Exploring Long COVID: Symptoms, Diagnosis and Management

Mild or moderate COVID-19 lasts for up to 2 weeks for most people. However, many who recovered from the initial infection of COVID-19 and tested negative continue to experience some long-term after effects of the disease. Such patients are referred to as “long haulers” having “Long COVID” – also known as “Post-Acute Sequelae of SARS-CoV-2 infection (PASC)”. Approximately 10%-20% of COVID-19 patients go on to develop long COVID. It is associated with a wide spectrum of symptoms ranging from mild to severe physical, cognitive and behavioral symptoms.

So, how is long COVID defined clinically? How is it diagnosed and what is being done to manage the condition? We are talking to Dr. Benjamin Abramoff of Penn Medicine to get answers to these questions and understand the nuances of long COVID. Joining Dr Abramoff on the panel is long COVID patient Charlie McCone sharing his story.

Full Transcript:

Shweta Mishra: Hello and welcome to CureTalks. Today, we are exploring long COVID, a condition that is puzzling the minds of researchers, clinicians, patients and caregivers alike. I’m Shweta Mishra and today we have with us Dr. Benjamin Abramoff from the University of Pennsylvania. Dr. Abramoff is the Director of the Post COVID Assessment and Recovery Clinic and the Spinal Cord Injury Program and Assistant Professor of Clinical Physical Medicine and Rehabilitation at the University of Pennsylvania. Joining us on the panel is patient advocate Charlie McCone, a previously active 32-year-old who has been dealing with long COVID symptoms since last two years now and is committed to spreading awareness through his writings and media interviews. Welcome to cure talks everyone.

Dr. Benjamin Abramoff: Thanks for having me.

Shweta Mishra: Thank you doctor, pleasure is all ours. Dr. Abramoff, it’s more than two years now that we have been hearing stories about folks who were walking miles and miles a day but are now being pushed in a wheelchair and about folks who have never had any kind of heart issues but are all of a sudden dealing with congestive heart failures and folks experiencing a variety of confusing symptoms about more than 200 symptoms that is linked to this condition. So, it’s all very confusing. So, what are we dealing with here and can you please break it down for us? How is long COVID defined clinically and what is the likelihood of someone developing the condition after a primary infection with COVID-19?

Dr. Benjamin Abramoff: Yeah. So, long COVID is really a pretty broad general term and it really, for many of the definitions includes patients who are critically ill in the hospital with COVID in the ICU, sometimes on ECMO, all the way to patients who had mild initial courses, maybe even they didn’t even realize they were that sick, who continue to have lingering symptoms, often times lasting months and months after infection. Now the WHO has a definition that’s become pretty commonly used and is one that is gaining traction clinically that individuals with long COVID have symptoms, at least three months from the time of their initial infection, those symptoms lasting about two months and cannot be explained by any other reasons for having those symptoms. And the symptoms abroad, some patients have fatigued prominent symptoms, some people have cognitively prominent symptoms, some patients have symptoms of pain, myalgias, muscle pain, joint pain. It’s a wide spectrum of different symptoms. Now what are the chances of having it? it’s hard to say because studies look at this very differently. The best studies, the prospective studies

estimate somewhere between a 10, maybe the 30% chance of having ongoing symptoms following initial COVID infection. Luckily, over time that rates seem to be going down with some subsequent waves of Omicron, Delta, Alpha, although even with the very small percentages with a large wave, like the Omicron wave those numbers can still be very very high.

Shweta Mishra: Right. I know thank you Doctor. We know research is going on worldwide and there's a constant flow of new information about the incidents, diagnosis and management of long COVID and we may not have all the answers but talking about diagnosis how our patients being assessed right now for long COVID and what diagnostic tests are being advised?

