# Why This Summit - The Intersection of Long Haul, Chronic Fatigue Syndrome and Other Complex Chronic Illnesses your options Transcript

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## Summit Introduction and Purpose

– Welcome, welcome everyone. This is an exciting day for us and I hope for everyone who's listening. This is the beginning of our Overcoming Long Haul and Chronic Fatigue Summit. We're going to start, which is a quick overview of the intersection of Long Haul Chronic Fatigue and other chronic complex illnesses.

I'm Dr. Eric Gordon and Dr. Nafysa Parpia is with me and we're gonna start off on a little behind what drove us and inspired us to do this summit. – Welcome everybody.

We're both so happy that you're here to join us. Dr. Gordon. I have been working together for a number of years now on patients who have complex chronic illness and we're doing this summit to bring hope and to let you know that there are options out there to heal your poorly understood symptoms.

There are a number of people with long haul and the rapidity with which it appeared has made it impossible for the medical community to ignore now. But chronic fatigue has been ignored for the past 100 years or so.

It occurred in clusters and in individuals here and there, patients were told they were just depressed or de conditioned or just not eating healthily or maybe they're just aging. And then the general treatments was to focus on sleep, created exercise, cognitive behavioral therapy and antidepressants.

## Chronic Fatigue and Long Haul Overview

These are the mainstays of traditional treatment of chronic fatigue. Not to say that these are not important. They are important methods by which to help people. But let's also just say that these treatments don't move the needle in our patient population. They've tried all of that.

These are still the main treatments being offered for chronic fatigue. And now the second pandemic long haul syndrome. – Our life's work has been studying and treating those with poorly understood chronic illness. We have been treating patients with these chronic complex illnesses for a long time myself more than 30 years and Dr. Parpia These illnesses include chronic fatigue, fibromyalgia, you know, chronic or post Lyme disease, many atypical autoimmune conditions for the community of physicians that have been treating chronic complex illnesses.

Long haul syndrome was not really a surprise. We the common symptoms that people were developing post covid were the same that we had seen post other chronic and other acute infections such as fatigue, brain fog, mood disorders, sleep autonomic dysfunctions, G. I. Issues you know, pol cardio, pulmonary conditions. And the thing that makes all these illnesses so difficult for the patient and for their doctors is that they usually have normal tests on the common evaluations for illnesses and that leaves everyone frustrated these illnesses are due to persistent inflammation, but the inflammation is found in tests that aren't commonly done.

The common tests are almost always normal and which symptoms develop depends on the individual's genetic tendencies and other previous infections or injuries.

This is an illness where inflammation meets your genes.

## Why Complex Chronic Illness Is Hard to Diagnose

– So one of the challenges in dealing with chronic fatigue over the years is that people were looking for a single

reason, one underlying path of physiology, one lab, one treatment and it should be the same in each patient, but each patient is an individual and this is what needs to be explored in the labs and the history taking of the patient.

– The desire to find a single cause of a complex chronic illness is what's held back the research on chronic fatigue. One of the things that has led to mark advance in understanding and treating something like HIV AIDS is that has a single well defined triggering organism. And we are now able to measure it and the measure of that organism, the levels in your blood gives a direct correlation to the severity of disease. So when you figure out a treatment that suppresses the organism, the patient improves – The difference between that and a chronic complex illnesses that chronic complex.

There are multiple different triggers that cause inflammation and then the expression of that is different depending on your genetic background in your genetic tendencies.

The triggering event does not necessarily produce chronic illness. The triggering event might be the spark, but the Tinder and the logs, it's different in each person.

That's what allowed it to flare and would allow it to keep going. That is what's individualized. – Many patients who have developed long haul are not always the ones who are the sickest.

Many of them, people just had mild flu like symptoms or even no symptoms. And a lot of them were generally healthy before the acute infections. This was not long haul is not a disease confined to those who are hospitalized.

And it's about what the acute affection with its inflammatory cytokines flare or perhaps the persistent spike protein, what that has caused, you know, what was dormant or actualized. And what had the potential to cause problems is now active response.

Perhaps now you're left with a little uh imbalance in your immune response. Now those infections that were quiet are now active and this was very puzzling to the medical community.

## Individualized Triggers and Immune Dysregulation

Nut interestingly enough there beginning to pick up on it, but it's something that those of us who've been treating chronic fatigue have been aware about for decades, you know, and we also saw it with Lyme disease that many times we could treat the infection and the bug seemed to be cleared, but the patient still had symptoms because the immune system was dis regulated.

And so post treatment Lyme disease and these things that people call atypical autoimmune disorders, you know, they're all times when we can remove the trigger, which is like recovering from the covid, but the immune system is continuing in inflammatory pattern – And that's supposed to preclude the medical establishment from taking these chronic illnesses seriously until long hall came and affected so many people the big red flag now. So, remember medicine tends to look for a single path of physiological event and then a single treatment.

