Breathe in Knowledge

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SPEAKERS
Dr. Susan Mathai, Ms. Shirley, Dr. Camille Pope, Ta-Tanisha

Dr. Camille Pope 11:20:46
Hi everyone. Thank you for joining us today. Welcome, welcome. My name is Dr Dr. Camille Pope, and I am our chief medical lead here for Acclinate and NOWINCLUDED, and it is my pleasure to welcome you to our virtual community conversation, where we are going to be raising awareness and sharing information and resources related to sarcoidosis, specifically pulmonary sarcoidosis and clinical research. So thank you for joining. We have a few guests with us today who are going to help us along in our conversation. Our first guest is Dr Susan Mathai. And Dr Mathai is a pulmonologist from Baylor Scott and White in Dallas, Texas. She cares for patients with advanced lung and respiratory diseases like pulmonary sarcoidosis and SOP D. We also have two of our amazing NOWINCLUDED community members joining us today. We have Miss Shirley Willis, who is a NOWINCLUDED community member who was diagnosed with sarcoidosis almost 25 years ago, and her daughter, Miss tatinisha Baldwin, who is also a NOWINCLUDED community member, and she is going to be talking about her experience firsthand as as the caregiver and daughter of a mom with sarcoidosis and helping her through her diagnosis, firsthand, and they are both joining us from Detroit. So welcome Doctor Mathai, welcome Miss Shirley and welcome Miss Tanisha, before we dive into our discussion today, wanted to do just a little icebreaker question to loosen us up a bit. So here we go our icebreaker question. If you could have any superhero power to help you manage your health, what would it be? And why?

Ms. Shirley 11:22:53
Superhero? You know? I guess I never really had a superhero power. I mean, even I know, but if I don't know about the superhero strength, she'll be able to strong, okay, Superman, be strong and involved.

Dr. Camille Pope 11:23:20
I love that. I love that. So having strength and being able to be involved, those are definitely superhero powers that can help you manage your health, yeah. What about you? Ty Tanisha, Oh, I get the same as your mom.

Ta-Tanisha 11:23:34
Yeah, I would definitely want to be strong. But I would also add that I would just be, tell me manage my health, or probably be like Mother Nature, like the person that can grow green things and like always eat fruits and vegetables and be next to the water. I forget what that person is called. It's a superhero that
11:23:52
creates Aquaman

Ta-Tanisha 11:24:00
create, like, I forget it's like poison ivy that can grow vines and all of that type of thing.

Dr. Camille Pope 11:24:05
Like, okay, well, we like that. That's a good superhero power. What about you? Dr Mathai,

Dr. Susan Mathai 11:24:14
I would love to be able to maybe go back in time like so, to do some time travel, to maybe change certain things that I did or decisions I made when I was younger. So that might be what my favorite one would be.

Dr. Camille Pope 11:24:30
I love that. Yeah, that's good. So going back in time and maybe some of the unhealthy choices, I would probably do that too. Definitely made some unhealthy choices back in the day and make healthier choices now. So going back in time and being able to shift some things, those are, those are, that's a good superpower too. So thank you. Alright, so we've loosened

everybody up a bit. We all know each other. We all know what our superhero powers would be. Why don't we, before we dive into our full conversation around sarcoidosis, sarcoidosis, have a quick poll for our audience members who are joining. So for our audience members who are joining, you can just drop your answers in the chat. Do you know what sarcoidosis is? Yes, no, I'm not sure. Let's see.

Dr. Camille Pope 11:25:30
Oh, several people know, haven't, will they No, as in Kate and Ow. Know what sarcoidosis is, that's awesome. Okay, we have a, yes, I know, but not as much we have a, not sure.

Dr. Camille Pope 11:25:49
Well, awesome. Well, thank you for your responses. I see some more coming in the chat. So it sounds like there is an opportunity for some great education and learning to happen here, since there are some yes answers, no answers and not sures. And so with that, we'll turn it over to doctor Mathai as she provides an overview of sarcoidosis and talks a bit about what the symptoms are and how it can affect the body. Yeah.

