“A Guy with Two Cancers Explores Treatments and Life” (Burt Rosen) [#112]

Brad Power
September 4, 2024

“Knowledge is power for me, so I started to learn as much as I could. I started to go to every support group I could find, and read everything I could find.” – Burt Rosen

“Even though I'm living with this crap inside me, I'm still trying to enjoy my life every way I can.” – Burt Rosen

“The stronger I am mentally, the stronger I feel physically, and the more I feel like I can overcome everything.” – Burt Rosen

“You're going to give me chemo, radiation, surgery, immunotherapy, or maybe a targeted therapy. But how do I take care of Burt? Everything you're going to do for me is designed to kill the bad stuff inside me. Nothing is designed to take care of the good stuff inside me or help my body deal with the bad stuff.” – Burt Rosen

Meeting Summary

"Engaged patients get better outcomes" is one of our core beliefs at the Cancer Patient Lab.

But what does a very engaged patient look like?

Consider the story of Burt Rosen. Diagnosed in July 2022 with two primary cancers (renal clear cell carcinoma and advanced pancreatic neuroendocrine tumors), Burt has done everything possible to make sure he continues to enjoy his life. He doesn't let himself be defined by his health issues and repeatedly pushes himself out of his comfort zone. Whether it is camping and hiking in Glacier National Park three months after a major liver surgery, hiking when he can, traveling, volunteering, meeting tons of people, starting nonprofits, learning all about Integrative oncology, and looking for full-time jobs, Burt does as much as he can to make sure his mental health is doing great since he feels better physically when he feels better mentally.

What has Burt Rosen learned?

- **Enjoy life as much as you can, despite your health challenges**, such as taking a solo road trip to Glacier National Park, jumping out of an airplane.
- **Adopt integrative oncology practices**, including yoga, diet, exercise, and meditation.
- **Live life and don’t let cancer define you**, a philosophy of "I can do it" and "I will do it."
- **Don’t get stressed when bad things happen.** Life goes on. Once you get diagnosed with cancer, there is no deal that nothing else bad will happen to you.
- **Learn as much as you can**, because knowledge is power. Go to every support group you can find; read everything you can find.
- **Surgery has risks that** nobody ever thinks about when they're making these decisions. Many people want to get it out as fast as possible.

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- **View cancer as a gift.** Learn to appreciate life, everything, and everybody. Figure out the things you don't appreciate, and cut them out of your life.
- **Never think of yourself as a “cancer patient”**, be very focused on who you are, and you happen to have cancer. Love who you are, not who you were.
- **Never shortchange the experience part of living with cancer** vs. the treatment part.
- **Focus on the time you have to take care of yourself** (>99%) vs. the time you spend in medical treatment (<1%).
- **Live one day at a time**, set a goal for today and get through today and don’t worry about things you can't control in the long term.

What does Burt do?

- He makes sure he has vegetables in every meal.
- He limits his junk food.
- If he can be outside, he goes outside.
- If he can take a walk, if the fatigue isn't too bad, he takes a walk.
- He does yoga.
- He meditates.
- He goes to therapy once a week.
- He takes some supplements, mostly vitamins.

What are Burt’s recommended information resources?

- For neuroendocrine tumors (NETs)
    - Neuroendocrine Cancer Awareness Network (NCAN)
    - Learn Advocate Connect Neuroendocrine Tumor (LACNETs)
    - The Neuroendocrine Tumor Research Foundation (NETRF)
    - The Cholangiocarcinoma Foundation (CCF)
- For pancreatic neuroendocrine tumors
    - Pancreatic Cancer Activation Network (PanCAN)
    - Let’s Win Pancreatic Cancer
- For integrative oncology
    - The Society for Integrative Oncology
    - CancerChoices - They do reviews of things like a keto diet, cite their scientific sources, and grade it in a couple of different categories, including confidence.
- For life with cancer
    - Triage Cancer
    - Cancer101
    - Cancer Patient Lab
- For links to all of Burt’s resources

How can you learn more about engaged patients and the better outcomes they have gotten and Burt’s views on living with cancer?

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- See our discussions with Ari Akerstein, Mark Taylor, Brian McCloskey, Robb Owen, and Brad Power
- Contact Burt at jburtrosen@gmail.com
- Read Burt’s blog: Adventures with NETs Blog
- Join one of Burt’s Facebook groups:
    - For people in Portland or connected to the Oregon area who have neuroendocrine tumors: PDX Netswork
    - For people from all over the world who don't want to deal with cancer politics: Adventures With NETs

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Meeting Notes

KEYWORDS

neuroendocrine, cancer, Burt, integrative oncology, treatment, tumor, ohsu, hospital, neuroendocrine tumors, patient, people, scan, cancer patient, talk, surgery, question, chemo, integrative, acupuncture, ucsf

SPEAKERS

Burt Rosen (63%), Rick Davis (11%), Brad Power (10%), Chris Apfel (7%), Emma Shtivelman (3%), Brian McCloskey (2%), Roger Royse (2%), Chad Magnussen (1%)

SUMMARY

Burt Rosen, a patient advocate and cancer survivor, shared his journey with two primary cancers: renal clear cell carcinoma and pancreatic neuroendocrine tumor. He discussed his treatment journey, including seven months of oral chemotherapy and liver surgery. He emphasized the importance of integrative oncology, such as diet, exercise, and meditation, in managing his condition. He also highlighted the need for better genomic testing and the role of integrative oncology in improving patient outcomes. The discussion included the challenges of accessing integrative oncology services and the importance of community support for patients.

OUTLINE

Introducing Burt Rosen

- Burt Rosen is a multi-dimensional patient advocate and survivor.
- He is a native New Yorker living in Portland, Oregon.
- His career has been in marketing, focusing on smaller and middle-sized companies.
- He was diagnosed with two primary cancers: renal clear cell carcinoma and pancreatic neuroendocrine tumor.
- He is involved in the integrative oncology world.
- He has a passion for volunteering.

Burt's Diagnosis and Initial Treatment

- Burt’s diagnosis started with a brain fog episode at a healthcare conference in Boston in May 2022.
- He was admitted to the hospital in July 2022 for ammonia buildup and internal bleeding, leading to the discovery of two cancers.
- The initial focus was on stopping the bleeding and then shifting to cancer treatment.
- The aggressive treatment plan for his neuroendocrine tumor included a dotatate PET scan and oral chemotherapy.
- Knowledge was important and he got involved in support groups to learn more about his condition.

Cancer Treatment and Lifestyle Changes

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- Burt’s treatment journey included seven months of oral chemotherapy and liver surgery in June 2023.
- He had lung surgery and decided to delay further surgery to attend his daughter's college graduation.
- He works to enjoy life despite his health challenges and shares his adventures, such as a solo road trip to Glacier National Park.
- He talks about the importance of integrative oncology practices, including yoga, diet, exercise, and meditation.
- He highlights the significance of living life and not letting cancer define him, sharing his philosophy of "I can do it" and "I will do it."

Integrative Oncology and Support Groups

- Burt discusses his involvement in integrative oncology and the benefits of practices like yoga, meditation, and a healthy diet.
- The Society for Integrative Oncology provides guidance on complementary cancer therapies for patient-centered care.
- Support groups provide community and connection.
- A balanced approach to cancer treatment combines medical interventions with lifestyle changes.
- He provides resources for participants interested in integrative oncology, including his blog and Facebook groups.

Discussion on Neuroendocrine Tumors and Integrative Oncology

- Brian McCloskey and Emma Shtivelman discuss their experiences with neuroendocrine tumors and the importance of early detection.
- Chris Apfel shares his experience with a neuroendocrine carcinoma patient and the challenges of finding effective treatments.
- Rick Davis and Burt discuss the importance of identifying neuroendocrine tumors early and the role of integrative oncology in cancer treatment.
- The conversation highlights the need for better genomic testing and the challenges of accessing integrative oncology services.
- Participants share their experiences with integrative oncology and the benefits of these practices in managing cancer.

Final Thoughts and Resources

- Burt shares his contact information and encourages participants to reach out if they have any questions or need support.
- He emphasizes the importance of community and helping others in the cancer journey.
- Participants discuss the importance of integrative oncology and the need for better access to these services.
- The meeting concludes with a reminder of the resources available for participants, including the Society for Integrative Oncology and Cancerchoices.org.
- Burt reiterates his commitment to helping others and encourages participants to stay connected and supportive of each other.

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TRANSCRIPT

Brad Power
This is the Cancer Patient Lab and our weekly webinar series.

Today we're honored to have Burt Rosen with us. Burt is a multi-dimensional patient advocate and cancer survivor. He's got a story to tell about how he's managed his own care. We've been friends for a long time, I think from even before he got all of his diagnoses and went on his treatment journey. He's based in Portland, Oregon, where I have family, and so I spend a fair amount of time.