Dr. Benjamin Abramoff: So, there's a couple things to think about. As of now we don't have a clinical biomarker, clinical test that is you have a score of 15 on your long COVID blood test. So, if you have long COVID and you have a score of 1, so you don't have long COVID. Now there are studies and investigations into potential biomarkers that can be a sign that patients are more or less likely to have long COVID but there's no one passed or one study that we know of yet that will tell somebody or tell us if somebody has long covid. Right now, it's really a clinical diagnosis, a diagnosis based on what symptoms they are having, how long they're having those symptoms. And as part of this, we always look for any other underlying conditions or diseases that may be explain their symptoms that are directly treatable. And we'll probably talk a little bit more about kind of what are the options and treatments for long COVID a little bit later but at this point we want to rule out other things that may be contributing to the symptoms and if clinically we've ruled those things out and they have symptoms that are consistent with long covid, patients will gain a diagnosis of long covid.

Shweta Mishra: Right. Thank you. That's a useful bit of information, Doctor. I know, we have dealt with several variants like you just mentioned variants of coronavirus over the past two years. Are there different types of long COVID depending on the Corona virus variants that cause the COVID-19 infection in the first hand? Do we know yet how the symptoms change based on the variants?

Dr. Benjamin Abramoff: So, I think the bigger issue, the bigger question, the bigger dichotomy is not necessarily between variants but severity, so it does seem that patients who are hospitalized or in the ICU, have somewhat a different clinical picture than those patients, that are more mildly affected at home. And so, patients and we've known this for a long time, patients, who are in the ICU or critically ill can develop a syndrome known as post ICU syndrome. And that looks often very different than the patients who have more mild illness. Now, there may be subtle changes over time. For example, smell and taste loss seems to be very much less prominent with subsequent waves and it was early on. And I'm seeing a lot less of that in clinic and talking to my clinical partners. But the that's not a major evolution over time. And we're not really seeing, in terms of things like fatigue and the brain fog and some of these other prominent symptoms, much of a change over time.

Shweta Mishra: Right. Thank you, thank you for sharing that, Doctor. Moving on to talking about some of the treatments currently available for long COVID. And we are seeing a lot of disparate answers to questions like these and it's understandable given the complexity of the condition but would be great if you could share, what we have learned so far, what is working optimally for most long COVID patients in terms of treatment?

Dr. Benjamin Abramoff: So, unfortunately and this is one of the things that as a research community we are working on for most of the symptoms we are still treating it, symptom-based and palliative. So, we think about how do we make you feel better? So, if you're fatigued, how do we, if you're not sleeping, we will give you medicine to make you sleep better, or we will give you a neuro stimulant to help you be more awake during the day? But ultimately, those types of symptomatic treatments are not what most of my patients are looking for. What my patients really want is something that will attack the root pathophysiologic causes of long COVID and that is something that we're still looking at and exploring. So, as of now we have developed programs that do comprehensive rehabilitation, cognitive rehabilitation for things like brain fog. Again, sometimes medications for symptoms that patients are having sometimes things like diet and exercise and

pacing and lifestyle adjustments can make a difference. But it's really on a case-by-case basis, based on what the patient is presenting with.

Shweta Mishra: Right, thank you and good to know that doctor. Let's talk about some of the initiatives that are going on to tackle long COVID and I know the NIH created the researching COVID to enhance recovery initiative that supports many researchers studying long COVID and under this initiative Penn medicine is recruiting pregnant people with or without COVID, those who have been pregnant between 2020 and now could you please talk about that study and a little more on other ongoing initiatives at Penn?

Dr. Benjamin Abramoff: Yeah. So that NIH study is a national research study funded by the NIH. It was given approximately 470 million dollars. So, it's an extremely large study to investigate the root causes and potential treatments of long COVID. They've recruited thousands of patients and they're really, they're kind of first has been looking at the history, the ideology of pathophysiologic mechanisms, but the goal and hopefully with time that study will transition to be more looking at clinical trials, which I believe are kind of in infancy and beginning to start soon but haven't really come from that study yet. But beyond that there's lots of national efforts and that recover studies, not going to be the only answer to this. It's going to take research at all levels from the basic science to the bedside to really find the best treatments for long COVID. And even at Penn medicine I'm working with a group looking at autoimmunity and auto immune factors as part of the pathophysiology of long COVID. There's a group that I also work with looking at the metabolomic and that's just here at Penn and there's many many other studies looking at different treatment regimens out there. Some of which have low levels of evidence, some of which have, trying to develop an evidence-based but certainly much much more effort is needed on, kind of at all fronts in attack of Long COVID.