This approach has allowed some of the miracles of modern modern medicine. It's not invalid. It just typically does not apply as well for illnesses that become chronic.

They're the ongoing symptoms have to do with your biochemical individuality. It's brilliant for acute illnesses and illnesses that have a single overriding cause.

And a very clear test that's positive in everybody who has the same illness. And we can find such a signal allows for that allows for the rapid development of treatments.

– And this is what we've learned from treating those with chronic illness that the inciting event and the chronic illness are not necessarily tied together. And usually there are imbalances that were present but often were not being expressed. How many of us had a prolonged post viral experience once or twice in our lives um where it took

That can mean that that bug is still hiding out or has changed your immune system a little bit. Anyway. So these are the things that we have seen over the years and other factors include an immune system that's predisposed to allergy, causing a lot of mast cell issues. A difficulty in metabolizing medications or getting rid of toxins. This again is a constant pressure and annoyance to your immune system.

## Long Haul, Lyme, and Persistent Symptoms

As I mentioned before, the chronic underlying infections that were quiet until your immune system was destabilized by a virus that really suppresses your normal immune response. Transient li but unfortunately, sometimes that's enough to leave long term consequences.

So just low grade immune dis regulation. So we can't forget that sometimes there are chronic low grade infections that many had just imbalances in the gut microbiome, sometimes in our oral flora or chronic dental infection in the jaw, you know, or chronic sinus infections, these all can put a weight on our immune system and after covid, we don't go back to normal.

– So these initial events that made the person sick, they're different in different individuals, but typically was seeing that the chronic symptoms are very similar.

We've actually seen this over and over again in our patient practice, for example, almost everyone with chronic Lyme or post treatment Lyme has something that has interfered with the normal immune response to take care of that infection.

Now, most people who get lime and covid for that matter, they get little to no symptoms and then they recover without issues. These are not our patients, it's not who we're talking about on the Summit.

So there is a subset of people who get covid or lyme, for example, they don't get well even after the infection is no longer active, none of the issues we're going to bring up on the summit are singular.

None of them stand on their own. It's typically many issues at once and many therapies at once that are needed. You gotta make sure that you're seeing doctors though who understand this, who understand the different therapies and have really studied the research as well. – Our first thoughts were when we saw post post covid and long haul that it was just another post viral sexually.

I mean not to minimize it, but we thought it was going to have the same patterns. And over the past two years it's become apparent that post covid is different Then post than the usual post viral CFS patients, there was a little different flavor to it. It truly is a new chronic illness.

It shares many of the same symptoms and a lot of the same underlying mechanisms as we saw with chronic fatigue before. But it does appear that the spike protein itself or some immune response to it and the new dimension.

## Spike Protein, Microclots, and Emerging Research

So anytime we see a new patient now with chronic complex illness, it's not quite with the same eyes, pre pandemic. You know, we're still looking for the same things we look for before, you know, tick borne disease, mold issues, parasite issues, environmental toxicities, you know, chronic viral things but and they all all these issues cause immune dis regulation nervous system, dis regulation, etcetera. But spike protein seems to be a little different. – So everybody who comes to our clinic, they do have these conditions assessed for and then and then addressed for as they pertain to each individual. We test for possible infections that got stimulated from the cytokine storm of acute COVID-19.

We test their immune system that when I say infections that were stimulated, I'm talking about infections that were dormant previous the cytokine flare of acute COVID-19 or perhaps their immune system has become dysregulated

So we do test for concurrent infections, we do test their immune systems. We do always consider spike protein involvement. At this point, testing for spike protein is still in experimental stages.

We're hoping that the near future these tests will be well validated and we hope that will help guide treatment. We do use this test with that caveat.

It's the best we've got at this point in time, we're also looking at inflammatory markers. Dr. Pretorius research is strongly suggestive that there are these difficult to metabolize micro clots that persist in the body. And perhaps there are even places where the spike protein can hide from immune degradation or perhaps even the virus persists all of this is still in the research stages.

But the evidence is beginning to slowly emerge that these theories could hold some weight to them – But at this point, things are not definitive. But hopefully as we have several labs in the United States who are trying to replicate Dr. Pretorius work and hopefully we'll actually have some testing that's available for patients sometime in the next year in 2023.

Okay, now a lot of people talk about the timer but it's a marker of of the breakdown of clots and it's a breakdown products of fiber which is a big part of making a blood clot.

And you know, if you have a disease that causes a blood clot you know, a pulmonary ambulance or a deep vein thrombosis, the deed I'm er will go way up rapidly because your body is working really hard to break down that clot.

Okay. But the mic and this is what's happening on in that 1st 23 weeks of covid. But when people are out several months, the micro clots that Dr. Pretorius and her group are concerned about.

## