“Expert Patient Navigation” (Deb Christensen, MSN, APRN) [#99]

Brad Power
May 29, 2024

“The thing that I do in my work that makes it so meaningful is having conversations with people.” – Deb Christensen, MSN, APRN

“The expertise that our PhDs hold are along the lines of cell signaling pathways and tumorigenesis, to biomarker investigation and discovery. They cover the gamut of understanding the biology at the molecular levels. That is important, and we've seen some really interesting input from them.” – Rebecca Driscoll

Meeting Summary

From their initial diagnosis, cancer patients and their caregivers are confronted with many challenges as they attempt to navigate the healthcare system, understand their disease, and deal with the emotional and social aspects of a life-threatening diagnosis:

- **Emotional stress**: Coming to grips with a life-threatening diagnosis while usually having no background in the disease, testing or treatment options, or the healthcare system.
- **Complex cancer landscape**: With a 94% growth in the number of cancer treatments available over the last five years, it is becoming more difficult for both patients and providers to stay up-to-date on rapidly evolving guidelines. The continuous approval of new tests and therapies means that what you know becomes obsolete every six months or so.
- **Information overload**: Patients and families have unprecedented access to information (97% of patients use Google), yet are overwhelmed due to the lack of information curation and medical education to interpret complex molecular biology.
- **Limited time with doctors**: Cancer patients have on average only 23 minutes with their oncologist, and healthcare providers are seeing an increased number of cancer patients. Tools to help enable shared-decision making are essential in making that limited time as efficient as possible.

Deb Christensen, MSN, APRN, is uniquely qualified to discuss how patients and caregivers navigate through the medical system and their cancer care journey. She has 20+ years of experience in nursing and has multiple certifications, including as an Advanced Practice Registered Nurse and Adult Gerontology Clinical Nurse Specialist with an oncology specialty. She was previously the Director of Patient Services for Cancer Commons and former System Lead for Oncology Navigation and Survivorship for a large healthcare system. She is regularly published by and a Contributing Editor for the Oncology Nursing Society’s publication, VOICE, and other nursing publications. Deb has committed the remainder of her working years to helping cancer patients navigate to the best possible care. Starting Cancer Help Desk is her “dream job” and every day is committed to helping patients and caregivers who can benefit from her experience as an oncology advanced practice nurse. Cancer Help Desk is a nonprofit dedicated to empowering individuals facing cancer. Their services range from guiding patients to optimal resources, tests, and treatments to connecting them with expert oncology nurses and PhD scientists for personalized care plans. Deb was joined by Rebecca Driscoll, Co-founder and CEO at Cancer Help Desk.

What are the challenges that cancer patients and caregivers face in navigating their care that nurse navigators can help with?

Testing
- Identify what tests to get, when to get testing done, and get access

Treatment
- Understand cancer treatment options
- Navigate clinical trials (identify, prioritize, get information, access)
- Assess molecular pathways and identify treatable targets
- Access treatments, especially off-label or non-standard, e.g., through expanded access, compassionate use, patient assistance
- Find a provider willing to prescribe off-label

Administration
- Schedule appointments
- Gather and review medical records
- Shop for service providers (identify, recommend)
- Fill out applications and paperwork
- Get insurance reimbursement

Coaching
- Prepare for doctor conversations
- Provide emotional support, listen, validate

How can scientists help patients and caregivers navigate cancer care?

- Provide an unbiased view of your case and offer personalized treatment suggestions, focusing on the biology of your cancer
- Analyze medical records and pathology reports

What lessons can you take from these navigation services to apply to your care?

Review these services to see which ones could be provided by a navigation service versus ones you could do yourself or get through other sources, such as your medical team or a network of fellow patients

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Meeting Notes

KEYWORDS

patient, cancer, work, talk, clinical trials, oncology nurses, oncology, navigation, rebecca, scientists, questions, cancer patient, services, nonprofit, doctor, deb, care, wanted, information, estrogen

SPEAKERS

Deb Christensen (53%), Paul van Camp (16%), Jeffrey Dwyer (12%), Brad Power (9%), Rebecca Driscoll (7%), Brian McCloskey (2%)

SUMMARY

The conversation centered around the importance of empathy, communication, and collaboration in cancer care. Speakers emphasized the need for personalized support and tailored treatment options based on biomarker testing. They also discussed the challenges of accessing alternative treatments, particularly for those with limited financial means, and the importance of improved communication between patients and healthcare providers. The speakers highlighted the value of patient advocacy in navigating the complex healthcare system and the need for a comprehensive approach that includes oncology nurses, PhD scientists, and companies.

OUTLINE

Introductions of Deb Christensen, Rebecca Driscoll, and Cancer Help Desk.

- Cancer Help Desk founders Deb Christensen and Rebecca Driscoll share insights on navigating cancer care.
- Deb Christensen shares her passion for nursing and oncology and her experience as a nurse navigator for breast cancer patients, then expanded to all cancers.
- She co-founded nonprofit Cancer HelpDesk to focus on patients' needs now. They use oncology nurses and PhD scientists to help cancer patients navigate clinical trials and biomarker testing.
- Oncology nurse navigators help patients understand cancer treatment options and navigate clinical trials.
- Scientists provide an unbiased view of each cancer case and offer personalized treatment suggestions.

Cancer navigation services, coaching, and resources for patients and families.

- Deb Christensen formed an oncology nurse advisory board to provide guidance on programs and campaigns.
- She coaches family members on how to approach doctor conversations and identify resources for expanded access.
- She discussed a young girl with brain cancer who was being treated at a top institution, but the mother was in conflict with them about the treatment. The mother preferred the

standard treatment, but the institution wanted to use a biosimilar that had never been trialed in pediatric patients.

Cancer patient assistance programs and clinical trial navigation.
- Deb Christensen advocates for involving multiple organizations in patient assistance programs.
- Cancer Help Desk offers personalized support for cancer patients, including scheduling appointments and navigating clinical trials.
- Rebecca Driscoll shares her experience navigating cancer treatment, including the value of PhD scientists in understanding cancer biology.

Cancer treatment options and the role of scientists in providing unbiased information.
- Paul Van Camp advocates for universal support for cancer patients, citing limitations in standard of care treatment.
- He expresses skepticism towards the focus of cancer research organizations on integrating scientific knowledge into patient care.
- Deb Christensen discusses the use of biosimilars in cancer treatment, highlighting the importance of scientific information in informing decisions.
- She emphasizes the challenges of navigating multiple opinions and perspectives in cancer care, with science providing a helpful framework for decision-making.

Patient advocacy, fee structure, and business model for cancer support services.
- Nonprofit organizations arm patients with information to advocate for themselves in medical settings.
- Cancer Helpdesk offers personalized navigation services for patients and organizations.

Cancer support services for patients and caregivers.
- Rebecca Driscoll emphasizes the organization's goal of serving patients at no cost, while also working with companies to provide additional value.
- The organization aims to help patients navigate complexities around genetic tests, providing logical steps and addressing physician concerns.
- Patients and caregivers at any stage can benefit from Cancer Help Desk support.

Challenges in finding off-label cancer treatment options.
- Jeffrey Dwyer shares his experience with the challenges of navigating standard of care.
- He seeks off-label medication from a medical oncologist and faces challenges due to institutional constraints.
- He expresses frustration with navigating medical billing and insurance coverage for off-label treatments.
- He needs to advocate for himself to seek alternative sources for hormone therapy, such as naturopath or supportive female networks.
- Patients may need to be prepared to collect and present research to their doctors to support their treatment decisions.

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- Paul Van Camp mentions finding physicians willing to prescribe off-label drugs, and Glenn Sabin is working on compiling a list of such people.
- Brian McCloskey asks how involved RxSpark gets in the process of accessing biosimilar drugs, and Paul mentions that they identify options for patients and work through the office.
- Rebecca Driscoll shared her experience navigating the complex healthcare system for a patient with leukemia.
- She emphasized the importance of finding the right provider who is willing to work hand in hand and advocate for the patient.

