

“Permission to Be Pissed” (Matthew Zachary) [#69]

Brad Power
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“We can't count on the government to do what the will of the people need. It's our job to force the government to do what we need to get done.” – Matthew Zachary

“How do you reclaim the attention of the American voter, as a pissed off patient at any stage, and build that new movement that the country deserves to accomplish X, and go into economic incentives?” – Matthew Zachary

“2023 has been the first year of the germination of the next great consumer health revolution.” – Matthew Zachary

Meeting Summary

Advanced cancer patients who are engaged in their care want to help themselves and others with their diagnosis, yet they often run into barriers and uncover breakdowns in the healthcare system. Some give up, a few work around the barriers to meet their own needs, and fewer still try to reform the system – to use the power of the people to force the government and big institutions (hospitals, insurance companies, pharmaceutical companies) to do what they should be doing.

Matthew Zachary, Principal, Matthew Zachary Worldwide; Founder and Chair, OffScrip Health; Host, “Out of Patients with Matthew Zachary”, is uniquely qualified to talk about how to improve the healthcare system. Matthew is a passionate advocate for putting the patient at the center of every conversation. Why? He is one. Diagnosed as a college senior with brain cancer, he wasn't sure he'd make his next birthday. That was 27 years ago. Hailed by *People Magazine* as “The People's Voice in Healthcare,” Matthew is one of today's most influential and visionary voices in healthcare, with a career spanning entertainment, advertising, marketing, nonprofit, digital health, public policy, life sciences, and broadcast media. As Founder of the award-winning nonprofit Stupid Cancer, Matthew started the young adult cancer movement in 2007. He was christened the “Podfather of Healthcare” for hosting “The Stupid Cancer Show”, the first streaming healthcare podcast before podcasts. Matthew is currently writing his first book, “Permission To Be Pissed: A Practical Field Guide To American Healthcare,” to be published by Mayo Clinic Press in late 2024.

How can we drive the next healthcare revolution – enabling more patients to access care that is personalized to their unique needs?

There hasn't been a consumer-driven healthcare revolution in the United States since twenty years ago. We are overdue for the next revolution. It will likely be a revolution in personalization of care. Citizens will force the government to do what we need that it will never do if we don't do what we need to do. Healthcare has to be the business of those who are living it, not just those

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who work in it. How do you activate the right people to accomplish changes, because right now, we are as deactivated as ever in this country, because there's so much noise going on?

Based on a look back at what has worked in the past to drive change in the U.S. healthcare system, such as the National Cancer Act in 1971, the National Cancer Survivorship Act of 1996, ACT UP ([AIDS Coalition to Unleash Power](#)), and the Affordable Care Act, if you build enough will, and you channel enough anger, and you put in the work, the country will do what the voters demand. Because they won't do it if we don't do that.

People who want to drive the personalization revolution in the healthcare system should:

1. **Focus on the finish line (vision) and then work backward:** What law needs to be passed to do what? Who's in charge of it? How do you rally the right people to influence it and to get it through more quickly? Get granular about a vision of greater personalization in healthcare and what needs to happen to achieve it. For example, an aspect of achieving personalization is that we need to capture and leverage more real world evidence, such as patients' experience with drugs to uncover personalized minimum effective doses. Every patient is an experiment, and real-world evidence is needed to show what is possible, what works and what doesn't work. How do we increase incentives to capture and use real world evidence?
2. **Engage stakeholders who have incentives to create that vision, such as diagnostic companies and big tech companies:** Unless you find the right people driving the narrative with the voice and the right consternation, nothing is going to happen. The only thing that's ever changed anything that protects patients from bad processes is advocacy and policy, working with other stakeholders. For example, if you now know that you want to capture and use more real world evidence, then what needs to happen to make that happen, and who needs to be involved? Think of it like a flow chart. In whose interest is it, besides the patient? Will it help with drug development? Will it help sell more drugs? Will more people live longer? Will it increase demand for diagnostic services and analytic services? What are the mechanisms that drive the real world evidence to do that? The healthcare industry incumbents (payers, providers, pharma) have never understood or pursued the economic value of being active partners in helping individual patients. There is room for diagnostic companies, like Tempus, Foundation Medicine, and BostonGene, and big tech companies, like Google, Amazon, Apple, and Microsoft, to join with patients to disrupt the dynamics of the industry. These companies make money from data and services, which they are increasingly providing in the medical space. There's a tailwind of AI that these companies have and what they can do with health data. Their services are better than what the pharmaceutical companies or hospitals are able to provide, giving doctors much better information about genomics and patient information, so that they can make personalized decisions for patients. What are their motivations? How would one go about inviting them to this conversation and seeing what they could contribute? Is there a role for employers?
3. **Assert patient power as business partners:** Incumbents in the medical industrial complex have a lot of power, and they have not adequately considered the economic role that we patients play in their financial gain. We should not be token participants to

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be allotted a slot on stage at a conference. We are at the dawn of industry incumbents recognizing that the right patients in the right pipelines can be business partners to help them be successful. Until we are perceived as seasoned executives who understand the business practices of the industry, the industry is not going to take us seriously.