Dr. Susan Mathai 11:26:18
Well, thank you. I'll try to keep things really brief, because I think sarcoidosis, and in practice, can be a really complex disease, but in some ways, on a the most the simplest way of understanding it is it's a systemic inflammatory disease. So it's a disease where there's inflammation in the body that is happening even though there isn't infection or there isn't injury in some other way. So it's inflammation that's happening in the body, and in sarcoidosis, that inflammation is specifically characterized by a kind of cell called a granuloma, so a clump of cell called a granuloma. And so the reason that pulmonologists, or lung doctors often end up being sarcoidosis doctors is because in the majority of cases of sarcoidosis, not all, but in the majority, the granuloma inflammation begins or certainly affects the lungs or lymph nodes in the lungs now, because it's a systemic inflammatory disorder, so that means it can it's systemic, means all over the body. Technically speaking, sarcoidosis can essentially affect almost any part of your body. And so what makes sarcoidosis really complex is that even in the most common place it can affect people is in the lungs, it can actually affect the skin, the eyes, the heart, the liver, the kidney, the bones. And so it can be really complicated, because a lot of times a lot of different doctors have to work together to get at the root kind of cause, or like to treat the sarcoidosis most effectively, and because it can affect any organ, that can also make it really challenging to diagnose. And as it may be, something that comes up in our conversation today, but a lot of times, getting to the diagnosis of sarcoidosis can be can take longer than patients and doctors want, because it can be a masquerader, so it can present and look like infection, or present and look like a tumor or a cancer, and it sometimes takes a lot of investigation and sampling of tissue to for your doctors to be able to come to the conclusion that for sure, what we're dealing with is sarcoidosis, and so it's a tricky disease in that way.

Dr. Susan Mathai 11:28:48
Do you Candace put in the chat? What are granulomas? So granulomas are just a clump of or a collection of cells. So we see them using like looking at tissue under a microscope, and it's just a particular kind of inflammatory cell collection and so, and it happens to be the something that can be found in infection. So probably the most common reason people can find granulomas in the body is in response to any kind of infection. But in sarcoidosis patients, we come to the diagnosis of sarcoidosis when we find granulomas in tissues and in. The body when we've already ruled out infection and we feel confident there is no infection. And so granulomas without infection is really like kind of what we're looking for as one of the most important findings to be able to diagnose somebody with sarcoidosis.

Dr. Camille Pope 11:29:49
Thank you. Dr Mathai, so it sounds like you have to rule out other things before you can determine that the granuloma is actually due to sarcoidosis and not a real infection. Exactly. Okay. So Miss Shirley, you've been living with sarcoidosis for 25 years now. Can you and tatinisha talk a bit about what your journey has been like. What were your symptoms when you first got diagnosed, and did the doctors think it was something else? And tell us like, what happened in the beginning, and a bit about your journey to today?

Ms. Shirley 11:30:26
Well, you know What? What? When I was diagnosed with it, I think I would get my annual exam, and I had went to the doctor for my annual exam, and I had dropped too much weight, which I thought I just looked good, but, and I wasn't worried about it, but I had dropped too much weight and and too short of a time. So she ran, had me, ran test on me, and then referred me to a specialist in sarcoidosis. And from that point on, you know, I was under his care. And what was interesting is, I have medical insurance of one entity, but they showed it referred me to another entity for a professional, and he, he kept me, you know, I went to see him for a few years. I know he's retired now, but he's the one that was the caregiver, and mine

was the sarcoidosis I was diagnosed with, was with my lungs and so with the medication and the constant care, you know, of monitoring and everything I seem to have gotten through it. I've even gained a little weight back, not as much.