Shweta Mishra: Absolutely, yeah. Thank you doctor. With that I would now like to invite Charlie to the discussion and Charlie before you go ahead and ask your questions to Dr. Abramoff, would you like to share your experiences with long COVID? I know you were a very active person before you contracted the disease in March 2020 a couple of years back.

Charlie McCone: Sure. Yeah. First of all, thank you for having me. Thank you, Dr. Abramoff for sharing your time as well. Yeah, I got sick, I just turned 30 years old in March 2020. On the first wave I was a "picture of health" kind of young working professional, I had gotten sick, I was coming back from a biweekly, three mile run, I do and I'd got home that night I had a weird pain in my chest and the next day I was probably short of breath for the first time in my life and then I was basically just laid out for 10 days and then by the third week I thought I was kind of getting better, but was starting to think how this is kind of lingering pretty long. I have never been out sick more than a few days in my life. So, the fact that I was still feeling run down and the third week was already sort of strange. Fourth week, I thought I was kind of like getting over it and by the end of the fourth week I was like, okay I don't think I have any symptoms I'm going to go for a bike ride and at the end of that bike ride, I came back and I just collapsed, all my symptoms came rushing back and that was the first time I had the typical long COVID relapse which is kind of a hallmark symptom of people who are experiencing this disease is they have symptoms and then they kind of go away for a little bit, then they exert themselves and then everything comes back. And it's kind of this Prometheus rock type of world- we are all we've been living in and then throughout that process, I had similar experiences by the eighth week I thought I was getting better, but then all of a sudden, I woke up one day and I had muscle twitching and peripheral neuropathy in my hands everywhere. And this was two months into this, and I was like, is this from the infection or do I have some weird disease? And it was around that time that I had gone online and at that point I thought, maybe I had some terminal cancer or something like that. I had no idea that there was the concept of a post infectious illness, even existed and then I found a support group online and there were just thousands of posts of people my age saying, hey, it's been eight weeks, I'm still really short of breath. And so that has been my worst symptoms, shortness of breath. I've had it now for two and a half years, it feels like there's an anvil on your chest. It's incredibly uncomfortable and it's very debilitating. And by the third month, again, I thought I was getting better, that I was turning a corner and then one day I woke up, I had a sharp left chest pain in my chest and then I walked to the kitchen, my heart rate was 140. And then at that point, I had a pretty extensive work up and they discovered I had a pericardial effusion which is an inflammation of the heart sack. They thought I had myocarditis but that was ruled out and at that point it was

suspected maybe some mild pericarditis or something like that. And I was subsequently diagnosed with POTS which is an autonomic nervous system disorder. Whenever I go up right, my heart rate races, my blood pressure jumps and that's a pretty common symptom or consequence for a lot of on COVID patients, about 67% or something like are developing some sort of autonomic dysfunction. And so, I tried to work through symptoms the first year and a half. I was completely housebound, and I could get through the workday, and I would just collapse. And I just kind of do anything else and that's pretty typical for a long COVID patients is that they feel like the answer is a week away or the next specialist away or the next month away because it is still in themselves that they're sick and they're just going to get better. And it took me 18 months to realize like I'm not getting better, and I collapse basically and at that point I went on a short-term disability and unfortunately right after short-term disability I was hoping to only be on it for a couple of months. I got re-infected, and I ended up in the hospital with pneumonia and it really deteriorated my baseline. And I'm still recovering from that a year later and right now I'm 32, my entire 30s with this condition I can do about one or two things in the day right now. Like I could do this and maybe one more thing and that's basically all the productivity I can do in a day, I have to rely on my partner full time as caretaker. So, I'm not really independent. I can't really work right now. My symptoms are still very severe cardiorespiratory symptoms. There is still not a good answer to why long COVID patients have this respiratory dyspnea, it's kind of one of the main a lot of the main investigations look normal. But there is some research that's coming out is really interesting around that I think but not a lot of answers, but I have a great team of doctors with me, they support me but it's incredibly challenging and debilitating condition.