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Meeting Notes

Discussion Outline

1. Introduction to Matthew. (0:03)
2. How did you get into the industry? (4:21)
3. How I started my own movement. (11:12)
4. What does it mean to have a book about cancer? (15:54)
5. The power of the people can force the government to do what they demand. (23:02)
6. Focusing on the finish line backwards. (27:36)
7. The rise of life-sciences companies. (35:03)
8. Matthew brings a different perspective. (41:53)
9. The perception of being just patients. (46:23)
10. Do you see a change in the healthcare landscape? (53:21)

Discussion Summary

- **Introduction to Matthew.** [0:03](#)
 - Welcome to the Cancer Patient Lab and Prostate Cancer Lab, Matthew Zachary, a provocateur, patient advocate and media star.
 - What Matthew is up to now, writing a book.
 - How we can collaborate.
 - Matthew was diagnosed with terminal brain cancer 27 years ago as a college senior. He was a concert pianist going to film school to write for Hollywood movies.
 - His early symptom was left hand loss.
- **How did you get into the industry?** [4:21](#)
 - A lot of how he shares his story today is through the lens of history, not necessarily what he went through, but the journey of being in this place at this time with these people with no personal effort to expect that to happen.
 - He used to fix computers.
 - He got the attention of a drug rep who asked him what he was doing and was able to license his album and give it away.
 - He was branded “the cancer tamer”.
 - Craig became his first lifeline into this cancer health policy, advocacy, adolescent and young adult cancer universe.
 - He became the country's first radio show host in healthcare.
- **How I started my own movement.** [11:12](#)
 - Stupid Cancer started as a live podcast, but it exploded as a brand at the onset of social media.
 - The Google Health initiative failed because it was ahead of its time.
 - How the young adult cancer movement was the bellwether of the success story for millions of Americans in their 20s and 30s.
 - How he stepped down in 2019 because of miracle twins.
- **What does it mean to have a book about cancer?** [15:54](#)
 - Stupid Cancer became so successful that it wasn't fun to work there anymore, so he stepped down and started a new podcast.
 - “The Cancer Mavericks”, a history series.

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- Thorndike advised the Hollywood folks that stood with the cancer in the early days to not come off as just another research group.
- His book, “Permission to Be Pissed”.
- Matthew gave birth to the first documentary podcast production studio for healthcare, and his show is the flagship for it.
- One of his favorite stories is about HIV/AIDS.
- **The power of the people can force the government to do what they demand.** [23:02](#)
 - The power of the people to force the government to do what it should be doing anyway.
 - The next great revolution was the breast cancer wars.
 - The economic benefits of these drugs prove themselves, but citizens need to force the government to do what they need to do.
 - The next wave of lobbying is about personalization.
- **Focusing on the finish line backwards.** [27:36](#)
 - Focus on the finish line backwards. The American Cancer Society is hungry for the right Americans to sign up and be trained to do this.
 - Get granular about what needs to happen.
 - For personalization to be realized, there needs to be more widespread capturing of every patient's life history.
 - Every patient is an experiment, and real-world evidence is needed.
 - The generic approach is to know what needs to happen, but need real-world evidence from more patients to justify it, and whose interest is it besides the patient, from a funding perspective.
 - Understanding the sociological landscape of survivors.
- **The rise of life-sciences companies.** [35:03](#)
 - The rise of life sciences companies that can provide more insight into cancer than ever before, and the challenges of integrating technology into care.
 - Translational medicine.
 - In the early stages of building a community, and how to accelerate the growth of the community.
 - How to invite the lead investment company to the conversation.
 - Physician sentiment should never be a barrier to what patients demand needs to happen.
 - Industry has never really absorbed the economic value of being active business partners to help patients.
- **Matthew brings a different perspective.** [41:53](#)
 - All of us want to help the bigger cause. All of us had hopes that we can affect bigger change.
 - Rick is on a clinical trial right now for targeted chemotherapy.
 - High multiplex immunofluorescence such as Akoya, which is a slice of tissue that is stained with three fluorophores bound to specific antibodies.
 - The frustration of not being able to make the technology available.
- **The perception of being “just patients”.** [46:23](#)
 - All of us could use that pump to help get precision testing to the next level, and it would help us.
 - There hasn't been a consumer health revolution in this country since 20 years ago. The business of healthcare has changed the perception of who will force change.
 - The role of tech companies in the healthcare industry, and whether there is room for Google, Amazon or other big tech companies to disrupt the dynamics of the pharma industry.

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- The business incentive for Google to take an active role in the healthcare industry.
- **Do you see a change in the healthcare landscape?** [53:21](#)
 - Companies make money from data and services. They are now providing better medical services than pharmaceutical companies or hospitals.
 - Post-pandemic 2023 has been the first year of the next great consumer health revolution.
 - Matthew shares his take on the Cancer Moonshot idea and what advocacy groups can do to change the speed of government.
 - Matthew talks about the early ACT UP initiative.

SUMMARY KEYWORDS

patients, cancer, years, policy, drug, people, country, called, maximum tolerated dose, personalization, brain cancer, advocacy, community, company, force, fda, aca, americans, doctors, cancer patients

SPEAKERS

Matthew Zachary (68%), Brad Power (13%), Rick Stanton (9%), Amit Gattani (5%), Brian McCloskey (5%)

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Meeting Transcript

Brad Power

This is the Cancer Patient Lab and Prostate Cancer Lab. This is one of our weekly sessions.

