Pancreatic Cancer Demystified

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Pancreatic cancer, signs and symptoms, disparities, genetic testing, clinical trials, patient services, treatment options, early diagnosis, patient advocacy, caregiver support, pancreatic cancer action network, somatic mutations, germline mutations, pancreas cancer center of excellence, patient education.

SPEAKERS

Dr. Colin Weekes, Fatima Zelada Arenas, MA, Camille Pope, Pamela Jackson

Camille Pope 11:25:57

Hello everyone, and welcome to today's webinar. Pancreatic cancer demystified. My name is Dr Camille Pope, and I am the Chief Medical lead at NOWINCLUDED, powered by Acclinate, where our mission is to empower communities to take actions for better health. And today, what we want to talk about is all things pancreatic cancer, so that you all our community members, can understand the signs and symptoms to look for, to understand some of the disparities that exist when it comes to pancreatic cancer diagnosis and treatment, and also what resources are out there for you as a patient, as a caregiver or community member or healthcare provider who is just interested in learning more and what resources are available to you. This webinar is being brought to you by again, NOWINCLUDED, powered by Acclinate, in collaboration with our amazing partners, the Pancreatic Cancer Action Network, also known as known as pancam. And so I will be moderating, but we have some amazing panelists joining us today, and so I would like to go ahead and allow them to introduce themselves, and then we'll just jump right in with having our discussion. So first we have Dr Colin weeks,

Dr. Colin Weekes 11:27:21

Hello, everyone. I'm Colin Weekes. I'm a medical oncologist, and I lead the pancreas cancer program at Massachusetts General Hospital in Boston, I've been taking care of patients with pancreas cancer for the majority of my career, and have focused on developing new therapies for pancreas cancer. It's really wonderful to be with you today.

Camille Pope 11:27:44

Wonderful thanks for being with us. Dr weeks, and then next we have Miss Fatima. Zalada arenas,

Fatima Zelada Arenas, MA 11:27:51

Hi everyone. Thank you so much for having me. My name is Fatima, and I'm the Senior Director of our Patient Services program over at pancan, and I've been with pancan for almost 15 years, working closely with patients and caregivers and others impacted by pancreatic cancer, and love the work that we do. So I'm so happy to be here today.

Camille Pope 11:28:10

Nice to have you. Thank you so much, Fatima. And then last, but certainly not least, we have Miss. Pamela Jackson,

Pamela Jackson 11:28:17

Hi, good morning everyone, or good afternoon. Pamela Jackson, I am a 13 year thriver. I'm also the chief compliance officer for mission, health care, home health and hospice. Awesome.

Camille Pope 11:28:33

Thank you for joining us, Pamela, so let's get started talking about signs and symptoms of pancreatic cancer. So you know Doctor weeks pancreatic cancer is often called like a silent killer, because the signs and symptoms can be pretty vague, and we know that it's often not diagnosed until it's in the late stages. So can you talk a bit about some of the signs and symptoms that patients, or, you know, not a patient, to diagnose, but signs and symptoms that we might want to look out for that might indicate that pancreatic cancer may be an issue? What are some of the things that you should know about?

Dr. Colin Weekes 11:29:11

Yeah, so I would say first of all is that pancreas cancer most commonly occurs in patients in their 60s and 70s historically, although one of the trends that we're seeing currently is that it's it's occurring in younger patients more more commonly. And so when I say younger patients, now, I'm talking patients in their 50s. More commonly, you know, it's a genetic disease that occurs over time. The symptoms that patients generally experience can be anywhere from a. Unabating abdominal pain, and usually it's in the upper abdomen, kind of, across the middle of the upper abdomen. Patients can also have back pain as

well, and that back pain is usually the upper back kind of between this scapula, and that's due to where the pancreas sits in the body. And then patients can also experience profound fatigue, night sweats. In terms of eating, they can lose the desire to eat or become full earlier they normally live when they eat a meal that ultimately can result in weight loss, sort of for untold reasons. And patients can also experience fevers, night sweats as well. And then it's pretty it's so there's two things that sort of can happen with pancreas cancer that patients can also experience. So because of one of the roles of the pancreas is to regulate your blood sugar. Patients who have diabetes and have had a historically well controlled diabetes. Commonly may have lack of control of their diabetes sort of prior to being diagnosed with pancreas cancer. And it's also common that patients who don't have diabetes develop glucose intolerance, so they have high levels prior to being diagnosed with pancreas cancer. Another role the pancreas is to regulate how you digest your food, and so some patients can also experience abdominal pain and bloating after they eat, as well as frequent loose stools after they eat as well, and that's due to the lack of enzymes that the pancreas produces when you when you digest your food. And then, I would say the third sort of symptom that's once again, an associated problem is that patients with pancreas cancer have a high propensity to develop blood clots, and so sometimes patients can develop swelling in one or both of their legs, and then when we evaluate that swelling, we'll see that there's a blood clot. And then we look a little bit further, and we'll see that they may have pancreas cancer. They can also have the same blood clots in their lungs, so they could present with shortness of breath, coughing, fevers associated with that as well.