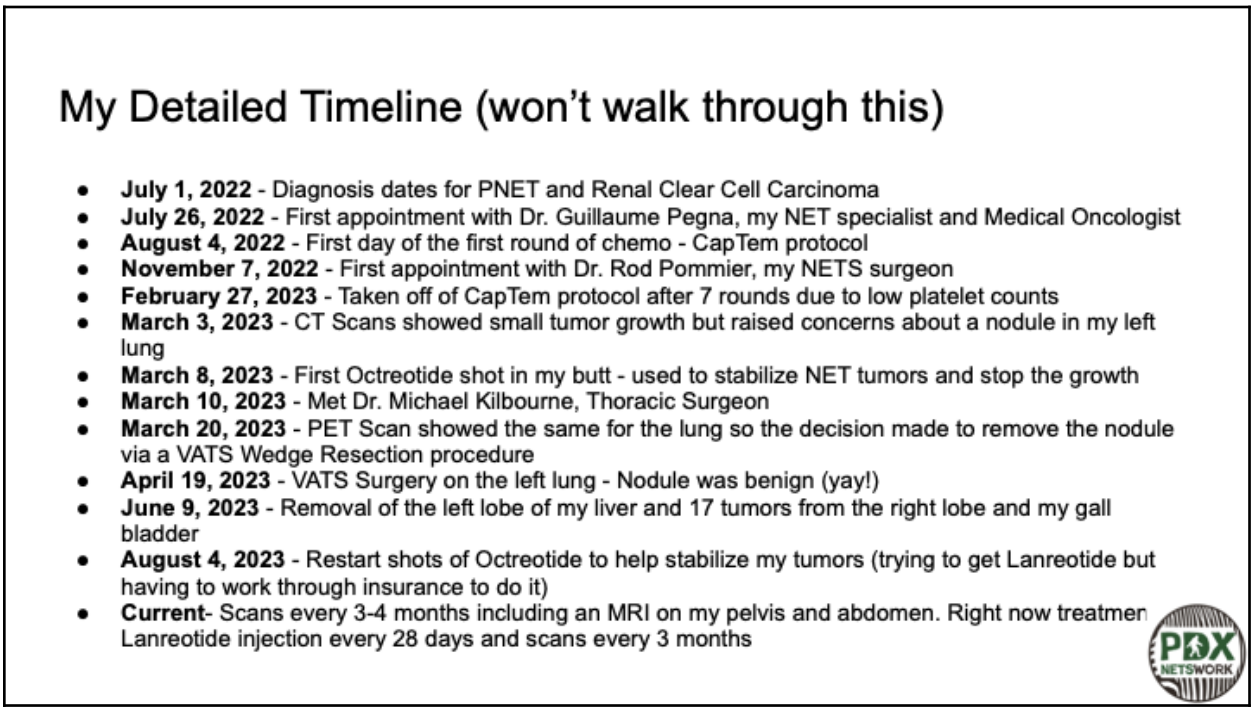
This is for information purposes only. We're just sharing medical advice with you.

We are a patient-led nonprofit, and we depend on the kindness of members and friends who donate money. If you're interested in donating money, please do so through our website.

Burt Rosen 1:43
First of all, thanks for introducing me and thanks for having me. I'm really flattered that you even asked if I would do this.

It's probably helpful if I introduce myself for 30 seconds, just so you have some context. I live in Portland, Oregon. I’m from New York City. I'm one of those rare native New Yorkers that don't really exist anymore.

I've been in marketing my whole life, my whole career. My passion is smaller and middle-sized companies or places where I can make a real difference in the world.

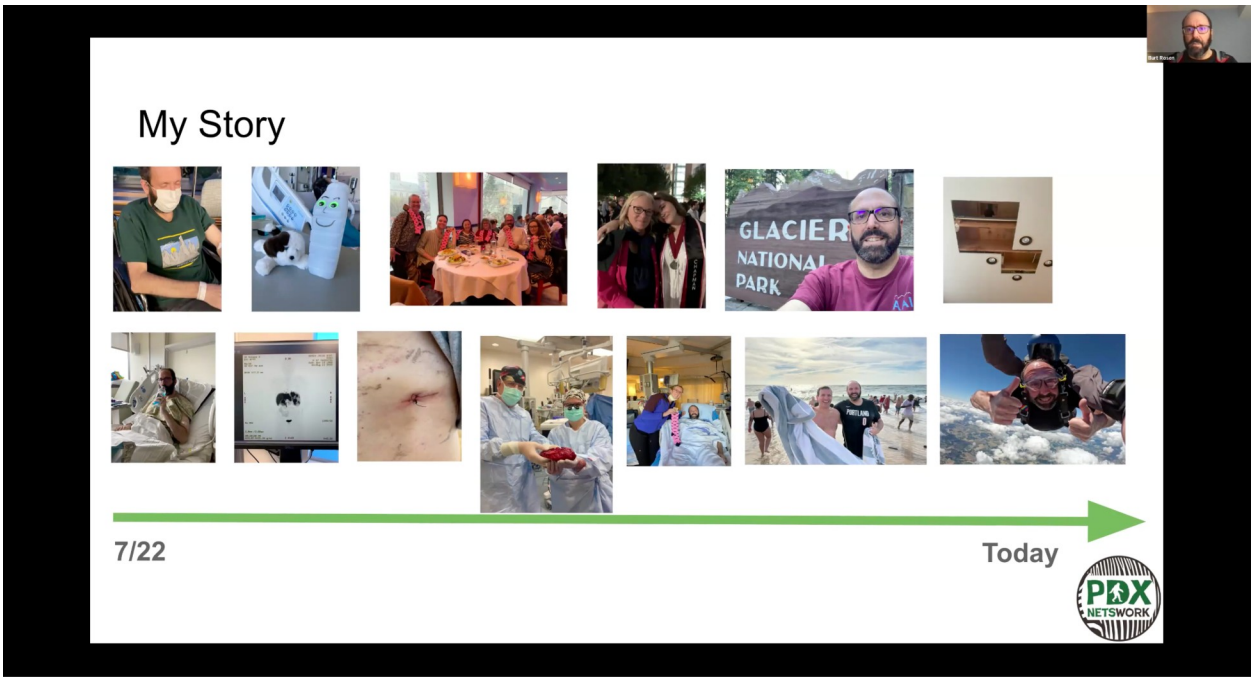


Two years ago, I got diagnosed. I'll go through some of that stuff in a minute. I have a very strange sense of humor, so I hope I don't offend anyone, but I like to say that I went to the cancer store on the “buy one, get one free” day. I have two primary cancers. I have a renal clear cell carcinoma, which is a kidney cancer, for those who don't know, and then the other thing I have is called a “pancreatic neuroendocrine tumor”. Neuroendocrine tumors are much less common cancers that can originate in a bunch of places, but it's basically a cancer of the endocrine system. Mine originated at the pancreas, spread to the liver, blah, blah, blah.

The last thing I'll tell you quickly is that, as Brad alluded, I spend a ton of time in the integrative oncology world. One of the ways I feel better is by volunteering. I volunteer a lot. I volunteer a lot in integrative oncology because I believe that it could help so many people, and so many people just aren't aware.

I'm married. I have two grown kids out of the house who both live in LA, and a small dog. So I just want to give you a little bit of context of who I am.

“A Guy with Two Cancers Explores Treatments and Life” (Burt Rosen) [#112]



Here's my story.

I got diagnosed in July of 2022. I also have chronic Lyme disease, and I had a horrible brain fog episode. My health had been declining for a while, so I was at a healthcare conference in Boston in May of 2022 and had a horrific episode of brain fog. I couldn't text anyone. I couldn't email anyone. If I tried to FaceTime, they knew something was wrong with me. I left the conference and flew home the next day. Obviously, if I was smarter, I would have walked into a hospital, because I could have been having a stroke, but flew home the next day, took the next couple of months, kind of got out of my brain fog. Then I relapsed, went to the hospital in July, got admitted for ammonia buildup in my brain and for internal bleeding. When you get admitted for internal bleeding, because it’s serious, they scan you all over the place, and that's when they found those two cancers. So I was in the hospital for about two weeks. The first priority for me there was to stop the bleeding. My wife and I kind of had a strategy we laid out, which was: phase one was just stop the bleeding, because that could immediately cause death. Phase two was to worry about cancer. So in July, for two weeks, I was in the hospital.

Like I said, I have a strange sense of humor, so, of course, we had to do some stupid things in the hospital, like put googly eyes on the urine bottle. Then I left the hospital, and it was time for phase two: to start focusing on my cancer. Neuroendocrine tumors are an uncommon cancer, so they found tumors in my liver and my pancreas and in my kidney. Because my neuroendocrine tumor was metastatic, it was already in my liver, and there were some other spots they decided to go after that one more aggressively. The scans I get are CTs, MRIs, etc, but we also get PET scans with a specific kind of tracker called dotatate, which is a radioactive tracker that activates receptors on the outside of the neuroendocrine cells. Once I got out of the hospital in July, I then found an oncologist at OHSU, which is the hospital I go to in Portland, and they ordered the dotatate PET scan, and that's by dotatate PET scan (on the slide above).

