“How to Survive the Health System and Get Good Care” (Philip Leming, MD, and Jillian Hunt, AOCNP) [#150]

Brad Power
July 2, 2025

“Patients are going to have better outcomes if they get engaged in their care, and they are not passive participants. They've got to challenge, they've got to ask questions, and we've got to figure out a way. All of those things are absolutely true. But the reality is the uneducated, motivated patient who doesn't know what questions to ask. Those aren't the patients that are seeking support. Those aren't the patients that are engaging with additional services. Those are the patients that are being spoon-fed whatever answer the doc is giving them, and they're not questioning that at all. So we have to figure out how to engage the patients and how to empower them to be part of their own journey and not just take everything at face value.” – Jill Hunt, AOCNP

“We really try in this role to empower patients; to make sure, number one, you know who's driving your bus, but number two, you make sure that all of the people that are on the seat in your bus are communicating with the bus driver.” – Philip Leming, MD

“If I can't do better than the guidelines, I need to not practice. I separate out oncologists into those oncologists that do nothing but quote guidelines, versus those that think beyond the guidelines. Because anything that's on a guideline is automatically somewhat out-of-date. Yes, you want to be aware of guidelines, but if you're working at the level that you should, your level of thinking should be far beyond any guideline, knowing that whatever you think is standard of care, there are researchers and people that are five to ten years ahead of that. Once you understand that, you're forever tortured because you can't just be happy with a patient getting something on the guideline. They're important, but they're what the consensus thinks. The guideline things aren't necessarily the best for that singular patient. If you work on the philosophy like we do, which is, if you can walk in the door, you're curable until proven otherwise in our eyes. You don't want to be taken care of by a physician who doesn't have that mindset. Because anybody that thinks that they know everything, then they're wrong. The research world and that science level is far beyond what's accessible on a guideline or a day-to-day practice. It doesn't mean you can always get access to all that, but your horizon should be at that level, not at a flat level guideline.” – Philip Leming, MD

Meeting Summary

Navigating the dysfunction of our current healthcare system is challenging. A squamous cell carcinoma patient recently said, "We don't know who is in charge of taking care of us." You need to grab one of your doctors and tell them to be in charge or find someone who will. It is disturbing how many patients have never been examined. You need a comprehensive review of all your medical history and develop an understanding of the core structure of your issues with your physician, e.g., your psycho-social issues. Every treatment you get is like another illness. You may have an issue that is four times your cancer risk. The basics are not being done correctly. Physicians are being asked to see too many patients with too little time, so they send patients to specialists. The economics of a medical education drive physicians to pay off their loans, e.g., leaving training sooner to start working.

Philip Leming, MD, Medical Director, Cincinnati Cancer Advisors, and Jillian Hunt, AOCNP, are uniquely qualified to lead a conversation about healthcare system dysfunctions and the approaches that cancer patients and caregivers should take to address them.

Dr. Leming’s extensive educational credentials include receiving two Oswald undergraduate research awards at The University of Kentucky , Graduating from The University of Louisville Medical School with High Honors and a member of AOA honor society and Phi Kappa Phi medical fraternity. He completed an internal medicine residency at The University of Cincinnati and was selected as Chief Medical resident. He also completed a fellowship in Hematology and Oncology at UC. He was then chosen to attend The National Cancer Institute, NIH which at the time was “the West Point of Oncology” where he spent two years in Cancer Research. He then returned to Cincinnati where he founded The Christ Hospital Cancer Research Department and remained the director until 2019. In addition he was a member of an elite oncology group providing hematology/oncology care to patients in Greater Cincinnati. In 2019 he was offered an opportunity to establish an independent oncology second opinion program supported by The Cincinnati Cancer Foundation headed by Dr. Bill Barrett. The program has grown from Dr. Leming and Jillian Hunt CNP to 20 members and now a second branch in Naples, Florida. Dr. Leming remains as the Medical Director.

Jillian Hunt, AOCNP, is an oncology nurse practitioner who has worked with Dr. Leming for the past 21 years. Jillian completed her undergraduate studies at the University of Cincinnati where she obtained her degree as a registered nurse. Her early career began at Cincinnati Children's Hospital in pediatric hematology/oncology/bone marrow transplant. In 2004 Jillian shifted her career to the adult setting working as an infusion nurse with Dr. Leming in private practice. As her passion for oncology grew she continued her education at Indiana Wesleyan University and obtained her Master of Science in Nursing and began her career as a Nurse Practitioner in 2011 continuing to work alongside Dr. Leming. In 2019 Jillian and Dr. Leming started the Cincinnati Cancer Advisors. This program aimed to “fill in the gaps” of cancer care, started initially as an independent second opinion program and has grown into a multi level approach to cancer care in both the Cincinnati and now Naples, Florida areas. Jillian serves as the Executive Director of Clinical Operations at both locations and continues to see patients with Dr. Leming.

What are the potential downsides of being a passive recipient of treatment?

- Incomplete understanding of your diagnosis and treatment options
- Potential missed opportunities for better care or alternative treatments
- Risk of receiving fragmented care without proper communication between specialists
- Possible medication errors or inappropriate treatments
- Higher likelihood of experiencing unnecessary procedures or tests
- Increased anxiety from not fully comprehending your medical situation

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What are the potential upsides of being an active participant in your cancer care?

- Better outcomes
- Longer survival rates
- More personalized care that considers your whole health, not just the cancer
- Better understanding of your diagnosis and treatment options; empowerment to make informed decisions about your treatment; ability to ask critical questions and challenge medical recommendations
- Reduced fear and anxiety through comprehensive education
- Ensuring proper communication between different healthcare providers

What are common dysfunctions you may see in your cancer care journey?

- **Fragmented communication**: your multiple doctors (oncologists, primary care, other specialists) not communicating with each other about your treatment, unsure who is "quarterbacking" your overall care
- **Inadequate examinations**: Doctors often document exams without actually performing thorough physical examinations, and rely more on technology and scans instead of basic medical practices.
- **Time constraints**: Your doctor has limited time with you due to system pressures and is forced to focus on documentation for billing rather than your comprehensive care, leaving them unable to provide detailed explanations about your diagnosis and treatment.
- **Referral problems**: You are shuttled between multiple specialists working in "tunnel vision" without understanding your complete situation.
- **Treatment decision challenges**: Potential conflicts of interest, such as academic centers recommending specific clinical trials that serve their institutional interests, while you have limited understanding of your treatment options.

How can you effectively advocate for yourself and ensure you receive the best possible care and outcomes within the fragmented healthcare system?

- **Ask questions**: Be proactive and don't hesitate to ask detailed questions about your diagnosis, treatment, and potential side effects; ask about the rationale behind treatments, potential outcomes, and how different aspects of your care interconnect; do not accept surface-level explanations; challenge your doctors when something doesn't seem right; do not be afraid to "be a pain" by persistently asking questions and seeking clarity.
- **Get second opinions**: Consider consulting independent experts who can provide comprehensive explanations and help you understand your specific situation.
- **Bring family members to appointments**: Having support can help you process information and remember details.
- **Educate yourself**: Try to learn as much about your diagnosis and testing and treatment plan as possible, so you can be an informed and active participant in your care.
- **Get a good doctor to take charge**: Find a “quarterback”; seek doctors who take time to explain things in common sense terms and help reduce your fear and anxiety.

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- **Ensure all your doctors are communicating with each other**: ask your doctor to call the referring physician, not just make an electronic request
- **Verify basic medical practices are being followed**: like accurate weight measurements

When should you get a second opinion?

- When first diagnosed with cancer, especially with a rare or complex type
- If you're unsure about your treatment plan or have doubts about the recommended approach
- When facing advanced or metastatic cancer
- If you're not responding to current treatment
- Before starting a major treatment like surgery or aggressive chemotherapy
- When considering clinical trials or experimental treatments
- If you feel your current doctor isn't addressing all your concerns or providing comprehensive care

How can you find and access a second opinion?

- If you’re in the right state, you can contact Cincinnati Cancer Advisors, which offers free second opinions sponsored by philanthropy, or use online resources like Cancer Commons which is also free.
- Check with local cancer centers or academic medical centers that offer second opinion services
- Ask your current oncologist for a referral to another specialist
- Verify the credentials and expertise of the physician providing the second opinion
- Gather all your medical records, test results, and imaging studies to share with the second opinion doctor.
- Check your insurance coverage and potential out-of-pocket costs

How can you learn more about navigating the health system to get good care?