Camille Pope 11:32:12
Thank you. Are any of those symptoms more common you know, at earlier stage disease, or all of those more common in later stage pancreatic cancer, like, what are some early signs that people can look out for? So maybe they're able to catch it or get checked out before it gets too advanced.

Dr. Colin Weekes 11:32:31
Yeah, I think those symptoms kind of all kind of happen throughout the disease. One thing I did, I did, I failed to say, is that sometimes patients will just turn yellow. They'll notice that the whites of their eyes are yellow. Their skin may itch. Their urine may turn very dark brown. Classically, it's described as being tea colored urine, and that's because of the tumors blocking the bile duct system, which drains the liver. So the symptoms that patients experience with pancreas cancer have to do with, you know, so for example, if they're if the tumors are blocking the bile duct system, that can be an early sign of pancreas cancer, but can also be a very late sign of pancreas cancer. So these, these signs and symptoms, unfortunately, are not associated with any sort of stage of the the disease, and which is why, unfortunately, most patients do present with advanced disease at diagnosis I

Camille Pope 11:33:25
see. Thank you. Well, Pamela is our patient thriver on the panel. Can you tell us a bit about your experience when you were diagnosed? Were there signs and symptoms that you noticed, and what was it like as you found out that you were had pancreatic cancer? Yes.

Pamela Jackson 11:33:48
Camille, so my story is kind of interesting. I was actually pregnant. I was in my third trimester, and my initial symptoms were I had a radiating pain going across my stomach, so my husband and I thought I was going into labor. I went to the hospital, and they started checking me, and then I threw a file, and they said, No, this isn't labor. There's something else going on. They ran test my lipase and amylase were elevated. And so when that happens, the way they treat that is, you go into the hospital for several days and you receive IV fluids. So I received IV fluids that time, maybe three or four for three or four days during that last trimester, I was admitted to the hospital an additional six times with pancreatitis and same thing. So I was on IV fluids each time, three. Or four days. Once I had the baby, I had an endoscopic ultrasound, and that endoscopic ultrasound did not show anything. And at the time, Norco was freely given. So I had maybe 3060, 90 day supply of Norco, I would have pain that radiated across my stomach at times. So I would, you know, take a Norco because the test didn't show anything. I was in Florida traveling for business, and I went to Disney World. And at Disney World, I, you know, popped a Norco and did the little excursion that I had signed up for, but I was in so much pain, I told my husband, I don't I'm going to come home early because I'm in a lot of pain. And he said, No, I want you to go to the hospital there in Florida. So I went and they ran tests, and they thought it was pseudo cyst, and it turned out to be Astin or Astin or carcinoma. But the saving grace for me, I think, is the tumor was positioned where my file, the flap couldn't open, and so that's where my excruciating pain was coming from. So fortunately, they were able to identify that, and from there, I had the tumor removed. Wow.

Camille Pope 11:36:12
Thank you for sharing your story. So it sounds like there were a couple of misdiagnosis before, you know, the physicians finally figured out what was going on. But then also, you know, the fact that you were pregnant kind of complicated things,

because you didn't know if you know, am I pregnant, or is it, you know, is it going into labor, or is it something else? And then you also mentioned a specific type of pancreatic cancer. So I'd love to hear from, you know, anyone on the panel who would maybe like to talk about the different types of pancreatic cancer, and you know, maybe the differences in signs or symptoms, or even, you know, the ability to treat those different types of pancreatic cancer, yeah, I

Dr. Colin Weekes 11:36:57
can address that. I think so the most. So one, I would say it's very common for patients to be having symptoms, get treated for those symptoms, and the symptoms might get better, right? So it's that is a very common scenario, because at the end of the day, when you think about sort of the way medicine is practiced, right? So medicine is practiced based upon the odds of a specific disease given a constellation of symptoms, right? And so pancreas cancer would not be on the top of your list for a lot of the symptoms that patients experience associated with pancreas cancer, given, you know, particularly in a young woman in her 30s, you know, you wouldn't even that wouldn't even really be on the radar for for a patient of that age. Anyway, so the different types of pancreas cancer. So the most common type of pancreas cancer is adenocarcinoma the pancreas. That's like when we think about pancreas cancer, that's really what we're talking about for the most part. I'd say the second most common type of pancreas cancer is what are called neuroendocrine tumors of the pancreas. And then acid nerve cell carcinoma is sort of a uncommon type of pancreas cancer, and there are some other less common types as well. The really, the difference in treatment of pancreas cancer is really sort of, I would say, is neuroendocrine tumors versus the rest. So neuroendocrine tumors are treated very differently than the other types of pancreas cancer. And then it's, it's interesting that we're talking about a patient with acid or cell carcinoma. So those cancers tend to actually do better than, say, the traditional adenocarcinoma. She Miss Jackson mentioned that she had to elevate lipase. So that is for acid cell carcinomas. That's actually the blood marker that we can follow for patients, versus for adenocarcinoma. We commonly follow a blood marker called ca 99 and the treatment for adenocarcinoma or asin or cell carcinomas or other sort of types of pancreas cancer in general involve systemic chemotherapy, traditional cytotoxic chemotherapy, whereas for neuroendocrine tumors, those are treated more with sort of biologic modifying agents. The ultimate treatment for the disease is will be dependent upon whether the cancer is localized to the pancreas or not. One. Or not it's receptable, or has it spread to other parts of the body, the liver probably being the most common in which case things like surgery and radiation would not be appropriate.

Camille Pope 11:40:01
Got it. Thank you for giving that breakdown. So what I'm hearing is that it's important for patients to understand the type of pancreatic cancer that they have, because there are a few different types, and treatment might be dictated based on that type. But then also, how far along is your pancreatic cancer? Is still on your pancreas, or has it spread to other areas of your body, meaning that it's like metastatic and that could also dictate the type of treatment and care that you get. I'd love to jump to our next topic, which is disparities in diagnosis and outcomes. So we talked about the different signs and symptoms, but I would love to hear from that Fatima or Dr weeks about like the disparities that exist when it comes to pancreatic cancer being diagnosed, we know that black patients are often diagnosed later and may have worse outcomes. So what are some of the things that contribute to these differences in different communities and underrepresented communities when it comes to the timing of diagnosis and also the treatments that are available and that the outcomes that we might see,

Fatima Zelada Arenas, MA 11:41:16
I can start, and then, if you want to jump in Dr weeks. So there's a lot of factors that go into this and that are related to outcomes in the black community, and then also an increased incidence of pancreatic cancer. Some of this is still information that's unknown, but we do know from research that, you know, various environmental, lifestyle, socioeconomic factors can contribute to these disparities. Other factors include various social determinants of health. So these are things that are specific to an individual's environment, where they live, you know, education, status, physical environments, things like employment as well access to health care and health insurance, and also social support systems. I think one thing that's really critical is that we need to work on ensuring that patients have access to quality health care, but also that they understand symptoms and risk factors related to pancreatic cancer, and then after diagnosis, I think it's really important for patients to understand all of their treatment options so that they can make truly informed treatment decisions about their care. I think that's really critical for patients to know what their options are, and that may include, you know, clinical trials, which we're going to talk about a little bit later, but all of the possible options that they may have so that they can really feel informed in making decisions about their care.

Camille Pope 11:42:41
Thank you, and I know we'll talk a bit later about some of those resources that pancan is actually able to provide to patients. Would anyone else like to talk about, you know, their thoughts on what contributes to some of these differences and how we can address them?

Dr. Colin Weekes 11:42:57
Yeah, I think so. All the factors that were outlined by Fatima are important. And I think environmental. I think so. There's an interaction between the environment in biology and genetics, and so what we know is that things that cause stress cause inflammation or sort of activation of the immune system. And they all and in in part of inflammation, you you get this sort of heightened repair process within the body. And so what that means, then, is that cells are proliferating or are growing at a higher rate. So how one develops cancer? It's it's a function of having a genetic abnormality that normally is cleared by our immune system, but if that genetic abnormality gets propagated into daughter cells or subsequent cells, that's how you develop cancer. And so in the setting of inflammation, the cells are, are sort of turning over or, or, or replicating very, very frequently. And as a result, the body can't stop the process and take out the abnormal cells. And so that increases the risk for someone developing cancer, right? And and so in patients who are of lower socioeconomic status, it has been shown that patients who self identify as black have a higher propensity to develop cancer based upon the interaction of some of these inflammatory processes with the. Genetics that lead to cancer. So it is an interaction between sort of the environment that we're in and and then the genetics of sort of cancer. And then there's also patients who have familial risk of cancer, meaning that they have they're born with abnormalities and genes that, in general, those genes function to stop the cells from growing to allow for editing or repair of DNA damage, and those are called tumor suppressor cell tumor suppressor genes. And so if you're born with with one of these genes. So the most common one that we talk about in the general public is braca, which is the breast cancer related gene. It turns out that those bracket genes are also important for development of pancreas cancer. So in the cancers that someone's at risk of, if you have a bracket mutation, pancreas cancer is one of those risks in addition to breast cancer and ovarian cancer and so, so there's that component of it as well. And so, as it turns out today, all patients who are diagnosed with pancreas cancer are are are supposed to undergo genetic testing to look for familial risk of pancreas cancer, and that is called germ line testing. We'll talk about somatic testing, I think, in a little bit. But so it's really interaction between, say, your environment and how that impacts biology. And then you know, certain, certain sort of, you know, societies, or members of societies in our in our country, you know, we tend to suppress symptoms that we're having. Not tell people that we're having these symptoms, not go to the doctor, right? So all those things are important, right? So I think now this is more of a sort of a population or societal sort of education that we need to do, which is what you know, which is great that we're doing this today, but that's really going to be important. The thing about pancreas cancer is that pancreas cancer is going to be the number two killer of of individuals in the United States by 2030 so it's projected to be the number two. And so it's really important for all of our communities to really understand what pancreas cancer is, really be really knowledgeable about as we're talking about the symptoms and really getting patients to see their doctors. You know more frequently if symptoms realize Thank you.

Pamela Jackson 11:47:38
Hi, Dr Folt. Can I just add, just from a different perspective, I'd have to say that I don't really fit the normal description of who you would consider to have pancreatic cancer. I have a Master's Degree in Health Administration, but I have to tell you, when I was diagnosed with pancreatic cancer, I really had no idea what it was. I've done outreach, you know, in the African American community, at the large mega churches about strokes and different disease states, but pancreatic cancer was not one that we focused on, so I had no idea. And I think that a lot of people do not understand what it is. They don't know where the pancreas is, the function or what to look for. And so in compliance, we have a state. It's a saying that says you see something, say something, right? So it really translates to if you feel something, say something and don't stop until someone addresses it would be very important.

Camille Pope 11:48:45
I love that. Thank you. So I heard a lot of things discussed here, the number number one being that they're different factors that can impact disparities. So there can be environmental factors, societal factors, stress, and there may actually be ways that, you know, if we can manage those things to, you know, decrease our risk of developing not just pancreatic cancer, but other types of cancer too. But then also sometimes there's familial risk. So it's important to know you know what your genetic risk is, and we'll talk a bit about that in our next section, like genetic testing. But then, from MS Jackson, thank you for letting us know that sometimes, like you know, you say people don't look like what they've been through, or they don't look like what they may go through at some point. And you can be, you know, very literate in other areas, in terms of your work and your career and your background. Around, but not necessarily know about certain health issues that could impact you, and it's important for us to understand those things as well, so that we know what to look out for, even if we don't necessarily fit, I guess, the the societal definition of what a potential pancreatic cancer patient might look like, like a young black woman who's pregnant, right, and is having this abdominal pain, so it's and that's why we have these discussions like this, these panels where we're inviting any and everybody to kind of hear these different stories and these different perspectives, so that they can have that top of mind. Should they or someone they know or love experience something similar? So I think this is a great segue into talking about genetic testing and Dr we should talked a bit about it earlier. I will say in my previous life, I actually was I worked at a pharmaceutical company as the medical director in the pancreatic cancer space and the drug that

I worked on required, or the the drug that I was the medical lead for, in order for patients to use it in to work as effectively as it could and should, they had to have a bracket two mutation. And so became very familiar with the role that you know braca and other genes can play, or gene alterations and differences in gene patterns can play when it comes to developing cancer, especially from, like, a family history standpoint. And I love that you brought up how you know we hear about braca, braca a lot, braca one, braca two. And people automatically think, oh, breast cancer, ovarian cancer, but having alterations and like your bracket gene can, you know, increase your risk for prostate cancer, pancreatic cancer, and potentially other cancers. And a lot of folks don't know that. So you know, if we could hear from our panelists about the different types of genetic testing. Like, what does that entail? And then, yeah, let's, let's hear about that.

Dr. Colin Weekes 11:51:57
Yeah, I guess I'll start. So there's, there's really two types of genetic testing that we do with respects to cancer. So there's what's called germline mutation analysis, which is what we're talking about now with the braca genes. So these are what I talked about before with familial cancers. So that is what mutations that you are born with, and those are passed down by your parents. And so in general, for if you thinking about familial pancreas cancer or familial cancer in general, generally, what we'll see is that there's a pattern of one side of the family, either the mother side or the father side of a given patient, where you see a series of cancers occurring in in that side of the family, and that then sort of says, Okay, Well, maybe there is potential for a germline mutation. The other type of mutation that we that we look at these days for treating patients with cancer are what are called somatic mutations. So the word Soma means body. And so somatic mutations are mutations that you acquire as you live your life. And so as it turns out, all of us who are living our lives have some degree of somatic mutation in our body, and normally, our body, our immune system, will surveil abnormal cells and clear a lot of those cells, but on occasion, it doesn't clear those cells, And you then are at risk for developing cancer. In the case of germline mutations, there's two copies of a given gene, which means so if you're born with a germline mutation, that means that you've lost one copy of the function of one loss of the copy of the gene. And in that setting, you need to lose, sort of the function of both genes when we're when we're talking about tumor suppressor genes, but it's very easy to lose now, the odds of losing the function of the second gene is quite high when you're born with loss of the first gene. So I'm going to, I'm going to address Candace Turner's question as I'm as I'm talking here now too. And so with respects to bracket one and bracket two mutations, so historically, we thought about those mutations being present in in the Jewish patient population, but they actually do occur in patients of African descent. It does potentially impact treatment of patients. So it has been shown that this class with drugs called PARP inhibitors, which is what I believe Dr Pope was referring to, are are now approved for what we call. Maintenance therapy in patients with braca mutant pancreas cancer. And there are some other genes that are that are in this pathway that involve the braca gene that are also commonly mutated in patients with pancreas cancer as well the and so. So really, the use of germline mutation analysis is really right now, is really to assess the risk of patients developing family members of a patient developing cancer, also in general, patients who have germline mutations, those patients tend to present at younger age with pancreas cancer. And most of this information I'm talking about is going to be relevant to adenocarcinoma, that's by far the most common form of pancreas cancer, and that's where most of the data exist. Unfortunately, acinar cell carcinoma is relatively rare, and so there's not a lot of data specifically to Aspen or cell carcinoma, and then somatic mutations. So those are mutations that you once again, you acquire as you live your life. In the case of pancreas cancer, the most common somatic mutation that we see is a mutation in a gene called K RAS. There's there's there's a number of different mutations that a patient can have. It's mutated approximately 90 plus percent of patients with pancreas cancer. The sort of the unique thing today is that there's now a number of drugs in developing development that are targeting KRAS directly, either targeting the fact that you have the mutation, a mutation in K RAS. And then there are also drugs that are targeting specific mutations that occur in in the K ras gene. So So today, we are now using these somatic mutations as potential once biomarkers of disease, but also potential ways to think about therapy for patients. And as we learn more about these drugs, so they are. These drugs are currently in early phase clinical investigation, so what we call phase one investigation, which we're sort of looking at safety, toxicity, dose finding and so, so they're only available to patients in that setting. So in terms of when we talk about clinical top clinical trial participation, by participating clinical trials, you then get access to these novel drug, drugs that may benefit, you know, patients. And so really, that's how we're utilizing these, these sort of different types of mutations that exist today for therapy for patients, and that applies across cancers, but definitely is something that applies to pancreas cancer.