“A Guy with Two Cancers Explores Treatments and Life” (Burt Rosen) [#112]

Pretty much everything in black is what's referred to as dotatate avid which means that the receptors light up due to the tracker, so illustrations of spots that could become cancerous. Then I had my diagnosis. I started on an oral chemotherapy agent called capecitabine and temozolomide, which is a pretty common protocol for neuroendocrine for pancreatic neuroendocrine tumors. It was great. I did it for seven months. It was all oral and at home, so no infusions. It was pretty mild. Some of my symptoms got a little worse, but I didn't really get new symptoms from the chemo. I did it for seven months until my platelet levels dropped too low, and I was well below 100. I think it was close to 75, and my doctor said, “Okay, we have to pull you off chemo. Now the next option is surgery.”

After I got the diagnosis, I believe that knowledge is power for me, so I started to learn as much as I could. This is a photo (see above) of one of the neuroendocrine support groups at a dinner in New York City. I started to go to every support group I could find, and read everything I could find. I've changed a lot since then, but it was a great way for me to learn as much as I could about my condition and people who went through it.

Then I was on a scan schedule of roughly at the time of one every one to two months. They do two scans for me. One of my scans is my abdomen, which they do with contrast, and my chest, which they do without contrast. In this month, which was March, they found a nodule in my lung, and then they thought that I had actually three primary cancers, which would have made me extremely unique, but they couldn't biopsy it because of the location and the size. They recommended, because I had other primaries, that they just remove it, because that way, if it had been malignant, at least it was gone, and if it was benign, at least we knew it. So my doctor could treat me, not having to worry about that. I had lung surgery in April.

After my lung surgery, they told me I was going to have to have a liver resection (surgery) because I came off of the chemo, but I decided that there are things in my life that were more important, and my daughter was graduating college, so I said to them, “I'm not going to do the surgery for three months.” And they said, “Okay, we'll give you some injections to hold you over for three months, and then we'll do the surgery.” I got to go to my daughter's graduation, which was pretty amazing.

One of the themes for me that you'll see a fair amount is that even though I'm living with this crap inside me, I'm still trying to enjoy my life every way I can.

Then, after my daughter graduated, hopefully no one's too squeamish, I had my liver resection. In June of 2023 I asked my surgeon to take pictures of what they took out of me because I was curious. This is him holding the left lobe of my liver, which they had to remove. They removed the left lobe and 17 tumors out of the right lobe and my gallbladder. They were actually supposed to remove my spleen and my pancreas, but I lost too much blood, but in any case, I had the liver resection in June. If anybody wants more tumor pictures, let me know. I'm happy to share them.

“A Guy with Two Cancers Explores Treatments and Life” (Burt Rosen) [#112]

One of the lessons I learned here was really valuable: a lot of people in the cancer world just want to get it out of them as fast as possible. And I have friends who are like this too. I had this liver resection in June, and the surgery itself, they couldn't do everything they wanted, but the liver stuff, which is the most important, they did, and thought they made good progress. But I came out, and as I was in recovery, they realized that nobody capped my IV, so I got a bunch of air in my bloodstream. They had to re-intubate me after I was already in recovery for about a day and a half. They had to scan my brain to make sure I wasn't having a stroke. They had to scan my heart to make sure I wasn't having a heart attack, and it was all because somebody made a mistake. The only reason why I wanted to bring this up is because a lot of people will say to me, “My doctor told me I'm inoperable. I'm so upset.” Or, “They told me the surgery is up to me.” I just want people to remember that the surgery might be able to help cure your specific condition or help with your specific condition, but there are a lot of risks involved in surgery too, that nobody ever thinks about when they're making these decisions. So that's why I bring that up there.

Like I said, I like to enjoy myself and try to live life. This was probably not my smartest move, but three months almost to the day after my liver surgery, I decided to go to an integrative oncology conference in Banff. Banff is an 11 hour drive from Portland, but if I went to Glacier, where I'd never been, it would add only two or three hours. I took a 10 day, 1800 mile solo road trip, including camping and hiking by myself in Glacier three months after my liver surgery. It was probably not the world's smartest move. I'd probably do it again, because I'm not that smart, but it was really important for me to be able to have something to look forward to. I did some Polar Bear Plunge stuff with people.

The reason why I showed this, and hopefully this doesn't cause more stress to people than most of our health, but we had a couple of leaks develop in our ceiling, and it was extremely stressful. You're dealing with your health, and then your house has issues. But one of the things that just always reminded me is, life goes on. Somebody said to me, “Once you get diagnosed with cancer, there should be a deal you never get diagnosed with anything else.” I agree with that across the board. Once you get cancer, you should never have a leak in your ceiling in your house, but that doesn't work. This stuff happens. It does keep me grounded a little bit that I do focus on how life goes on around me.

This year, because, like I said, I'm an idiot, and I like to enjoy myself, on my two year anniversary, I jumped out of an airplane. I had never done it before. I like to scare the crap out of myself. I like to push myself. I feel like, if I'm not doing some kind of stupid things that scare me a little bit, I'm not keeping myself as interested as I could be, etc, etc.

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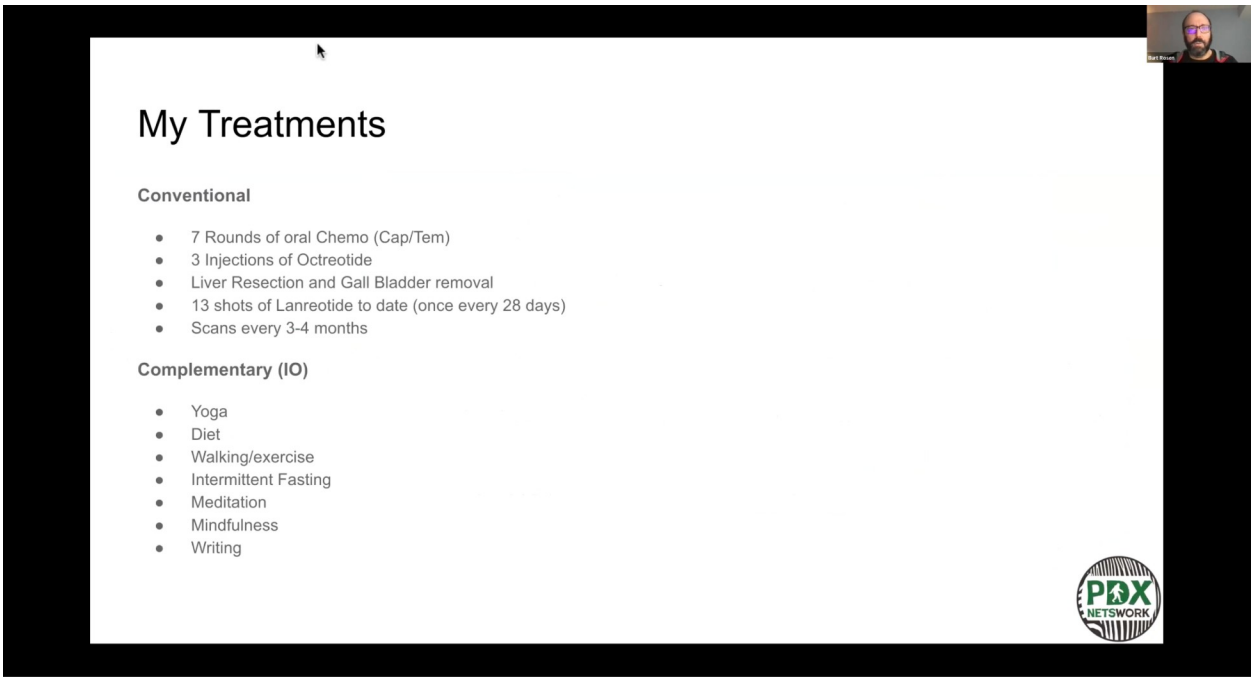
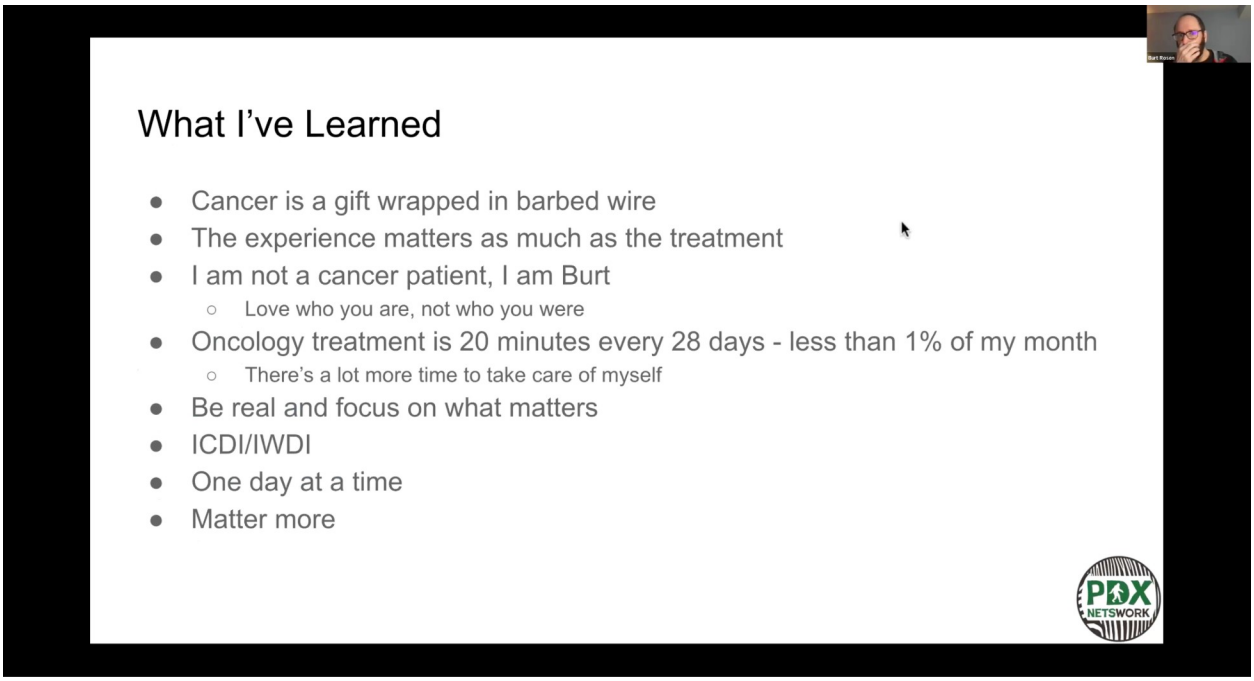


The treatments that I have had. Seven rounds of oral chemo. I get a shot every 28 days. It's called a somatostatin analog. If you need it or want it, just ask me later. I get scanned every three to four months.