- Go to the Cincinnati Cancer Advisors website for information about their services
- Contact Phil Leming at philip.leming@cincinnaticanceradvisors.org or Jill Hunt at jillian.hunt@cincinnaticanceradvisors.org
- See previous Cancer Patient Lab discussions on navigating cancer care:
    - “Empowering Cancer Patients: Navigating the Complexities of Diagnosis and Care” (Ari Akerstein and Brad Power) [#130]
    - “A Rogue Cancer Patient Gets Better Outcomes” (Ari Akerstein) [#109]
    - “Getting Access to Your Cancer Treatment" (Chris Beardmore) [#73]
    - “Making Decisions in the Complexity of Healthcare” (Michael Liebman, PhD) [#144]
    - “Opening up Access to Cancer Data for Patients" (Frank Nothaft) [#76]

For the video recording of this conversation, please see here.

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Meeting Notes

KEYWORDS

Cancer Patient Lab, second opinions, Cincinnati Cancer Advisors, Naples Cancer Advisors, philanthropy, healthcare system, clinical research, malignant melanoma, patient education, comprehensive care, communication, medical oncology, patient engagement, clinical trials.

SPEAKERS

Phil Leming (51%), Jill Hunt (23%), Chris Apfel (8%), Brad Power (6%), Rick Davis (6%), Lori Mckitrick (3%), Helen (3%)

CHAT CONTRIBUTORS

Rick Davis, Chris Apfel, Russ Hollyer, Allen Morris, Helen, Lori Mckitrick, Alexander Lalov, Jill Hunt

SUMMARY

Cincinnati Cancer Advisors is a free second opinion service for cancer patients. Phil Leming, a medical oncologist, and Jill Hunt, with 22 years of collaboration, established the program five years ago to address healthcare system deficiencies. They emphasized the importance of comprehensive patient care, thorough examinations, and effective communication among doctors. The program, now with 20 team members, includes specialists like Dr. Abdul Jazieh and Robin Zon. They highlighted issues like fragmented care, inadequate patient examinations, and the need for patients to be proactive and informed. They also addressed the challenges of generic chemotherapy drugs and the importance of patient engagement in their treatment.

OUTLINE

Introduction and Background of Cincinnati Cancer Advisors

- Jill Hunt and Phil Leming are from Cincinnati Cancer Advisors and Naples Cancer Advisors.
- Their services are free, sponsored by philanthropy. They provide second opinions in person.
- Phil Leming shares is a medical oncologist, trained at the National Cancer Institute, and has experience in private practice and clinical research.
- Phil Leming and Jill Hunt decided to establish an independent non-denominational second opinion oncology program.
- The program was initiated by Dr. Bill Barrett and started with minimal resources, including no phones, computers, or electronic medical records.
- Their initial approach is spending two hours with each patient to answer all their questions and educate them on their diagnosis and treatment options.
- The program has evolved to fill gaps in cancer patient care, especially during the pandemic, allowing families to accompany patients to appointments.

Growth and Team Expansion

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- The program has expanded, now having about 20 people, including medical partners like Dr. Abdul Jazieh and Robin Zon.
- The team includes specialists in various cancer types, such as breast cancer and gynecologic tumors, and has a comprehensive approach to patient care.
- They emphasize understanding the patient as a whole person before addressing their cancer, which is the philosophy behind their comprehensive internal medicine assessments.
- The program has become a training ground for patients and families to learn how to navigate the healthcare system effectively.

Challenges in the Healthcare System

- The healthcare system is fragmented, with patients seeing multiple doctors without comprehensive care.
- Communication among doctors is important to avoid negative consequences for patients, such as drug interactions and inappropriate treatments.
- There are examples of patients receiving inadequate examinations and diagnoses, leading to unnecessary procedures and missed opportunities for early intervention.
- Time constraints impact doctors, leading to a reliance on technology over basic medical practices.

Patient Empowerment and Communication

- Patient engagement and empowerment is important in their care.
- There are examples of how they educate patients and families to understand their diagnoses and treatments, reducing fear and improving compliance.
- The program aims to empower patients to ask questions and push back when necessary, ensuring they receive the best care possible.
- There are challenges in dealing with a fragmented healthcare system and a need for better communication and coordination among doctors.

Second Opinions and Patient Outcomes

- In a specific case of a patient with melanoma, they provided a comprehensive explanation of the patient's diagnosis and treatment options.
- The program aims to make patients more informed and engaged, leading to better outcomes and reduced fear.
- Patients should know as much about their diagnosis as their doctors, emphasizing the need for education and empowerment.
- Second opinions play an important role in providing patients with a better understanding of their care and improving their overall experience.

Peer-Driven Support Groups

- Finding the right "quarterback" to manage a patient's care, especially in rare cancers, is important.
- There are academic conflicts of interest.
- It is important to get independent second opinions.

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Addressing Suboptimal Care and Communication

- Chris Apfel asks about situations where care is suboptimal and how the program addresses it.
- Their approach is to call treating physicians before and after consultations to ensure clear communication and avoid misunderstandings.
- They discuss the importance of accurate weight measurements for dosing medications and the challenges of ensuring proper documentation in medical records.
- The program aims to bridge gaps in care by providing comprehensive assessments and educating patients and doctors.

Patient Engagement and Education

- There are examples of how they empower patients to ask questions and be proactive in their care.
- The challenges include dealing with fear and the need for patients to be informed and assertive.
- Support groups and peer-driven initiatives can help patients navigate the healthcare system.

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TRANSCRIPT

Brad Power
This is the Cancer Patient Lab.

We're honored to have Jill Hunt and Phil Leming with us today. They're with Cincinnati Cancer Advisors and Naples Cancer Advisors. I've known Phil for some time when he was transitioning from starting up Cincinnati cancer advisors. They provide second opinions. Is it for free, or is it fee based?

Phil Leming 0:28
It's for free, sponsored by philanthropy.

Brad Power 0:32
Yeah, sponsored by philanthropy. In that regard, it's somewhat like our friends at cancer commons but Phil's seeing people in person, like a regular visit to a medical professional, which he will describe in more detail. He has some particular points of view about the way the system works and the way the healthcare system could be improved based on his many years of experience that I think you'll find very interesting. Before we get started, I should do the disclaimers or the housekeeping at the front. This is for information purposes only. This is not medical advice. We try to arm our patients with information they can take to their medical team. Everything we do is open and public. If you're concerned about your name, image or anything you might say being made public, you can change your name, turn off your camera and not say anything. We are a nonprofit, 501, c3 and depend on donations from people to keep us operating. We would appreciate any donations which you might make on our website using the donate button. I'll turn it over to Phil and Jill.

Phil Leming 1:55
Jill and I've worked together for 22 years now. My background is a medical oncologist. I did my most recent training at the National Cancer Institute outside of DC. Subsequently I went into an elite private practice in Cincinnati for many years, and then joined one of the hospitals. I was the founder and director of the Cancer Research Program at the Christ Hospital in Cincinnati for 30 years and have a long standing background in clinical research specifically in malignant melanoma. Five years ago, Joe and I were persistently noticing frustrations in the healthcare system. We were frustrated with leadership, so we decided to escape the world that we've lived in for a long time. We were offered an opportunity to establish a completely independent non denominational Second Opinion Oncology program that was somewhat unique. It was sponsored by a large foundation of business people who wanted to do something good for Cincinnati but didn't trust hospital systems. We were tasked with starting this concept by Dr. Bill Barrett, who was the idea person behind all of this. We were given a small office with very little furniture, no phones, computers or electronic medical records, and said let’s make this happen. I was put in connection with Brad when we were trying to get off the ground. His contacts, help and support was extraordinary and instrumental in us being able to become what we are now.

Jill Hunt 4:35

It was actually really fun. When we first started, we really weren't even given a direction, just second opinions and wanted to see where it goes. It allowed us to slow down the care of cancer patients and give them the time to ask questions, educate them on their diagnosis and their treatments. Depending on what part of their journey they were on, whether it was a new diagnosis, advanced diseases, progressing on standards of care or had failed multiple lines of treatment and were now looking at potential clinical trial options. We treated every patient the same way and every new consult was blocked for two hours. By the time that they left, every question that they or anyone with them had, was answered. We opened our doors in January of 2020, not realizing that a pandemic was right around the corner. During a time when cancer patients could not take anyone with them to the doctor's offices, their treatments or appointments, they were able to bring their families to our appointments and were given the time to process and answer all of the questions. What we found was that as time evolved we realized where the needs were. Our program has continued to evolve to fill in the gaps for cancer patients and the care that they receive. It's been a really fun journey, but was almost comical in the beginning because we put two completely clinical people in an office and said, “just do this thing”. We knew how to take care of people and how to do that when we needed help. We walked in on the first day and realized we didn’t have a phone or any internet, so it was a fun journey. Now we've got a great supportive team, and we're really impacting Cincinnati and the Naples area, just with all of the patients that we're reaching.