Camille Pope 11:57:48
Thank you, Dr weeks. So then one last question around genetic testing for Pamela. So because you have the rare type of pancreatic cancer, I'm assuming you didn't get genetic testing, but maybe you have had it. So we have you. And if not, would you consider it? And if so, what was the experience like? Definitely.

Pamela Jackson 11:58:07

So at the time, I did not have any genetic testing, and I have not had any, but I do have children, and I am interested in having genetic testing for my family. I would most definitely welcome the opportunity to participate in genetic testing myself as well as my children.

Camille Pope 11:58:30
Thank you for sharing. I

Dr. Colin Weekes 11:58:32
can just add one piece to that Sure. So in if we're doing sort of genetic testing, and what, what, what we would apply, would apply to Pamela would be the germline mutation analysis right to see if her family's at risk. So what we what, the way that we would approach that is we want to test the patient who has the disease, right, to see if that patient has a specific mutation, and then that then if you were going to test, say, her children or members of her family, we'd be looking for that specific mutation in those individuals, right? So it's really important to start with the patient first, you know, and then I think, the other part of this conversation, which may be a little bit more much to get into now, but is, what is the consequence of having a positive test, right? So, for example, if you have a positive brachi mutation, as a say, a young teenage girl or boy, right? That has implications for, you know, what do you do? You know, there's, you know. Do you do? Sort of prophylactic mastectomies, prophylactic oophorectomies, which means removal of the branch, removal of the ovary. Is, you know, do you do medical suppression of ovarian function? So all those things sort of come into play. And so it's really important to do this germline testing with genetic counselors who can help you navigate the consequence of a positive test as well as the consequence of a negative test. And what we're finding is that a negative test does not necessarily mean that you don't have an abnormality. So as technology improves in our capacity to look to find the rare, rarer genetic mutations, like if you tested someone today versus that same person being tested 10 years ago. They may have had a negative test 10 years ago, but today they would have a positive test. So it really is important to do these genetic testing that we're talking about germline testing in a very sort of controlled manner. It's, in many cases, it's simply just a blood draw, or they can, like, get some DNA swab right from your mouth. So it's very easy to do, but you do want to have the appropriate support to help guide you with the results of that test.

Camille Pope 12:01:05
Thank you. I think that's great context there. So what I'm hearing is you want to start with the patient first, but then also ensure that their genetic counselors and other providers who can help guide and may have those discussions based on whatever those results might be, but it is certainly something to consider as a as A patient.

Pamela Jackson 12:01:28
So can I just add one more thing? Dr weeks, I want to thank you. I've learned more today than I have ever. I really feel enlightened, but I definitely be would be interested in testing for myself, because I carry stress internally. He would never know the amount of anxiety or stress, and I'm feeling, if you're looking at me, but on the inside, there's like a turmoil. There's just a storm grooming, and you don't know it, I don't scream. I don't, you know, I just so I would be very interested in testing for myself.

Dr. Colin Weekes 12:02:05
So I think, you know, Pam, we're not that much different in terms of how we manage stress, and I think that is, you know, a common theme amongst people of color, right? They they have to function in the world. They can't. They do have sort of unique stresses, and we don't always manage stress that well. And so that's why, I think, in going back to the question about these disparities and sort of black folks and so forth, is, yeah, that stress does impact your biology on multiple levels, cancer being one of those, but it has other implications too. And so absolutely, and I'm glad I can be informative for for folks on the call.

Camille Pope 12:02:53
Thank you all. This is great. Thank you for sharing Pamela. Thank you Doctor weeks and Fatima for being so knowledgeable and being able to inform all of the attendees. And you know, again, I'm hearing so much in terms of just like the support, that support that is needed, really just in life. I mean, sure when you're diagnosed with an illness, but even just managing those things to help prevent stress, or help you better manage your stress, because that'll ultimately help with preventing disease later on. In some instances, I'd love for us to now transition to our next topic, which Dr we talked a bit about, and that's clinical trials. And so Fatimah, we can start with you. You know, what's the importance of clinical trial participation when someone has been diagnosed with cancer, you know, or at least considering clinical trials, and how would one go about maybe finding an opportunity? And what are some common misconceptions that may keep people from participating if they do have an opportunity offered to them?