Dr. Benjamin Abramoff: I want to say I think Charlie your stories if I had to give it a typical case of somebody with severe long COVID symptoms and severe long haul, I would say that it's very common and there's thousands if not hundreds of thousands of people out there with similar stories to Charlie's.

Shweta Mishra: Right. Thank you for sharing your story, Charlie and the fact that you are here, despite your difficult symptoms is really commendable. Thank you so much for that. And thank you for your advocacy. Please go ahead with your questions for Dr. Abramoff now.

Charlie McCone: Sure. Yeah, my first question Dr. Abramoff is so it seems like there is kind of like a massive promising information out there and I'm particularly interested in are there any conversations happening in your world between long COVID clinics? Because now, it seems like there are respective long COVID clinics with respective treatments. Stanford, I saw them and they're saying 50% of our patients improve with low dose Naltrexone. Then your Dr. Petrino say about a lot of 70% of our patients, get better with autonomic conditioning and then you'll hear the Montana Clinic say, 90% of our patients are improving with nebulized prednisone. But it doesn't work with regular inhalers or regular prednisone, it has to be nebulized. And so it seems like there's a lot of promising anecdotal case studies that maybe want further investigation and I'm wondering are there conversations happening or is there some type of plan to try and standardize treatment because there are a few long COVID clinics that just don't feel like they're really doing anything but there are some that feel like they have some things that are working and I wonder if you could just elaborate upon what might be happening behind the scenes, or what may you think should happen if nothing is?

Dr. Benjamin Abramoff: Yeah. So, the main place I think that is happening is the American Academy of Physical Medicine and Rehabilitation has a long COVID clinic collaborative. It's made up of about 36 clinics around the country and that also includes Patient Advocates as part of that effort and it's a form that has developed some guidance statements on long COVID. Again, they always tend to be a little bit more on the conservative side, just in the interest of safety. But there's a lot of discussion that happens at that level. And there's also many kinds of smaller research pockets of conversations happening. Maybe not on the clinical treatment side, but certainly on the kind of basic science pathophysiology side. So that's happening between many different institutions. But I do think that there needs to be more discussions of this and beyond that there needs to be clinical trial. So, if things are really working, whether that's low dose Naltrexone, which does definitely work with some patients or that physical therapy and different physical therapy protocols, which certainly works with some patients. Those trials need to really happen so that we have no concrete evidence and I want to personally see more from the NIH, the funding that's out there

going to these studies that are really looking at clinical trials because that's the only way we're going to get answers. And I hope that this focus as important as I understand the pathophysiology is so we can get to that.. Sure idea, which is what everybody wants. We also need to do treatments so that you will feel better right now and if we need to spread those we have to go to works.

Charlie McCone: Great. So, yeah, that makes sense. I mean, nobody's going to say like this works until there's evidence to say that. Is there any type of like funnel that's happening that you're aware of like, hey, this is working, this person said this is working, lets pitch this for a clinical trial or is it just like contingent upon the fact whether a researcher or physician actually plugged into research and they kind of have that network, I guess I'm just a little bit concerned that there's going to be these treatments that are promising that never make it cross or up the stream to clinical trial and I'm wondering, is that just kind of luck of the draw or just depends how ambitious, or adamant the respective physician, specific group is, etc?