Phil Leming 7:17
We've evolved to have 20 people total. One of our other medical partners, Dr. Abdul Jazieh, served as the head of the University for several years and later was the head of the largest cancer program in Saudi Arabia for 15 years in Riyadh. He moved back from Riyadh to join us and become our innovation international person. Dr. Robin Zon joined us as the breast specialist, and she's just finished the year as the president of the American Society of Clinical Oncology. ??Andy Ganagundo??, another nurse practitioner, who was just elected as the President of the Oncology Nurse Practitioner’s organization nationwide.

I'm the medical director, and I set the tone. The tone is physician, first, consultant second, meaning that every patient gets an ultra comprehensive Internal Medicine assessment of every square inch of themselves. This is done prior to us addressing the oncology question is the philosophy being that if you don't understand the person that has the cancer, that you can't effectively do a good consultation for the cancer problem. And as as time comes, as Joe alludes, as times gone on, we've had we we've been able to be a window into the changes in good and bad, I guess, of healthcare, and have been able to realize that our role is way more than just being a consultant to give people in new ideas of their particular cancer and and what we're we're picking up is a lot of deficits in healthcare that patients you know come in with and that we are now having to figure out ways to help help people and also to help physicians deal with the systems they're working in and filling in the gaps in not only primary care, but the oncology space. And then we're finding that part of our role is home. It's like a training ground to teach patients and families how to get the kind of care that they really need within the current healthcare system, and it's different than it was five and 10 years ago, and particularly for older patients who are accustomed to a single interns watching over them. The whole world is flipped up, and that's not the kind of care that people are getting now, but they have to. You can still get good care, but you have to understand this and work with the systems.

Brad Power 10:40
Can you give some examples of some of those changes you've seen and things that patients should be aware of?

Phil Leming 10:47
Yeah, and Joe can jump in on this too. What's kind of surprising is the number of patients and families that we will be getting into all the history of that patient, and we realized that the patient and their family, they're seeing like five and six different doctors. And I'll look over at the family and the patient and I say, Okay, well, who's taking care of you and the family and patients look at each other, and they, you know, very commonly look at each other and go, well, we don't really know so that the system is very fragmented. It's very tunnel visioned in regards to capable positions that are not, either allowed to or are not taking the effort to comprehensively care for people, but refer them to a specialist of that area, and it becomes burdensome for people with, you know, for transportation, they may not feel well. They could be older. There's a lot of factors where we're finding situations where one doctor should be able to handle a lot of this that they're just not. The systems are not facilitating that. They're facilitating multiple referrals to multiple specialists, rather than, you know, one, one or a few physicians caring for the people.

Jill Hunt 12:29
And the problem with that is that you have, you know, say you are actively on treatment and you're seeing your medical oncologist, and your medical oncologist elects not to manage the respiratory infection that you have and tells you to go see your family physician for that. So then the patient goes to see their family physician, and the family physician treats them with antibiotic x and this and that, however, doesn't actually communicate it with the treating medical oncologist who is actively treating the patient for their cancer, and so then, without any real awareness they've now, you know, potentially put them on a medication that could impact the effectiveness of The treatment that they're on for the sheer fact that that nobody's communicating on what they're doing taking care of the same patient. And it's really frustrating, because when Phil and I were still actively in practice at the hospital, once a patient was on treatment, we treated them for everything. It didn't matter you. You get the sniffles, you get a sore throat, you get a cough. I don't care if you have a primary care physician. I'm glad that they that you have that person. They can refill your yearly medications, but while you are actively on treatment, because there are so many things that can impact the effectiveness of your treatment or how you're managed. We're your quarterback, we are your bus driver, and we'll keep everybody else posted. So it's really hard, and we really try, in this role to empower patients, to make sure, number one, you know who's driving your bus, but number two, you make sure that all of the people that are on the seat in your bus are communicating with the bus driver. Because if you go to your cardiologist and they pick up something and now they're ordering additional testing and they put you on a different medication, but they haven't talked to your medical oncologist, and potentially one of the drugs that you are on is potentially cardiotoxic. There are so many things that intertwine that if they're not communicating, the care of the

patient not only can be fragmented, but overall can impact and how. Poor outcomes for the patient.

Brad Power 15:03
So you have the luxury of doing the right thing, of designing what's best for the patient and being integrated around what's best for them. Alan has a question in the chat here, asking about the cost side of this is, I mean, I guess, as you're describing, if they have a negative consequence from a side effect that doesn't get managed, or something or complication with an interaction with something else that on net, they're worse off. But at least from some standpoint, the luxury you have of spending, as you said, two hours on that intake is something that I don't know, if everyone has, you know, in the regular system, has luxury.

Phil Leming 15:46
Well, the the only thing that I everything, Brad, that I would say that, that along the same line, is a a disastrous level of physicians not examining patients, and multiple, multiple examples, for instance, where a patient has, Say, a disease that's metastasized to a lymph node. I say, a lymph node in the neck. And this is a real example. Actually, a patient with a known malignancy had evidence that the patient and their husband noted, palpably noticed lymph node enlargement in the neck, the patient called their family doc. The family doc did not examine the patient. Patient was referred to a thoracic surgeon because a CAT scan said there was some nodes in the chest. The thoracic surgeon never examined the neck. The thoracic surgeon took the patient in for an invasive procedure, surgically to biopsy a lymph node in the chest, when in actuality there was easily detectable, palpable nodes in the neck. The procedure did not get adequate tissue in the chest. The patient was then sent to an ENT doctor who did examine the neck for the very first time out of five physicians, and commented that the nodes in the neck were obvious, and they did a simple neck biopsy of a node and got the diagnostic answer. But if you've tracked, if you looked at these kind of cases, the the cheapest, most cost effective thing to do is listen to a patient and examine them. And that could have, you know, the cost difference, and with that on that one patient, not not counting, the morbidity was, you know, was very significant. So what we're seeing is, you know, patients that have been seen by four or five, six doctors, all of their notes will document something on an exam that's like a normal abdominal exam, and we bring the patient and examine it in the liver is halfway down to the pelvis and grossly enlarged and abnormal. And everybody is documenting their exams, but they're probably never not doing them. And in many clinical settings, your ability to help people is stemmed from listening to the patient and doing an exam, which, if in a lot of settings, that saves a lot of money and morbidity. A common finding that we're seeing, whether it's a person in an academic center or in private sectors. It's in the last five years, it's been a dramatic increase in people not getting thorough examinations, and then in occasional settings. That could be a major, major impact. So, you know, it's and I'm not, and it's not a not trying to blame Docs because they're given so little time to see patients. It's easy to write, you know, 12 scan orders, it'll it'll take no time for that, but it takes more time to do an exam than it does to order an expensive test. And. And in, not uncommonly, if patients go to emergency rooms, the doc that's seeing them doesn't get doesn't ever examine them, they get as far as the doorway, order a bunch of CAT scans and blood work, and walk out. So the the one thing that we always point

out is whether you know, whether you're in music, medicine or martial arts, the the basics of of a profession are the are the basics for a reason, and that the difference between a master and those professions and in a beginner is that the Master does the basics correctly every single time. And what we're, we're we're seeing is the basics are being pushed out of the way by technology. That is not always the best thing for a person.

Brad Power 21:02
It sounds like it also could be lower cost on net, if you're, yeah, saving those expensive tests

Phil Leming 21:09
well, and just, you know, and it's also the you know, timing of of cases and, and it's like we try to teach residents and people and other docs, is in our world, it's not that we have we know everything because we don't. That's probably our The first step is realizing that you don't know everything, and then realizing that it's not so much you know. It's how you think and and so any patient that comes in, we can, we can help them, and we can, we can think through the problem and then facilitate what's in the in their best direction to deal with that particular cancer. And so the like you pointed out, we have the luxury of time. And the the average physician spends most of his time documenting epic notes so that the hospitals get paid and has very little time to do the actual doctoring.

Brad Power 22:22
There's been some discussion in the chat about people wanting to access your services and where you are available. Jill, you had a response there. Do you want to just give voice to what you'd already written down there?

Jill Hunt 22:34
Yep. So if you want to learn more just about our organization and things like that, you can go to our website, which is Cincinnati cancer advisors.org. So several people have asked what states that we currently are working in. So the rule currently, especially if we are doing telehealth visits, is that we have to be licensed in the state in which the patient is actively in when we see them. So for our docs in Cincinnati, they are licensed in Ohio, Kentucky and Florida. Dr Zahn, who sees our breast cancer specialist. She is, she also see. She is also licensed in the state of Indiana. Mark Randall, who is our gynecologic tumor specialist. He is also licensed in South Carolina, and then MJ, Dr Jahan Zeb, who sees breast and lung in our Florida location. He is also look licensed in Florida and Ohio.

Phil Leming 23:54
That's, that's everything. And I'm in and I'm in Maryland

Jill Hunt 23:57
also, oh yeah. And you've got Maryland so, so So we've, we've had some patients like we had a patient who lived in West Virginia, just across the border of Ohio, and they literally grabbed their laptop and their air pods and went to a Starbucks across state lines, a that We we've made it work for patients who aren't necessarily in one of the states that we, that we actively are

licensed in. So if someone is located in New Hampshire, could they travel to see you in Maryland? Yes.

Lori Mckitrick 24:51
If they travel to you, and they do the initial consultation, but they want, of course, they're going to continue their chemo and rate their actual treatment in their home state, just or their home area, you still quarterback and communicate with their primary, whoever's overseeing the chemo and radiation in that area. Or do you take that over? How does that work?

Jill Hunt 25:25
I would say that not the quarterback. We might be able to coach the quarterback and kind of help them along, maybe make some connections with some national thought leaders, or, you know, other, you know, make recommendations in regards to potential treatment options or testing or whatever else the patient needs, but at the end of the day, it is ultimately at the discretion of the treating physician to take our recommendations or leave them. So although we've used been used to being the quarterback, and it is really hard to not be the quarterback when you know how to do it the right way, but it also empowers and enables the local and treating physicians to step up their game. So

Lori Mckitrick 26:19
yeah, and I think you know, what you're saying is, you know, the way our healthcare system is built today, I've got many dear friends who are endocrinologists or primary care physicians, and the way the health systems are is they want, you know, they want you to be Chick fil A. They want you to be efficient and get more patients through because then they can build RV use. And in every patient, you know, one of my dear friends, she, you know, she sees a lot of the geriatric where it's a large, you know, they have a lot of CO morbidities, don't have the time. She's like, I can't do a 15 minute visit and do justice. And that's where the challenge is even in oncology, all these other services, it's all about the RVU and the time spent with patients. And what gets missed is all these, you know, everything that's going on and the handoffs and communication. I'd I'm a speech therapist in my first life, and I saw a lot of head and neck cancer patients, and our local entities would find laryngeal cancer, they would cut it out and never send them to an oncologist. I would say, I really think, you know, trying to not cross any lines, but I would recommend that they just get an opinion, because I knew that they weren't being treated completely for and there was going to be a reoccurrence, a likely reoccurrence, so I would inadvertently, but it happens way more often. And the challenge is, patients and families, if you're not in the medical field, you don't, you don't know what to ask, and you don't know what you should be doing. So the medical community, we should be guiding them and putting them, you know, giving them the best possible. And I thank you for doing that there at your

Phil Leming 28:15
but I think you hit right on. You're right on the money there on the is what we see the same, same situation in that, you know, we were all trained like Special Forces, you know, in, in such that, you know, you were an internist first, and then you're, you were a consultant, so that when a patient came in with a cancer thing. You didn't. You didn't tunnel vision. The answer on the

cancer. You, you, you, you, you treated the person as an entire thing. And you, you, you, you kind of had to be a physician. And in it, honestly, I don't, I, I, I'm a little hard nosed, but I don't give docs a break or tell me that they they're they just don't have the time. Well, then push back on the system. The problem that you run in that's developing, though, is a lot of the young people that come out or have you know, unless they're coming from wealthy families are carrying these astronomically high school loans. And so if you got a young person and they in in they're almost always being, you know, joined into some system that owns them, they can't push back too hard because they got to have a job to pay these ridiculously high loans, which can be anywhere between three and $500,000 straight interest loans that there. So there's, there's a whole dysfunction in the entire healthcare system that you know is, is in that of. Of the their argument that there's not enough positions, but yet, the application approach to medical school is ridiculously bizarre in in the US and in the they're not fixing some of the basic causes and and so what happens is everybody is shifting to technology, which you know, where one where all you really need is one doctor. Now you got six and and you can't tell me that that's not more expensive, because you go to a doc and they have a they feel a tendency that they've got to do something. But maybe, you know, if you just had one person looking over at all, you could avoid a lot of cost, a lot of hassle to people and in, you know, and now, the systems are such that the standard of care is that, well, you shouldn't be taking care of this. You should send them to an endocrinologist and and, you know, when we did the work, we didn't need an endocrinologist, you know, but the but if the standard of care becomes this for everybody, then if something goes wrong, are they medical, legally at risk? So the there's all these screwed up factors in healthcare right now that could be easily dealt with by empowering physicians to be physicians. It, but the systems are lining up against them a bit. So part of what we do, we find, is it's necessary to empower patients and families to give them the okay it, to push back, to ask questions and to be a little more assertive in a nice way, and then we're a backup. And if they have problems, we can be their hired gun, but the reality is, the system is complex, and it's in for people that are not in the healthcare world. It's overwhelming, particularly if you're dealing with older people. So yeah, if you can sense a level of frustration that we're feeling, it's real, because it isn't hard to take care of people. It just takes time. And you know, it's actually cheaper to make the correct diagnosis and avoid stuff than it is to do it the way we're doing

Brad Power 32:45
it. Phil, I just wanted to pick up on a conversation you and I had before, which was you said, when you give these second opinions, often, you spend the time with the patient, their family so that they under they get all their questions answered, they now understand much more clearly and maybe confirms what they were already getting treated. But now they understand why and wherefore and how it fits and everything, and then it allows them to become the engaged patient, because they understand more. Can you speak to that contribution? Return them to their doctor, a more effective patient,

Phil Leming 33:19
right? So what we'll just give you an example. Jill and I just saw a consultation before we started. The the thing here is a gentleman with a moderately high risk melanoma with lymph node involvement, and was seeing a good local position, getting immunotherapy, and the

treatment was, sort of is correct, but we methodically go through and explain the basics of of where you know, the basics of the diagnosis, the cancer stage, and bring it down to basic common sense. You know, we describe it between mechanical and personality of the cancer, but, but then we also pull out the original research data that that proved that this immunotherapy drug had benefit in in survival and why, but also showed the patient the survival curves, so that we could actually point out that, you know, yes, here's here's the benefit, but you're not without some risk. But in the time frame, if you get out a six months, your gambling odds are better. You get out a year, they're much better. And if you get out to two years, you're almost home free, but But with that, that is the actual truth, the data that they can work on so the patient can be appropriately aware of what he needs to be doing, but also to eliminate the inappropriate, terrorizing. And fear that they're going to die in it. You people go away with Okay, I understand this now, and I understand why I'm going to have to get scans frequently during this period, and it'll be better at a later period. We also explained that, you know, 80% of the recurrence of something you can pick up on your exam, so you and your family, self exam, this examine the area and and so the patient goes away. The doc was giving the right drug. But the missing part for the person in their family was the understanding and the the reassurance and the fact that the gambling odds were actually quite good for the patient, but they but he still had to be vigilant and, and that's a, that's a real time example. We just finished, you know, 15 minutes before we started this, this, this event, Joe, you want to add anything?

Jill Hunt 36:08
No, I I think that what I'm as you're talking I'm I'm over here frantically answering all the questions that are going into the chat. So just to hit, just in case anybody isn't looking in in the chat, some of the things people are asking are, you know how let's see there was a really good one. Sorry. There's been a lot I've been busy.

Brad Power 36:42
Some of those have come from Rick Davis, and he's got his hand up. Why don't we let Rick, why don't you just have this same exchange you've been having in the chat in the voice recording here, Rick, what were some of the points you were making?

Rick Davis 36:56
Well, this is interesting to us because your model, Jill and Dr lemming is very similar to what we do within our support groups, except ours is peer driven and yours is medically driven. So technically, we do not provide medical advice, except on occasion, we have peers who are also HCPs. That allows us to do that, but we find our way around that we are. And there are people in this, in the audience, who have attended our groups, and you can listen to our support groups, because we record a lot of them. It's all about finding the right quarterback. We try to guide people to quarterbacks that we know will sit and will listen, and invariably, we're pretty successful in doing that. Russ is saying, well, not all Gu medics are good. No, not all doctors are good. But if, for example, you're looking for treatment for prostate or Gu, prostate is our mother load, but we we have groups of pancreas, we have we have groups for thyroid, we have groups for non cancers, and in every group we make sure that the peer moderators are well educated for some of these cancers, and particularly the GU cancers. I think it's impossible for a general

practitioner to be up on general medical oncologist to be up on everything that's going on. They just can't. They cannot do it. There's too much. And as good as they are, and maybe they're well aware of the NCCN guidelines for, say, prostate, which I've got to tell you, a lot of general medical oncologists are not on top of, and we are sending the patient the NCCN guidelines to deliver to their doctor. A general medal cannot stay on top of of everything, but just on a broader basis, we're doing a lot of the same thing. We're helping people with their financial resources we met. We're talking about drug interactions we have. One of our moderators was a career pain psychiatrist at the VA. So he lived with crossing with contraindications and cross interactions, and so that's in his forefront. But I can't tell you the number of times somebody said, Well, I'm on this drug and I'm taking that drug, and we say, well, you know, those two don't, don't really mix. Now, how and we do this nationally, so And of course, we don't, we don't worry. We we don't have, we're not subject to HIPAA, because we're all peer to peer. So it. It. I am so empathetic with what you do. I love it. I'm sure that we're going to have Florida people that will be will will be able to shift, shift over to you. But I think my biggest concern is in some of these high research areas and and rare cancers. I don't know how you I don't know how you can stay on top of it, short of making sure they're seeing the best doctors available to them. Sorry, I went on a little bit, but you're sort of touching a lot of chords. No,

Phil Leming 40:35
no, you're you sound like you're part of the club here. Yeah, yeah, no, you're doing phenomenal. You know, to be able to do that nationally and help that many people with what you're doing is just amazing. I think that, I think you're, you're absolutely right. I think the volume, you know, it's, it's, it's, it's complex, the volume of information, as you well know, if you know, you go to, say, the American Association Cancer Research meetings, and you know, they'll fill up a space of a football field with abstracts on boards, uh, twice a day for five days, right? And, and, and trying to, you know, stay up on even one area. I think what you're pointing out is there this, this will be one area where the machine learning world will be helpful, but you can't, you know you need. You need what you need. You still need a quarterback to take care of people. And you know, the one of the biggest problems is the systems are not encouraging quarterbacks. You know, the financial side of it is like your other person mentioned this, you know, they're more interested in RPU stuff than they are, you know, the short term three month spreadsheet rather than the long haul. And there's so many factors involved in any any one group or person has a hard time, you know, reversing any of this. So we're all scurrying around trying to fill in the gaps to help people as best we best we can, but we're not able to get to the root causes, you know, and that's the that's the frustrating part in this. And in spite of that, the cost of healthcare just is ridiculous, you know, in the cost of medications. You know, sort of a tongue in cheek approach. I, I did a calculation on some medicines can using the gold standard per weight, and in the if you started gold standard, gold standing, stand the cost of medications for weight, you would be absolutely, unbelievably shocked by the quantity of the cost per weight and and so we've got a lot of factors, but also like anything

Jill Hunt 43:18
to like Your big concern, and it's a concern across the board, because more and more of the academic facilities are getting to the point where the physicians are only seeing you know, one

or maybe two specific tumor types. So then you you you're having a hard time finding a general medical oncologist if you think about what a quarterback actually does, what makes a quarterback a good quarterback, it's not just the fact that he's calling the plays, it's the fact that he knows how to think, he knows how to think fast, and he knows how to pass the ball when he needs to, and how to Find the person to pass it to. So if you, if you look at it from a full analogy standpoint, it's not like we saw a patient couple weeks ago that had a they were a misdiagnosis in in the process, we were able to figure out what the patient's actual diagnosis was, and their diagnosis ended up being something that there's literally, like six cases that have been documented. There is no one that is going to be a national thought leader on that specific diagnosis. However, how do we get the patient to where they're going to get the best care possible? How do we connect their treating oncologist locally with someone who's going to be able to answer those questions. So it's, it's about connecting the dots for the patients and making sure that they are getting the right care and and you have to, you really do have to call the shots. You know, we there was a little discussion going. On about Gu patients and the NIH National Cancer Institute. We don't send anybody to an to an academic facility or to a clinical trial. We don't make recommendations on facilities. We make recommendations on specific studies by specific investigators, and we connect the treating oncologist with those people, so that the patient isn't blankly, being sent to the Ohio State or the Cleveland Clinic or MD Anderson, because what's going to happen is when they get sent there, they're going to hear only what MD Anderson has, or Sloan Kettering, or Moffitt, or any of the academic you only hear what they have if you don't have someone that is looking over everything for you and looking for what is the best trial for the patient? Every academic facility is going to have a clinical trial that is great for that patient to go on, right?

Rick Davis 46:05
I'd love to comment on that, because one of the biggest issues that we face is this academic conflict of interest, and it drives us nuts. You know that if you send a person, especially to an academic center, but even to some of the some of the better non academic centers, and they're running a trial, they'll push that person into the trial that we bring them back to us, and this trial isn't right, or this trial doesn't have an adequate control arm, or what have you, the docs don't tell you, and we've taken it up. We've taken it up with the dots. I mean, it's a huge, huge issue. And just as much as there's a financial conflict of interest with private practitioners, there's an academic conflict of interest with a lot of practitioners,

Phil Leming 46:53
and if the majority of the research is drug company sponsored, and if, if and and for young investigators, it's a requirement for them to put people on their studies. Otherwise they don't get advanced in the system. And that's a large amount of the funding for the research. It's both an academic and non academic centers is coming from a drug company. If they, if they don't fill the quota on their on their trial, they don't get any more trials. So, you know, you have the thing that is, you have to know all these dynamics, like you're pointing out. You have to, you have to know all these, all these dynamics and and educate the patients on that. And also, you know, the the I don't, you're, you're absolutely right on, on, on some of this, the the the concept that that a patient, a doctor that you're seeing, that is, is owned and controlled by a system is the in years

past, you get the sense that they're independent. They have my interest only in mind, you would hope now you you have physicians that are being specifically told from their system what they have to do that you you start wondering, is that in your best interest, or is it in the system's best interest? And so there's another the whole nother level of interrogation of a system when you when you're when you're sending them someplace. So when we send people, we, you know, we're when we were in I ran the research department for 30 years at one of our big, private hospitals. In the 30 years, I never put a patient on a on a clinical trial, unless that was the best treatment. But that, I can tell you, that's not the way most places run. You know, they it's more like, is the patient eligible for that particular trial? Not is that trial the best for the patient and but that's that kind of work you're doing, what I think a lot of places are trying to do is, you know, we're trying to make sure the patient's getting the best care in a lot of times, a clinical trial might be the best care and the cheapest, but it takes Some time and thinking and effort, and, you know,

Jill Hunt 49:42
because we try to empower patients and tell them, like, look when you walk in with your physician, you should know almost as much about, if not more about your diagnosis than your physician, right? You should be asking. The questions you should be pushing back. This is, this is your life. You have a vested interest, so we try to empower them. But you also are also dealing with the fact that you have people who are currently functioning in the fear part of their brain, because if with new diagnosis, if they've got new metastatic disease, they're terrified. And so how do you empower patients to take, kind of, to take the reins and to get in the game when, when their their brain isn't even functioning, and at the capacity that it needs to, because they're they're terrified.

Rick Davis 50:38
Well, we can, I can definitely offline talk to you about that. I want to get a couple more people that work. I want

Brad Power 50:45
to get to a couple more people. Chris and Helen have some comments in the chat. Chris, can you you had a number of questions? Can you choose one or two that you want to focus on?

Chris Apfel 50:57
Sure? So just to clarify, you provide second opinions, so that means you're not treating the patients. Is that correct? Correct And and so, so one part would be, first of all, getting all the information together, so you have, you have assistance and the team, or you get access to the to the portal, so that you can collect all the information when a patient comes through that kind of prepared for you, right? Because it that could be quite a time effort to get this set up, to

Phil Leming 51:27
get started. No, yeah, we have, we have a team of unbelievably gifted people that even in the middle of our consult, if I'm if I'm missing something that I need, Jill will text our our team in

within 10 minutes, I will get the data from whatever system we need. Okay, it's just amazing, great.