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TRANSCRIPT

Brad Power
This is another weekly webinar of the Cancer Patient Lab.

We're happy to have Deb Christensen from Cancer Help Desk to share her perspective on helping patients navigate cancer care, which is what we're all about at the Cancer Patient Lab.

This is for information purposes only. We're trying to help patients get information that they can take to their medical team. But this is not medical advice. You should review whatever you hear today with your medical team.

The Cancer Patient Lab is a patient-led nonprofit community, and we would welcome any donations that you might be inspired to make.

We've known Deb Christensen and Rebecca Driscoll for ages. They're good friends. They've been doing this kind of navigation support for patients for a long time. Recently, they formed Cancer Help Desk. They're about a year old. Rebecca is the founder and CEO, and Deb is the founder and the leader of the navigation services.

As is typical with our format, she's going to introduce herself, introduce some key messages, lessons learned, insights, how they do their work, the services that they provide. Then we'll reserve the lion's share of our time for questions and answers and conversation to understand how people can access these services and what the services might mean for their care.

Deb Christensen 2:27
The thing that I do in my work that makes it so meaningful is having conversations with people. I haven't been joining the Cancer Patient Lab meetings. I'm going to make amends to that and start attending because I really do like to hear your conversations and learn from you as well. I hope that I can share something today that you, even conversationally, can learn from each other.

A little bit about me. I have had multiple careers in my life. I never really thought I wanted to be a nurse. But my mom went to nursing school. I was doing hair. I was sewing, I was doing all kinds of other things. But following her example and the thought of being able to help people in a meaningful way, I went to nursing school and got into surgical services initially.

Then I wanted to do something a little bit different, a little bit more. I love change. So I applied for a nurse navigator job in oncology. I didn't know anything about oncology. You think that nurses just know the whole gamut because you went to school, or doctors know the whole gamut. But you really focus on your specialty, wherever you are. You learn that really, really well.

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Oncology was a whole new dialogue for me. I learned so much from the people that I talked to. The first two years I learned more from the patients than I learned in any classes or conventions or anything because that's where the meaningful work is done. I was a nurse navigator for breast cancer patients initially. I would go into the chemo suite and talk to three or four people there, and there'd be seven people that I didn't talk to. I didn't like that. I felt uncomfortable, not talking to everybody. So I told the director I wanted to do all cancers. That's what I did for many, many years. I am so grateful to have that experience and not have had a specific cancer specialty. I know a little bit about a lot of different types of cancer and have a foundation for learning from that.

I was charged with standardizing their navigation across the entire system. We had 22 different hospitals. We had seven different nurse navigator pods, if you will, at different facilities. We didn't even know each other's names. We were just working very independently within the region that we were in. Over the course of the next two years, I was able to bring us together and standardize some of the processes across the system.

Then I decided maybe I wanted to retire because it got a little political, and I didn't want to deal with it, truth be told. I retired for six weeks, and it was driving me nuts. So I went to work for a nonprofit. I had never considered that before. It was wonderful meeting people. I met Al Musella through the nonprofit; Brad Power through the nonprofit; Rebecca Driscoll through the nonprofit, other people that come to Cancer Patient Lab I met through through this nonprofit; and had some really successful time there.

Then when they changed directions a little bit, myself, the CFO, and Rebecca, who was the CEO of the company at the time, decided that we still wanted to focus on patients in the now. That's what Cancer Help Desk does – focus on patients in the now, what do you need now at this particular part of your journey? While we want to learn a lot and change the world of cancer, we were wanting to do it one person at a time in a meaningful way.

That's a little bit about me, and about why I wound up here at the Cancer Help Desk.

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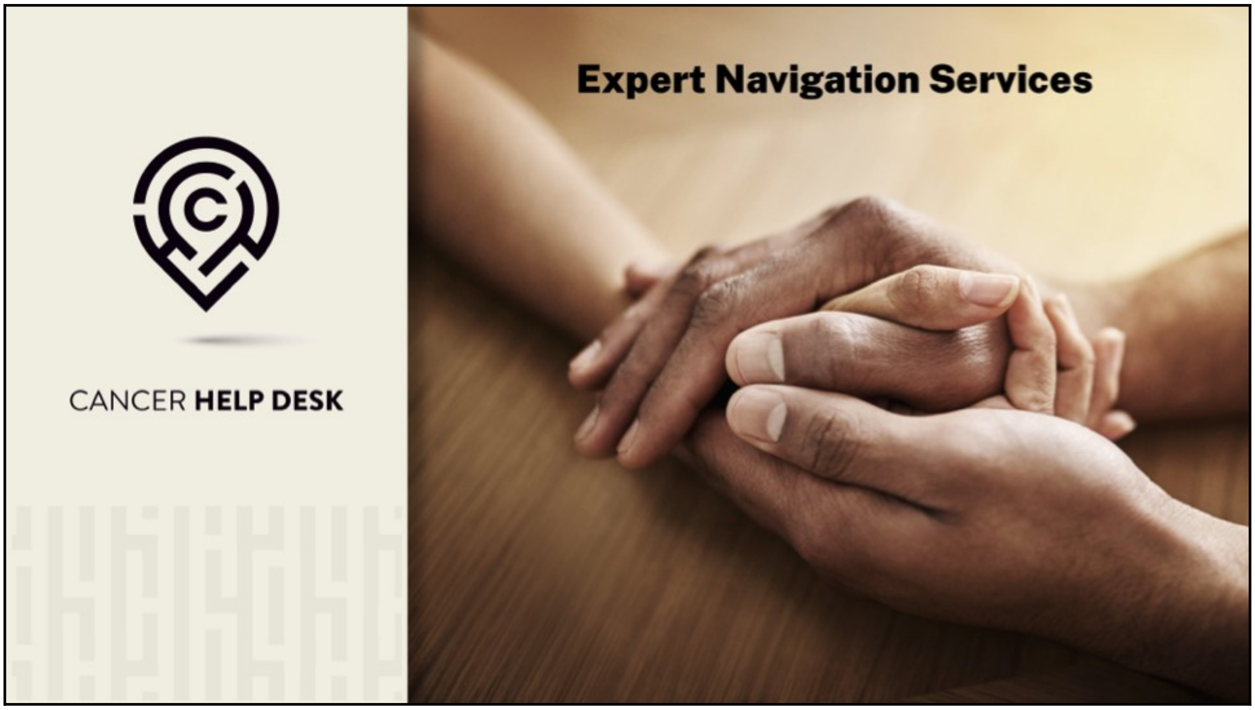
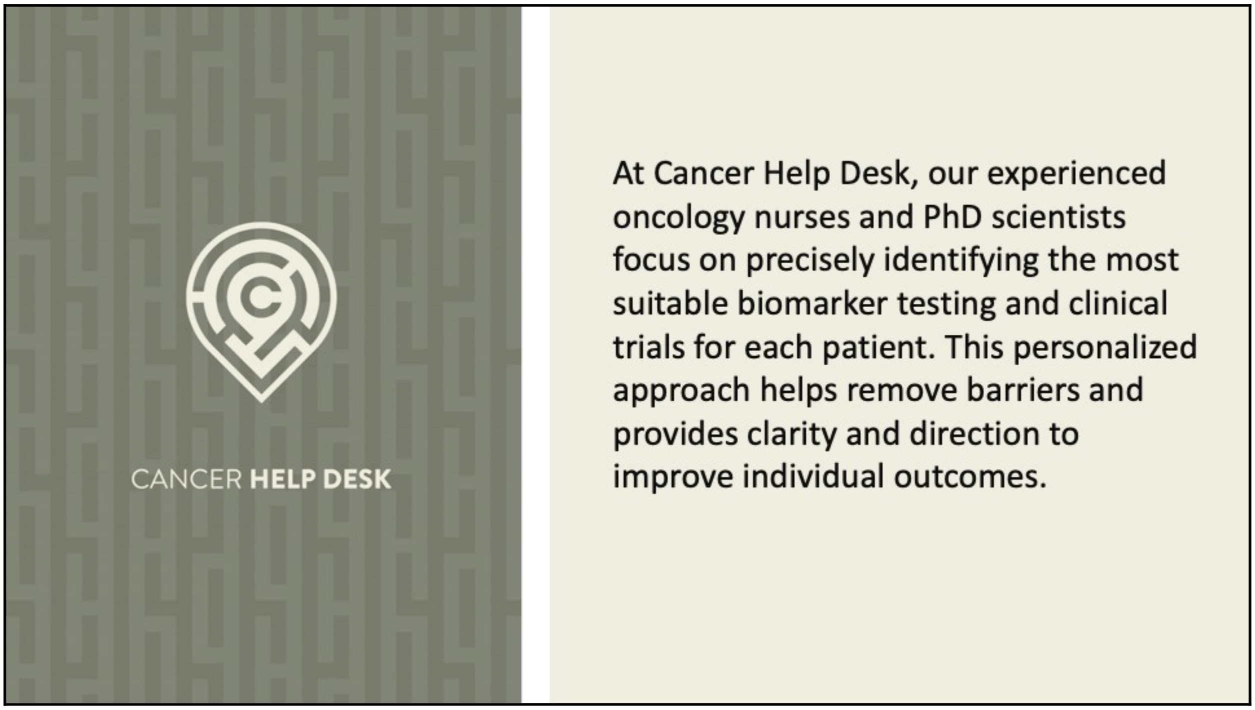