Dr. Benjamin Abramoff: Yeah. And I hear definitely where that concern is coming from, I think that as of now, a lot of it is kind of one-off clinics and clinical folks who have something that works, or they think it might work. And then they do a trial before it and I don't think there's a national network of clinical trials, and hopefully the RECOVER project will incorporate that a little bit more to what they do. As they kind of move forward, it's always slow when you're kind of going through this big, huge bureaucracy of something like the RECOVER trial. I would love to see some sort of clinical network of clinical trials, for multi-centered large clinical trials, that really build that support to get some of these things that are promising into a regular person's hand, it's going to take funding to be honest with you, which I don't think we've seen for that type of effort yet. And again, even at that level, you need to have some sort of early data that supports it before going to kind of the larger scale multicentre clinical trials.

Charlie McCone: Got it. Yeah, okay, can I go then to my next question. From your vantage point as somebody's treating long COVID patients what do you see is kind of your current immediate biggest barrier to improving the quality of care for these folks. I think maybe the most obvious answer would be clear-cut clinical trials so you could have treatments but I fear some doctors say like I'm spending way too much time fighting insurance because they're not holding up their end of the bargain or I'm not getting compensated for doing all this disability paperwork and longer consultations, or there's just my colleagues aren't educated enough, and they're kind of causing more issues. I'm telling them to do one thing and I'm getting another thing. So, I guess till your last point, it's I find to be interesting as well. But is there anything that kind of repeatedly comes up to you as like, I really need this taken care of and off my plate?

Dr. Benjamin Abramoff: Yeah, I mean I think the ultimate barrier which again is kind of not understanding the root causes. So, for clinician, it's kind of in the nature of a lot of physicians that they want answers and they want to be able to say hey, you have hypertension, well, here's I know the hypertension medicines that work, take A, take B and then take C and living in kind of this milieu of an uncertainty is challenging for many clinicians out there and also kind of your other point certainly to do, what we do here in our clinic and many of our academic centres that are have hosting post COVID clinics, or long COVID clinics would be very challenging to do in an environment that like a private clinic or a private practice or smaller clinic where you don't have the resources of a major institution, because there are definitely are lots of disability issues that come into play, insurance issues that can come into play at times and it can be challenging to get consultants to sometimes to see these patients if you're not in the right setting and I've heard of clinics that have shut down because they couldn't get those resources in place. So, certainly those are barriers there are clinics out there they're doing it and I really applaud them who are really putting in the time and effort, but it is definitely challenging and I think to your last point, there definitely also needs to be more education of clinicians out there. I think it's definitely changed over time when I first were seeing patients in June of 2020, the percentage of patients that said they're getting gas lit and it was all in their head and it's not real symptoms was like really 95% plus. Now it's a very small number and it's usually one clinician that they come to that kind of dismisses them. Most clinicians now I think recognize this as a real entity, which I think is a real big positive step in the right direction. But certainly, that doesn't necessarily lead to them knowing to have accurate clinical care. And at the same time part of that is because we don't know the ideal clinical care. So, these things are all really tied together to one another.

Charlie McCone: Got it. So, in your day-to-day you would say just your biggest barrier is just not having clear-cut pathophysiological understanding of the disease and the biggest solution to that is just better faster, clinical trials?

Dr. Benjamin Abramoff: Yeah, I think ultimately that's the answer and then the other thing that I always like to kind of bring into this conversation, as it may not be one thing and it may not be the same for every patient. Certainly, as I mentioned before, it's probably very different from that patient is in the ICU and critically ill for in bed for two months, three months, in some cases, and the person who's mildly ill at home. But to me, there's certain extent, it just makes sense that somebody who has predominant symptoms, may be very different patient and have a different pathophysiology, and the person that has very prominent Neuropsychiatric cognitive symptoms.