Jill Hunt 51:53
We have a majority of the patient's records and and we do all of their records from the time of diagnosis all the way through what is current, and not just the medical oncology notes, but we want primary care notes, because it's not just about the cancer diagnosis, it's about the whole patient. So our team is well trained to know, like, if the patient has been seen by cardiology or pulmonology or nephrology, if they whatever ologists they have, they're pulling notes and records and labs so that we have the full picture when we see the patient

Chris Apfel 52:29
and and how often do you encounter situations where you feel the care is suboptimal and and that the patient so are you then interacting also on behalf of the patient? Are you also connecting with the other ologists, oncologists or hematologists, or whatever? And so do you have one on one conversations? And how are they? Are they collegial? Or could there be even situations where where they feel kind of that somebody is looking over their shoulder and that that it kind of scratches on their ego. And how is that usually happening?

Phil Leming 53:11
Well, it's, first of all, I try to call the treating physician before the patient comes in. I also, if I get a call on a patient that's one that's wanting to be seen by us, I will call the patient for a kind of an introduction prior to them actually coming in, because a lot of times, I can alleviate a huge amount of anxiety that they're you know, a 10 minute phone call can alleviate allow people to sleep better. It's like anything you know, our job is not to be critical. The bottom line is to make things better and to educate sometimes it's like anything there's there's ways of helping physicians do a better job, knowing that none of us are perfect, and that your job is to and that we have the luxury of time. So you have to understand, most docs are sort of paranoid in general. They're under high stress. They're they're frustrated that they can't do the kind of job that they want to do because of the pressures they're under. And so if we see something that's definitely off, and it's rare that we see something that's deadly, but every once in a while we do, and if we do, then it's like the United Nations. You know your your job is to know that person a little bit know how to approach them so that they do. You know, they, they make sure they're doing the right thing in that maybe the next time this comes up, they they do it a little better. Every once in a while you get somebody who's not receptive, but I'd say that's just extraordinarily rare. Most docs are appreciative, because when we've done surveys more than 80% it's almost like 90% now, of all the patients go back to their primary doctors, happier with their own doctor, because we've been able to explain things that their doc doesn't have time to do.

Chris Apfel 55:38
Okay? So a lot is actually communication where the physician usually doesn't, the system doesn't, and allow this is the enough time to explain what is going on.

Phil Leming 55:52
And if you would, if you would say, the singular most significant problem in healthcare now is the failure to communicate, okay, you know, across

Jill Hunt 56:05
a lot of areas, and that is something that we really make sure that we do well, the pay the physicians get a full written consult, but they get called before and after the patient, and we typically will send an email with kind of some some like the Cliff Notes version of what's coming in the full consult. But when I say like, we do it the old fashioned way, we pick up the phone and we have a conversation, because there's something to be said about having that, the connection and the back and forth, and giving them the opportunity, and when we found errors, there is definitely some finesse.

Chris Apfel 56:47
How difficult is it to get them on the phone, to call you have a team that coordinates that, because I could imagine that

Jill Hunt 56:54
lemming calls all of the physicians from his cell phone. So if you're and most of them have his contact saved, you know a lot of the docs in the Cincinnati, Northern Kentucky, in our general area already. So if you see Phil lemming pop up on your phone, you don't send that to voicemail. So usually, most of the docs either answer when he calls or they call back within the day, a majority so

Chris Apfel 57:24
you have their cell phone numbers and you call them directly, and it's okay,

Jill Hunt 57:29
and that's part of building the network to provide better care for the patients.

Chris Apfel 57:35
Understand, if you have patients who want to go beyond what's called standard of care. How do you handle that? So for example, we have a functional oncology, precision oncology platform, so we can take patient tissue, we can actually test it on cytotoxicity or antiproliferation of a range of drugs that could be within standard of care, or it could actually go beyond of that, if a patient is requesting that in the standard oncologist, often what's not within the guidelines is resisted. But there are treatments, and you are certainly also aware of it, that are outside of guidelines that are actually well documented to be effective, and sometimes patients want this. Do you help those patients? Or how do you handle that? So

Phil Leming 58:29
You're touching on an area that is a little touchy.

The way I approach it is, if I can't do better than the guidelines, I need to not practice. I separate out oncologists into those oncologists that do nothing but quote guidelines, versus those that think beyond the guidelines. Because anything that's on a guideline is automatically somewhat out-of-date. Yes, you want to be aware of guidelines, but if you're working at the level that you should, your level of thinking should be far beyond any guideline, knowing that whatever you think is standard of care, there are researchers and people that are five to ten years ahead of that. Once you understand that, you're forever tortured because you can't just be happy with a patient getting something on the guideline. They're important, but they're what the consensus thinks. The guideline things aren't necessarily the best for that singular patient. If you work on the philosophy like we do, which is, if you can walk in the door, you're curable until proven otherwise in our eyes. You don't want to be taken care of by a physician who doesn't have that mindset. Because anybody that thinks that they know everything, then they're wrong. The research world and that science level is far beyond what's accessible on a guideline or a day-to-day practice. It doesn't mean you can always get access to all that, but your horizon should be at that level, not at a flat level guideline. So that's how, that's how you got to, you have to do this. So just because something's not on a guideline doesn't mean it's not a potentially, you know, good thing. And a lot of the things that become guidelines who are not not well respected before they were proven to be helpful,

Chris Apfel 1:01:04
right? So we had in one of our cancer patient, cancer patient lab meetings, because sukatmid presenting, who was a dean of Emory at some point, and he has a memory Morningside Center for Innovative and affordable medicine, and is, actually, is with his wife, is actually working on what they call financial offerings. So these are sometimes drugs of patent, FDA approved drugs, basically repurpose drugs. It's one part, and we, we have a testing platform for that. But then there are also other phenomenon where, where, where they observed that histamine levels plays a role on responsiveness, on immunotherapies, but also there are, there's good evidence for other intervention, especially in the early stage, such as nutrition, as well as physical exercise and activity. So lifestyle interventions that are usually not discussed, or oncologists are completely staying out of this, even though there is good evidence for that. And they showed a meta analysis that I was very impressed with. It came out 2024 that showed that morning infusions correlated with markedly better outcomes in cancer patients, and they tried to implement that, and that was a meta analysis on over 3000 patients, 18 studies, and it's a quite consistent image picture, and that's and it's really difficult to implement

Phil Leming 1:02:34
that, no but that, what's comical about that is that's a people are acting like They had a new discovery. If you go back probably 30 years, there was a whole push on chronobiology and chemotherapy administration and and there was I, I have the guy's book on my on my shelf that did a lot of incredible, phenomenal animal work in the chronobiology that was very strong, but it was hard to implement, so they didn't have it. The The interesting part is, the chronobiology of immunotherapy is the exact opposite of what the chronobiology of chemotherapy is. Chemotherapy is early morning. Corona biology for immunotherapy was afternoon and and so there's in a different life. I did about 15 years of nutrition, metabolism in the cancer space, and

we're extremely strong on pushing that. And I always tell people ask what they can do. I always quote George Sheehan, who is the medical editor of runners world, and it says, do those things that make you a healthy animal. And it pretty much covers the covers the ground, you know. And we could talk a long time, but, you know, there's, there's, it basically comes back to what's necessary to keep you as an organism optimally functional and healthy while you're treating the cancer thing. And it's, yeah, no, we're, you should come here. We can have a lot of fun. Okay, we'll do

Chris Apfel 1:04:24
that, and we should have an offline meeting anyway. So I'm very interested in what you're doing. This is actually, this is really, really important, and I think one of the challenges that patients have is educating themselves. And Jill, you said that the patients need to basically know as much about their disease as their oncologist. Unfortunately, I agree with you. The problem is so if you want to superior care, you can't. If you want a superior outcome, you cannot just go with standard of care. You need to think about yourself, what you can do yourself, and you need to understand the. Disease. Now, not every patient is a medical professional, and not every patient has a college degree, and I think and not every patient has the fields empowered to be able to do something about it. And I think that's a real challenge. I think I could imagine that there are some patients that are inherently based on their background and profession and education, etc, are very well suited to take action and to be proactive and know what they're doing. But am I? One of my concerns is it may not be achievable for a wide number of patients who do not have that, that that mindset. It's probably also question of mindset and education, and it's it's a really steep climb. We, who lived as the healthcare have lived in the healthcare system. For us, a lot of things are natural, but for patients, they hear it for the very first time, 10, 20, 50, words that they've never heard before. And, and it's really, really hard, I think, for patients, we

Phil Leming 1:06:08
we try to make it common sense, you know, because I, if you really look at it, I mean, we, every cancer that you see, you can dissect into the same basic principles. And it's, it's really very simple at its essence. And trying to, you know, you can't the complexity of the sciences is huge, but the basics are really pretty simple and, and we try to emphasize that, you know, and I think you're absolutely right. You have to be a chameleon, and part of the art of it is knowing how to insert yourself into that particular patient's world and and we always do it by no matter how old or sick a person is. I never ask a person, what work did they used to do every single person, no matter age or condition, I always ask them, What kind of work do you do? Because the impact allows you to open the conversation at a more personal level, and then you find out what that person's about, and only then can you effectively learn how you can educate or teach that person. It's a bit of an art form, but it really works.