Expert Navigation Services

CANCER **HELP DESK**



CANCER **HELP DESK**

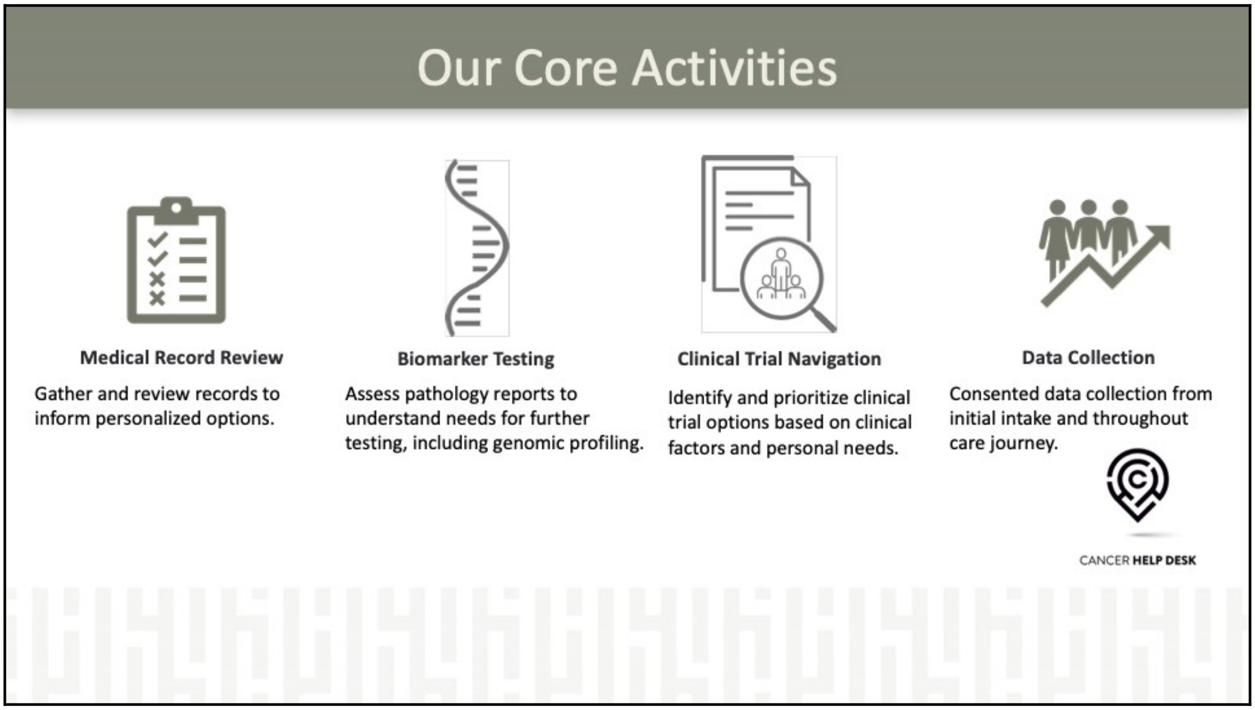
At Cancer Help Desk, our experienced oncology nurses and PhD scientists focus on precisely identifying the most suitable biomarker testing and clinical trials for each patient. This personalized approach helps remove barriers and provides clarity and direction to improve individual outcomes.

At Cancer Help Desk, our unique claim is that we use both oncology nurses and PhD scientists. That was new to me. I had worked with many, many doctors, and doctors are great. They have their ways about them. But working with a scientist was very different – understanding how they saw cancer, recommending different clinical trials, and really focusing on the biology of cancer. I was in the oncology world where cancers were treated as a specific cancer, and this was the treatment. We were just barely getting into the genomics and NGS testing. I was fortunate enough to be with one of the physician scientists that really brought that into our system, and I sat on molecular tumor boards with specialists from all over the country and heard all of these letters and names and tried to figure them out. I took notes. It was a crazy time. Now it seems a lot more commonplace. We use our PhD scientists, as well as our oncology nurses, to help patients identify the most suitable biomarker testing, as well as help them with clinical trials.

As I got out into the nonprofit world, I realized that there were some big gaps that weren't happening. They weren't happening in the system I was in very well, and it was a robust system. I knew that it wasn't happening well anywhere else. That was helping patients navigate clinical trials, and helping them understand what they didn't know. You don't know what you don't know. You get into this experience. It is overwhelming, at the very least, and you don't know what to ask for. The questions to ask your doctor have changed dramatically from, “What is the treatment? What is the goal of the treatment?” To “When can I get my biomarkers done?” and advocating for those biomarkers to be done. Different tests come up as well.

The Cancer Help Desk approach is using both the scientists and the oncology nurses to assist and help patients navigate.

There have been times that I've thought, “Do you really need a nurse for this?” But as I have conversations with people, you really need a nurse for this because answering those clinical questions in real time becomes really meaningful to the person that I'm speaking with.



Our Core Activities

Medical Record Review
Gather and review records to inform personalized options.

Biomarker Testing
Assess pathology reports to understand needs for further testing, including genomic profiling.

Clinical Trial Navigation
Identify and prioritize clinical trial options based on clinical factors and personal needs.

Data Collection
Consented data collection from initial intake and throughout care journey.

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Deb Christensen 10:10
Some of the things that we specifically do. We can gather records, review medical records, and then assess if biomarker testing has been done? Do you even know what biomarker testing is?

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My strategy when I first contact a patient is to just ask them, just have a conversation. Through that conversation, I glean whether biomarker testing has been done, do they even know about biomarker testing, so that I have a good jumping off point to begin educating.

Clinical trial navigation. I'm sure anyone that's delved into clinical trials recognizes that it is very complex. Even when you've been sifted through, and you think somebody qualifies for a clinical trial, there'll be something that falls through. At Cancer Help Desk we really feel like having plan A, plan B, plan C, that you have plans in place, before you need them. Hopefully you won't need them, but you have them anyway.

Then consenting patients for data collection. Helping in the broader scope of learning more about cancer, how to beat cancer, how to treat it, effectively.

Deep Domain and Clinical Expertise

Leadership and Science Team

Rebecca Driscoll
CEO & BoD

Shelley Frisbie
CFO & BoD

Deb Christensen, APRN
CPO & BoD

Karena Kosco, PhD
Scientist

Caitlan Karousos, PhD
Scientist

Board of Directors

Ken Bloom, MD
Pathology Expert

Ramy Ibrahim, MD
Immunotherapy Expert

Diane Dell'Armo
Medical Science

Mike Looney, PhD
Patient & Caregiver Advocate

Susan Martin
Philanthropy Expert

Feroz Mohummed
Technology and Innovation

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This is some of our leadership team. Rebecca, who's on the call, Shelley is our CFO. She's traveling today, or she'd definitely be here with us. Two of our scientists.

I really can't say enough about how they look at a case so much differently than a doctor. They're able to provide an unbiased view. It's a scientific view of the case, versus what their experience has been, because they're not treating. They offer suggestions. For example, I was doing a clinical trial search for a lady that was very interested in immunotherapy. She has ovarian cancer and was very interested in immunotherapy and other types of therapy. Through my search, she did qualify for a few immunotherapy trials. I gave those to her preliminary and then had the scientist review and the scientists came back, and she said, “She's got this mutation, which really makes her cancer resistant to immunotherapy.” That wasn't just not something that I knew. It was something that she shared with me. I was able to take that back and share it with the patient that I was talking to. That was really helpful.

This is our board of directors. We've got a great board of directors, and it's continuing to grow.

Oncology Nurse Advisory Board

Oncology Nurse Advisory Board 2024

Cindi Cantril, MPH, RN OCN, CBCN

Sheila Gwinn, BSN, RN, OCN

Susan Bruce, MSN, RN, OCN, AOCNS

Jessica Brodbeck, MSN, RN, AOCNS

Heather Askren DNP. NP-C, RN, OCN

Hilary Deskins, BSN, RN, BBA

ONS

AONN

ACCC

COA

Rx/DX

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One of the things that Rebecca and I wanted to do right out of the gate was to get an oncology nurse advisory board. I put out a call through the Oncology Nursing Society, and was amazed at the response that we got. These are high caliber nurses. They are all in leadership positions but still wanted to do something in the nonprofit world to assist other people and extend their reach. Whether you know them or not, they are outstanding nurses, and wonderful, wonderful to work with. They help advise us on our programs and on different campaigns and things that we have coming up. They advise us on what things are working in their institutions, or in their oncology world, and what we can implement into the Cancer Help Desk.

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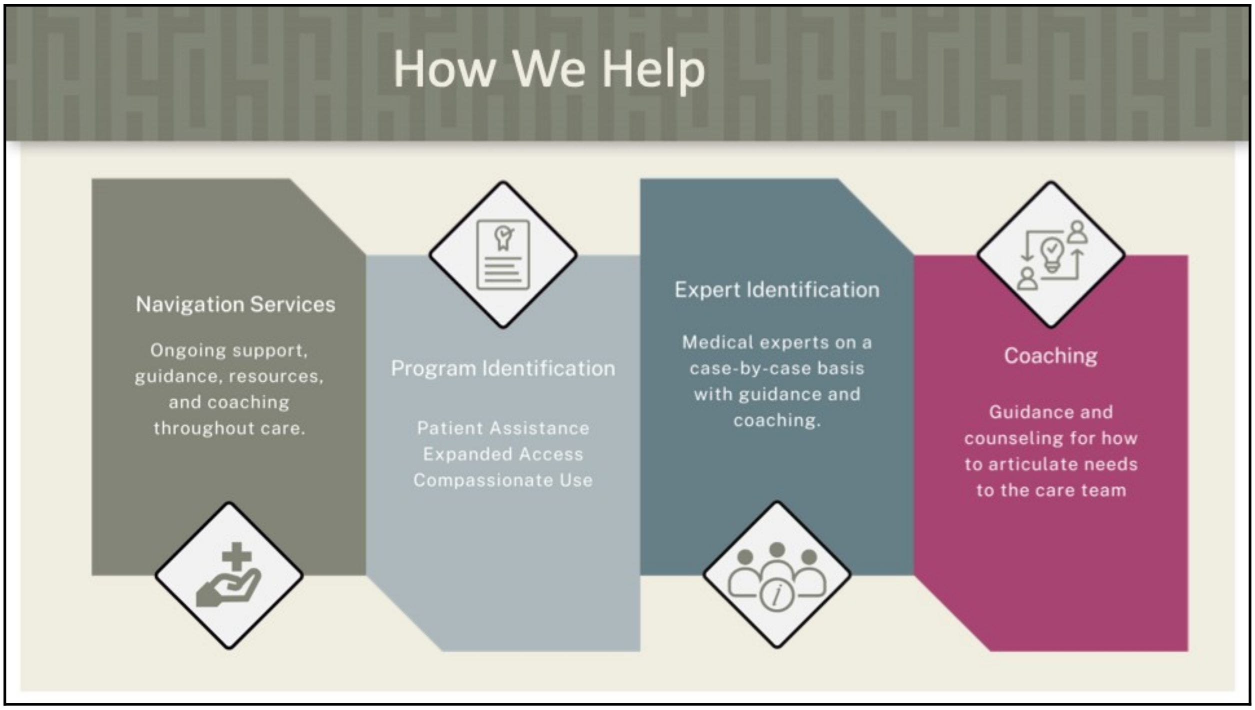


How We Help

Navigation Services

Ongoing support, guidance, resources, and coaching throughout care.

Program Identification

Patient Assistance
Expanded Access
Compassionate Use

Expert Identification

Medical experts on a case-by-case basis with guidance and coaching.

Coaching

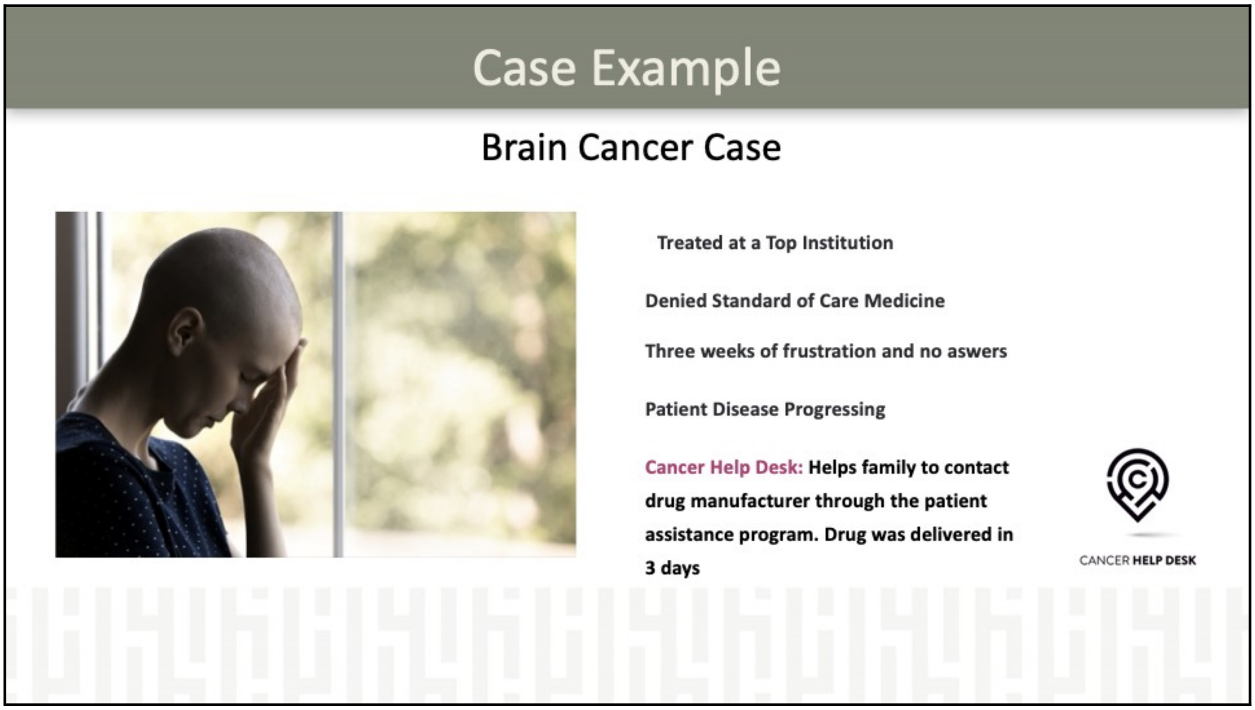
Guidance and counseling for how to articulate needs to the care team