Charlie McCone: Got it. Yeah, I guess I was trying to get at is that in the advocacy community right now, the patient advocacy community, there's a lot of varying different opinions around, what's the biggest priority. And I was just kind of curious from a physician's point what you see and that kind of seems to land on, we just need clinical trials and that's the best and our advocacy is pushing for that. Since it seems like, I'm also on the patient steering committee with Stanford. They are trying to get clinical trials off the ground, and I think right now their hope is to try and get one started by the end of the year. However, that's I think on the fastest timeline imaginable, it could still be another year after that or multiple years that there is anything to take away from that could be applied and translated clinically. And so, I guess while we are still dealing with this public health crisis, there are not any gold standard treatments for this yet. However, there are a lot of emerging case studies that say hey 20 patients improved on this. There's no Placebo or control arm and there are 100 patients approved on this and patients are bringing this to their physicians and they're saying, I'm not touching that and they're saying, well what are you going to do for me then. We're two years away from using that as a tool what do you think is the right framework to kind of meet patients where they are, take some of the emerging evidence into consideration, look at some of these case studies as… What you think is the right approach as a physician trying to help patients right now? I think there's a lot of varying opinions around we shouldn't do anything until there is a randomized control trial and I think there are some physicians saying hey, this is a low-risk drug. It looks like it's helped 20 patients, helped another one patient, and let's give it a go. What you think is the right approach to that?

Dr. Benjamin Abramoff: Yeah, I think that's a really challenging and complex question because I don't think there's a single like threshold or line. I think there's a kind of have to way different aspects of it, way different pieces. The way, what's the risks, what's the benefits, what's the level of evidence, where it does exist, what's the cost? There are people out there who are trying to make a lot of money and there is a psychological reaction, certainly a lot of money on a treatment, the chances of having a beneficial effect go up. ..

Charlie McCone: Oh, really?

Dr. Benjamin Abramoff: There's also the element of what are you hearing from your colleagues, what if it worked anecdotally in your experience, how severe is it to patients' symptoms, were they tried in the past. I'm not against all treatments that haven't gone through double-blind placebo-controlled studies, and we prescribe those fairly routinely. But I always start with the things that are simple, that work, that are 100% safe or 95% safe before we jump to the things that are more experimental or have risk of side effects. And then there's some things that honestly have had poor evidence that, they're so not well done, and patients will bring to me and say, hey I saw this study and I look at the primary data and I'm really not convinced by it and the risks are pretty significant of taking those drugs, let's say. And that's where some of this conflict between patients and clinicians can come in. So, I think that we're having these conversations because that conflict has been there at the get-go sometimes, when we have had conversations of why I prefer this treatment over that treatment, this is where my threshold lies. I've had very, very few negative interactions at the end of the day or whatever where you really felt like, hey I'm being ignored. It's I think part of it is just taking this patient's symptoms seriously and having somewhat of a plan and a path forward.

Charlie McCone: Anecdotally have you had success with some off-label drugs and treatments, that have kind of raise your eyebrows, you're like, I want to see the data on this? And I guess, are there like, two or three drugs or therapies that you find to be reliable first line…. for the patients you're seeing?

Dr. Benjamin Abramoff: Yeah, so I don't think there's really been anything that's been to me like a light bulb and saying like this is it, this is the treatment that's going to work for everyone. I think one thing that we always do is and what works best a lot of time is, treating the underlying comorbidities whether that's insomnia, whether that's pain, whether that's fatigue, by treating those comorbidities kind of intern patients often feel better. I think proper therapy is really important for doing it the right way, whether that's addressing the dysautonomia, whether that's addressing the brain fog with cognitive retraining, those things can also be very effective. Now, off-label medications I don't know if this is the right forum to kind of go into recommending one over another. But I think there can certainly be considered, you mentioned low dose Naltrexone for some patients that's a reasonable option. Duloxetine or SNRI medicines can be helpful for patients with neuropathic pain, with, energy issues, we have medications that can help with pain and sleep. So, it's just really on a case-by-case basis and what symptoms a patient is experiencing.

Charlie McCone: How far away do you think we are from long COVID clinics, having like a standard of care treatment? Like we know like this where maybe 80%, 70% of long COVID clinics are doing the same thing and reliably helping patients get better.