Helen 1:07:48

Jill, did you want to address my question in the chat? It's about measuring my weight.

Jill Hunt 1:08:03
I did answer that. She was saying how, in the time that she's been getting treatment, how when she goes into the office, they don't weigh her, they just ask her how much she weighs, and they write down what she says. And my response to that was, I have literally watched Dr Leming almost have a stroke. In regards to patients that we were actively treating that we looked down at the weight, and the weight is the exact same weight for the last three visits, and we asked the patient like, did you get on the scale today? And they say, No, they just asked me how much I weighed. I promise you, after that happened, that medical assistant never made that mistake twice. So this is one of those where, if you find yourself in a situation where, I mean, because, as Helen had brought up, a lot of the medications that are given are weight based. They are calculated the day of treatment. If you are not getting on the scale, then it is not being accurately calculated. So if they just ask you how much you weigh, then your answer is, oh, you know what? I don't know, maybe I should get on the scale. Play dumb. Get on the scale. Yeah,

Helen 1:09:26
well, they don't have one. So this is like, I've had, I mentioned the head. I've had two big surgeries, six chemos and 22 events, and it's always my word. You know, what's your weight

Jill Hunt 1:09:36
to a medical oncologist office, and they do not have a scale.

Helen 1:09:41
I've not been, I have an oncology center at a big hospital here, and I've never been on a scale.

Phil Leming 1:09:47
They sounds like, sounds like, you need another center?

Helen 1:09:51
Yeah. Well, now it's over. I just finished it. But the point is that, like, a vast and so I've lost 12 kilos in this process. And I just, I'm always, like, shocked that they don't ask. Ask me. And Avastin, for example, it's, as you said, it's by weight. It's like 15 milligrams per kilo, you know, so if I've lost a couple of weights, and so anyway, that was my first question. It's because it's quite systematic, and I see people having very severe reactions. And I always wonder, and I always say, you know, did you, I don't know, did they over medicate you? You know, my second question was on an article, and this maybe is really not related to what we're talking about, but I was shocked to read recently that there was an article in the stat update by the medical journal that vital chemotherapy drugs used around the world have failed quality test putting cancer patients more than 100 countries at risk of infective treatments and so on and so forth and so it was shocking to read how little the generic chemical chemo drugs and other drugs are being monitored for their components, we know and and what's really weird is, like this past two weeks, I've seen so many women in my ovarian cancer groups having just, like, having having recurrence or just failed. And, you know, it maybe it's just a time month or whatever, but it's, it just makes me wonder, you know, and I don't know where the generic drugs are going, mostly to poor countries, but definitely UK was mentioned as well. But I guess there's just no way to

address this question for lay people or for the hospitals themselves, because it's a regulatory thing, right?

Phil Leming 1:11:36
Yeah, I don't have a lot of I mean, the generic drugs are supposed to be passed through, you know, testing that makes them equivalent, and so I don't know what the status that is, I'd have to look into more detail, but I obviously want to be able to trust that the drugs that you're getting, whether they're generic or brand name, are equivalent, and if, if they're not, then there's a problem.

Helen 1:12:10
Yeah, it is supposed to be equivalent. The problem lies for the companies that are or for the agencies that are supposed to be regulating it, you know, like, yeah, it's a shocking, it's a shocking number of treatments, you know, that people are getting either too much or too little.

Brad Power 1:12:34
I would like to give Phil and Jill an opportunity to say any closing words that they would like to leave us with.

Phil Leming 1:12:47
Our general role is we're like “oncology grandparents”. We get to play with the kids and send them home.

Stick to the basics, whether it's getting the weight, or doing a simple examination, or taking a stethoscope out to listen to your lungs. The basics do not change. You have to be aware of the technology and the new science, but you cannot give up on the basics of medicine. It's been stable for centuries. That's the biggest message. That's the part that's important. Communication is like life in general, the thing that gets most people in countries in trouble is not communicating well.

It seems like there's a whole lot of people doing good work. Brad I can't give you enough accolades for pulling all the all the people together that you do, and all the work that you've done to help so many 1000s of people. I know I've said it, but I we're so grateful for all the help that you gave us to get started and the continued help that you're doing with this this program, obviously. So you need to get a gold medal.

Jill Hunt 1:14:28
I definitely say, especially with the group that we have here, I'm probably preaching to the choir – that patients are going to have better outcomes if they get engaged in their care, and they are not a passive participant. They've got to challenge, they've got to ask questions, and we've got to figure out a way. All of those things are absolutely true. But the reality is the uneducated, motivated patient who doesn't know what questions to ask. Those aren't the patients that are seeking support. Those aren't the patients that are engaging with additional services. Those are the patients that are being spoon-fed whatever answer the doc is giving them, and they're not

questioning that at all. So we have to figure out how to engage the patients and how to empower them to be part of their own journey and not just take everything at face value.

Phil Leming 1:15:30
Yeah, if anybody remembers Bernie Siegel in his books many years ago, where he described the patients that were somewhat of a pain to the healthcare world, because they push back and they ask lots of questions and harass things. They also were the group that did the best and live the longest. But that's, you know, it's recycling the same knowledge that was, you know, brought up in the past, like a lot of things,

Jill Hunt 1:16:00
We used to do that all the time. When we had patients that would come in for new consults, I would say, “Please be a pain in my ass. Call. Ask the questions. Don't just sit at home and worry about something or have a side effect that you think you just should be having because you have cancer and you're getting treatment. Call. Ask the question. Bug me, that's what I'm here for.”

“How to Survive the Health System and Get Good Care” (Philip Leming, MD, and Jillian Hunt, AOCNP) [#150]

CHAT DISCUSSION

00:21:37 Rick Davis: Replying to "How long has the con..."

At least 15 years or more. I have experience with Nurse Navigators at UCSF pre-2010.
00:23:07 Allen Morris: Reacted to "At least 15 years or..." with 👍
00:26:55 Rick Davis: This is akin to what we do at AnCan, except through peers and support groups with expert Moderators. We promote a well qualified QB. We have HCPs but they are peers.
00:27:54 Allen Morris: Your comprehensive, time and resource intensive, approach sounds like "Cadillac care" which sounds ideal, but if translated over the whole system would be cost prohibitive to our medical economic system. Do you agree or disagree?
00:28:34 Rick Davis: AnCan agrees - HCPs rarely look at contraindications and cross interactions.
00:29:16 lorimckitrick: if someone lives in SC and gets a second opinion can / do you manage their care?
00:29:40 lorimckitrick: or do they live just there in Cincinnati or Ohio area?
00:30:09 Russ: Reacted to "or do they live just..." with 👍
00:31:33 Jill Hunt, NP: Replying to "Your comprehensive, ..."

That is why our program was created, because unfortunately the focus on cost and pressure for physicians to see more patients in less time is where our current health care system is. We have to find a better way.
00:31:41 Russ: 1. How does someone go about contacting you, setting up appointments, looking into the scope of what you do? Prepare for a consult?
2. Do you do video consults/meetings? If not, what region(s) does the patient need to reside at?
3. Do you talk to people with rare cancers like squamous cell carcinoma or NEPC?
4. Can you kind of talk someone out of the idea that eating lots of good food is going to cure squamous cell?
00:32:49 Alexander Lalov, Indiana, US: Reacted to "
1. How does ..." with 👍
00:33:16 Jill Hunt, NP: Replying to "if someone lives in ..."