Navigation services, as I said before, is meeting people where they are. That's an overused term. But really, truly, in the moment that you're in, what is the help that you need? Right now. That's what we're able to give through resourcing. Cancer Help Desk doesn't do it all. But we do know companies that do certain pieces of this well. We're not associated with them financially, but we're associated with them because they do a good job, and we know they do a good job. We can provide people with those resources, as well as coaching.

I never thought of myself as a cancer coach, but I'm actually a pretty good cancer coach in the long run. I've been working with a family right now, and we have multiple conversations. She will ask questions about how she should approach the doctor about this. “Would you do this? Would you do that?” I'm very, very invested in the care of their loved one. It's been just a joy to work with her, and help coach her along without giving specific advice. Because it's difficult.

We can identify programs like patient assistance, expanded access, compassionate use, basically the same thing. We can identify those places that can help with that, and I'll share a story about patient assistance in a little bit. One of our board members is a cancer survivor. The most important thing he wanted to know was, “Who's on my team? Who are the experts that I need to have on my team?” At this previous organization, one of our scientists was able to identify his A team. He is doing exceptionally well with this care.

We have a list of specialists that we know are more open-minded. Some of the larger facilities struggle with the open-minded piece of it because they have more constraints based on their institution. Knowing who some of the forward thinkers are in the different cancers, and then being able to suggest those is part of our coaching and guidance. We call it guidance. I think of a navigator as a guide, more than anything else, just guiding you along the cancer planet. I mentioned there's coaching throughout this. I don't know about you, but it always helps me to bounce ideas off of somebody else. That's pretty much why you're here, right? I mean, to talk with each other and have these rich conversations and agree to disagree. But owning your health and owning your journey is so important.



Case Example

Brain Cancer Case

Treated at a Top Institution

Denied Standard of Care Medicine

Three weeks of frustration and no aswers

Patient Disease Progressing

Cancer Help Desk: **Helps family to contact drug manufacturer through the patient assistance program. Drug was delivered in 3 days**

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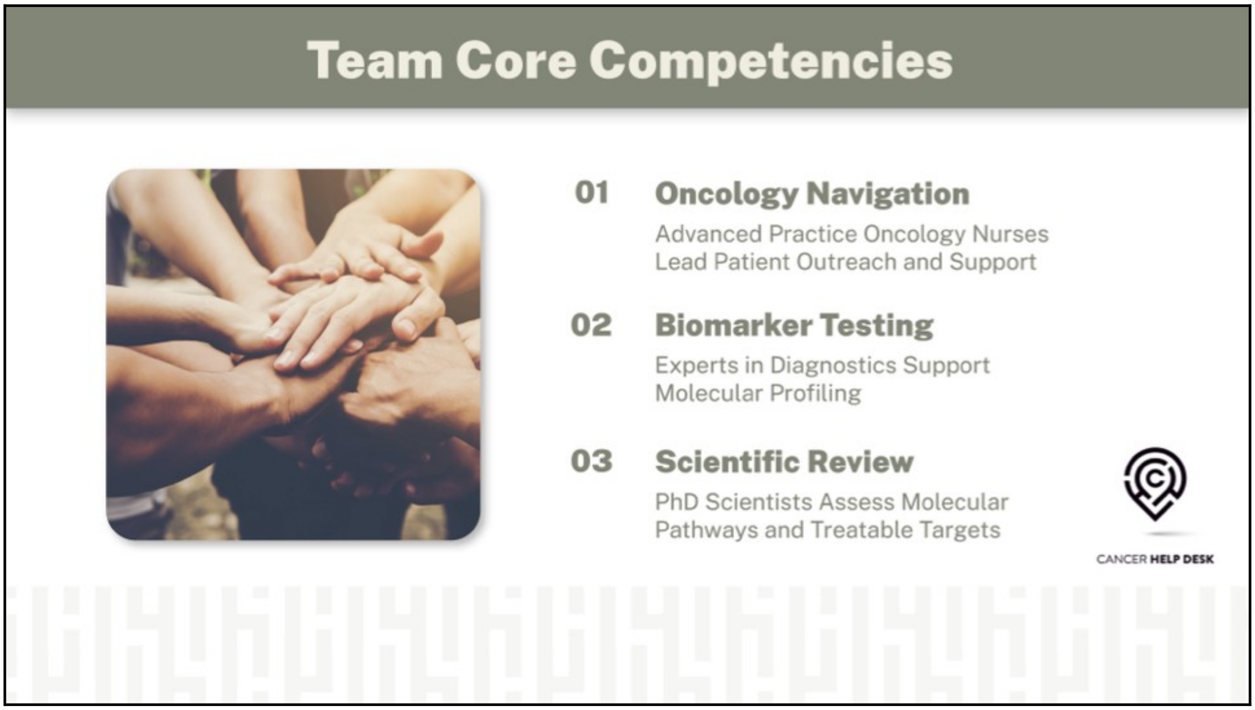
This was a tough case. It was a young gal with brain cancer. She came to us a little bit late in her treatment course. It was a recurrent glioblastoma. She was being treated at a top institution. The mother was in a lot of conflict about what to choose for her daughter. We started the conversation, and then she preferred texting. She was texting me and sending me this different information about her daughter. And she says, “Can you believe it? This institution wants my daughter to be treated with the generic. The biosimilar of – I believe it was Avastin. But that biosimilar had never been trialed in pediatric patients. The mother wanted her to have the standard treatment. They had appealed. The office had appealed a couple of times. I just thought to myself, it had been like three weeks, and they weren't getting anywhere. The little gal was getting sicker. It was tough. I thought, I'm sure this institution has reached out to patient assistance. I'm sure they have, but I'm not going to assume anything. I'm going to ask, and so I sent the application. I said, “I'm sure you've already done this, but you may be able to get free drug from the drug company, which was the case. They had not done it. They did reach out and the drug was delivered within three days. Unfortunately, it wasn't in time. The disease had progressed. It was unfortunate, but it was one way that showed us that you should never assume anything and turn over every stone, as you move through this and make sure that these things have happened. Because again, we're going to come back to: you don't know what you don't know. You don't know if there's a patient assistance program. Nobody told you there was a patient assistance program that you could actually possibly get free drugs from.

Another question that I get sometimes is, “Is it okay if we have multiple organizations?” Absolutely. You should involve whomever you're feeling that you're being supported by and getting helped by. This isn't a competitive world here. In our book, we just want to help in any way that we can.