We're honored to have Matthew Zachary, who is a provocateur, patient advocate, and media star, with us. He'll introduce himself and do a better job.

Matthew is a longtime friend. When I was early in my cancer journey and trying to help other people, he dissuaded me from launching a podcast. It's a tough job, and there's some downsides to it. He also interviewed Kasey Altman. One of the hackathons we ran was for Kasey Altman. Matthew and I were checking in again recently, and he told me that he's transitioning from his previous role into a new role as a media celebrity and writing a book. We can find out what he's up to now, and maybe how we can collaborate.

Matthew Zachary 2:26

You can be my publicist anytime. How's that for a job description?

Brad Power 2:31

Yeah, happy to.

Matthew Zachary 2:33

This is one of those. “I'm sorry you're here, but welcome to the party” kind of things, right? No one wants to be here. But we're here, and maybe it's a better problem to have if we at least have each other.

For those that don't know me, I was diagnosed with terminal brain cancer 27 years ago as a college senior. At the time, I was a concert pianist going to film school to write for Hollywood movies. My early symptom was my left hand's loss of fine motor coordination, which is a strange thing to experience as an artist. I don't fault the doctor for thinking this was brain cancer. I was misdiagnosed for many, many months to the point where I was having seizures and all the horrible stuff that happens when you are improperly diagnosed with a giant tumor inside your brain. I got very lucky. I have no explanation how the hell I'm still here 27 years later, but I had surgery and Turkish prison level radiation, which was the protocol back in the 1990s. And there was no chemotherapy that did anything beneficial for brain cancer back then. I said “no thanks” when they wanted to give me chemotherapy, which was radical at the time. They yelled at me and my parents for “How dare you question us.” My world, as it exists today, is largely irrelevant because we've made progress in 27 years. Back then you just died, and it was like “walk it off” therapy, that we all know as 1970s and 80s kids. “Put some Bactine on it, and you'll be fine” was a version of what they told me. There really were no communities in those AOL dial up times, and there was nothing you could do about this with corded phones and whatnot.

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A lot of how I share my story today is through the lens of history, not necessarily what I specifically went through, but the odd Forrest Gump-like journey I've been on by happening to be in this place at this time with these people with no personal effort to expect that to happen.

I used to fix computers. I soldered motherboards at eight years old. My dad brought home computers. I used Tandys and Commodores, and I learned how to fix Macintoshes back when they really sucked. It was an odd commodity to be the tech kid at 22 years old who was just trying to not die after all of my surgeries and whatnot. But I found a niche for myself fixing computers at all the ad agencies in New York City. There were very few Mac people in the 1990s that knew how to do that. I just slotted into these agencies as a contractor, and whatever I was doing for a couple of years, but I wound up spending about 10 years in the ad world beyond it. And this is all during the emergence of Adobe PDF and Photoshop and QuarkXPress and layout design and Pantone colors. I got into creative and brand and designed logos. I learned all the backend creative stuff about brand planning and whatnot. All of that was institutionalized in my head. And it explains a lot of the choices I made because I was informed by that career I wasn't expecting to have.

The short jaunt is that I did wind up rehabilitating myself on my own over four years to play again. But I couldn't go to grad school. I was too sick to do that. But I wound up giving piano concerts for the American Cancer Society's Relay for Life events around the city. It got the attention of some drug rep who asked me what I was doing. I had recorded some songs that I wrote before and after I was sick, and I produced some albums for myself back when you could self publish CDs. And this rep got a hold of this album. This isn't a replicable moment in time story. This was before regulations that put a pin on pharma bribing doctors, like Purdue, exploded. They were able to license my album, slap a brand on it, and give it away in six figure quantities around the world. That got me some press as this 24-year-old kid with no story to tell, except I'm still here sometimes.

I was branded “the cancer tamer”, which has a village of fanatics. I really enjoyed being labeled that. That caught the attention of people in DC who were running cancer advocacy initiatives at groups you may know. It was early LiveStrong before the downfall. There was a group like the National Coalition for Cancer Survivorship, the Children's Cause for Cancer Advocacy, the Patient Advocate Foundation, and I was kind of plucked out of the ether. “We need to know you. We want to know you. How would you like to be a cancer advocate?” I said, “What the fuck is a cancer advocate?” Who knows what these things meant at the time. They basically said, “We want to help you make sure the next you has a less crappy experience.” I'm like, “Sign me up, whatever this means.”

I met my first peer. Again, better problems to have. We have peers today. There are platforms that help us meet people that are just like us. I was wandering the earth like Cain. I had no idea that there were other 20-Somethings that were going through this. And again, it is just the randomness of kismet and karma. I met a guy named Craig. Normally peers tick one or two boxes: relatively the same age and diagnosis. Craig ticked like eight boxes on the first date. He was in his 20s. He had brain cancer. He was bald. He was Jewish. He was from New York City.

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He went to my university, Binghamton, and he was in my acapella group. And I didn't know him for some reason. So these are seven things on the first date, and Craig became my first lifeline into this cancer health policy, cancer advocacy, adolescent young adult cancer universe.

Two things happened because of that. I met a woman named [Ellen Stovall](#), the late Ellen Stovall, who was a luminary from the 1980s, who forced so many things to happen in survivorship and advocacy rehabilitation, Medicare reimbursements for post treatment care, that LiveStrong institutionalized, through evidence-based, best practice standards of care. All of the things that we have today, where we actually care about who you are as much as what's in your body, were born in the late 1990s. She became my first mentor.

Her friend was a woman named [Selma Schimmel](#), who was also like a riddle, multi-cancer survivor. She was an AM radio host. She worked for NPR. She built her own AM radio platform, and lugged tons of equipment, from cancer event to cancer conference to cancer conference and broadcast live from these events, and recorded interviews, put them on CDs, gave them away, and pharma bought all the media. Selma became my other mentor. And she offered me the opportunity to host my own show, on behalf of back then the Gen Xers and the younger boomers who were the community in the early 2000s. I became the country's first radio show host in healthcare, because someone put a microphone in front of this face for radio. I got the chance to build a media presence in the country that didn't exist before. There were no podcasts. This was a live show you had to find the time to listen to. It wasn't like, “Friends, you can watch it, 30 years later, whenever you want.”

That encouraged me to start my own movement. You may have heard of Stupid Cancer. The origin of Stupid Cancer was largely based in branding and marketing and community. There really was no unilateral way to look at equity and parity. It wasn't about what you had, it was about what you have in common. If you had disease-specific things, there were groups for you that could do that. So all that happened, and then it really exploded.

Matthew Zachary 12:08

Basically, I built a brand at the onset of the dawn of social media. We were on every platform, and we were everywhere. We did live events, and we did massive trade shows, and road trip public relations stunts. My show was getting a million listeners or downloads or streams a year because there was nothing else out there that was serving as the voice of everyone who was really pissed. I built a brand promise within Stupid Cancer with a lot of intention. It was permission to be pissed. It was a way to become part of something bigger than you and make the next person's experience less terrible. I ran Stupid Cancer for 13 years.

Along the way, I was plucked by Google to advise their Google Health initiatives, which tanked and failed because it was ahead of its time. I got invited to be part of some early digital health transformation investment relationships. They didn't understand the value of how a patient is more than just a claims code, and that we are active participants who do not yet know how to be leveraged for community organizing and drug development and influence in the country.

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All of this was fomenting in this extraordinary anthropologic way. I was looking at this from this crazy crow's nest because every year I kept living, there was so much progress happening. The end result of the young adult cancer movement was the ACA (Affordable Care Act), which was, with all its faults, the bellwether of the success story for millions of Americans like me, who were in their 20s and 30s that needed the preexisting condition to go away and to just shut up the insurance companies and get your policies to 26. There's no good time to get sick, but I was 21 and a half, and at 22 had to go on a policy of my own at \$3,800 a year, that my father had to take out a HELOC (Home Equity Line of Credit – a second mortgage on a home that provides a credit line you can borrow against up to a certain limit for a certain period of time, usually 10 years) to pay for. Progress is the theme of what I talk about. The Stupid Cancer show just kept growing and growing. The organization raised close to \$14 million in my tenure there, and it became a really influential brand in rallying millions of people to policies and studies and surveys. Generationally, we were institutional in bringing forth legal policies on infertility rights, and screening rights, and getting breast cancer down to 40 years old.

I'm very proud of that. It's still thriving. I stepped down in 2019 because I have miracle twins. I was infertile. Thanks to young adult cancer advocacy, I met the right people who got my wife and I to figure out how we could become biological parents when I had no sperm and she had one ovary from separate Dermoid cyst surgery, which was a challenge. My kids turned eight in 2018. They finally realized that daddy wasn't there. That, coupled with the fact that Stupid Cancer became so successful, it wasn't fun to work there anymore. It became a job. So I stepped down.

I had every intention of starting to think about writing a book, or going on the speaker circuit, and all the usual stuff that might be expected. Then the pandemic struck. So I wanted to get back on the radio or the podcast world. I started a new show called “Out of Patients”, which is the sequel to the Stupid Cancer show, and all those listeners flocked over to that. I've been broadcasting that show since the fall of 2018. I've done almost 500 episodes. It's every Tuesday and some bonus episodes on Thursdays.

I got to tell the story of my heroes, who the country may not know, in a Ken Burns-endorsed eight-part history series documentary podcast on advocacy in America across the last half century. And how we got from there to here. And what “here” means because we were there, and it's called, “The Cancer Mavericks”. That has been listened to nearly a half a million times with no marketing, because it's a story of other people's heroism, upon whose shoulders we don't even know were standing. And our role here today as people living in a space we never asked to be in is, “What do we do with this?” I will out myself as a JRR Tolkien nerd and quote Gandalf, “We must make the most of the time that's been given to us.” End of nerd moment for that.

I also advised the Hollywood folks at Stand up to Cancer in the early days on what they needed to really do to not come off as just another research group. They did a great job. Like any organization, they have to revisit what their purpose is. But in the documentary, one of my other heroes was the late Hollywood legend, [Laura Ziskin](#), who was one of the cofounders of [Stand](#)

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[up to Cancer](#). I pay tribute to her amongst many other people like Ellen Stovall and Selma Schimmel in the documentary.

That started a conversation on, “Why don't you have a book yet?” I was like, “Well, tell me more. What does it mean to have a book?” When I was in my office at Stupid Cancer, I had a 10-foot wall with four shelves of endless books. Everyone loves to express themselves. Books are really important, though not really necessary. I figured, “What book does the country need to read?” Not, “What books should I be writing?” To wrap this in a bow, my book is called “Permission to be Pissed – A Practical Field Guide to American Healthcare”, and it's coming out with Mayo Clinic Press in 2025. The goal of the book may be a little antithetical to common thinking about what's wrong with the American healthcare system. I don't want to fix it. I want to break it. And there are some subtle things that can happen legally, ethically, and morally that Americans don't know they can do that are hidden in plain sight because there's never been the scale to bring those messages in simple terms to millions of people at a clip. I'm on a wonderful path now in the next two years to figure out how I serve the country, what role I will have, as a national public figure, scaling beyond oncology, per se.

In between the pandemic and now I gave birth to a startup, which is the first documentary podcast production studio for healthcare. My show is the flagship for it.

I don't know why I'm still alive. I joke that you should never look under the hood. But we all look great. I don't really have a cat poster success thing to share. It's more like, “We didn't ask for this shit. What do we do with it? How do we support each other in a way we never thought we could do because we didn't ever have the chance to do it 20 years ago?”

Brad Power 21:26

Thanks for that introduction, Matthew. You're a great storyteller.

One of my favorite stories is HIV/AIDS, and how a set of inspired advocates pushed the FDA to accelerate access to the cocktails that were going through the formal steps of a randomized clinical trial, which costs a billion dollars and takes five to ten years. But these were patients that needed treatment now. There are ways that the FDA can accelerate their approvals. They did that mostly through lobbying and pressure from Congress and hearings and that sort of thing. Since you sometimes stray into that sort of policy and try to get the government to align with the interests of patients, what do you see in that area? Do you have any comments on whether that HIV/AIDS experience is replicable?

Matthew Zachary 22:40

There have been, I think, four or five great consumer health policy revolutions in this country since [the National Cancer Act in 1971](#). In “The Cancer Mavericks” we talked about how a woman named [Mary Lasker](#) shamed the entire Nixon administration to do better. She spent a half a million dollars, taking out a full page ad. She was a socialite, with tons of money. But she did an amazing thing. She forced the hand of the government to throw a ton of money at the National Cancer Institute. That was the first time it was demonstrated that the power of the

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people can force the government to do what it should be doing anyway, because they are our employees, as taxpayers.

I then look at things like the Orphan Drug Act and the ADEA (Age Discrimination in Employment Act) in the early 1980s. I looked at the [National Cancer Survivorship Act of 1996](#), forcing the hand of the government to add covered benefits to people that were living at the time.

[ACT UP \(AIDS Coalition to Unleash Power\)](#) was an extraordinary moment in this country to demonstrate that if you build enough will, and you channel enough anger, and you put in the work, the country will do what the voters demand. Because they won't do it if we don't do that.

I would argue the next great revolution was the breast cancer wars, which took major cues from ACT UP. They staged demonstrations at major pharmaceutical companies to demand that medications be made that weren't about curing cancer. They're about your quality of life along the way. Things we take for granted today, like antiemetics, didn't exist when I was diagnosed. I was throwing up 20 times a day for weeks at a time until we found a drug that was in like Phase Two that I paid out of pocket for that changed my world because I wasn't throwing up 50 times a day. They fought for drugs like Procrit and [iemand] and Zofran and [kytril] and others that were all about your quality of life, because they were able to figure out that if you have a better quality of life, you will live better, you will live longer while you're on it. So the economic benefits of these drugs prove themselves, but citizens had to force that.

The next one would be the young adult cancer Gen X, younger Boomer revolution, which forced the ACA. I have not seen a similar uprising in voters for health care since then.

So my response is that [this country is overdue to rally voters to force the government to do exactly what we needed to do that it will never do if we don't do what we need to do.](#)

Brad Power 25:54

What do you see that might be the foundation of that ask, or that thing that we need to solve?

In this community, it would be something around personalization. In the system we have the pharmaceutical companies do randomized clinical trials and come up with population level monotherapies, but personalization, which might involve drug combinations, or off label uses, what have you, the system doesn't quite embrace those as rapidly as we might like.

We have with us Kaumudi Bhawe and Emma Shtivelman, who are molecular biologists who advise cancer patients. They're at the intersection between that understanding of molecular biology and what might be a personalized solution.

That's my soapbox. That would be my candidate. But I don't know, what do you see as the thing that might be that next wave of lobbying?

Matthew Zachary 27:00

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I would approach this as: **what law needs to be passed to do what?** What CMS influence, what FDA, what needs to happen to make something happen? You approach it from the finish line. You need this to happen. **A bill needs to be introduced to force that to happen. What is that bill? Who's in charge of it? And how do you rally the right people to make that influence it needs to get through more quickly?** I think it can be viewed as simply in linearly as that. You just focus on the finish line, backwards.