Ta-Tanisha 11:31:41
So the partner, she always that I probably is reason why I'm here is because I was living with her at the time, and she started coughing a lot, and she went to the doctor, and they all of a sudden, she had asthma, you know, like, how did you get asthma in this big, grown age, right? And so she was for about, maybe, I want to say, six months to a year she was using, was it a Lego the inhaler with the steroid, the purple one, and it was like brand new on the market. That's the only reason why I remember. So she had, she was using that consistently, you know, and was coughing up phlegm all the time. And that was, that was, like a year before they diagnosed her with sarcoidosis. So that's, that's how it started. It's like, you know, all of a sudden she has asthma. We never had asthma. Asthma doesn't run in our family. No one has asthma. And then all of a sudden, here she is and losing weight and losing weight, right? But she did look good, so we like, go ahead, sure, you know? So, yeah, so, but that's, that's when it started like,

Ms. Shirley 11:32:50
and I think sarcoidosis was new to it wasn't new, but to the it was new to the doctor that I was saying it had, and that was her thought process. And then she referred me, you know, to the testing, and then referred me to a specialist in that field. And I think, you know, because all I was thinking is, you know, even though I was short, you know, I lost a lot of weight and I would and I attributed to doing a lot of walking and shortness of breath, you know, I attributed, you know, I had something to say. Well, I'm getting old, you know, maybe that's what that is. But once I went for that physical, my doctor got alarmed, and she sent me through all these tests, and then ultimately referred me to a specialist in that field.

Dr. Camille Pope 11:33:41
Got it. Thank you for sharing what those initial symptoms were so Doctor Matt, let me ask you, is that, especially for pulmonary sarcoidosis, are it? Are those the most common symptoms, weight loss, coughing, and is asthma like, like, new onset asthma? Is that a common like, misdiagnosis?

Dr. Susan Mathai 11:34:04
Yeah, I think probably cough and maybe sometimes shortness of breath can be some of the early signs of sarcoidosis. The tricky thing about sarcoidosis is it can present with just those kind of symptoms, but can also sometimes present as Miss Shirley was sort of describing with like asthma, like symptoms as well, if the airways are really inflamed. And the tricky thing is that asthma itself is also under. Diagnosed, and sometimes, even though it is a little like we don't typically think about asthma as showing up in adults, there are a lot of adults that do develop asthma, or asthma in relation to exposures or their changes in their environment. And so that one of the challenges of sarcoidosis is that it you doctors are kind of trained to think about the common things first, right? And so just like Miss Shirley kind of describes her, doctors initially wanting to treat her for just for asthma, because that's probably, you know, statistically, what they see more commonly than sarcoidosis. Sarcoidosis is still a rare disease. Relatively speaking, it's not rare for people like me who are like have practices and focus specifically on sarcoidosis and other interstitial lung diseases, which is a bigger family of a certain kind of lung disease. But for the average doctor, it is a little more rare, and so that's part of the reason that sometimes it can take a while, like she's describing, where you kind of sometimes are treated initially for things like asthma, before enough investigation, and probably I don't know exactly what Miss Shirley's doctors did in terms of testing, but often getting a CT scan and things like that are really helpful to be able to actually see the changes of sarcoidosis before coming to a diagnosis. And usually it takes in a typical after a typical doctor visit if your symptoms are not super severe, or maybe just start off as a mild cough, it may be a little bit before somebody jumps to getting a CT scan, which is often what we need to kind of push, push ourselves to start thinking about sarcoidosis more seriously.

Dr. Camille Pope 11:36:22
Got it so really have to watch those symptoms and how they develop and see what additional tests might be needed to make the diagnosis. I Oh, Miss Shirley, I think you're on mute. So we'll There you go.

Ms. Shirley 11:36:38
What I what I think, even with my doctor, is the whole idea of sarcoidosis was just coming to the forefront. And I think she was, you know, she was interested in these different diseases, and when I started developing all these symptoms, that's how she caught it. You know, we caught it. So then they sent me through all kind of tests, and they caught it early. You know,

Dr. Camille Pope 11:37:06

we do have a comment in the chat, a comment and a question from Miss jonice, who says her late husband was diagnosed with sarcoidosis in his 70s, and sorry, he was diagnosed when in law school at Harvard, maybe it was a misdiagnosis, because they did a splenectomy, so they removed a spleen, and he never knew why that was necessary, and are they still doing that, and why? So are there maybe, like, unnecessary surgeries that happen because of misdiagnosis? Dr Mathai, I don't I think