Fatima Zelada Arenas, MA 12:04:10
I I'm happy to answer that question. So there's, you know, one of the most important things that we oftentimes talk about through our Patient Services program is just that patients should be aware of all of their treatment options, and that includes clinical trials. And one, you know, some of the common misconceptions are more around, you know, not getting good care. If you're on a clinical trial, a lot of patients are afraid that they're going to be experimented on, or that they're going to be guinea pigs. That's something that we hear a lot, you know. So oftentimes, clinical trials can provide actual access. Us to better treatment options and also give patients access to cutting edge treatments sometimes. So like Doctor weeks mentioned earlier, there's a lot of things that are a lot of therapies that are being investigated right now, and many of them are available only through clinical trials. And the other piece that's really important about clinical trials is that clinical trials are really the only way that we're going to continue to make progress in pancreatic cancer, in treatment options, you know, even in in diagnostic tests and everything that you know is around pancreatic cancer, it's treatment, you know, diagnosis. We are only able to make progress through clinical trials because every therapy that's approved today has gone through the clinical trials process in order for it to make it to be approved and accessible to you know, everyone. One thing that we see about clinical trials is that participation is really low in general among patients with pancreatic cancer, but definitely racial and ethnic minorities are persistently underrepresented in pancreatic cancer clinical trials, so we want to make sure that patients are aware of all of their options, including clinical trials. And so one service that we provide through pancan is that we actually have a comprehensive database of clinical trials that are happening in pancreatic cancer, and we can help patients locate clinical trials in their area, really based on their diagnosis, the stage and type of pancreatic cancer that they have and their treatment history, because if you have been on certain treatments, sometimes that makes certain clinical trials not an option for you, or others may be an option for you, and so we're able to run a really personalized search for patients to help them locate clinical trials in their area. And I guess to to end, I'll just mention that it's it's so important for patients to participate in clinical trials, because everybody wants to see themselves represented, and if we're not testing therapies and all of the patients that are actually impacted by pancreatic cancer, then we're not really able to make progress, you know, against the disease and develop new treatments. And so it's so important to be aware that clinical trials are an option for you, and also to seek out resources to help locate, you know, that information, and I think all of those things will help us increase participation.

Camille Pope 12:07:19
Thank you, Fatima, that was great. Does it's amazing that pancam provides those services, and they also seem very, you know, personalized, and a lot of folks might not know that that is an offering, so I appreciate you walking through that and also highlighting some of the the value and the benefits of participating in clinical research. Did any of our other panelists anything to add? I see Pamela, you're back. Welcome. So glad to see you again.

Pamela Jackson 12:07:52
Yes, I actually, if I can, just want to provide a more vulnerable perspective. When I was diagnosed in Florida, you know, the doctors there told me you need to go home and you need to get this out immediately. So go as soon as possible and get this out. So like I said, my story is a little different. At the time, I worked for Kaiser Permanente, and I was in the compliance department. So my husband, my biggest advocate, he called the CEO, and that just started a flurry of things to happen for me, which were blessings. My surgeon was the head of surgery for Kaiser, and so my story really is different. But the surgeon, he wanted me to participate in a clinical trial, but we were told to get home and get it out as soon as possible. So I declined. The interesting thing about it is, by the when I was diagnosed, May, I'm going to say April 1, I had the surgery, April 30, and the tumor had grown significantly between that time. So it's a it's an interesting place to be in. Do you do the clinical trial and see what happens? Or, you know, move forward with getting the tumor removed? So that's, that's the situation I was in. It grew really significantly between just in three weeks. Wow.

Camille Pope 12:09:31
Thank you so much for sharing that perspective and some of the you know, the challenges, but the hard decisions that you have to make, you know, and it's already you have this diagnosis, and then it's like, okay. Say, Well, so what, what do I do? There's so many unknowns, and that perspective of, you know, the fact that you've offered a clinical trial is awesome, because a lot of times people are not offered the option to participate. But then, you know, you just sharing how you had to, had to weigh that versus, you know, having, like, an immediate surgery and seeing how the tumor in your case actually grew quite quickly. And we know that might not be everybody's situation, but certainly appreciate you sharing that perspective. Thank you.

