point I considered what I really wanted to do, and decided I wanted to go back to grad school (doing molecular, computational biology). To test that I wanted to do a PhD. I then went to UCSF for a few years. I’m glad I did because I realized that academia is not for me.

I was fortunate to have been in Silicon Valley in the early 2000’s.

I had good insight into myself as a bench researcher, that I really like it maybe half of the week, and then I really don't like it, because I like a mix of team and individual. I think of it like a cross; part deep, part horizontal.

Because I was at UCSF, it was fairly easy to parlay a lot of those skills into roles valued within the ecosystem that was around me. From there I was off to the races doing growth marketing and then product manager roles. If you don't know what that is, it's like a Venn diagram of three circles: designers, engineers and business people, and you're right in the middle, deciding what to build, how to build it and what success looks like - and to do this at scale. And so I've done that at some pretty big companies, like I mentioned. I was at Facebook, and Walmart Labs had a really large team there building out pretty big scale stuff, and also at smaller, scrappier companies.

So I've seen it firsthand myself, and how to think about things, and how to at least read some white papers. And so not being scared of the jargon, which I think was a really important factor, because there's a lot of jargon to cut through.

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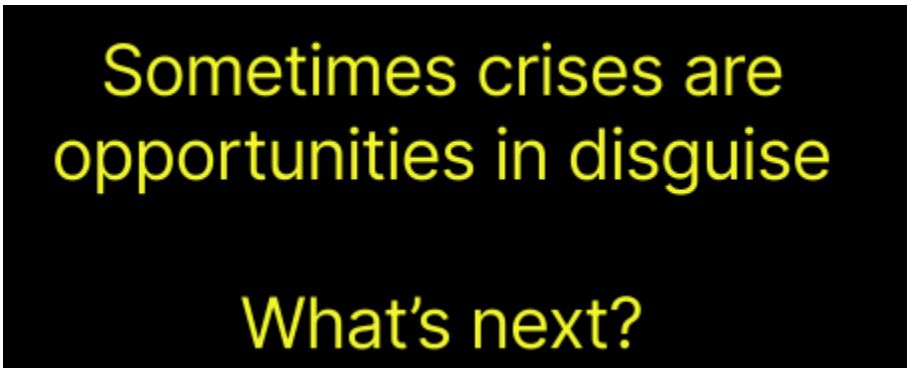
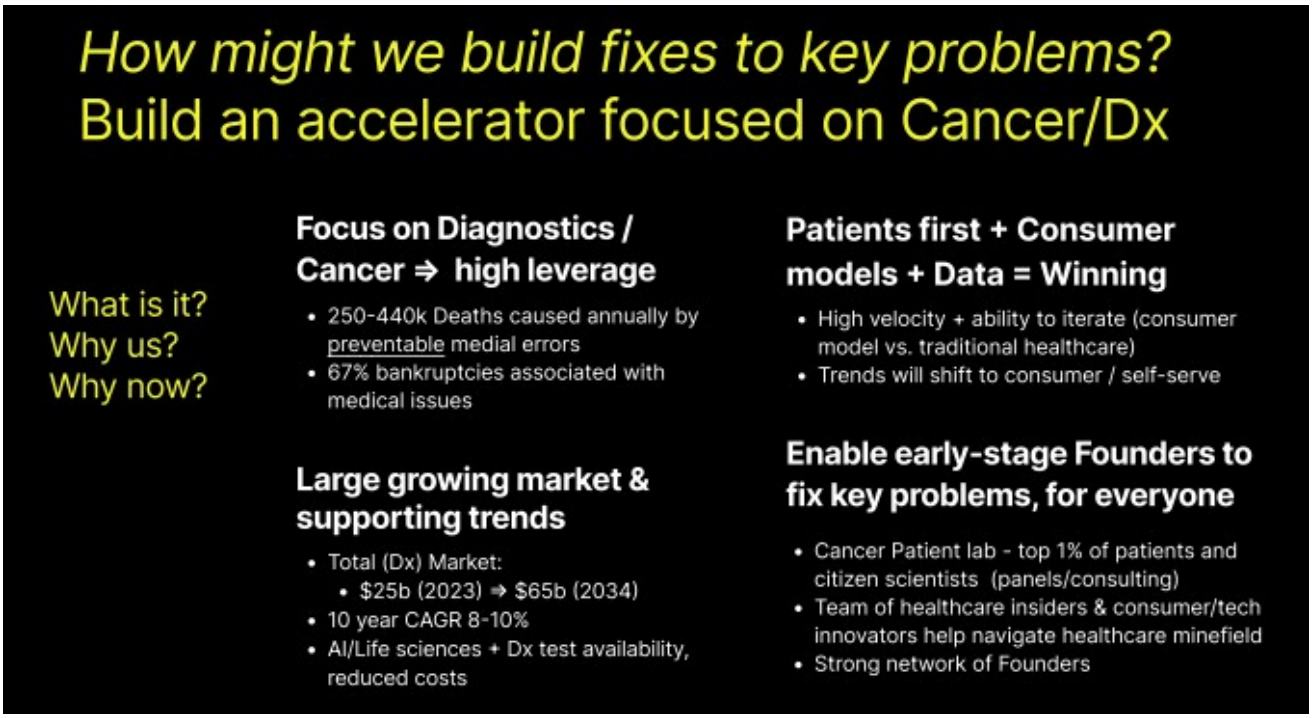
I was comfortable with that. The combination of those things in the rearview mirror did allow me to question, challenge, think for myself, from the bottom up, or from first principles, as they say, about what was actually happening, combined with a distrust of the medical system.

I mean, for God's sake, a lot of my friends are doctors, and I know how goofy they can be, and I love them, but, you know, like life and death like you gotta triangulate. So what that actually points to, I forget who asked that. Was it? Alex? I apologize, Alexander. What it points to is another thing that I'd be remiss if I missed, which was, when I was in I mentioned the chemotherapy, and you're sitting there, it's kind of like sitting on the bus. It's a cross section of everybody in society. Cancer doesn’t care who you are.
And the thing that was really top of mind for me was that I felt like I had a lot of access, and yet it was still so hard. Like, maybe I have a little bit more willingness to go there and challenge and read papers. But nevertheless, the access gaps, like with when I run the counterfactual and think about if I had just done what my primary oncologist said, which is, I think the majority case, like the base case, like, I mean, it would have just turned out really differently and and so I think that's a good also motivator on helping to fix some of these disparities.
A person shouldn't have to go to these heroics and put this amount of effort into to get a decent outcome.

one one slide. How about that?



Crises are opportunities in disguise. I drew a lot of lessons, and the question that I ask myself is, how can I be useful in helping to make some of this better? And I think so I'm working on some ideas for company concepts around making this whole thing better.



But when I think about maximizing good, I do think that the notion of an incubator or an accelerator is a more scalable approach to actually helping to address some of the challenges in the market, some of the reasons that I think this is true, and some of the like focal points that Brad and I have certainly been going deep on recently include a focus on Diagnostics as a key lever in the market, in the just costs and outcomes space. I'm not going to read this slide, but the market trends are positive. They're growing, and I think there's a lot of supplementary trends, or second order trends, that will help fuel that.

For the past few years I also have worked in health tech, building telehealth, second opinion and EMR-related products as well. In this role I did see that schism between building for patients like now we're talking about tech, software, solutions to deliver, and some of the challenges there. They’re pretty hard, particularly because you're not building for patients, first and foremost. Everyone will tell you they are, but they're not. They're building for whoever pays. The ability to work closer to a consumer model, where one can iterate and move at high velocity and “error correct”, is really important.

The focus is on enabling, basically building out an ecosystem with some of the network, and I think it's a good lead into like this group as well, potentially getting involved. But this group is, I mean, it's an astonishing group of people who are really taking their care, the bull by the horns and getting better than standard of care, as somebody mentioned earlier. Probably much better than what the standard of care even the top level would actually look like.

So a key question is how might we enable a group of Founders to actually use technology and bring some of the innovations that are happening in the market to deliver that in a more scalable fashion?

“A Rogue Cancer Patient Gets Better Outcomes” (Ari Akerstein) [#109]

Brad Power
I would give my own version of what you were just talking about, what we're trying to achieve with the accelerator. I'll just give a quick look at it, and then I'd like to cue Chris Apfel, because he's right in the middle of the space that we're talking about. And Brian is a monster for more data is always better. We're actually founded by Bryce Olson, who said, “mo data is mo betta”. Brian is the most tested and analyzed person probably anywhere.

What are the additional tests you can get? And then how do you decide? So it's an issue that wasn't an issue when you just had immunohistochemistry, and that was it or immunohistochemistry plus DNA sequencing. But now you can get a half a dozen tests. And the question is, which test should you get? When should you get them? And how would you then integrate the information from all of them, which is just a huge opportunity that you know, doesn't, I don't think anybody's really addressing. We had our session with Tony Magliocco, of Protean Biodiagnostics. He's in that space. Chris is in that space.

We see a huge opportunity or opening that needs help from a patient's point of view on navigation.

Chris, did you have any comments on what either Ari or I have said, if you don't mind?

Chris Apfel 53:14
First of all, I want to thank Ari for this wonderful presentation. I really enjoyed the decision trees and again, how you work through there.

I would love to see which kind of interventions have then supported your spontaneous remission.

In terms of your feelings with Kaiser, I can very well understand that, and I also think that as a whole, for a community health care provider, they are doing an outstanding job, and are probably the most cost effective and quality oriented system that exists in the United States. So, I think they're doing an outstanding job. But whenever you are having something that's really serious, it's really important.

What struck me is you said that informed and engaged patients have better outcomes. I feel the same. I'm an evidence-based data person, so I looked and searched the web and couldn't find support for that. I've actually just looked up a systematic review where it actually looked at the question of whether you actually have better outcomes when you are engaging in clinical trials. I've actually enrolled patients in clinical trials, and in clinical trials, you actually are under strict supervision to really provide at least a standard of care. So you have much more supervision. Diagnostics is going on, and you may actually be, if it's randomized, you may even be randomized to a more effective treatment that is on the horizon.

So it wasn’t obvious to me, the meta analysis or systematic review didn't come to that conclusion. I haven't had the opportunity to really research that, but what I recall at some point in terms of differences in quality of care, which is actually interesting, because when I'm getting asked by friends here, should I go to Stanford, or should I go to 10th or and when I was up in Marin, the question was, well, I go to Marin County or to the Marin General Hospital, or should I go to Stanford? But now it's also Stanford for large surgeries. It is already published, and I was about to download this paper that there is large cancer centers, or there are other hospitals that that leverage the branding of large cancer centers and create some strategic alliances, but the surgical outcomes for complex surgeries are inferior at peripheral hospitals compared to large cancer centers, and it has to do so. I'm an anesthesiologist and intensivist by training. It has also to do with a lot. Has to do with standards and infrastructure. And just because Marin General Hospital is now also a UCSF hospital, doesn't bring the quality up and the support system and the infrastructure to that level that that's number one, number two. I actually also believe that patient engagement is associated with better outcomes.

There is an interesting website, blog and book from Dr Arkel Giorgio. The book is called Healthcare Choices, and her podcast is called, “Speak up for your health”, and what you have there actually fits very well. She'll interview people for about 20 minutes, and then comment on that. The idea is really to encourage people to really speak up for your health. And you did this in a formidable way, what is, and I do think you would be ideal for her podcast. What I found striking and, and I'm actually thinking, not only for the podcast, I actually think there should also be a publication. I would love to work with you on a project like that, because what's interesting is this 180 degrees different perspective, depending on who you ask and I am a true believer that when people take the approach that Brad Power with his Cancer Patient Lab has basically built up this amazing community. I believe people have better outcomes because they are better informed, and only if you are best informed you can make this decision. I also believe that this is part of it, but it would be interesting how to put more subs to it, and that that was going a little bit far far astray from the question in terms of diagnostic and more data. I have more to say on that. I would love to follow up offline with you as well.

Bill Paseman 1:00:11
I have a comment about again, it all fits into some of the stuff that you're talking about, but one of the things that I've done is I've used ensemble reasoning to inform my choices for clinical trials and radiation and stuff like that. Basically the idea of a tumor board, you go on and ask lots of people lots of questions, once you get something that comes back that makes sense to you, then you go on and act that's sort of the approach that I've been taking, and that also fits in well with the points that have been brought up about now better better informed people make better decisions for their own health care. And so the question comes up is, what is the mechanism that you should pick to become better informed? I basically use, you know, I use the I'm old so I can go on and do a fair amount of Medicare to pay for my questions. And it's, and that's my approach. But there are probably approaches other than that to have patients inform themselves about their care.

Ari Akerstein 1:01:05

That hits a nerve in terms of how much let's maybe frame it up like you can do it in a bespoke way. You have good friends, and you're part of the Cancer Patient Lab.

The other way is like, how do you do that in an automated way that produces access to a broader scale of people who may not have that level of education, interest, network, access even to Centers of Excellence, language barrier? There's all kinds of blockers there.

There's two parts. How do you do it on the bleeding edge, to just push the standard of care as far as can be, and then how do you bring up the base and give that to the broadest set of people in an automated platform delivery fashion? I don't know the answer to either one. I have a few intuitions, but it's a really good and hard question.

Brad Power 1:02:04
Ari, you will want to talk to Bill Paseman. He's a rare kidney cancer survivor and an engineer, and a successful entrepreneur in Silicon Valley. Using a similar kind of problem solving, background and culture from the Bay Area, and also a cancer survivor.

Allen Morris 1:02:34
You are big picture guys. I learned this word, believe it or not, I didn't even know this word is called “process". Are you a process guy?

Ari Akerstein 1:02:49
Not at all. Not even close.

Allen Morris 1:02:55
Do you think what you're doing is something like what Brad's doing?

Ari Akerstein 1:03:07
“What Brad is doing” in which way?

Allen Morris 1:03:09
He's trying to solve the problem with cancer and everything under that.

Ari Akerstein 1:03:19
Brad, what do you think?

Brad Power 1:03:22
Yes, I think we're actually highly aligned in trying to help people make better testing and treatment decisions. To me, that's a process. That's a decision process. You're a role model for how you've navigated that, and what we are proposing to do is to make that available to more people. So what you did, given your advocacy for yourself, how can we make that more available to people that aren't as aggressive as you are? So that we can make that not only available to the 1% but available to who knows?

Ari Akerstein 1:03:58
Maybe it's the word. I'll reframe the word, Allen, and you tell me if, if this lands. But maybe “systems thinker” is the way to put it?

Allen Morris 1:04:09
I like this. Systems Analysis. Is that good? You like that?

Ari Akerstein 1:04:15
I don't hate it. It's okay. Sounds good

Allen Morris 1:04:17
Bill Paseman brought up the concept of the tumor board, and I'm going to tell you what my concept of that is. It's sticking in the same room a lot of people that speak different languages, that don't normally get in the room together. I'm talking about the big picture. It's called the Tower of Babel. You guys are process people. You're trying to figure out what the best processes are to figure cancer, whether it be delivery to patients who are, whatever the sub topics are. The elephant in the room, in my opinion, is everybody speaks a different language, everybody has a different specialty, so it's very I can tell you, in tumor boards, you guys don't go to them regularly. I do. I'm going to make it up. There's arguably 100 plus fields in medicine. I get in the room with all these fields, and it's absolutely clear to me, they don't speak the same language. I mean, you can imagine an ear, nose and throat doctor. How much is he going to know about gynecology when he doesn't seek gynecology? He has no experience. All he has is the knowledge base of when he was in medical school and communicating with other people that might have or recognizing there's an organic logic problem, and he has to triage them to somewhere else. So yeah, I'm sorry I'm doing the Tower of Babel situation. So I think really, if you want to make the process work, you have to be able to get not only different languages in the room, but somehow have translators. Okay? Because I can tell you, I'm beating my head against the wall here because I'm a pathologist, and nobody speaks pathology, including, like, I asked Dr Armstrong a question about Gleason three, and I realized it's a ridiculous question. He's an expert in prostate cancer. He has his own answer. I know it's a medical oncologist's answer, and he has no understanding of the pathology. My question really should be to Jonathan Epstein, who's the guru in prostate cancer. What I'm trying to say, is you're going to beat your head against the wall if you really want to get the process done, like in a great way, in an optimized way, you're going to beat your head in the wall on the wall, just like I beat my head on the wall when I talk to all the second fields in medicine.

Ari Akerstein 1:06:50
Can I jump in with a couple of thoughts and a question for you?

What I think I heard is, the Tower of Babel. You have many languages that are incompatible with one another. You're talking past one another. But there's also an element, a very strong element of bias implied by what you're talking about. Which is, I'm a gynecologist. I see the world through … you know what I’m saying.

You’re going to have bias based on your training. You're going to have languages that are incompatible. There's no universal language. Let's just say that everybody can speak. There's an assumption that the people in the room are the clinicians, primarily as the decision-makers to assess what the right thing is.

I heard three assumptions inside of that, if that's accurate.

My question to you, not to lead the witness too much with those assumptions, but I give you a magic wand. What actually is the right solution to getting the best answer?

Allen Morris 1:08:01
I know what the answer is: it's the Amsterdam model, but it is not possible.

There's four things. There's established medicine. It's no secret. Everybody can get it. It's in compendiums. There's no secret to that. It's established.

You guys are trying to be on the fence between the fence to the frontier. I'm going to divide the frontier into immediate, intermediate, and future. The intermediate to future world, which most cancer patients are not interested in, because their window is six months to a year, especially GBM and pancreatic cancer patients.

The two frontier things are immunotherapy and precision medicine vis a vis targeting the molecular pathways. In those two things, the people that speak that language all have the clinical medicine vs. basic science divide, which has been astronomical forever, but it's starting to get closer and closer.

If you really want to bridge this, the two fields are basic molecular biology bridging with molecular pathology. But the crazy thing about that is there's really no molecular pathologist, even though everybody will beg to differ, because it's in its infancy. There are molecular pathology departments now in every academic medical center in the country, but they're in their infancy. I can give you numerous anecdotes of how I know they're in their infancy. Then you have basic molecular biology, a completely different language.

I witnessed one guy that started to make it sound like he was bridging it, and that was Michael Castro. Not only was he bridging the two, but he was trying to bridge the two with AI. AI is a language I know nothing about, but it's clear to me that if you want process pushing, obviously AI is where it's going to be, as far as the intermediate and the future.

Bill Paseman 1:10:19
I have a comment I'd like to make on that. I'm giving a talk on this, in fact, next month, but in terms of the tumor boards, one of the things I'm putting into my tumor boards, in fact, are LLMs. I go on and have a different LLM from different vendors, and each one trained in a different way, and each one has a voice in determining exactly what the next decision is. And that's a couple of things. First off, it goes on and addresses scalability, because we don't have to go on and

have a bunch of guys with egos in a room to do this stuff. We can battle out with these other machines that are doing it as well. And the second is that if you have rare capabilities, like you're talking about with respect to molecular pathology, I can still go on and have, again, this is going to take a while to develop a molecular pathologist on each and every tumor board that these people participate in. So I'd like to throw that out there. Bill,

Brian McCloskey 1:11:22
I’m going to make it a little bit more tactical. Ari, when you look at your focus on diagnostics, I have had the same inclination when I was diagnosed with prostate cancer eight years ago, that what was missing from my care was truly understanding my disease and understanding it from a lot of different angles. So just curious what your experience has been with diagnostics and how you've approached it?

Ari Akerstein 1:11:56
I've realized how limited my own personal diagnostics are. I think the way you framed it is perfect, which is like understanding your disease from many different angles. What became very clear to me in going through my own experience was how kind of myopic the standard of care was looking at a bunch of receptors and maybe a little bit more, doing a FISH study, PET scan. That's great, but the amount of daylight between that and what's actually available outside, like, through, if you were to pay an expert to run all the set of possible diagnostics on you, and get that concierge model going like no doubt you will get more information, some of which may be noise, some of which may be signal to producing a better outcome.

But it's very clear to me how limited a blood panel is to see what's happening. I went recently to Dana Farber to talk to my oncologist. “Should we be doing liquid biopsy? How? I don't know, what are the new innovations?” Because I'm a little bit concerned that the way I found the tumor in the first place was luck. I maintain that if I was, say, 20 pounds heavier at the time, and running less and whatever, I probably just wouldn't have found this thing. And then it becomes one of those cases of, “Oh yeah, I dropped dead.” Like, out of nowhere. Who knew? And so the advice given from Dana Farber, which is a high trust place. I trust my doctor. Every year or six months, we'll do some blood panels. As well as I do, that doesn't really pick up all that much, or maybe they will, and you'll get lucky with a white blood count, but there just isn't a lot of need for that.

What's out there that might help with detection? Brad and I both have kind of follicular, let's say, and he's telling me the tests he's running through Tony Magliocco. I'm like, “Oh my God, I need to be getting those.”

At this point, I'm fairly educated, and I still feel totally uneducated on the set of tests that are available. I do know that that set of tests is rapidly growing in various ways, and the amount of signal that will be coming in will be large and ever growing how actionable it is with respect to the standards of care, a big question mark. Probably I wouldn't be super optimistic about fully folding those data points in, but I guess that's my experience. I'm very keen to understand

what's out there in terms of the diagnostics based on various condition types. I also know how limited the standard of care actually is, having seen it firsthand.

Brian McCloskey 1:14:58
If you could wave a magic wand, what would you want from advanced diagnostics?