We have to be licensed in the state the patient is in. We are currently licensed in Ohio, Kentucky, Florida, we can also see specific diagnoses in South Carolina and Indiana.
00:33:51 Jill Hunt, NP: Replying to "
1. How does ..."

cincinnaticanceradvisors.org
00:34:22 Jill Hunt, NP: Replying to "
1. How does ..."

Yes we do virtual visits but the patient has to be in a state we are licensed.
00:34:30 Jill Hunt, NP: Replying to "

“How to Survive the Health System and Get Good Care” (Philip Leming, MD, and Jillian Hunt, AOCNP) [#150]

1. How does ..."

Yes we see rare diagnses
00:34:45 Alexander Lalov, Indiana, US: Reacted to "We have to be licens..." with 👍
00:35:01 Rick Davis: Replying to "
1. How does ..."

Take a look at the website - lots of your Qs answered, Russ.
00:35:03 Russ: Replying to "
1. How does ..."

Thanks. What states are you licensed in? Or is it all stated on a website? (I can look myself:)
00:35:11 Russ: Replying to "
1. How does ..."

Thanks!
00:35:28 Jill Hunt, NP: Replying to "
1. How does ..."

I’ll need more detail on “can I talk someone out of” comment 🙂
00:35:33 Russ: Replying to "
1. How does ..."

This one? "How do you address misconceptions, such as the belief that consuming large amounts of healthy food alone can cure squamous cell carcinoma?"
00:35:57 Russ: Replying to "
1. How does ..."

I'm dealing with someone who comes up with this stuff every single day. And sometimes says I said it.
00:36:17 Rick Davis: Replying to "
1. How does ..."

What States do you work in?
00:37:52 Russ: Replying to "
1. How does ..."

So, if someone is located in NH could they travel to see you in MD?
00:37:59 Russ: Replying to "
1. How does ..."

Oh, you just answered....
00:38:43 Rick Davis: Replying to "
1. How does ..."

“How to Survive the Health System and Get Good Care” (Philip Leming, MD, and Jillian Hunt, AOCNP) [#150]

It is exceptionally hard to stay current in all cancers. For example GU/prostate or bladder. You don't appear to have a GU med onc - how do you address that?
00:39:17 Dr. Chris Apfel: Dr. Leming and/or Jill, are you exclusively providing 2nd opinions, i.e. not treating?
a) There is a reimbursement code for that, right?
b) How often do you come up with a different evaluation? 20%, 40%, or even 60%?
c) How is your relationship with your colleagues and the patient relationship to their treating physicians?
d) What kind of professional insurance would you need to have?
00:39:23 Russ: Replying to "
1. How does ..."

Along those lines, oh geez you're answering my question
00:42:23 Helen: 1) I’m always shocked that not one medical person in my two year journey with this rare ovarian cancer has actually checked my weight before my 2 surgeries or my 6 chemos or 22 Avastin treatments. Yet, medications are dispensed by weight. They take my word for it. What if my scale is off by 2 kgs or not functioning properly. I see some women who have horrific side effects or recurring too soon and it raises questions… (I’ve lost 12k since my dx) Any comments?
00:42:23 Alexander Lalov, Indiana, US: Reacted to "Dr. Leming and/or Ji..." with 👍
00:42:51 Helen: 2) I was shocked to read recently that “Vital chemotherapy drugs used around the world have failed quality tests, putting cancer patients in more than 100 countries at risk of ineffective treatments and potentially fatal side effects, an investigation by the Bureau of Investigative Journalism (TBIJ) reveals.” Question: How do we find out or push to see what regulations our cancer treatments are undergoing especially if generic ones are being used? This is quite worrying as some people esp in poorer countries but also in UK, for example, are receiving too much or too little of the chemo treatments. Is this something you are able to address? Is it impossible to know?
00:44:01 Jill Hunt, NP: Replying to "
1. How does ..."

@Rick Davis Actually both Dr. Jazieh and Dr Leming have depth in GU/Prostate, we also have a strong connection to the GU malignancy division at the NIH/NCI. However you are correct that it is hard to stay up to speed on ALL of the tumor types. Most of our docs have a focus on 2-3 tumor types. If they don’t know the answer then they have a connection to a national thought leader to help guide the question
00:45:50 Jill Hunt, NP: Replying to "1) I’m always shocke..."

I have NO words. This is not OK at all. I have seen Dr. Leming almost have a stroke because I patient was not weighed before treatment. This is a situation where you have to advocate for yourself. Demand they check your weight every single time.
00:45:57 Rick Davis: Replying to "
1. How does ..."

@Jill... We are not great fans of th NIH/NCI prostate resources . We've seen several exmples of mistreatment. Happy to discuss. They give us very little confidence.
00:47:16 Russ: Replying to "
1. How does ..."

NCCN? cancer.gov?
00:47:18 Jill Hunt, NP: Replying to "
1. How does ..."

@Rick Davis we send patients to NIH/NCI for specific treatments not for a “see and treat as you see fit”
00:48:24 Jill Hunt, NP: Replying to "
1. How does ..."

@Russ NCCN is a guideline (great starting place and a way to stay out of medical legal trouble) but should not take away the physicians ability to think through the entire patient and their diagnosis.
00:48:44 Russ: Replying to "
1. How does ..."

Thanks
00:48:49 Rick Davis: Replying to "
1. How does ..."

Tx for the clarification, Jill. Btw, our experience with bladder and prostate is that for best treatment, you must have a GU MO. Even good genral med oncs are not up to speed.
00:49:35 Jill Hunt, NP: Replying to "
1. How does ..."

Cancer.gov is an ok system. It just isn’t always kept up to what is actually currently open and recruiting. This is why it is important to have a network of national thought leaders
00:49:48 Russ: Replying to "
1. How does ..."

Depends. I have dealt with some very questionable GU MOs. My PCP seems to know more (at least about some common drugs used).
00:51:59 lorimckitrick: Patients and families don’e know what to ask what to expect - they hear cancer - I am helping a 20 year old newly dx stage 4 osteosarcoma of femur in lungs and spine as well - and his single mom - to not only think about tx - but his nutrition - the legal side that mom and he need to get HCPOA paperwork - yes she’s his mom but he’s now an adult - fertility - they want limb sparing becasue he wants to get back to pitching college baseball… all the other things that come with cancer - financial distress - legal - nutrition - physical fitness -

caregiver support - fertility - ………. A finding the right course of treatment but then surviving the journey physically, mentally, finacially
00:52:04 Russ: Replying to "
1. How does ..."

Exactly!
00:56:56 Russ: Replying to "
1. How does ..."

Let me follow up on that: do you take full control of the case, or do you work alongside the existing medical team—which might already include a solid GU medical oncologist—by reviewing for drug interactions, recommending areas for further evaluation, and providing that kind of supportive input?
00:58:29 Hilary Elkin: Reacted to "Dr. Leming and/or ..." with 👍
01:06:24 Rick Davis: Jill we have developed techniques to help folks 'Be Your Own Best Advocate'. Happy to discuss.
01:06:47 Jill Hunt, NP: Reacted to "Jill we have develop..." with 👍
01:12:53 Rick Davis: It's much easier to do what CCA is doing when it's within a local area with name recognition. Hard to do nationally.
01:14:28 Rick Davis: We've established name recognition with a lot o docs, mosty GU, who will respond to us. We hae ZERO name recognition amongst genral MOs.
01:14:31 Jill Hunt, NP: Replying to "It's much easier to ..."

That is why as we opened a second site the physician that is on staff has to know the landscape of the area. A national approach would be based on choosing thought leaders in the geographic area to continue the program. It could not be run by a “home base”
01:15:56 Rick Davis: Replying to "It's much easier to ..."

Agreed - but if you develop acceptance and name recognition of of your approach, that will be immense.
01:24:10 Rick Davis: Dr. Leming - we recently came across a study that suggested immune oncology is best administered early in the day. I have to find it for you.
01:25:31 Dr. Chris Apfel: Rick/Dr. Leming/Jill: This is the meta-analysis that Vikas showed.
01:26:06 Russ: Fascinating. I wonder about other therapies? RT/SBRT/RP/BAT (BAT seems like it could be a yes but I have never seen a study) Thanks, Rick and Chris.
01:28:08 Helen: Thank you for this presentation. Yes, gold medal for Brad!
01:28:32 Russ: Very good presentation. Thank you.