Team Core Competencies

01 **Oncology Navigation**
Advanced Practice Oncology Nurses Lead Patient Outreach and Support

02 **Biomarker Testing**
Experts in Diagnostics Support Molecular Profiling

03 **Scientific Review**
PhD Scientists Assess Molecular Pathways and Treatable Targets

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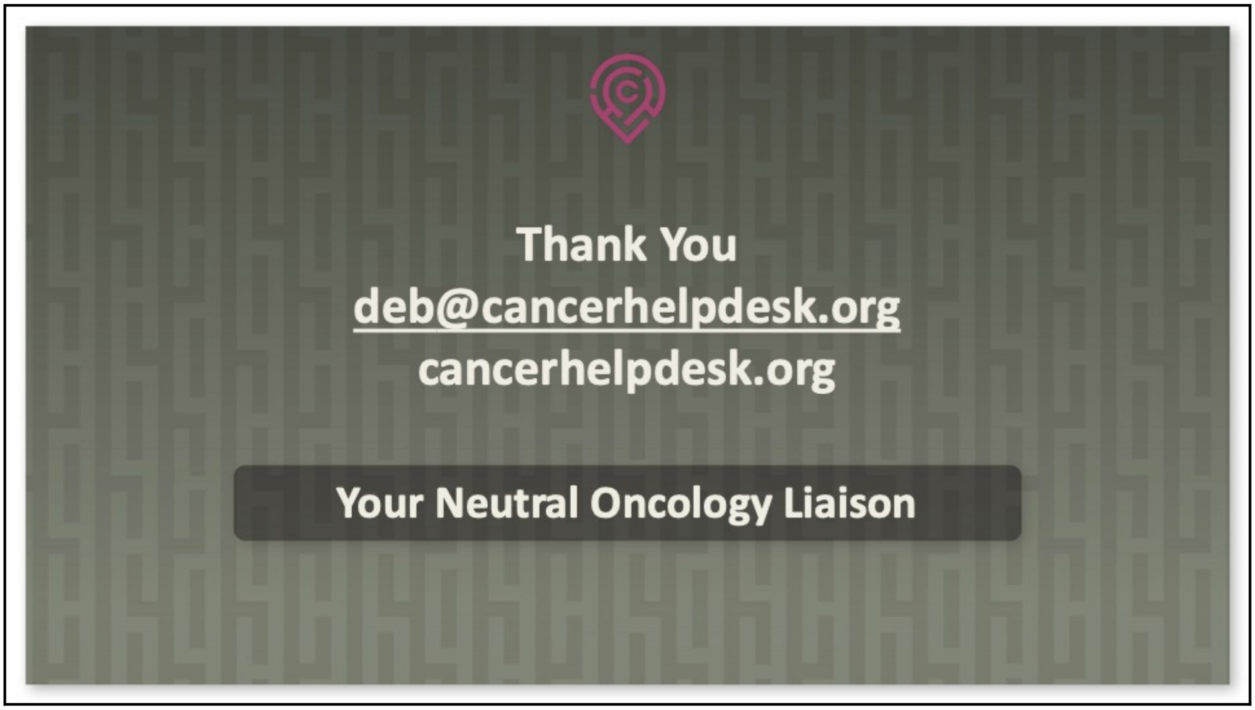
Deb Christensen 20:01
In summary about Cancer Help Desk and how we work. Again, we were founded by three females that are passionate about helping people in the moment, using oncology nurses to be the first point of contact. When they visit our website cancerhelpdesk.org, they can schedule an appointment right away, to have me give them a call. It's a convenient time for them, it's a convenient time on my schedule, and I'm the first person that they talk to, to really get that assessment. Then our experts in cell signaling biomarkers, our scientists, can really help and then the scientists can review the entire case. That is the main crux of our services.

Navigating clinical trials – what we found to be helpful based on what people have said to us is that Cancer Help Desk will contact the clinical trial sites after helping with our scientists and nurses helping triage these lists of clinical trials that maybe you've received from an NGS report, biomarker report. Maybe you've received it from another organization. Maybe you've researched them yourself. We help you to prioritize those for you. Then we can reach out to those clinical trial sites on your behalf and get more information. Oftentimes, people when they're ready to do clinical trials are just not feeling their best. So it's nice to have somebody to be able to do that legwork for them. That's another thing that we offer.



Thank You

deb@cancerhelpdesk.org

cancerhelpdesk.org

Your Neutral Oncology Liaison

Rebecca, I don't know if I missed anything that you want to add.

I would love to hear your experience of navigating your own journey. Maybe that's a little selfish for me to ask, since I haven't been attending the meetings, and what you found really helpful and what you found more discouraging. I would be interested in that.

Brad Power 22:19
Rebecca, was there any color you wanted to add?

Rebecca Driscoll 22:41
No, that was great. Deb.

I guess the only thing I would add in regards to the PhD scientists, since we've got expert patients here, is the expertise that our PhDs hold are along the lines of cell signaling pathways and tumorigenesis, to biomarker investigation and discovery. They cover the gamut of understanding the biology at the molecular levels. That is important, and we've seen some really interesting input from them, especially from one of the scientists that does cell signaling pathways and tumorigenesis. It's really interesting to have her input because she understands tumor evolution, especially when you're thinking about the endocrine system. Take that into consideration when we just talk about a PhD. We look for PhDs that have unique understandings and training around different parts of cancer.

Paul Van Camp 24:01
My background: I was diagnosed in 2007 with prostate cancer, proven to be advanced within a couple of years. I went to my local hospital where I was just discharged a week ago. They have

a great cancer center. They had a navigation program for breast cancer in place, which was highly regarded and an excellent model. I studied that and saw how great it was for the patients to have access to an educated viewpoint to guide decision-making and navigate emotional support and other needs and integrate them into an individual's case. I said, “Why is this only available for breast cancer?” So I joined the board of that organization, and we transformed it into every cancer, every gender, every age. Everybody is eligible for navigation for their cancer, and that's not cancer-specific. I'm a little suspicious of the cancer-specific model. I'm an advocate for the universality of support for cancer patients.

There's a couple of things that arouse my curiosity. One was with your example patient who was denied standard of care treatment. That is really weird. Because of what we encounter usually, and especially really frequently in advanced prostate cancer, where I am deeply immersed all over the country. At the top institutions they're not allowed to even consider any therapy or an avenue of approach which is not established as the standard of care. They can be fired from their MD PhD senior staff position if they suggest considering something that's outside of the standard of care. This can be an enormous obstacle. Then we see patients needing to leave these institutions and establish care at more enlightened institutions. The standard of care is always changing. It's a vague amorphous thing that very, very slowly moves towards inclusion of best evidence and practices. But it's by no means the end all and be all. Just wait a year, and you'll see it has changed. So that's something that again, I'm suspicious of, and ready to challenge, and this has been our experience.

The next question I have is about your PhDs scientists. Who do they work for? What is their research focus? For what do they get paid? Because if they're not also clinical oncologists working on the front line, how do they integrate the scientific knowledge into what's best for this patient today, which is your focus? Because a lot of times they have an ax to grind. They want to pursue their own specialty of research, which may be much more broad, and biomarkers that have not yet proven themselves to be applicable for decision-making today. So how do you keep the focus on educated experienced care of the individual patient, and not get diverted by this?

I'm curious about how many of your board members actually work for Cancer Help Desk, and how many are working somewhere at other institutions? Are they volunteering and throwing their expertise in, which is great? But how devoted are they to picking up the individual patient at the inception, at the intake, where you are? And then say, “Okay. Here's where we start, and how we proceed.” A lot of which you relayed about analyzing medical records and pathology reports, and then biomarker analysis is great. I would just have questions about whether the focus is kept on the individual patient throughout the whole process.

Deb Christensen 28:54
I'm going to answer just that first part of the second question, and then I'm going to let Rebecca talk about our scientists a little bit more.

In that particular case that I was talking about, that insurance company didn't want to pay for the initial drug that was used, say, Avastin. They didn't want to pay for that. They wanted to use a biosimilar. It's a similar drug, but cheaper. It wasn't a change in the standard of care, per se. But the biosimilar drug had not been trialed with pediatric patients. This mother was a huge advocate for her daughter. She wanted her daughter to get the drugs that had been trialed in pediatric cases. If I alluded to the standard of care piece, I'm sorry about that. It wasn't that it wasn't standard of care, but it was that the drug was generic, not the brand. It was a biosimilar. You will find a lot of insurance companies are going in that direction too because they're cheaper.