I'll give you one example. I was able to help in the lung cancer space. There's a lot of similarities in the lung cancer space, but there's a lot more drugs in that space now. And these companies are desperate to get things passed through all their gaps. The data is there and X, Y, and Z. Nothing you guys aren't aware of. And there's a lobby group within the American Cancer Society that spends their days endlessly focused on introducing bills at the state level, or the federal level, training patients to speak X, Y, and Z, building the signatures and driving those conversations and accelerating what could take five or ten years to two or three years. And they're hungry for the right Americans to sign up and be trained to go do this. So that's very linear. They know exactly what needs to be passed to accomplish this to get this drug to these patients at a reimbursable level: X, Y, and Z. I was able to drive 5000 Americans who are not part of nonprofit communities, to just sign up through my show, because I was able to build outreach. I won't get into the business model. But that's a demonstrable success story. Now they have the patience they need because they know what the finish line is. And it's up to them now to do what they're supposed to do. If there's a corollary for that, who is the policy group on the good side of Americans, and they're working on X, Y, and Z? And they need voices and they need influence. I'm very topline about this. You can get granular in terms of what it is specifically that needs to happen. But **unless you find the right people driving narrative and voice and the right consternation, nothing is going to happen because the only thing that's ever changed anything that protects patients from fuckery is advocacy and policy.**

Brad Power 30:06

I would argue that for a personalization to be realized, we need much more widespread capturing of every patient's life history – an observational registry of every patient. Our colleagues from Cancer Commons and Marty Tenenbaum share this vision. That would be the view that every patient is an experiment. We need the real world evidence that comes from those experiments.

This was highlighted in a recent session we had on personalized dosing with a couple of our colleagues in this community, who made the point that drugs are approved at maximum tolerable doses. That is not what patients want. Patients want a minimum effective dose. The only way that that will be uncovered is through real world evidence, because they're not going to run clinical trials to find out what's the minimum effective dose. They're quite happy that they got the drug approved at the maximum tolerated dose. That's good enough, and they're going to prescribe that.

Amit, who is in this meeting, is a case in point. He can't tolerate the maximum tolerated dose of chemotherapy. So they have come up with a fraction of that. If we had Amit's experience, and it

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was published, we might find that a quarter of the maximum tolerated dose is adequate to get the effect. And that's only going to come through real world evidence. We need the FDA and the regulators to start to consider real world evidence as evidence for certain applications like this, as opposed to their very strong leanings towards the gold standard of a randomized clinical trials and the expense that comes with that.

I'm just taking your suggestions and taking it to the next step on this. Maybe you can respond to that.

Matthew Zachary 32:11

That is much above my paygrade to respond in a granular fashion. But it does speak to the generic approach, you now know what needs to happen. And that's the most important thing. The fact that you now know what needs to happen is then what needs to happen to make that happen. Working backwards, you now need real world evidence from more patients to justify this and substantiate this. What is the mechanism? And then whose interest is it besides the patient? From a funding perspective, from an effort perspective, in whose interest is this? Will this increase script lift? Will this help drug development? Will they need to sell more drugs? That's the job. You have to think about this from the pros and cons of a capitalistic system that we don't really want, but we have to deal with, which, again, is a challenge unto itself.

Think of Ralph Nader. He forced them to cover the seat belt cost because they didn't want to deal with all the insurance problems. Is there a version of that today, that this benefits more people, they're more compliant? More people live? Here's the data. What are the mechanisms that drive the real world evidence that you require to do that? I don't have an answer to that, because I'm thankfully not affected by prostate cancer, maybe brain cancer was enough at this point in time. But just basically understanding the landscape, almost like the sociological landscape. How many survivors are there in this country? Do you know the answer to that? How do you activate them? That's a conversation to have. What information you need from them is another conversation. But what do you do with that data to get it to policy to force the change you want? And I'm looking just as almost like an org chart, or like a flow chart perspective.

Brian McCloskey 35:03

I was actually going to tee this up, Brad, before you did, I'm going to stay on the personalization train just a little bit.

Matthew, you've been around the block. You've seen the evolution of medicine over the years. One of the things that we see is the rise of life sciences companies that can provide more insight into our cancer than ever existed. For example, Tempus Life Sciences didn't exist ten years ago, or nine years ago. They're a gene sequencing company for cancer patients. That's a necessary element to unlock personalization.

But one of the challenges that we face as advanced cancer patients is actually integrating that technology into our care. There are many different roadblocks, from how do I manage my tissue, to how do I actually access and own my tissue? How do I determine where that tissue is

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going to go? What are the vendors that I want to use? How do I convince my doctor that the insights from any of these advanced diagnostics can make a difference in our care? Too often, we find that doctors are inclined to hit the easy button and use the standard of care. Well, we equate the standard of care with what Rick has called the conveyor belt of death. We are talking about translational medicine here – how do we get all of this amazing science to get integrated at the patient's bedside? And right now, the patients that are on this call, and others that are in our community, are trying to pull that science across the bridge. There's not an easy mechanism to do that. Almost everybody here has a story about that.