Dr. Susan Mathai 11:37:39
it's hard for me to say without knowing more information specifically about what was going on with him, but certainly sometimes in sarcoid, like a common thing, or a thing that we see from time to time for sure is that sarcoidosis can cause enlargement of the spleen. So because the granulomas and sarcoidosis can often gather in lymphoid tissue, which is like the lymph nodes that get swollen in your neck and other parts of your body when you have an infection, those often get swollen in sarcoidosis and your spleen is an area of concentrated lymphoid tissue, and so in some sarcoidosis patients, a spleen gets really, really big. And if the doctors were concerned about the size of the spleen and possibility of rupture, or they were worried that there was something else that it was too large, it's possible that they removed it for that reason, or if they thought that they weren't sure yet whether it was sarcoidosis and they this spleen, could it maybe was what showed them the signs that it was, in fact, sarcoidosis. So I to know exactly what, why they removed his spleen. I think I'd have to know more about the specifics of his case. But I think, like, you know, sometimes when spleens are dangerously big, that can be a reason for doctors to consider that.

Dr. Camille Pope 11:38:59
Wow, that's interesting. I don't think I know. I didn't realize that there was a connection between sarcoidosis and an enlarged spleen. So there's some good knowledge that you dropped there Doctor Mathai and I think Miss jonis, that can help explain why your husband had to have that done and then wasn't then eventually truly diagnosed with sarcoidosis. Okay, so we're going to keep it moving along. I do believe we have a video to show here where we have more of Dr Mathai talking about sarcoid. Doses and providing education on that, and Miss Shirley providing a bit of a reaction to what Dr Mathai is sharing with us in the video. So are we able to cue that up?

Ms. Shirley 11:39:47
My understanding of it is some kind of disease that's

Ms. Shirley 11:39:53
consistent to black people. So one of the things that the patient mentioned is that that sarcoidosis, she sort of said that sarcoidosis is, if I heard her right, a disease that affects black people. And that is true that many black people. Do you know that many sarcoidosis patients are black or people of color, but it actually affects people of any color, and I think that is something important for both doctors and patients to know that it's not specific at all to any one ethnic or racial group. So I have patients who are Indian, I have patients who are white, I have patients who are Hispanic, I have patients who are black. So it's not specific to any one particular ethnic or racial group, and can affect anyone. So just because you're white or you look different than a person that you know has sarcoidosis, that does not mean that you cannot also have sarcoidosis. So I do want to mention

Ms. Shirley 11:40:53
that lost a lot of weight, but I thought it was because I was walking a lot, and I found out that I had sarcoidosis. I didn't even knowing really what that was, but was put on medication for sarcoidosis and monitored with that for a couple of years, and I don't know if it went away, but I haven't had any problems with

Ms. Shirley 11:41:15
the patient. Also mentioned that sarcoidosis can, that it kind of comes and goes. And for some patients, that is true. Sarcoidosis can, for some people, is something that's almost found accidentally. So a patient, many of my patients come to me because they're like, well, somebody said my chest X ray is abnormal, or my lymph nodes are swollen. And we go through the process, the diagnostic process, and biopsy that tissue in it, and it turns out to be consistent with sarcoidosis. And in some of those patients, the sarcoidosis just kind of is there and doesn't really do much, either for many years or for the majority of the patient's life. That's that's still sarcoidosis and a subtype of sarcoidosis, there are other patients who have sarcoidosis that kind of like she's saying, comes and goes. So there are times where it flares up and is really active, and the patient does have to work with their doctors to treat it, to get it under control, and then it can kind of go into remission, where it becomes sort of quiet and isn't as big a deal in the patient's life. And often we can achieve that. Sometimes that happens without medication, and in other times, we use medications to achieve that remission. So