I don't know that I mentioned that Cancer Help Desk is a nonprofit. We have a lot of people that are supporting us while doing other things as well.

We have to come back to the point that we aren't telling people what to do. We are empowering people with information to take back to their oncology team – similar to Cancer Patient Lab. So here's this scientific, unbiased information – biased by science, I guess. But science to me is about as unbiased as you can get as you can be a little bit black and white. Taking that information back to your oncology team, informing your decisions.

I'm working a case right now. There are so many different opinions, so many different avenues to take, it's so difficult and challenging for the people involved with this case to be able to make a decision for their care. Sometimes it can be a little bit challenging for people to get a lot of different opinions. The science helps to sift through that by giving the scientific perspective.

Do they stay focused? Do they do other things? Yes, they do. They have other roles and other part-time jobs as well. We charge for the scientific review. But it's minimal. It's only really enough to cover the price of our scientists. That's why we wanted to be a nonprofit, to not be in the business of taking money or not need support that would bias our decisions. That's why we feel like we're a neutral oncology liaison for people. Does that answer the question?

Paul Van Camp 32:26
Yes, to a degree, thank you for that.

When we're looking at talking to experts, we're talking about who are the very best clinical oncologists in the country and in the world, who are actually creating the clinical trials based on the best available emerging information, and following through and then refining them into the next generation of trials. The top docs in the field, and usually for a specific cancer, sometimes multiple. Those are the people that we want to hear from, and discuss, and have consult on our own cases; not somebody who is a PhD scientist, and is working in the field of immunology, and you've got this vast array of topics, but how has it been applied to human beings with this diagnosis at this stage? If they can’t address that, then I would say, “Thank you very much for your service.” I try to find that other source, that is so informed that they can say, “No. This is a much better avenue to explore,” whether it's a clinical trial, etc., than this or this or this, and that requires a degree of experience and knowledge and judgment, which is extraordinary. It's not common.

Brad Power 34:05
Building on Paul's question, how does it work with your relations with the patient’s medical team? On the one hand, they could view you as a great asset, who's going to come up with ideas. On the other hand, they may be trying to move down a path, and you're disrupting their progress. You educate the patient on things that they should bring to their medical team, and then arm them with the information. What are the sources of evidence that would be persuasive to that oncologist who you're asking to change, perhaps, the path they were headed down.

Can you describe a little bit about those dynamics?

Deb Christensen 35:03
Yes. It works both ways. It depends on the provider. We have worked with doctors that are very collaborative with us. Those doctors tend to be the ones that are more cutting edge, that want to do different things. I have had situations where a doctor was very upset. I had to apologize and talk with them and say that we weren't trying to necessarily instruct the patient on doing anything specific. It was more that we knew that they were in control. It's a moving target in how we present ourselves and the information to the patient. All of our reports, anything that we give, stresses, “Talk with your oncology team. They're your quarterback. We're here to arm you with information to share.”

Brad Power 36:09
Building on another point that Paul was raising, is around your business model. You’re a nonprofit. You've got staff, and I guess they're part time. Can you describe a little bit about how your business model works? In order to access your services, presumably, you're making nominal charges.

Can you talk a little bit about your fee structure and how patients access your services?

Deb Christensen 36:45
The first two and a half hours of any service that people call us for, there's no charge. For that we want to establish the relationship. We want you to know if we can do the job that you need us to do. We can accomplish quite a bit in two-and-a-half hours. We can provide personalized resources, as well as some preliminary clinical trials, and then introduce the scientific deeper dive. We help you navigate clinical trials, whatever type of service it is that you need. Some people want just navigation. They just want to have a navigator at the ready. We just try to cover our costs for those types of services.

We have a fee structure for organizations and for physicians that want navigation for their patients. They are similar to a cable company or something where you have different divisions of service, and you add on more service. We have four levels of service that we offer to organizations. We're allowing our patient contact with us to grow organically, and focusing on the expert navigation and scientific review to companies. We are working with a company that needs a nurse to answer questions that are coming in on a diagnostic test that patients want to know more about. They don't want to hire a full time nurse. They've hired Cancer Help Desk to help with that. They pay us so that we can offer our services at a lesser cost to patients.

Rebecca, I want you to talk to that a little bit because I am not really smooth on the whole business model. I just like to talk to people.

Rebecca Driscoll 38:48
Our goal is, if we could, to serve every patient at no cost. That's our goal. That's not realistic at this time. We are mostly self-funded today. We raised very little in the amount of donations just like Cancer Patient Lab. We submit for grants, sponsorships, the typical nonprofit route.

Then to Deb's point on working with companies – we know the complexities. For example, I know that you guys have talked about BostonGene. We're not working with BostonGene, I'm just saying that there are complexities around what they offer. It requires some of that additional input from scientists and oncology nurses. How do we apply this back to the clinic and what's going on with this patient right now, in this moment? That's a service where we're able to work with companies because they don't hire staff like us. That's an area that we're really focusing on to help patients navigate through some of the complexities around these tests. Being able to talk to them with their clinic or even getting access to that test. BostonGene is a great example. There are plenty of physicians saying, “I'm not going to order this test.” How do we help the patient get access to that test, talk them through it, and then help provide the logical steps to get there to where it's not threatening to the physician? We can help that patient get what they need. That's an area where we know that we're providing added value not just to the patient, but to those companies. That's where we're making, hopefully, some money to cover our costs for our time. It's expensive to have oncology nurses and PhD scientists. I'm sure you all know that. That's our goal, and to continue to offer the services at no charge to patients.

Brad Power 40:55
What is the profile of the ideal patient or caregiver who comes to Cancer Help Desk? If I'm a patient listening to this, or reading this, what would my profile be, so that I would say, “I'm really the right one for using your services”?

Rebecca Driscoll 41:20
It used to be that in our previous organization, we really were supporting late stage patients. Our goal is to get it earlier and earlier, because we know that there's a lot more that can be done earlier on in the disease. We're really helping anybody. I wouldn't say it's a very specific profile of a patient. As we continue to grow, we'll bring on other PhD specialists. That's why we're diversifying our board and doing some unique things to make sure that we really can provide that support. But I wouldn't say that we've said, “We've got a specific profile of a patient.” Do we tend to get later stage patients? Yes. Now we're starting to get some earlier stage patients. So I don't know.

Deb: Do you have another answer to that?

Deb Christensen 42:18
We were very thoughtful with our name, Cancer Help Desk, to be inclusive of anybody that needs help. I'll keep going back to the fact that we want to help people with what they need in that moment. We know that the journey changes. As it changes, we want to be there with their needs as well as with what they need. Anybody can benefit from speaking with someone, having a conversation. Sometimes I offer very little in the way of information. Most of the time I listen, and maybe ask some thoughtful questions. People will say, “You have been so helpful.” They'll just gush on about it. I'll think, “Have I really been that helpful?” But having someone to talk to, someone that validates their experience, can make a lot of difference.

Jeffrey Dwyer 43:31
I've learned a lot from Paul, and other patients, through internet advocacy for prostate cancer. When I started out on my prostate cancer journey five years ago, I knew nobody who had prostate cancer. Nobody. So I started looking. Eventually I got on to three of four online advocacy groups. You read the postings, and you start saying, “I'd like to talk to this guy.” or “I'd like to talk to that guy.” or “I don't agree with this one.” But if you post it on there, you get into a pissing contest with them online, so you don't do that. So I built up a group of about two dozen men from around the world that I contacted, and they contacted me back, and they were the most helpful. Paul was one of them. I would ask them practical questions.