From your vantage point, how can we affect that? How can we bring about change? We're doing it on an individual basis. We're building a community here. We're just in the early stages of building that community, the patients that you have on this call, They're all unbelievable. They're all super intelligent and motivated. They're the mavericks. They could be in a Ken Burns series, for sure. But, I'd just love to get your thoughts in terms of how do we supercharge this? How do we accelerate this?

Matthew Zachary 38:04

it recycles back to the same dogma. **Is it in Tempus's interest? It clearly sounds like it's in their interest. What are they prepared to invest in to move this forward on behalf of the people. Clearly, they'll make money off of it. They'll be able to prove demonstrable data that accelerates what this community needs.** I can't speak on their behalf. I don't know what their motivations are. Clearly, it's revenue and growth and probably getting bought one day, but put your head in the mind of a lead investment company. **How would one go about inviting them to this conversation and seeing what they could contribute?**

I'm spitballing here, but we did the same thing with Patients Like Me back in the 2000s. They had gotten a little askew. We had to course correct them because they couldn't quite get oncology right. This was before they sold. Their investors finally came around to realize that if they threw a little more effort at this, they would accomplish what they needed to do to grow and be successful. That was in 2010, 2011, 2012.

Is there a version of that with the Tempuses in this space, where it's in their interest to get actually actively financially involved to solve for this?

I can't speak to physician sentiment, it sounds like you've put together a decent cohort group of medical professionals that can speak to the value of this with their MDs behind them. I don't think physician sentiment should ever be a barrier to what patients demand needs to happen. **But it also speaks to the fact that industry has never really absorbed the economic value that we have to their financial gain. We're not token puppets to be allotted on a stage somewhere at a conference. We are active business partners to help them be successful, or we should be perceived as active business partners to help them be successful.** It's the old, “Do well, do good” idea that can exist in certain forms.

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I know the metastatic breast center communities are finally getting some comeupance in this fashion by rallying voices and finding the whole, “You're too sick, we're not going to even give you compassionate use.” They're fighting for that. And it's starting to work, because they realized, the industry realized, that they can profit and have economic gain and improve patient outcomes by sustaining the livelihoods of these women and their families. So we're at the dawn. It shouldn't have taken this long. **But we are at the dawn of industry recognizing that the right patients in the right pipelines are business partners, and not tokens to be dangled on with stupid websites that no one visits.**

Rick Stanton 41:53

What a great and different perspective you are bringing to us. I think all of us had hopes that we can affect bigger change. At least from my journey, I'm getting closer and closer to the end, and those hopes are getting a little rougher over here. I really appreciate you and the kind of possibilities you bring to the table. I wanted to mention that because all of us want to help the bigger cause. We don't want to just fall off the table, and “There went Rick.” We all want to help. Thank you for being here.

I had a couple comments that are just little points. I'm on a clinical trial right now. It's a targeted chemotherapy. There are two arms of my clinical trial, 2.0 mgs per kilogram and 2.7. MacroGenics is the sponsor of the drug. I'm very hopeful that I'll get some mileage out of it. It is not just going after maximum tolerable dose. Biopharma, which I always tend to defend because I worked at Amgen so many years, is not just going after, “Let's sell 2.7. We make more money.” It's not like that. In fact, phase one was 3.0. So I'm appreciative I got on the 2.7. I was kind of happy. I thought I'd just mentioned that it's not biopharma's intent to just keep hammering maximum tolerable dose. I don't think that's a true thing.

Then I have just one other point of frustration, because I was very optimistic about high multiplex immunofluorescence, such as Akoya. You take a slice of a tissue, you iteratively stain it with three fluorophores that are bound to specific antibodies, and you can query your tumor microenvironment for T cells and B cells. You can see the immunosuppression that's going on. We really fought for that a year and a half ago. This would really help. It's not only the genomics, but it's the gene expression that's happening. Maybe adenosine is driving my immunosuppression. What can we do here? We've been unable to break through and make this technology available. It's Research Use Only. It's not for you. It's not for a patient. It's still Research Use Only.

Matthew, since you're here, this has been a very big frustration for me. We're finally getting proteomics up. But it's been a slog, just even getting to proteomics. Mutational and variant data has been a real challenge.

Then what do you do with it? I love my doctors, but they go, “Yeah, okay, that's good, but it's not really clinically actionable. I'm not going to pay attention to that data anyway.” I feel like all of us could use that pump to help get this precision testing to the next level. It would help us.

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Matthew Zachary 46:46

A quick reaction is I think it speaks to the perception that we're “just patients”. Everyone on this call is a seasoned executive. We know where bodies are buried. We understand the loopholes and how it works. **Until we are perceived as seasoned executives who understand the business practices of the industry, the industry is not going to take us seriously because we're just going to be pigeonholed as patients.**

Your tenure at Amgen – I've been working with them since 2012 – demonstrates the skills that should be taken more seriously, because you should lead with your experience and be defined by your cancer, not lead with your cancer and be defined by your experience. It is a different perspective.

I had this huge rant on LinkedIn when someone called me “a professional patient”, like I went to fucking cancer college. Stop, just stop. It just speaks to the dynamic of semantics. Multiple myeloma is also doing this. They finally recognize that there is a patient with multiple myeloma who spent their entire career in pharmaceuticals and understands this. These people are getting sick in their 60s now who understand this, but they're still being just cast as patients.