One of the things that's also really important to me, as Brad alluded to, is all the integrative oncology things I do. I do yoga. I'm very conscious of my diet. I try to walk and exercise when I can. I intermittent fast every day. You can find science. It's pretty much anything now, but I said to my naturopath once, “What do you think about intermittent fasting?” And she said, “You have a lot of issues going on with your organs. It's probably not a bad idea to give them some more rest.” That makes a ton of sense. So I do stuff like that. I meditate every day. I focus on my mindfulness, and I do a fair amount of writing, which I also find therapeutic. It's always important to me that when somebody says, “What treatments are you going through?”, that I don't just talk about the pills I take or the injections I get.

“A Guy with Two Cancers Explores Treatments and Life” (Burt Rosen) [#112]



These are the things that I've learned.

In a lot of ways for me, cancer has been a gift. I've learned to appreciate life. I've learned to appreciate everything and everybody much more. I figured out the things I don't appreciate, and I've cut them out of my life as well as I can. So I've grown a ton as a human being. So despite the fact that, of course, nobody wants to have cancer, I definitely, personally have had some silver lining coming out of it.

One thing I learned really early when I joined all those support groups is there's a ton of focus in the world on treatment. Like the first support group I went to, it was me who had just been diagnosed within a month or two, and a whole bunch of people who had had the disease for over 15 years. The big discussion was, “What kind of gel do they put on their butt before they get their injection?” I don't even know what the injection is. I don't know how to tell my mom I have cancer. I started to realize that there's this big divide between the living with cancer part and financial and family and relationships and all the other things, and the treatment part. I never want to shortchange the experience part. So it's something I actually focus on a fair amount, and I blog. Some of the integrative stuff is there too.

I will never, ever call myself a cancer patient. I am very focused on who I am, and I happen to have cancer. I'll tell people that a bird who happens to have cancer, like I have eczema or allergies. I don't call myself a cancer patient. I feel like it defines me. I know words are a big topic of conversation in this world, but for me, it's very important that that's how I look at myself.

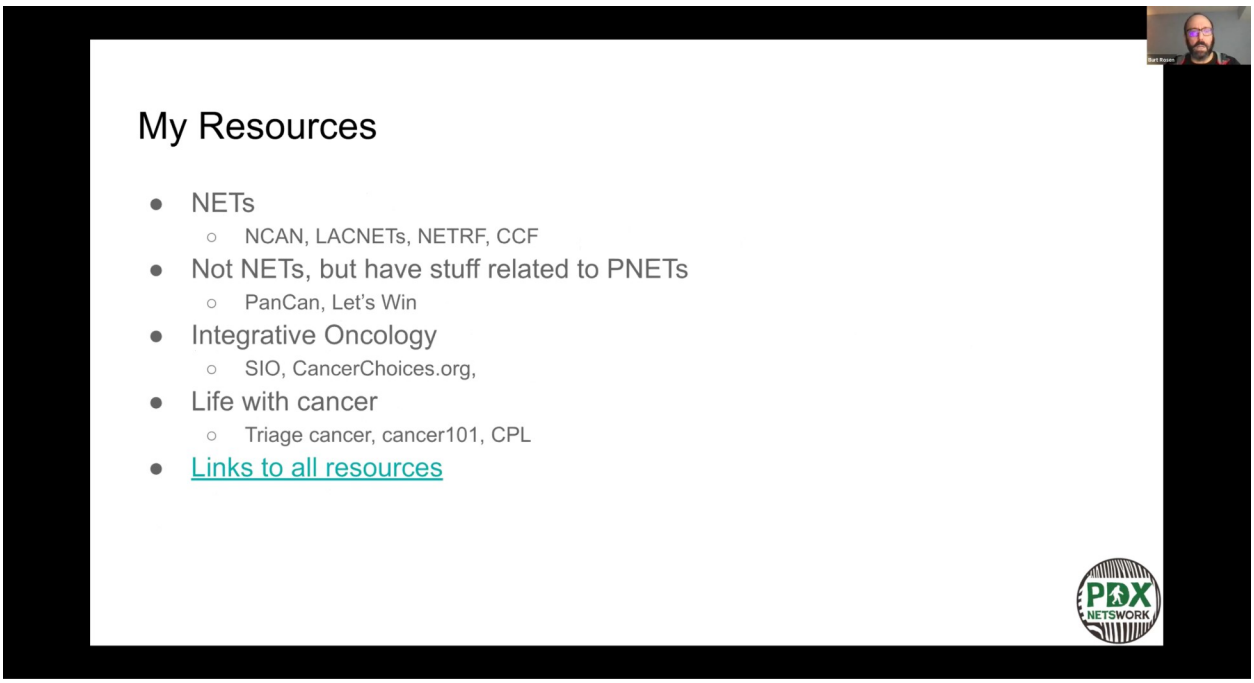
I did this for fun the other day. My treatment is I get an injection once every 28 days. I tried to figure out what percent of my 28 days is that treatment. It's three quarters of a percent of a month that I get an oncology treatment. It also gave me some more perspective on how, like the

other 99.25% of my month, I can be focused on ways to take care of my body and do other different types of things. It was important for me to understand that we put all this emphasis on the medical side of treatment, but living life is a much bigger percentage of your time.

The other things that I would really talk about here, two things quickly. What is my ICDI and IWDI? “ICDI” stands for “I can do it.” And IWDI stands for “I will do it”. I found it’s really, really important for me to plan things for myself that I have to look forward to and to prove to myself that I can do things. Jumping out of an airplane was a good example. I wasn't that nervous, but you're jumping out of an airplane. I did it, and I was so proud of myself that I did it, and I looked up to it. I was excited about doing it. Before I prepped mentally and all the other stuff. Having that thing to look forward to was going to scare me. Memories that I can take coming out of it are really, really important. My Glacier National Park trip was one of those things that I would put in that category.

The last thing I would say quickly is just the “one day at a time” thing. I know it's used a lot in Alcoholics Anonymous, but when I was in the hospital when I initially got diagnosed, we spent a lot of focus on one day at a time. It's very easy to think about, “Well, what's going to happen if my scan in eight months isn't good?” Let's set a goal for today and get through today and not worry about things you can't control in the long term.

Those are just some of the things I've taken away.



There's nothing private. These are some of the resources I have that I use. I blog a lot, so that links to all resources is a link to my resource page on my blog where there's stuff about neuroendocrine tumors, stuff about kidney cancer, integrative oncology, etc, etc.

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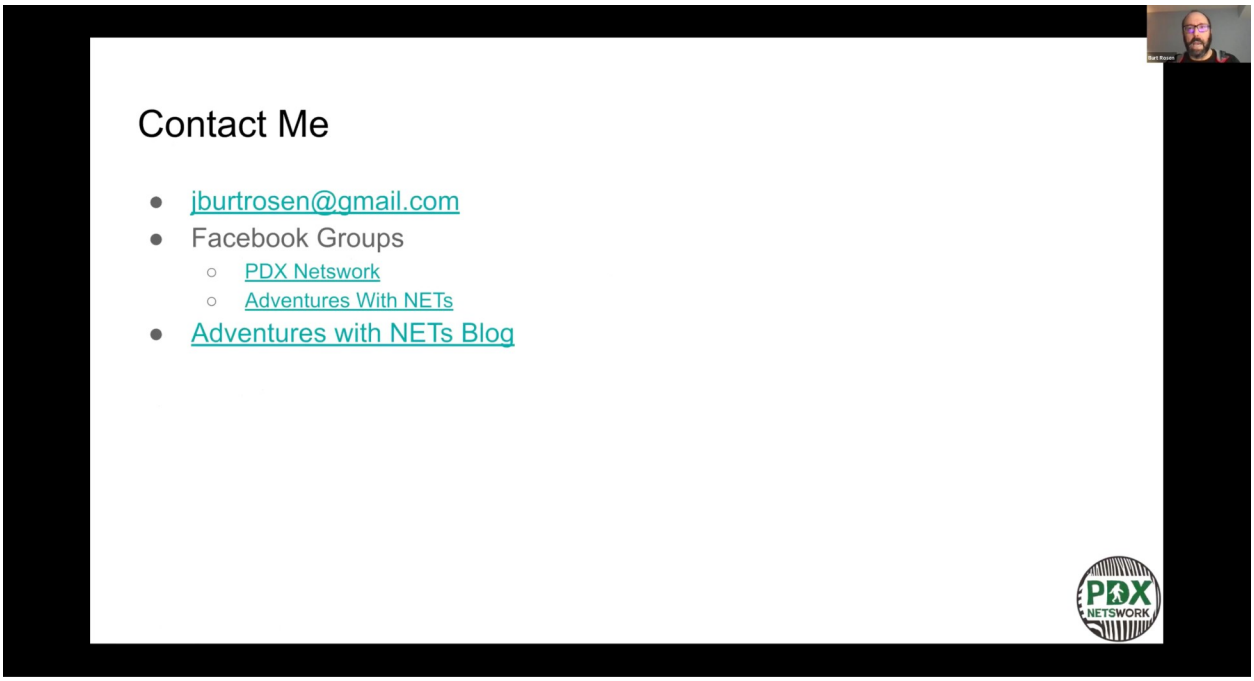


There's my contact info, if anybody wants to get a hold of me. Here's my email.

I run two Facebook groups for people with neuroendocrine tumors, one in Portland, which you can actually see. That's my logo in the bottom right corner. One for people in Portland or connected to the Oregon area who have neuroendocrine tumors. And one that has members from all over the world, which isn't location-specific, but there's a lot of politics in cancer, and I wanted to set up communities for people who didn't want to deal with politics.

Brad Power 18:58
You mentioned the neuroendocrine aspect. Neuroendocrine came up in prostate cancer for our friend Amit Gattani, and Brian also had some indication from his BostonGene research of neuroendocrine. We've had connections with the Neuroendocrine Tumor Research Foundation, which is one of the ones you mentioned.

Brian: Any questions or comments about neuroendocrine that you would have for Burt?

Brian McCloskey 19:41
My cancer is not pathologically displaying neuroendocrine disease, and so I'm not really looking at it that way right now.
Burt, just to help you understand. I had a multiomic analysis done by BostonGene where they looked at my genomics and my transcriptomics, and they did a whole bunch of other stuff. I did have a higher than normal expression of synaptophysin, and so that could be a precursor for neuroendocrine disease. I've been battling this for eight years, but it's not showing up in pathology. That's an interesting finding in and of itself.

How do you relate what you're getting from transcriptomics to what you're seeing in a lab, under the microscope?

I know it's one that you don't want, and I know it's a tough one, but right now, I'm not treating it that way.

Burt Rosen 20:49
That makes sense. It's not a type that a lot of people know anything about. If anybody knows anyone who's dealing with it, or hears of anybody who knows someone who's dealing with it, and you want a connection for them, you can feel free to give anyone my email address. I try talking to people and try to help people every time I can.

Brian, one last thing just to say to you. The good thing about neuroendocrine is people can live a really long time. I know people who've lived over 30 years since diagnosis. Not everyone does, obviously, but some do. It's serious, of course, and by the time they diagnose it, most of them are already stage IV, like mine, but it's fairly indolent, and it grows.

Emma Shtivelman 21:43
If I add the transformation of prostate cancer to neuroendocrine phenotype, it's really bad because it's high grade. It is treated with lanreotide. It’s unusual that he received chemotherapy first. But the disease was very widespread, so there must have been a reason for that, and as Burt mentioned, the grade was probably one or two, in spite of the cancer being highly metastatic. And again, as Burt mentioned, this is completely different. The treatment paradigm is very different for low grade neuroendocrine cancer. I'm also interested.

You mentioned that you had renal clear cell (RCC), and that was simply removed?

Burt Rosen 22:42
They don't want to treat the renal clear cell because to treat the kidney, they have to either do partial or radical nephrectomy, and they're worried if they do that, because of the risks inherent, they could screw up the treatment for the neuroendocrine, which is the more serious. For right now, they're not doing anything. I'm not worried about the neuroendocrine. I have teams of people looking at that. I'm terrified. I go get a scan one day and somebody goes, “Oh, your kidney tumor grew or spread.” That scares me. I see they're not doing anything about it.

Emma Shtivelman 23:16
Because with another patient who had precisely the same two cancers as you do.

Burt Rosen 23:25
There's a syndrome called Von Hippel-Lindau (a rare, inherited disease that causes the growth of tumors and cysts in multiple organs).

Emma Shtivelman 23:30
No, he doesn't have it.

Do you have it?

Burt Rosen 23:33
Okay. I don't have it either.

Emma Shtivelman 23:35
He tested negative too.

Did you have molecular analysis, or mutational analysis?

Burt Rosen 23:42
The hospital I go to is called OHSU in Portland, Oregon, so they did genomic testing on me, and they came back and said I didn't have any mutations that they picked up.

Emma Shtivelman 23:50
That's fairly typical. It's the same situation as for the other patient that I work with.

Burt Rosen 23:56
I would love to get a better genomic analysis than OHSU, like from Tempus, or someone like that. I tried to do it through Tempus, but I didn't have enough tissue.

Emma Shtivelman 24:07
It's also quite often that neuroendocrine tumors do not have a lot of mutations that can be pinpointed as triggers of cancer.

Chris Apfel 24:37
To give you some background, I'm the founder and CEO of Sage Medic. We have a functional profiling platform. We can create microtumors from a patient's biopsy within a day, and then have a test result within seven to 10 days. We are actually the opposite of what organoid research does, or PDX models do. I saw that there is this connection or relationship with PDX, and so the functional profiling very often overcomes the limitation of genomic testing. But that said, it's not that there is one size fits all, and there is just one thing that is the right thing.

I'm dealing with a neuroendocrine cancer patient from the UK at this point who had on the gastrointestinal esophageal junction, a tumor that was surgically removed stage 2 or two years ago, and now we have liver mets that were initially responding to treatment and had now been resistant, and it's actually growing quite fast. We have done our sensitivity testing, but I also wanted to have this complemented with a good genomic and transcriptomic analysis. And that's out of my space.

I'm interested in your view, or the view of this community, for it's a high grade neuroendocrine cancer. It grows at roughly a millimeter a day. That is relatively rapid, and so I would like to have a solution by yesterday.

Burt Rosen 26:32
Is it a neuroendocrine tumor, or is it a neuroendocrine carcinoma?

Chris Apfel 26:36
Carcinoma.

Burt Rosen 26:37
The neuroendocrine carcinomas will be different because they're much more aggressive. The carcinoma is much more aggressive than neuroendocrine tumors. There's neuroendocrine carcinoma, which is generally high grade neuroendocrine tumors.

Chris Apfel 26:56
It has adenomatous (benign) parts as well. He had a gastrectomy (stomach surgery to remove all or part) and hepatectomy (liver surgery to remove all or part).

Burt Rosen 27:03
Tempus is really good. PanCAN, for those who don't know, has a program called “Know your tumor”, where they have a deal with Tempus, and they'll get you genomic sequencing of your tumors for free for pancreatic tumors, whether it's neuroendocrine or the adenocarcinoma. I tried to do it, but there was hospital politics, and there wasn't enough tissue.

Chris Apfel 27:38
How much tissue do they usually need?

Burt Rosen 27:43
I think it's normal. My problem was that my biopsy was done at one hospital, and then I started getting treated at a different hospital. I couldn’t convince the different hospital who treated me to deal with the paperwork of getting Tempus tissue samples. I'm not convinced anybody went out of their way to make it happen. I couldn't tell you how much tissue, but I don't think it's anything out of the ordinary. It's what you would get out of a biopsy. You just need slides.

Tempus wants tissue. Liquid biopsy is a whole other topic.

Rick Davis 28:33
They can do it from blood. There's things happening at OHSU, and we'll talk offline later, but I would like to connect you to someone. I'll send you an email afterwards, and we'll talk.

Burt Rosen 28:50
OK. That'd be great.

Brad Power 28:55
Just going back to the Neuroendocrine Tumor Research Foundation. When we spoke to them they were interested in a video series where they do interviews with patients and talk about

neuroendocrine and pancreatic cancer, neuroendocrine and prostate cancer, etc, just to lay it out. I know they wanted to talk to Brian and Amit for an interview there.

Brian, did that die out?

Brian McCloskey 29:31
Yes. I've done a number of them. We did. I don't think I ever saw the finished product, though, so I'm not sure if it was ever published.

Brad Power 29:41
We should follow up with them.

Burt Rosen 29:44
Is this somebody I introduce you to? Is it Jessica Thomas?

Brad Power 29:48
Our former community member, Amit Gattani, was very much focused on his neuroendocrine cancer. He was donating to them, and then we connected with them and talked about collaboration.

I should have mentioned before how I got to know you through the Society for Participatory Medicine, where you were president.