Dr. Colin Weekes 12:10:25

Yeah, so I would say that I think what Pamela and also Fatima have highlighted is, I think it's the importance to be, to be seen, at least get, at least try to be seen initially, by someone that's a pancreas cancer center of excellence. I think the treatment for pancreas cancer is evolving quite rapidly. And so it's, it's a very nuanced disease, and it's, it's, it's in terms of whether someone should go to surgery right away, versus getting chemotherapy followed by surgery, whether they're receptable, not resectable. Like all of these things, are really nuanced decisions and thought processes that both the care team has to go through as well as the patient. I also there's a question about sort of the caregivers, which I also liked, Pamela story talking about her husband being her best advocate, right? And so the other thing that I think what's happening in in the pancreas cancer world and cancer in general, is sort of understanding the the the complex nature it is to be the caregiver of a patient with pancreas cancer or any cancer, right, and and also trying to maintain the health of those individuals as well. And so I think all of these things are really important in terms of just how do we take care of patients? I think it's been pointed out in this conversation that education is key, and this is where I want to start my conversation about clinical trials. So what we know about clinical trials is that patients who are treated on a clinical trial, they have better outcomes than patients who are not treated on clinical trials. It doesn't matter what the trial is, just in general, if you say patients they treated on a trial, they have better outcomes, and that's because they have increased access to their care team. And so you know, things don't fester when a patient's on a trial, like, if you're having abdominal pain, that's new, we're going to look and see why you're having abdominal pain, and maybe there's an abscess that you've developed, and that's why you're having abdominal pain, versus not investigating that until the patient's really sick, and now they're in the ICU, and all these things are going on. So that's, I would say, point number one about clinical trials. Point number two is that it is a way for pancreas cancer patients to get access to novel therapies. Because we don't have a lot of therapies for pancreas cancer, right? So if you look at the treatments that we use for pancreas cancer, it's two basic chemotherapy regimens. One's called FOLFIRINOX. The other one is gemcitab. There was a recent, you know, approval of a regimen called now laterfox, which is sort of a fancy fofirinox, but the end of the day, it's cytotoxic chemotherapy is the treatment that we have. Whereas if you look at lung cancer, lung cancer has a lot of biologic agents, they have immunotherapy, they have all these different therapies so that are approved drugs for the disease. So there's lots of options to treat someone with lung cancer. Breast cancer is even more so. So the only way for patients to get access to these novel therapies is part of the clinical trial. And so for, I think for patients of color, it's, it's really important that that you are seeing at an academic medical center where these trials are available, that's how we're going to make the inroads in in patient outcomes. What also is developing is this, is this concept of ancestry, and the role of ancestry in in cancer biology and potentially cancer therapy. And so ancestry versus saying self identified race, right? So I would identify as a black person, but my ancestry might be that I'm you know of West African ancestry, right? And so if you look at patients who by ancestry, what we see is that there may be differences in the in a in the disease based upon ancestry. So for example, it could be that patients with pancreas cancer who. Are of West African ancestry. This is not true. I'm just making I'm just saying this for conversation sake, that they may have a more inflammatory tumor, in which case, maybe an immunotherapy may be more, may work at a higher level than it does, sort of, generally speaking, in in sort of pancreas cancer in general. But excuse me, will only be able to know that information if patients are actually participating in the trials, right? So patients who reflect that ancestry are participating in trials. And so it is. It is important in that I would say that most, most drug approvals are based upon trials in which there isn't a lot of diversification of patients on those trials, and so they may or may not represent the disease disease process for patients of diverse backgrounds. And so it really is important to to have diverse patients participate in trials. I think, as a clinical investigator, I've been doing it all my all my career, we have to do a better job of educating patients in terms of what the disease process is that they have. What does the trial truly do to benefit the patient. How does the trial really impact their standard of care? Are we adding to the standard of care, or are we doing something in lieu of standard of care, right? And if we're doing something in lieu of standard of care, what do we know about that that thing that we're doing, right? So are we harming patients by doing something in lieu of standard of care. So, and then I also, and then I think also explaining the different phases of clinical trials, and we're kind of running down on time, but that will also be important, right? So one of the things that I'm really working on is this concept of patient education and really being able to inform the patient, but and their family. So, you know, I commonly am asked to see VIPs and and, and I will do that and, and the point I'm making here is that these individuals have access to the various highest care, whereas other members of the society don't have access to that care. And then you also have to be able to meet patients where they are, so be able to provide them the information they need at level which they can receive it. And I think we have to really do a better job in medicine as a whole, but in cancer in particular, and pancreas cancer even more so, of developing educational tools that patients, not only patients, but patients families, right? Because the end of the day, it's the family who ultimately ends up making this decision. The patient's a member of the family, but if members of the family can understand what is being discussed, then when they go home as a family and discussing it amongst themselves, then they can also have an educated conversation about what is being considered for their loved ones. So it's really important, I think, for the medical community to do a better job in terms of providing educational materials around clinical trials. And then, you know, in this case, pancreas cancer.

Camille Pope 12:18:16

Thank you, Dr leaks, oh no, it looks like we lost Pamela again, but that is okay. Um, so again. Really great perspectives and lots, lots of Jim shared. I don't even think I can recap everything that you all share just now as it relates to clinical trials, but I do believe it would be really important for us to talk about the different resources that are available right when it comes to understanding a pancreatic cancer diagnosis, but also clinical trial opportunities. Fatima, you mentioned a bit about what pan can has to offer. You know, I know that one of our main missions, from a NOWINCLUDED perspective, is to educate around clinical trials as well, and also various disease states that impact our communities the most. And so if you go on the NOWINCLUDED website, we have a whole landing page that talks about clinical trials and the different phases, and we're talking to our community members and hearing their their concerns, but then also learning that many community members have participated in clinical research, and we're encouraging them to share their stories with their family and friends and other folks that they know, so that people don't necessarily See it as such a such a scary thing, not that it it shouldn't be scary, or can't be scary, but when you can see somebody, and you know somebody who is, you know, an aunt, an uncle, or a neighbor who has done this, and they're still here, they're still okay, and they had some access and, uh, you know, a healthcare provider who's able to explain some things to them. Them and they participated in, you know, it wasn't necessarily a guinea pig situation, then you might be more likely to consider a clinical trial. So I think there are a lot of different elements that could serve to help our communities understand the importance of being part of clinical research, and also know that, again, if we're not included in the research, and how do we really know, from an ancestral perspective, not just what we look like, but where we real come from, whether those drugs work for us, especially when we know that there are certain genetic alterations that can impact how well the drug works. And so really appreciate just all the perspectives there, and in our last couple of minutes, would love to hear about any of the additional resources that pancan has to offer. And then I see Pamela is back. Thank you again. I know that having some challenges with the stream, but that's okay. We'll love to hear from a patient perspective, Pamela in the last couple of minutes, what are the resources that you found to be most valuable to you?