I mentioned that there hasn't been a consumer health revolution in this country since 20 years ago. The business of healthcare has changed the perception of who's going to force that change. **It has to be the business of those that are living it, not just those who work in it.** This is more of a generic response. But you're a classic exemplar of someone who spent their entire career helping other people. And now you're the one that needs the help. No one asked to get sick. But how do we take advantage of the perception that we have to industry? And what does that mean? What is the entrepreneurial, PE (private equity)-backed business of people like us, that can be taken more seriously? Is there a PE that wants to start a patient group, like a PAC (political action committee)? Can there be a PAC that does this? There isn't a cancer PAC in this country.

So again, I'm spitballing. But I start to think about how I'm still perceived as just a brain cancer patient. And yet I reach a half a million people on my show and know where these bodies are buried, and I'm not doing anything right now. We have that power in us because of our career experience. Why should we settle for being considered as “just patients”?

Amit Gattani 49:49

I have three questions for you.

It sounds like you worked over at Verily. A lot has changed in the past few years with generative AI and how the speed and accuracy of AI is moving up. Do you see a role for tech companies? We are all semi-dissatisfied with the dynamics of the pharma companies, the policy and the practitioner, and the dynamics that exist between them.

The question is: What does it take to disrupt it? You talked a lot about policy and all that stuff. But is there room for a company like Google or Amazon or any other big tech company to really

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disrupt those dynamics, because now there's a tailwind of AI that these companies have and what they can do with the data and information. Since you've been in that space with Google, I wanted to get your sense of that.

Matthew Zachary 51:04

The early Google conversations were just, “Will Americans trust Google with their health data?” And we're having the same conversations today. Who can we trust? I mean, again, with Theranos, Purdue, and the like, it just reinforces this absolute negativity towards the industry. Payers (health insurance companies) are a separate conversation, but they have a lower reputation than Congress. That speaks a lot to this. It's, “Where are the wins?” Again, I just go back to what is the business incentive to Google to take an active role in this? And how do you make the business case to Verizon Health? They're spending a ton of money on infrastructure right now. What is their role in this because they want to hop on the AI bandwagon, but they need to make sure the hospitals have the bandwidth to do it.

Look at Walmart. Forget Walgreens and CVS at this point. If you look at what Walmart is trying to accomplish in rural America, where they're the biggest employer in the country, they have more employees with cancer than any other company in the country. What is their business incentive to take an active role in all of this? I'm a generalist in these responses, because once you get granular, your head explodes. It is a larger thematic approach to **how you activate the right Americans to accomplish x, because right now, we are as deactivated as ever in this country, because there's so much more other noise going on.**

That also tees up the moment in time with LiveStrong. There was very little noise back then. That was the FDA. That was post 911. And that was kind of it. Right? We weren't worried about all the other things that we are focused on today. **How do you reclaim the attention of the American voter, as a pissed off patient at any stage, and build that new movement that the country deserves to accomplish X, and go into economic incentives?**

Amit Gattani 53:21

These companies make money from data and services. That's the foundation of that, and now they are providing services in the medical space where they can do better than what the pharmaceutical companies or hospitals themselves are able to do, so that doctors have much better information across all genomics, across all patient information, so the doctors can make individualized decisions. That would be the economic incentive.

It takes a little bit of time. My question is, “Do you see a change happening here? Or will we still be going the way we have been going?”

Matthew Zachary 54:05

It's just now starting, I would say post pandemic, **2023 has been the first year of the germination of the next great consumer health revolution.**

Amit Gattani 54:18

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Second question: Since you have been involved in a lot of cancer policy-related stuff, do you see the economic efficiency of what we are doing as a country in the US with research money grants versus other countries and what they are able to do? There are better models than the US that exist where it's much more efficient, both from a time and money perspective to get some research and drugs through the pipeline and actually get it to the patients.

Matthew Zachary 54:53

Now that's a “phone a friend” conversation. I don't have a direct answer to that. I wish I did.

Amit Gattani 55:01

What's your take on the Cancer Moonshot? Do you have any hopes from that, or see that will do something?

Matthew Zachary 55:11

“At the speed of government” is my response.

Amit Gattani 55:17

What can advocacy groups and people do to change the speed of government? Because, again, the government is a partner in that. What can advocacy groups or others do to make it more effective?

Matthew Zachary 55:38

I would say there are certain things we can count on with the government. But there are mostly things we shouldn't count on. It's not our job to count on the government for things that we need to happen more quickly than the government. The Cancer Moonshot is a nice idea, but God knows who's going to be president, and what's going to happen after the fact.

So many wonderful initiatives that Obama put in place post ACA – there was something called “the Early Act” that was bolted on to ACA which guaranteed intragenic recompense for women with metastatic breast cancer as free reconstruction for life. And women with stage four and stage treatment, basically, post mastectomy, women get free reconstructive for life. Debbie Wasserman Schultz put that together. Once her reputation got sullied, and Trump took over, they got rid of it, which is why they're now fighting for this again, which is ridiculous.

We can't count on the government to do what the will of the people need. It's our job to force the government to do what we need to get done.