Burt Rosen
Yes. a while ago, a while ago.

Brad Power
Could you inform everyone here what the Society for Participatory Medicine is about?

Burt Rosen 30:30
It started a while ago. I don't know if people have ever heard of Dave deBronkart. He also goes by “E-patient Dave.” He's probably one of the first patient advocates. Certainly one of the first e-patient advocates. Amazingly dynamic. Amazing energy. I worked at a company called Health Spark, and we did pricing transparency for health plans. We would ingest claims data and then show members your procedure could cost x. We did some client summits, and we had Dave deBronkart and Danny Sands, who are co founders of the Society for Participatory Medicine come speak. They're all about bringing an equal voice from the patient side and the caregiver side into healthcare. It’s more about promoting how doctors should work with their patients and listen to their patients and a lot of that kind of stuff. It's been a while since I've been there, so I'm not really sure about all the stuff they're doing now. I focus. I do a lot of volunteering, both in the neuroendocrine world now and in the integrative oncology world. I do a lot with Society for Integrative Oncology.

Rick Davis 31:50

Well, Emma kind of said what I wanted to say, which is that neuroendocrine is a very big deal in prostate cancer, because about 20% of men with advanced prostate cancer find that their cancer morphs to either a small cell, neuroendocrine-like tumor. We deal with it a lot. We spent a lot of time talking about it this past Monday, if anybody wants to listen to the recording. We try to identify it as early as possible. The big issue in prostate cancer is identifying and there's some really great research out there right now based on the expression of a protein called DLL3 (Delta-like ligand 3, an inhibitory notch ligand that is highly expressed in small cell lung cancer and other neuroendocrine tumors but minimally expressed in normal tissues). I suspect these are neuroendocrine carcinomas and not neuroendocrine tumors, but I don't actually know. I'd have to go back and look at the DLL3 research and see what it is into.

DLL3 is being examined in the context of many neuroendocrine cancer tumors, because one of the issues we've had is that there isn't sufficient product. People that we've referred to Misha Beltran at Dana Farber and Rahul Agarwal at UCSF haven't been able to get the test because there hasn't been enough product. It's really for those men who do have advanced cancer. They've really got to be looking all the time to make sure that their cancer is not morphing. One of the ways to do that is to compare a PSMA scan, which is very comparable, to the dotatate scan that Burt was talking about, to an FDG scan, because then you can see if your tumors are all expressing PSMA, or if some of them are not. Neuroendocrine small cell tumors don't express PSMA, so they can change into a situation where they were, but they're not now, and if you see a difference between those two scans, you know you've got a problem. The key, as we understand it – we work closely with UCSF, and especially their BRCA Research Institute, where they deal quite a bit with NET – is if you can find the NET early, you can treat it. For the NET carcinomas, the preferred treatment is a platen, but I didn't see you got a platen.

We're talking about a different type of tumor to your NET, but if you can catch it early, you can treat it. Most of the GU (gastrourinary) medical oncologists don't look for it, and they don't catch it early, and that is a huge issue, because that's why we lost our dear Herb Geller, whose cancer morphed, and his docs at NIH and Hopkins just didn't catch it, and they should have.

Roger Royse 35:57
I'm curious about some of the other lifestyle choice changes that you made, because I don't think that's less important. It's more fun to talk about pharmacology. But it's an important part of some of the other changes, if there were any. Were there?

Burt Rosen 36:26
I volunteer a lot in the integrative oncology space. I'm very active with the Society for Integrative Oncology. I know a bunch of people in other integrative oncology organizations. I have to say this first: we are all 100% different, and we react to things differently. We experience things differently. I am very, very lucky. Despite the fact that I have two primary cancers, one that's advanced, I am very lightly symptomatic, so I pretty much do what I want. I try to be as empathetic as I can, because a lot of people can't. But I always want to say that, because I don't want to say things and say, “Oh, wow! Look how great I'm doing.” Because of all this stuff. I'm just a different person. Maybe that was a babble.

To answer your question: one of the things I learned early was when I left my oncologist office, it's like, “Okay, you're going to give me chemo, radiation, surgery or immunotherapy, or maybe a targeted therapy. But how do I take care of Burt? Everything you're going to do for me is designed to kill the bad stuff inside me. Nothing is designed to take care of the good stuff inside me or help my body deal with the bad stuff you're killing.” That's how I got into the integrative oncology world.

I'm not hardcore by any means. This is an easy example. Every meal I eat now I try to make sure I have vegetables in the meal. I love junk food, but I try to limit myself a lot on junk food. If I can eat healthier junk food, I try to eat healthier junk food. If I can be outside, I go outside. If I can take a walk, if the fatigue isn't too bad, if I can go take a walk, I'll go take a walk. Yoga I was doing regularly until the studio I go to change stuff, so I have to get back into that. But yoga, for me, made me feel better every time I did it. Meditation has really helped a lot, because it's really helped me stay grounded, and it's let me not go into an anxious state. It's taught me so much. Like, if I go take a walk now, because I've been meditating for a while, I'll start to be conscious of every foot placement, or if I'm in a crappy mood, I'll go take a walk. I'll start asking myself, “Why am I in a crappy mood?” And I'll start talking to myself to figure some of this stuff out. I go to therapy once a week. I do some supplement stuff, mostly vitamins. I do some iron supplements because my ferritin is low and things like that too.

I would do all the IO treatments I could do. I'm on Medicare now, and Medicare, which is idiotic, doesn't cover acupuncture for anything other than chronic lower back pain. But I was doing acupuncture every two weeks before I went on Medicare. So I'm a big believer in all of this stuff.

The biggest points for me on the IO side are that they can help my mental health too. The stronger I am mentally, the stronger I feel physically, and the more I feel like I can overcome everything. There's no harm. Because I meditate, there's no possibility of doing any damage to myself. So if it can help me, why not take the risk?

The hardest question for me that I get is people say, “Oh, you just started chemo. What's it doing for you?” And it's like, “Well, I started chemo. I changed my diet. I'm sleeping better. The weather changed.” There are all these different variables that I've also learned that there is no one-to-one. Yes: chemo might have shrunk my tumors, but it probably was more successful shrinking my tumors because I was eating better. I was eating more fiber, more vegetables. My head was in a better place. I'll always look into that stuff.

There's a great site called cancerchoices.org. It is all about integrative oncology, but it's written towards patients, and they'll go through and they'll do reviews of a keto diet, and they'll cite their scientific sources, and they'll grade it in a couple of different categories. I've used them a lot because it's a really good resource for figuring out which of these things to try.

Roger Royse 40:57

You were diagnosed the same month I was, and I can tell you've gone through a lot more than I did, but you know, even now, two years later, I've hit the point where I am so tired of being a patient. I would like to be able to think about something else for a change. How are you holding up? Have you kind of reached that point, and are you able to do that?

Burt Rosen 41:24
I get a shot once every 28 days, and I have to go to the hospital to get the shot. I hate feeling like a patient. To me, feeling like a patient means I'm not independent, I'm not self sufficient. It triggers me in a lot of ways. One day a month, on the 28th day, I feel like a patient, because I'm going to the hospital, I'm getting a wristband, I have to have a nurse do the shot. Especially, it's an idiotically $30,000 shot. It's it. That's hard. The rest of the time I really focus on what I said before. Like, I'm not a cancer patient. I'm Burt. I have cancer, neuroendocrine tumors. Somebody told me when I was diagnosed to think of it as a chronic illness. So that's helped, because I've lived through chronic illness with chronic Lyme disease too. The more I can be myself and do things that keep my mind engaged, the better I feel.

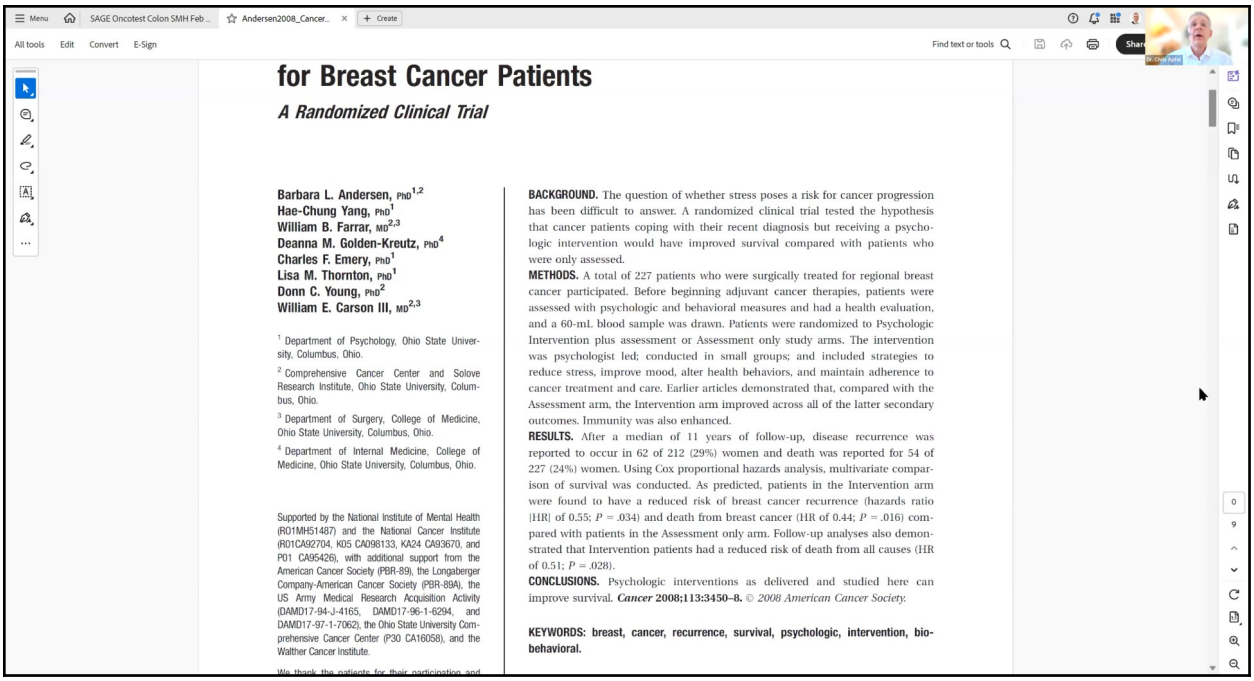
Like I'm trying to get a full time job right now. I am convinced that even though I'm not sure yet how that works with my fatigue and upcoming surgeries and all the other type of stuff, I'm convinced that's going to help my brain so much.