Pamela Jackson 12:20:48
Most definitely, I have to say that I leaned primarily on Pan can. They were the source of truth. For me, I was fortunate to actually develop a relationship with Pamela Acosta, the founder, and so I really utilize their services. I was kind of in the shadow. So let me say, my husband utilizes services. I was more hidden. He was my my block and a shield, but we definitely relied on pancan for just about everything. So thank you, Pan can.

Camille Pope 12:21:25
That's awesome to hear. And besides the clinical trial finder, pancan, Fatima, are you able to discuss any other resources that are available?

Fatima Zelada Arenas, MA 12:21:34
Definitely happy to share. So I it's it's wonderful because we have a really amazing and compassionate team over at pancan That's part of patient services, and we're really available to provide information and resources to anybody that's impacted by pancreatic cancer about any topic. So treatment options, symptom, side effect management, diet and nutrition, we can connect them with specialists in pancreatic cancer. We also have a wonderful precision medicine program. We I know we talked about both genetic testing and somatic biomarker testing, and we actually have a know your Tumor Program, where we provide biomarker testing and we cover the cost of that testing for patients. So that's something that we provide as well. And then we just provide free educational materials answer questions. We can help patients prepare questions for their healthcare team and just really give them support throughout their journey. And we, like I said, we have a really compassionate team of case managers. We also have a wonderful navigation team that helps to provide more hands on support for patients, you know, particularly around things like clinical trials or any other barriers to care that they might be running into. We can also provide information on things like genetic testing, help individuals locate genetic counselors. So we're really here to help patients, families, anybody that's impacted by the disease throughout the entire journey with pancreatic cancer. And we're we're available, and we're happy to help. So

Camille Pope 12:23:01
yes, thank you for sharing lots of resources, patient navigation, resources, clinical trials, all the things for you and your caregiver and other community members supporting you as a patient. So that's that's really nice. Um, in our last minute, any last words of wisdom or calls to action from our panelists, we'll start with, let's start with Pamela, because I think she went off mute.

Pamela Jackson 12:23:29
Yes, can I just my story is a story of hope, and I just wanted to end with some positivity. Eight months after I finished my chemo, I did radiation, chemo for six months, eight months after I became pregnant. Now, at the time, there weren't any

women. There was no history of anyone with pancreatic cancer getting pregnant. So my OB said, You know what, I don't think this is going to work. I said, You know what, I have to ride this out and see what happens. I had a healthy baby girl. Her name is Nia. She was born on 1212, 12 at 1314, PM. So amazing, radiation and everything. Love

Camille Pope 12:24:15
it. Yeah. Thank you for sharing and what is meant to happen and is meant for you, and that is an amazing story of hope. And so we wish many blessings upon you and your family. Thank you for sharing. Pamela, that's That's great. Um, doctor, weeks. Fatima, any last, last words of wisdom or calls to action for our listeners or attendees before we log off.

Fatima Zelada Arenas, MA 12:24:37
Just want to say, you know, we're here to help and support. If you haven't, if you have questions, if you need resources, please reach out to pan can. And then also, there's always. Hope and you know, make sure that if you you know your body best, if something doesn't feel right, that you seek out, that you know support, that you go to your healthcare team and really advocate for yourself if you need to. So thank you so much.

Camille Pope 12:25:03
Fatima, hope and advocacy for yourself.

Dr. Colin Weekes 12:25:06
Yeah, and I would just say, I know time is up, but I would just say that it's really important for patients who ultimately are diagnosed with pancreas cancer, whatever form of pancake cancer, it is, to be seen at a pancreas cancer center of excellence, so that you can get the optimal care. And it may not be that the you know, the care itself is delivered at that center, but I think at least being seen initially at that center to really get a full understanding of what your situation is and what the treatment options are, and if there's any clinical trials that would be relevant to your situation, I think that's really imperative. And then I would also say that self advocacy education in our communities is really going to be the key to battle this going forward.

Camille Pope 12:25:55
Thanks, Dr weeks, and so what we're hearing from you is seek out treatment at those centers of excellence, and I'm sure pan can, with all of the resources available, are able to help patients identify where those centers of excellence are nearest to them so that they can get the most advanced treatment and options available. So thank you for highlighting that, and thank you for joining as our panelists. Thank you for all of our to all of our attendees. We appreciate you for being interactive and asking questions. Please feel free to reach out if you have any additional questions and we will see you on our next webinar. Hope everyone has a wonderful day. Thanks. Bye,

Pamela Jackson 12:26:37
bye. Thank you. Bye