When I ran up against the standard of care roadblock Paul mentions, I asked my physicians about something that I learned online from a patient somewhere. They said, “Oh, no. That's not our standard of care.” And then I had to say, “Well. What the hell is standard of care? Why can't we even talk about this, if it's not standard of care?” Then you have to find out what the standard of care is. Then you realize that there's a lot of financial, institutional, and professional blocks between you, the patient, who's just trying to learn about what people are using around the world, not just in America. So we learn that stuff. Then we realize that there are roadblocks.

I was interested when you were talking. I said, “What do I need right now?” I'll tell you what I need right now. I need a medical oncologist physician who will order me various transdermal estrogen – either hand me the prescription, or tell me how to get it worldwide. Because when you try to get the estrogen in the United States, you are blocked from it. You cannot get it. So that's a problem. I need that right now. I tried to find it myself through the narrow paths around the country. But certain narrow paths can't write prescriptions in different states. It's all controlled statewide. So in Massachusetts, they can't write a prescription, but they can in Vermont. Or when you go to Vermont, which is an hour drive for me, you find that, “Oh. I don't want to take you on because you're a Massachusetts patient. I'm nervous about that. So thanks for calling.” (We'll never see you again.) So you start that hunt to find a particular medication you want, because when you talk to your center of excellence facility, Mayo, whatever they are around the country, they are not anxious to talk to you about anything that is off-label or non-standard of care.

So that's what I'm looking for now. And it's hard to find, because when you do find them, those urologists, those oncologists, very few of them are not now affiliated with major institutional, either academic, or non-academic, facilities. And like Paul said, their jobs depend on it. They don't step out of line at all. Because if they do, they are threatened by their institutional legal staff, or their insurers are really the big ones – the medical malpractice insurers.

So you're out there on your own. You really are, unless you want to do standard of care. In some situations, you do not want to do it. I can tell you right now, on ADT drugs for me, my comorbidity that Paul mentioned, is open heart surgery. I had five bypasses less than two years ago. As soon as you start to read the side effects of ADT (androgen deprivation therapy), besides osteoporosis, besides pre-diabetic, besides a lot of things, you realize, there's some alternatives to that. One of them is transdermal estrogen, but you have to try to find it, and who's going to monitor you? How do you get your blood tests every month to make sure that you are not exceeding the limits? So it's a big deal. And if you're looking to get paid for that, and I'm your customer, you have to tell me how you're going to do it before I write anybody a check ever. Because if it's coming from Medicare, fine. If it's coming from Blue Cross Blue Shield, fine, because they have been paying all my bills. But I have to get any bill that gets paid by Medicare approved by Medicare. Blue Cross Blue Shield won't pay anything that Medicare won't pay.

I wonder how these patient navigator groups that I read about and follow up with are going to do something that I'm having trouble doing on my own. Maybe they've got openings into different groups, but usually it's not a PhD scientist. It's getting paid by an academic institution, because they don't want to go near anything that's off-label.

Deb Christensen 50:03
You have a point there. What you're asking for wouldn’t be something we would be charging for anyway. It doesn't fall within our service scope, necessarily. If you call me today and tell me that that's what you need, I'll spend two-and-a-half hours networking with my network to see if we can find something like that. If we can't, we can't, and I'm sorry. You're not out anything really one way or the other. So I would love to take that on.

Paul Van Camp 50:41
It's such an important point, that you have to be your own advocate to such a degree. You have to be a hunter. If you've decided, you've researched this, and transdermal estrogen is going to be a benefit for you and far, far outweighs the harms, then, yes, you need to collect the research and print it out and have the reference and be prepared to take it to your doctor and say, “Okay, if you're not giving me this, then you're putting me at risk.”

Challenge the doc, whether he is a medical oncologist or not. You may want to end up changing doctors, like I did. I had my first medical oncologist when I was starting chemo. I wanted to ask him about nutritional support for it using phytochemicals with some reasonable evidence that helped with prostate cancer. He wouldn't even have the discussion. He said, “No. I don't do anything that's out of the NCCN guidelines.” meaning the standard of care. And I said, “I have those on my computer and can read them myself. I know what they say. So if that's all you're going to do, what do I need you for?”

Jeffrey Dwyer 52:06
I had the same thing, but mine started with proton beam services. I asked my physician for a referral to a proton beam facility. They would not do it. That was my first. So I left them. We'll see. Now I'm on my own.

Paul Van Camp 52:30
For your estrogen, you may have to look further and wider. Maybe you have already. Maybe a naturopath. If you go to a naturopath, don't even mention prostate cancer. You need this for your osteoporosis and your cardiovascular risk. You just keep it in a separate box.

Or if you have a significant supportive female in your circle or in your family who's of menopausal age, maybe they can get a prescription. I'm not saying to do that. I can't advise you to do that. I don't practice as a physician anymore. I can't prescribe, but I can say, “Hey. Here's another avenue that I personally would consider pursuing.” Sometimes these advocacy groups online, like this one in particular, but also Health Unlocked in advanced prostate cancer, the main lobby may not be good for broad questions because you will get too many crazy ideas from the fringe. But if you say, “How do I get transdermal estrogen? I'm having trouble getting it.” You're probably going to get 20 really good ideas from all over the world about how you might pursue that.

Jeffrey Dwyer 53:53
That's how I got what I've done.

Brad Power 54:01
To underline this, what we're talking about is finding physicians willing to prescribe off-label. Glenn Sabin, our good friend, is working on trying to compile a list of such people. So, Jeff, we could point you to ask Glenn if he might have any ideas for you. I'm sure, Rebecca, you run into that all the time as well.

Brian McCloskey 54:31
We're talking a lot about access. To bring it back to the case that you mentioned with the woman that you helped find a biosimilar drug: How far do you get involved in that process? You mentioned that you identified an option for that person or that family to follow. Do you actually make the calls – from a very tactical level? I'm just curious how involved you get in that, because access, as we just talked about here with Jeff and Paul, is a really tough thing. I went through it recently. It's very time-consuming. There's a benefit to the patient, if somebody else can take that ball and run with it. Because if one avenue doesn't work, then we need somebody who's got the knowledge to figure out, if plan A doesn't work, we'll try B, C, D, whatever, so that this patient doesn't have to worry about it.

I'm just curious how involved you get in that whole access challenge?

Deb Christensen 55:41
In this particular case, I needed to work that through the office. I worked directly with the office personnel on getting them the application, what the doctor needed to sign, what they needed to do. As a navigation service, we can navigate the patient to that. I think Reagan Udall is another avenue that people can do now. “Do you want me to fill out the paperwork? I could fill out the paperwork. We could do that.” That's part of a patient-to-navigator type of thing, and I’m happy to do that. Unfortunately, not everybody has the means to do that. Looking for how involved can we get. Sometimes I get overly involved because I make a connection, and I can. I'm at retirement age, and I can do that. It's not all about money for me.

I agree. It can be totally frustrating. Sometimes you hit a brick wall. I hate that. That's probably the only thing I really dislike about this work is when I hit a brick wall, and we can't figure out a way to go further. Of course, I shared a story where we were successful.

I was working with a gentleman that had leukemia, and he wanted a compassionate use on a drug that the company was not offering. We had to work through different avenues. He had to work with his doctor as well because the doctor had to prescribe it. They were willing to prescribe it before we could get much further. Sometimes it definitely is about finding the right provider that can work hand-in-hand and that's willing to work with you. I've met some extremely brilliant doctors recently, but unfortunately the price is a little out of range for many people.

Brad Power 57:57
Thank you very much for sharing your experience and points of view.

Any closing words before we wrap up?

Deb Christensen 58:11
I want to thank you all for your comments, your questions, and your thoughts. I will reflect on those and appreciate the opportunity to speak to you all and share some time.