Dr. Camille Pope 11:42:38
show, awesome. Thank you. So we learned a bit in that video about the different signs and symptoms, how sometimes sarcoidosis can almost, you know, remain dormant, but then sometimes it can flare up. And then we also talked before that about sarcoidosis commonly being misdiagnosed and doctors thinking it's something else. So we have another question in the chat for our audience and community members who have joined us today, you can or drop your responses in the chat. Have you or someone you know ever experienced a misdiagnosis? Doesn't have to necessarily be related to sarcoidosis, but just in general, your physician diagnosed you with one thing you found out later, it was something else. I know I've had this happen to me, so I actually think that's kind of common, but we'll see, oh, we have yeses, yes, yes, yes, with exclamation points and people emphatically talking about how they've experienced misdiagnosis in the past. Well, thank you all for your responses. In just a second, we'll turn it back over to Dr Mathias so she can speak about the importance of the doctor patient relationship to make sure that the doctors really listening to patients who come in and talk about their symptoms, so that we can lessen the times that these misdiagnosis occur. But before we get to that, I do want to have Miss Shirley and tatinisha back on and just talk a bit about the type of support and care that is required when it comes to supporting a family member who might have a diagnosis of sarcoidosis. So tatinisha, can you talk a bit about what it's like being Miss Shirley's daughter and helping her manage and thrive with her her sarcoidosis? So. Her past.

Ta-Tanisha 11:44:33
My mother is so funny. So I just want you to know that she has been pretty much able to manage and I'm I'm sorry you guys can hear them construction behind me, but she's been pretty much able to manage her health. She has a team of doctors. She still walks every day. And, you know, she eats what she wants to eat, and and exercises. I mean, because she had other things that they wanted to focus on that will also help her lungs. So she the exercising helped her a lot. And, yeah, she joined the gym so, so we haven't really had to, you know, take care of Shirley in the way that you would think, like she's been living with the disease more than anything.

Ms. Shirley 11:45:28
Yeah, I had to keep it moving, you know, because I still had a job that I had to go to every day. And if, if you work in the corporate world, you have to really keep your foot moving. And then I had a staff, you know, I was like in management, so I had a staff that I had to, you know, keep things moving every day. So I just, just kept it moving, you know, took my medication, took care of all my doctor's appointments, did the exercising, join the gym, did the walking and everything. So I think maybe that kind of, and then I don't drink only on special occasion. That's okay. She's telling us how
11:46:13
to, you know, I let no know, she doesn't

Ta-Tanisha 11:46:15
have any bad habits, per se, things that would would normally, you know, inflame someone's system. Other than, you know, she, she would eat some fried food, yeah, you know that other type of things. But, you know, we also come from a whole long line of people that, even though we, you know, that don't really complain. So, you know, like she said, She's keeping it moving, like the diagnosis, it is what it is. And just, you know, how can I just make it

Ms. Shirley 11:46:44
through? Yeah, yeah. And I think that that kind of keeps you going when you have other things to think about. You know, the staff that I had to worry about, a job that I wanted to keep, and children, you know, and and, you know, grandchildren, grandchildren. So it just kept me from thinking about it, yeah, you know. And just keep it moving. Even now, I just keep it moving. It's always moving.

Dr. Camille Pope 11:47:10
That's great. I so it seems that having that support system has helped you keep it moving and live and thrive through your diagnosis. Miss Shirley, but it's also helped you to so you appreciate the support, but it also helps you kind of keep your mind off of, you know the diagnosis. It allows you to still live a full and thriving life. But rosemary, Miss, Miss Rose, who is part of our NOWINCLUDED team, um, she's also putting in here how important it is to rest and take care of yourself so that that balance is true.

Ta-Tanisha 11:47:47
Yeah, she gets a lot of sleep. Yeah, no, we're not sleep deprived in this family.

Dr. Camille Pope 11:47:52
That's, I know that's right, I subscribe to that too. Get your rest. I am with you

Ms. Shirley 11:47:57
and to eat, right? You know, I try to eat, you know, I might, well, I haven't stopped at McDonald's lately, but I might stop at a fast food every now and then. But I kind of like cooking my own food most of the time, or having my kids Cook, which they don't do anymore. Kind of hurt my

Dr. Camille Pope 11:48:14
feelings. Special treat when they come cook. Yeah. So you guys mentioned that Miss Shirley has, in addition to the family support, has a strong health care support team surrounding her too. So Doctor Mathai, can you speak a bit about the importance of that health having the right healthcare providers in place around you as a patient to help you manage your diagnosis and thrive, and making sure those lines of communication remain open? I