I honestly try to forget about it as much as I can.

Roger Royse 42:46
I hear that. Thank you.

Chris Apfel 42:57
I wanted to comment on the integrative oncology stuff, because I have looked in the last couple of months a little bit more into this. There is a very interesting talk from Lorenzo Cohen from MD Anderson Cancer Center. See https://www.youtube.com/watch?v=QXzY4ox7kTM. He also cites a number of benefits for prostate cancer patients. I've recently looked into the benefit for breast cancer because somebody else was asking me in that regard.

“A Guy with Two Cancers Explores Treatments and Life” (Burt Rosen) [#112]



for Breast Cancer Patients

A Randomized Clinical Trial

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We thank the patients for their participation and

BACKGROUND. The question of whether stress poses a risk for cancer progression has been difficult to answer. A randomized clinical trial tested the hypothesis that cancer patients coping with their recent diagnosis but receiving a psychologic intervention would have improved survival compared with patients who were only assessed.

METHODS. A total of 227 patients who were surgically treated for regional breast cancer participated. Before beginning adjuvant cancer therapies, patients were assessed with psychologic and behavioral measures and had a health evaluation, and a 60-mL blood sample was drawn. Patients were randomized to Psychologic Intervention plus assessment or Assessment only study arms. The intervention was psychologist led; conducted in small groups; and included strategies to reduce stress, improve mood, alter health behaviors, and maintain adherence to cancer treatment and care. Earlier articles demonstrated that, compared with the Assessment arm, the Intervention arm improved across all of the latter secondary outcomes. Immunity was also enhanced.

RESULTS. After a median of 11 years of follow-up, disease recurrence was reported to occur in 62 of 212 (29%) women and death was reported for 54 of 227 (24%) women. Using Cox proportional hazards analysis, multivariate comparison of survival was conducted. As predicted, patients in the Intervention arm were found to have a reduced risk of breast cancer recurrence (hazards ratio [HR] of 0.55; $P = .034$) and death from breast cancer (HR of 0.44; $P = .016$) compared with patients in the Assessment only arm. Follow-up analyses also demonstrated that Intervention patients had a reduced risk of death from all causes (HR of 0.51; $P = .028$).

CONCLUSIONS. Psychologic interventions as delivered and studied here can improve survival. ***Cancer*** **2008;113:3450–8.** © *2008 American Cancer Society.*

KEYWORDS: breast, cancer, recurrence, survival, psychologic, intervention, biobehavioral.

There was a very exciting paper, and it says psychological intervention improves survival for breast cancer patients, and it's not only psychological intervention, it is a lot of nutritional and physical activity, exercise and lifestyle changes. It's quite an impressive paper.

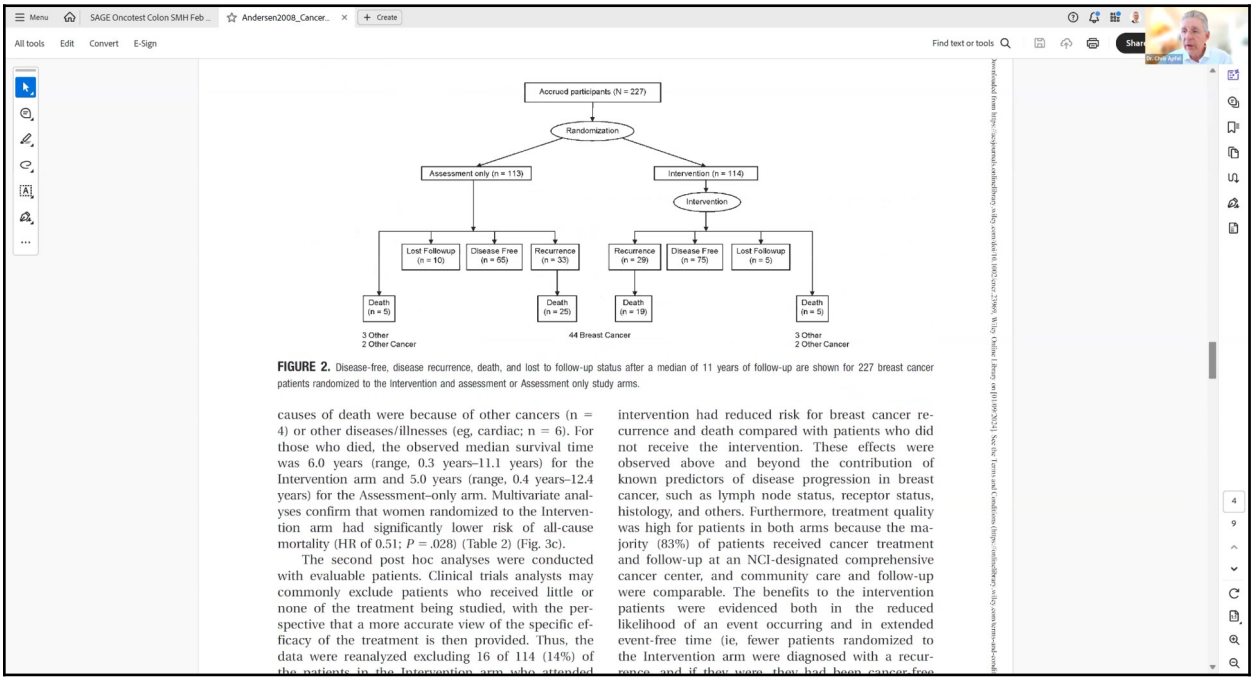
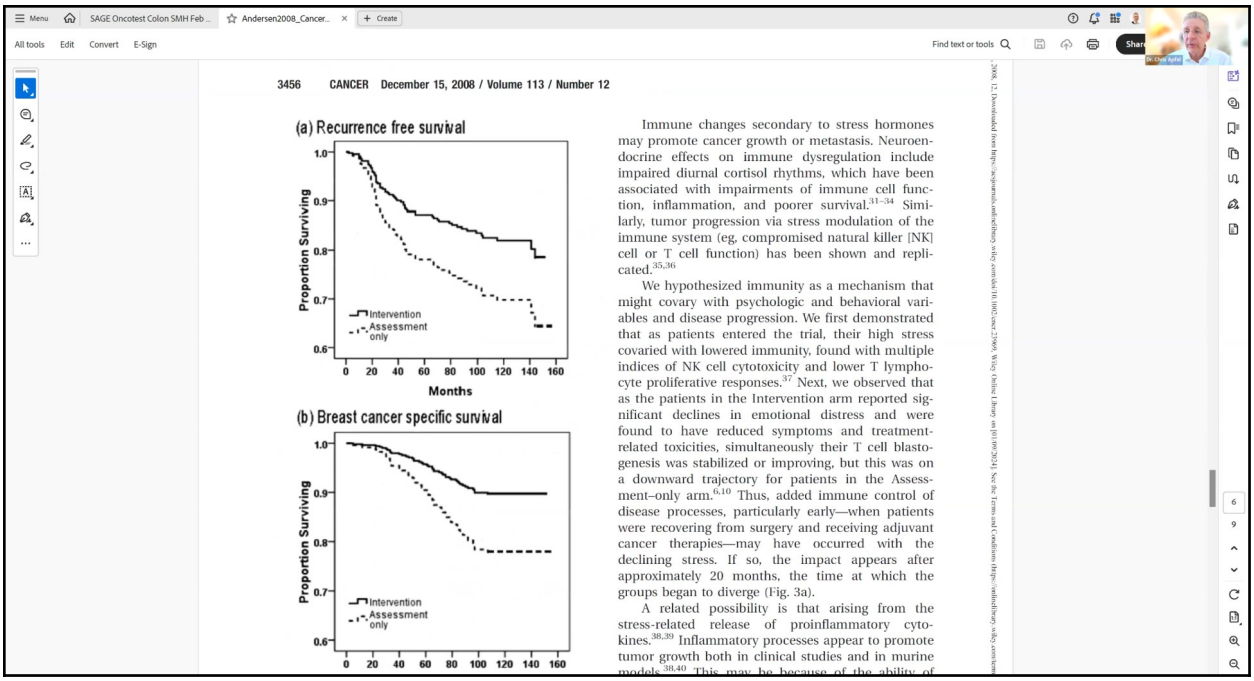


FIGURE 2. Disease-free, disease recurrence, death, and lost to follow-up status after a median of 11 years of follow-up are shown for 227 breast cancer patients randomized to the Intervention and assessment or Assessment only study arms.

causes of death were because of other cancers (n = 4) or other diseases/illnesses (eg, cardiac; n = 6). For those who died, the observed median survival time was 6.0 years (range, 0.3 years–11.1 years) for the Intervention arm and 5.0 years (range, 0.4 years–12.4 years) for the Assessment–only arm. Multivariate analyses confirm that women randomized to the Intervention arm had significantly lower risk of all-cause mortality (HR of 0.51; $P = .028$) (Table 2) (Fig. 3c).