Dr. Benjamin Abramoff: I think we're still so much far away. I think we're probably not within a year of that happening. Maybe two years would be my just off the cuff estimate, but there's still going to be a lot of time before we get that kind of cookie cutter approach. But I'm also very hopeful and optimistic and maybe this is a false optimism that we'll be able to find some medications that really helped with the underlying causes of long COVID or are more targeted to the underlying causes. Because even medications like low dose Naltrexone, my gut impression is it's more of a symptomatic treatment and not a root cause treatment.

Charlie McCone: Yeah. Thank you for that. I guess one kind of more granular question I have is do you think long COVID has kind of highlighted or exemplified some kind of problems with the current medical structure approach, or do you think it's just that it's a new disease and the system is fine and it just needs to wait for the science to catch up. I'm wondering if you have any thoughts on whether like well no this actually expose some like problems with how our approaching care or as opposed to like no the system is fine, we just don't have the data and we need to wait for that to catch up and that's going to help us.

Dr. Benjamin Abramoff: So I guess off the bat, I think everybody is frustrated by the pace of this and the pace of research and I think that it's always been the case with research and specially government-funded research is very slow, that's where things like you're doing as an advocate can really come in is if you with private foundations and things like that, or if there's a long COVID foundation that really had substantial funding for kind of the root cause, the root home or some of that. I think some of this research could be, maybe moved a little bit faster and I do think there's other fundamental issues in terms of providing complex care and reimbursement for that, the social resources for social work, or for clinical coordinators, that is needed in many conditions, and I think long COVID does exemplify some of those issues. I think if there were more resources focused for some of these chronic diseases, it would help in multidisciplinary care and would help with clinical care as well.

Charlie McCone: Do you think that need is going to remain even as we get more data around long COVID and there's going to be the need for a bigger push for more integrative care within the clinical setting or do you think we're going to find a couple of treatments that work for long COVID and it's going to kind of continue business as usual works or maybe a little bit of both depending on the institution and such?

Dr. Benjamin Abramoff: Yeah, I mean I think that need for integrated care is going to remain and I think that I would be, I'm hopeful that there can be some novel strategies around long COVID that can help push that forward as a concept. And I'm somebody that is optimistic that long COVID might be a platform to help others with the kind of complex chronic diseases that have had difficulties getting answers and getting

treatment in the past. But I think we're still early to see kind of how this all plays out. And there's even bills sitting in Congress, that haven't been acted on that could help support these types of efforts in terms of complex clinical care.

Charlie McCone: Got it so you think that will be a need and is a need?

Dr. Benjamin Abramoff: Yes.

Charlie McCone: So, you mentioned earlier that in June the first summer around, 90% of patients were kind of not being believed and now that has increased a lot. What are you seeing in your world around people's perception of long COVID? I think patients are obviously, they see it, we see it, I see it improving but a lot of patients, I have friends still reaching out saying my doctors they don't think there's anything wrong with me, I have all these things. So, it just seems there's still some either lack of education or still some suspicion around what it is. And I guess what one frustration COVID patients have is like yeah we need clinical trials now, we need all this advocacy now, we would love to see the physician and clinical community rally around that need for long COVID treatments the same way they did around how everybody should get their vaccines. There was no hiccup in that but then long COVID it's like you see some physicians they are like well we're not really sure what it is, is it even a thing and there are other physicians like I know it is a thing. It though seems like there's still kind of a dialogue happening within the clinical community. What do you see happening? What would you like to see evolve?