Dr. Susan Mathai 11:48:54
Oh, there you okay. So I think that one of the most important things for a patient with a chronic disease, and I'm going to categorize sarcoidosis as a chronic disease, because for most patients, it is, it is a lifelong diagnosis. There's no sort of cure for sarcoidosis, even though some patients can have sarcoidosis that becomes more dormant at different times of their lives, any any chronic disease, diabetes, heart disease, sarcoidosis, SOP, D, asthma, the most important thing to getting the best outcome that you can have is to. Have a care team so doctors and nurses and and I'm including everybody in a doctor's staff, you know, the schedulers, the folks that answer the phones, having a team that you feel like you can communicate with, because chronic disease management is comes down to paying attention to your body and also having your care providers pay attention to it too and react appropriately to changes that you're feeling and your symptoms. And so sometimes a patient will tell me, Well, you know, I've been seeing this other person and I want to change, but I don't want to hurt that other person's feelings. It's like, no, the doctor's feelings are not. I mean, we are human, of course, and we deserve to be treated with respect, but our but what's most important is that we find the right doctor for you, so the doctor and doctor's office for you, so that you can feel heard and feel cared for. Because if you if there isn't, I tell my patients sometimes, you know, before I met my husband, there, I went on dates with a lot of nice gentlemen, but I didn't marry those guys because it wasn't the right person, right? There's nothing wrong with those guys, but they are not right for me, and so I think about that a lot, I try to give them that example. Sometimes with doctors like sometimes you may not have the right vibe, or don't feel like you can be honest with one physician or another, and so it may take a while to find the right person, but I think that if you have a chronic disease, I myself have a different chronic disease, it's really important to me that I have a doctor that I can talk to and whose office I can reach out to when I need refills on my meds, when I feel like I need to change my meds. You know, these are important parts of the journey that you're going to experience as a patient, and it may take a little while to find the right team for you. I wish always that it didn't take patients a while, but I think that is so important. And I hope I wish for every p i hope that i am that doctor for a lot of patients. And I think every doctor really wants to be that person for for patients, and so that's why we went to medical school. But if you're ever needing if you find that there's a particular team that works better for you, I always advocate to patients, be part of the engage with that team, because you're on a lifelong journey, and we need to just find the right match for you.

Dr. Camille Pope 11:52:12
I love that. So it's a chronic illness, it's a lifelong journey. So you got to have the right partner partners and feel free to date around and break up as needed. That's That sounds like a great key takeaway for talking about the importance of having the right health care provider team around you as you're managing your diagnosis for the last few minutes of our community discussion going to shift gears just a bit, and we want to talk a bit about clinical research and the importance of clinical research to care, especially when it comes to sarcoidosis. And so we know that, you know, clinical trials are often an option along with, you know, lifestyle modifications and different medications and treatments that are available for many diseases, including sarcoidosis. So Dr matthaa, can you talk a bit about how clinical research works for sarcoidosis patients and the importance of patient involvement in resource and research initiatives,

Dr. Susan Mathai 11:53:16
yeah, so the clinical trials in general. So the clinical the word clinical trials really refers to when, when scientists have found or have reason to believe that a medication might be helpful for a particular disease or patient population and but the but you have to actually do a clinical trial to show the regulator. So like the FDA and other agencies around the world that determine whether drugs are effective and safe, we have to actually prove that these drugs work before they get approval to and can be covered by insurance or Medicare, Medicaid, and so clinical trials are the kind of process of doing that experiment in the real world, to taking a medicine and Giving it, giving some people a placebo, which means an inactive pill. So usually, like, like, the idea of, like, a sugar pill, and then some people get the real medicine, and doctors have really, have to say up front, these are the ways we're going to measure if this medication works or not. And you compare those who got the medicine