Ari Akerstein 1:15:07
I think I would want a platform that is delivering what Tony Magliocco or somebody like that at scale. Tell me what tests I need to run. What data should I be looking at to help me understand how I can be optimizing whatever I'm doing right now, such that I don't have to interface with the medical system as much as is humanly possible? Optimize my costs, optimize my outcomes and my health, take advantage of opportunities for diagnostics that are maybe loosely coupled from the medical system inside the medical system, if warranted, and then help me sense, make from that data, what actually is the right thing for me to do as a as an individual, as an n of one or whatever, but also do it in a way that I'm not breaking the bank to do this Like I have friends that are paying 1000s of dollars for, like, Peter Attia kind of thing, and you're like, Oh my God. Like, this is just out of reach for every I mean, it's great, right? Like, sure, I wish I had that, but, I mean, that's not me, and that's not most people. And so I think it's also leveling the playing field on the data access and interpretation to people that aren't going to be the people like all of us talking. I think we're all going to speak the same language, have the same sets of dispositions, and that's just not what most people like nor should it be, really. But could you build a platform or a system or whatever to take advantage of a lot of the emerging technologies that you know aren't going to be utilized by as many people as they should be to make the best possible decisions and get the best outcomes and cut costs from the system. So it's a bit of a hand wave answer. I don't know exactly what it should look like tactically, but it'd be roughly something in that strike zone I think makes sense.

Brad Power 1:17:01
Ari, what’s the final word, anything you want to say, summing things up here?

Ari Akerstein 1:17:13
First off, I'm really honored to be with this group. I think this is really like a group that most people should aspire to be like, who are dealing with these sorts of issues, and it's really, really rare from everything that I've seen. Brad, giant kudos to you for, like, keeping this thing going.

I hope that some of these approaches are maybe useful. I would be happy to talk about them further. But also, as we kick off this accelerator, Brad and I, I do think there's probably a role, and this is exploratory for this group, some of the people in this group, depending on your interest to potentially get involved in help some of the participants in this accelerator to stress test ideas to, giving ideas of your own based on your own knowledge and insights, which runs, obviously very deep, looking at you like Allen, lots of lots of understanding of various parts of this domain that a lot of people just don't have and probably would benefit from in building out solutions to this.

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CHAT DISCUSSION

00:26:42 allen morris: There is a paradox in cancer prognosis: that the most aggressive cancers can be the cancers that are curable; whereas the cancers that are most indolent are usually incurable, but you can potentially live as long as those without the disease: the latter also a notion of cure, even though they are incurable.
00:27:33 allen morris: Dr. Gould: a giant in evolutionary biology.
00:29:39 Roger Royse: Stephen Gould was also one of the first things I read when I was diagnosed - chrome-extension://efaidnbmnnnibpcajpcglclefindmkaj/https://people.umass.edu/biep540w/pdf/Stephen%20Jay%20Gould.pdf
00:31:41 allen morris: Gould died at age 61 of bile duct (in essence pancreatic) cancer. I had the honor of hearing him lecture.
00:36:01 allen morris: What gauge needle?
00:38:53 Rick Davis: Navigating Kaiser is a real skill. Sadly, it is not ideal for anything more than community medicine.
00:46:51 Rick Davis: KFF is Kaiser Family Foundation; does he mean KP - Kaiser Permanente?
00:49:00 allen morris: Spontaneous regression/remission occurs to a significant extent, in many cancers including CLL and skin squamous cell carcinoma.
00:49:39 Noel Resch: Reacted to "Spontaneous regressi…" with 👍
00:50:06 allen morris: Was the differential between follicular grade 3A and diffuse Large B cell lymphoma?
00:55:05 Ryan Moon (he/him): How did you discuss your diagnosis and situation with your children?
00:55:10 Alexander Lalov: I may have missed at the beginning of the meeting, but...

What was Ari's primary occupation at the time of his diagnosis?
00:55:38 Ryan Moon (he/him): Replying to "I may have missed at..."

Product manager, I believe
01:12:02 allen morris: Ditto with Chris: we have branded Stanford cardiovascular care up here in the community hospital setting
01:12:35 Rick Davis: As AnCan says... "Be Your Own Best Advocate"
01:12:36 ari akerstein: Getting 2nd opinion vs. not getting it can be a proxy for engagement
01:12:54 ari akerstein: And I have seen data that 2nd opinion vs. none => better outcomes.
01:14:04 Noel Resch: I have to go, but thank you, Ari!!!
01:14:08 ari akerstein: Reacted to "I have to go, but th..." with ❤️
01:14:26 Noel Resch: Reacted to "I have to go, but th…" with ❤️
01:14:33 Noel Resch: Reacted to "I have to go, but th…" with ❤️
01:14:35 Noel Resch: Reacted to "I have to go, but th…" with ❤️
01:14:48 Noel Resch: Reacted to "I have to go, but th…" with ❤️

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