Dr. Benjamin Abramoff: Yeah, I think there's a couple things here. One like I mentioned before, I think it is getting better on that front, but I do think that it's still an issue. And I think sometimes when a clinician says, there's nothing wrong with you, what they're really reflecting is hey, we did all this testing, we did a chest x-ray, we did a chest CT scan, we did a cardiac Echo and all that came back normal, so you're not having. There's nothing I can do for you. Charlie, you don't really have anything wrong with you, even though you're sitting there saying, there's something wrong with me and I think that really speaks to kind of a lack of maybe understanding some of the more investigative clinical research that's being done that still can show abnormalities even when normal testing is showing kind of no abnormalities and people forget that even something that may be normal in the normal range, might not be your normal. And so even though you can walk on a treadmill for 10 minutes and that's within normal limits as an athlete who's doing three mile runs before, that might be significantly different for you. So, I think there's a few components of sometimes when a clinician is saying, hey, we don't know what's going on, or there's nothing wrong with you on our objective testing that we've had for years and years and years. I also think that this also speaks in some of the complexity of it. And so, when issues are complex and there's not one thing like a vaccine to kind of rally around, it makes the advocacy efforts much more challenging. And so, I agree, I think there should be more funding and I try to advocate as best I can for more clinical care, but I think sometimes many of the clinicians don't know exactly what they're even asking for and how they would ask for it.

Charlie McCone: Yeah, I think that's the issue that I'm getting at is that it's like, I sympathize, the first year, all my doctors luckily, I think most of them believed me, but are like you look good. I don't know what to do? Like, I believe you, I want to help you, I just want any other tools at my disposal, and I sympathized with them. And my question is that when we need more clinical trials, is it the issue? Is that the Physicians don't know what clinical trials to advocate for? I guess my thinking is like, I would imagine there'd be more like of a more pressure from the medical community on the research, government community like hey, we need tools here. Like you guys got to keep up to speed because I got all these patients. I can't do anything from them until you guys help me out here. And I feel like there is that sometimes I feel like I could be a little bit more of that to put to it in a light way.

Shweta Mishra: All right, thank you Charlie. Great questions and great discussion between the two of you. I'm afraid we are running out of time, so I just have one more question before we wrap up the show today, Doctor, do you have any advice for recovery for long COVID patients, any exercises that you recommend or any food supplements that you see are working for the patients?

Dr. Benjamin Abramoff: Yeah, I think a lot of times it's such a complex question and it's very different for each individual how severe their symptoms are, where they are in the recovery process. I would say my general advice for somebody who has long COVID or who has had COVID and just knocking over it. The first thing that kind of the earliest period is not to push things going back, to make sure you're resting, to listen to your body, as you're recovering in those first weeks to months after infection. I think getting a close clinical relationship with your PCP and following up with them even if you think you're on the road to recovery, just to keep them in the loop, in case things don't go in the right direction is a key step of this too. And then the other thing is if you can get it established, I know it's very difficult and there's long wait times, but if you can get established with the long COVID clinic sometimes they can give you resources that can be very helpful.

Shweta Mishra: Thank you. Thank you, Doctor. Charlie, quick advice for your fellow long haulers.

Charlie McCone: Yeah, I mean there are things that can help in treating, especially if you can get a diet, like my mom reached out to me yesterday and she says, my friend, she went to her cardiologist and she said her heart's fine, but every time she stands up, it goes to 130. I'm like that's POTS and that's actually treatable or there are medications that can help with that. And then to me that's one of the biggest things that I feel like, there's a need for just more clinical education on, is that's something patients will present with that if they're referred to a physician with the right understanding of that can actually improve their quality of life. That couldn't necessarily improve their underlying cause that's something that has helped me. And so, I would say just stay persistent, make sure you find a physician who if they don't know what to do, at least there's going to like there are dedicated to help finding the right team for you. And yeah, there are things that can help.

Shweta Mishra: Thank you. Great advice, Charlie. Thank you, Dr. Abramoff, very helpful advice and with that, I think it's time to wrap up today's show and thank you very much for such an informative session and addressing all our queries on long COVID. Charlie, thanks for agreeing to join us today, despite your condition, and guiding the panel with your very thoughtful questions. We also thank the University of Pennsylvania, and this talk will be made available on curetalks.com. Until we meet next time thank you, everyone, and have a great day.

Thank you.