versus those who did not get the new medicine. Yes, and if the predetermined outcomes are better in those who have received the active medication, and if there are no signals that the active medication causes any harm or severe side effects that are that are bad for patients, then the FDA and other regulatory bodies will consider approving that medication to be sold in the marketplace and and given to patients. The reason that clinical trials are important is they're the only way for us to know what is real like, what really works to help people what is safe and and what we should recommend to patients. And without clinical trials, we don't want to just kind of follow, you know, just what people kind of believe in their heart without any evidence to be the case. And so that's why clinical trials are important. It's how we develop new treatment and understand what works and doesn't work. And what's really important is that we really hope, in doing clinical trials, that the patients that are in our clinical trials reflect the actual population of patients that we hope to help with medications. For a long time, there has been a concern in the world of clinical trials that clinical trial participation, it doesn't include enough diversity, so doesn't include people of different ethnic and racial backgrounds, and so that we may be under like not representing the real, lived experience of the diverse community in the United States that we're trying to help. And so we're really and this is particularly important in sarcoidosis, which, as I mentioned, can affect people of any any racial or ethnic background. And so one of the things have been hard, isn't sarcoidosis, is it's been a while since there's been been large clinical trials in sarcoidosis, if you are currently ongoing. And I think that those of us who treat sarcoidosis are really hoping that these clinical trials that are currently ongoing allow us to offer our patients more evidence based and more efficacious medications in the near future than what already exists out there. There are a lot of options out there for medications for sarcoidosis and but there are many patients that still are not getting the clinical outcomes that they want and the disease control that they want with the currently available medication. So we're really hopeful that some of the new drugs that are being studied in clinical trials will be good options and better options for our patients in the years to come.

Dr. Camille Pope 11:57:25
Thanks, Dr Mathai, that's really helpful. Thank you for explaining. You know, what is a clinical trial and what's the importance of people being involved, because it's really the only way we kind of know that drugs are going to be safe and efficacious, and not just, you know, all willy nilly prescribing things that may not work. And also the importance of having diverse and in diversity and inclusion of clinical trials, because when the drugs do get approved for use in the real world, they're going to be used by a variety of different people, we want to make sure that the drugs have been evaluated in a variety of different folks as well. I believe we have a one more polling question for our community members who have joined the call. If we could pull that up, how willing are you to participate in clinical research? Willing? Yes, maybe not sure, not willing. Would love for you to drop your responses in the chat, and while you're dropping your responses in the chat, we'll turn it to miss Shirley and tatinisha. What are your thoughts about clinical research? Would you ever consider clinical research? Have you ever been offered a research opportunity? What are your thoughts there?

Ms. Shirley 11:58:35
Well, I'm, I'm currently in Alzheimer's research with the University of Michigan and Wayne State, and I think they combined efforts this year, last year, where, you know, they have their own divisions, but they're crossing over, and I've been in that research program for a few years now, and that's that I kind of understand the need for that type of research. And then I want them to make sure they know when I go crazy, at least I have a at least I'll have advanced notice, you know,

Ms. Shirley 11:59:20
you know, but I've been participating, okay, okay,

Ta-Tanisha 11:59:28
I'm in a research study or research. Program called all of us. And I think it's global, maybe, like I gave them access to everything, and it drew my blood and tested it, you know, I guess whatever researcher doctor is doing some kind of research, they could use my data in their in their pool of data. So, yeah, I've been in that for a year.

Dr. Camille Pope 11:59:56
That's really cool. I didn't know that you guys were actually both involved in clinical trials. But the last question, before we maybe go through any additional questions in the chat, can you just share what what made you say yes, when the opportunity came to you to be involved in research, whether it was the Alzheimer's or all of us like, why did you say, Okay, this is something I I'll do. I think

Ms. Shirley 12:00:19
my my father had Alzheimer's, or as we watched his decline over the years, and he was the way he he was like a happy old man, the only thing that disrupted his environment is when we tried to discipline these kids around him, and he couldn't handle it. So I wanted to, you know, we didn't. We just kind of monitored him as as he progressed with the disease or what

have you. But it, it brought to light the need for us to make sure, you know, that it that do the study and make sure that, that we get a grip on it, if, if it comes around, you know. And I just wanted to know, you know, if this is what he had, is this is, is something, yes, something that I would get. So at least I have somebody watching me

Ms. Shirley 12:01:18
times a year to, you know, do all the blood tests and all the questions and answers and things like that, and it's and hopefully it's beneficial to the researchers. Awesome. So

Dr. Camille Pope 12:01:29
it sounds like you were encouraged by a prior diagnosis from a family member, get ahead of it and also contribute to the community the research. Yeah, large, yeah, awesome.