The second post hoc analyses were conducted with evaluable patients. Clinical trials analysts may commonly exclude patients who received little or none of the treatment being studied, with the perspective that a more accurate view of the specific efficacy of the treatment is then provided. Thus, the data were reanalyzed excluding 16 of 114 (14%) of the patients in the Intervention arm who attended

intervention had reduced risk for breast cancer recurrence and death compared with patients who did not receive the intervention. These effects were observed above and beyond the contribution of known predictors of disease progression in breast cancer, such as lymph node status, receptor status, histology, and others. Furthermore, treatment quality was high for patients in both arms because the majority (83%) of patients received cancer treatment and follow-up at an NCI-designated comprehensive cancer center, and community care and follow-up were comparable. The benefits to the intervention patients were evidenced both in the reduced likelihood of an event occurring and in extended event-free time (ie, fewer patients randomized to the Intervention arm were diagnosed with a recurrence, and if they were, they had been cancer-free



If you look at the Kaplan Meier curves on the outcomes here, if this were a drug that could be sold with IP, this would be a blockbuster, billion dollar drug. This is basically the effect that you get from an immuno-oncology drug if it works on a selected population. This one is broadly applicable.

I just wanted to comment on that and allude to that, and anybody who's interested can then take a look at that.

Burt Rosen 44:26
I don't know if anybody lives in California, but the Society for Integrative Oncology has its annual conference this year in October in Irvine, California. I'll be there. I went last year. That's why I went to Glacier, because I ultimately went to Banff for the integrative oncology conference, and this just might be my own passion, but it blew me away. To your point, no one who's doing research in the integrative oncology world is doing their research to make billions. It doesn't exist. You go see research that's really focused on, “How do we help people?” No one's making a lot of money off it.

I saw this one research presentation that was done where people studied the effect of playing golf on men with advanced prostate cancer. Not surprisingly, they found out if golf is your passion, then you play golf. It's going to make you feel better. But just like going to a conference where people are asking questions about that.

Or there was another study that Lorenzo Cohen was a part of all about hypnotherapy on women who develop pain from breast cancer treatments. It was just such an interesting way to think about the world that goes so much in such different directions than the Western oncology world. It's a soapbox for me, but it's been really interesting, and I probably learned more and thought

differently because of being involved there, certainly than for many of my Western treatments. What are the NCCN guidelines? Great, we tried this box. Let's go to this box. Integrative oncology can be a whole bunch of different stuff.

Rick Davis 46:13
Integrative oncology is part of the NCCN guidelines now, and many of the NCCN comprehensive cancer centers do have integrative groups, like Osher, for example, at UCSF. OHSU has one now. What's important is that most of the treatments they offer are free to cancer patients at that hospital. But as you probably know, you mentioned the cost of acupuncture, but you can probably get free acupuncture at the OHSU integrative center.

Burt Rosen 46:58
I’ve tried. OHSU, much to my chagrin, and this is one of my personal objectives, doesn't have an integrative oncology center. They have some services, but they're all disparate and loosely organized, and they're the one major health system on the west coast without an integrative oncology center. Medicare states that you can only get acupuncture if you're prescribed with chronic lower back pain. So I got my oncologist to say that one of my symptoms is chronic lower back pain. And then, OHSU, they have a naturopath who does the acupuncture. So she was about to do it, and then she found out that Medicare wouldn't approve a naturopath performing acupuncture. Medicare only reimburses for MDs who perform acupuncture. I'm sure most people can imagine, there's not a lot of those in the world. The MDs at OHSU who perform acupuncture, one is an anesthesiologist and one is a neurologist. They both have full-time jobs. Nothing to do with acupuncture.

Rick Davis 47:54
I need to connect you with somebody. I will do it right after this, because that is really, really surprising. With the money that OHSU has through Knight, I just can't believe that they don't offer that to their patients. That's really sad.

Burt Rosen 48:13
You'd be surprised. I'm a big pain in the ass to them. I'm an advocate within OHSU. I've met a ton of people there. I reach out to them all the time about things like this. They have amazing people there. The institution itself is extremely bureaucratic and, yes, political and siloed. At the provider level, maybe, but their hands are tied.

Rick Davis 48:43
For example, at UCSF, MD Anderson, MSKCC, Northwestern, if you need this type of treatment, it's accessible to you through their integrative centers.

Burt Rosen 49:04
There are also organizations who will do it for lower income people. I am about to get a second opinion from MSK in a couple of weeks, which I'm excited about. I know the integrative people there. They have a great integrative oncology group.

Chad Magnussen 49:40
From what I've seen, at Mayo, and the major medical institutions, in integrative oncology, they need to have so much data. If you go to an integrative hospital that's not a major institution, it’s hard for them.

Brad Power 50:28
I just wanted to underline something that Burt said before about Cancer Choices: in addition to the questions they'll answer about various treatment options, they'll also cite the evidence which you can bring as ammunition to a doctor to try and persuade them.

Burt Rosen 50:55
They're good with citing sources for sure. The Society for Integrative Oncology website is integrativeonc.org. They have a bunch of stuff posted there too. One of the things that's really helpful on the integrative side is that SIO and ASCO do joint guideline development. There have been joint guidelines issued on anxiety and depression and pain and fatigue. Because ASCO and SiO do them together, there's no question on the credibility. There shouldn't be a question anyway, because SIO only does science-backed research, or they only support science-backed research, but the ASCO guidelines.

One of the things that's hard for me with SIO, is that their marketing is horrible. We should all know the ASCO guidelines like, if they're non pharmacological treatments that have been proven for depression and stress and anxiety, it's like, “Who wouldn't want to try that before they pop another pill?” Sorry, that's my own bias.

Brad Power 52:01
We had a session with Donald Abrams, who works on that SIO ASCO guidelines.

Burt Rosen 52:09
He's great. He has my favorite quote, “Cancer is the weed. We need to tend to the garden.”

Rick Davis 52:17
He runs the Osher Center at UCSF.

Brad Power 52:26
Burt, any parting words of wisdom?

Burt Rosen 52:34
No parting words of wisdom.

If anybody wants to reach out and talk about anything, just feel free to let me know.

One of the things that I've also learned about myself is talking to other people and then helping other people really matters. So if I can do anything ever, let me know. Like I said, I'm also a marketing guy, so I give marketing advice or health stuff.

“A Guy with Two Cancers Explores Treatments and Life” (Burt Rosen) [#112]

“A Guy with Two Cancers Explores Treatments and Life” (Burt Rosen) [#112]

CHAT COMMENTS

00:13:55 Rick Davis: rick davis rd@ancan.org
00:21:03 Rick Davis: dotatate - think PSMA for NEC timors. Telix is one of the suppliers as for PSMA scans
00:32:31 Rick Davis: Burt and others - consider our Men Speaking Freely Group . Talk about anything BUT treatment. Next meeting Thursday, Sept 5 8.00 pm Eastern in the https://www.gotomeet.me/AnswerCancer. FREE & DROP IN. https://ancan.org/speaking-freely/
00:34:24 Dr. Chris Apfel: What kind of genomics/transcriptomic analysis/company would you think might be best for NEC patients?
00:39:07 Rick Davis: OHSU used to be very solid. They did all the genomic testing for the Prostate Cancer Dream Team West
00:41:22 Rick Davis: Could they not use blood??
00:44:57 Rick Davis: AnCan's buddy/Advisory Board member John Novack is heavily involved with Society of Participatory Medicine
00:52:29 Dr. Chris Apfel: There is an interesting talk about integrative oncology from Dr. Cohen at MD Anderson. Dr. Lorenzo Cohen: Integrative Medicine, Cancer Prevention, and Lifestyle (youtube.com)
00:54:14 Rick Davis: Acupuncture should be free for you, Burt, at https://www.ohsu.edu/primary-care/integrative-medicine
00:54:27 Dr. Chris Apfel: In the second half he cites quite a number of excellent studies showing the benefit for life style changes for prostate and breast cancer. What I found very intriguing is this paper and it's not only about psychological interventions but overall lifestyle changes