Ta-Tanisha 12:01:42
I just thought. I just thought all of us was, I want to say cool, if that's the right way to say it, like the way they described what the research would do. And, you know, being being a black female, you know, we're not always represented in these studies, so the fact that they reached out and asked and gave all and I have an app, and so I take surveys all the time, and, you know, I just thought that it was just a very non invasive but thorough research study.

Dr. Camille Pope 12:02:19
Thank you for sharing, so you wanted to also contribute to the science and like the way it was described to you, and knew that we're often underrepresented so well. Thank you. Well, we have just a couple of minutes left. Are there any additional questions we can maybe take one in the chat, are there specific diets that someone has to adopt once diagnosed with sarcoidosis, or certain foods to stay away from? I think that would be a good question for you. Dr Mathai,

Dr. Susan Mathai 12:02:53
so I think that there's no one specific diet that I would say that I, you know, think has evidence to say that that's like better, except for the one that's better for everybody, which is, you know, to focus on eating like Whole Foods, right? So foods that are not processed, you want to try to eat things. And so the way that I try to describe that to patients in my clinic, when I'm trying to explain to them, like, what, what a whole food means, it's like, it's not just the, you know, grocery store, it's the it's like a food that looks like what it is, so not processed, so not something that's made in a factory, but something that, if we asked our great, great, great great grandmothers, if we put that food in front of them, would your great, great, great great grandmother, know what that is? Would look like food to your great, great, great great grandmother? Okay, then maybe that is not processed, right? So it didn't have to go through a factory and get sprayed into a specific shape or something to to be food. And so, fruits, vegetables, proteins are, you know, trying, trying to, kind of, again, eat things that, that, you know, in general, healthy for you. So I try to get my patients to stay away from ultra processed foods. I try to help them get towards a healthy weight, if that, if either I don't want people to be underweight, as some sarcoidosis patients and other patients with chronic disease actually lose weight, too much weight, and others. Are, are, you know, heavier, and I we want to get towards a generally healthy weight and to be active, right? So sometimes it's not about looking a certain way, or, I think it's about feeling a certain way. So you can be the same weight and be unfit as you can be very active and be the same actual weight number, but it's about getting up and walking around, not being a couch potato, things like that. So I try to work with my patients on those kind of goals. So there's not a specific diet that sarcoidosis patients need to be eating or anything. It's just it's a kind of general advice I give all my patients and and my family members and just people I care about. The one thing I will say is a number of medications that are currently used to treat sarcoidosis can stress out the liver from time to time, and so typically, we do really want to make sure the patients are moderating alcohol use, and so that they're because alcohol can really stress out a liver, and so we don't want that to interfere with like the treatment process. Great.

Dr. Camille Pope 12:05:40
Thank you. Dr Mathias, so it sounds like not a specific diet, but just overall health and wellness. Not eating processed foods and getting exercise are ways to help manage the diagnosis, and if I remember correctly, Miss Shirley says she's doing all of those things. So we're, yeah, well, we have come to the end of our breathing knowledge, virtual community conversation. I'd like to thank our panelists, Doctor, Doctor Susan Matai and our two NOWINCLUDED community members, Miss Shirley and her daughter, Miss Tanisha, we appreciate you. We appreciate your insights and for taking the time to share with our community. Today, for those of you who are on the line, would like to encourage you to join NOWINCLUDED. We have a whole you know, platform focused on various health topics of interest for you, we have a lung health circle if you are specifically interested in lung health, and if there are any questions that we were not able to answer for you today, feel free to email us at hello@nowincluded.com, and we will get an answer to you post this conversation so again. Thank you all for joining. Thanks to our panelists, and hope you have an amazing

12:06:57
day. Thank you. Thank you.

Dr. Susan Mathai 12:07:00
Great to be with you. Bye. You.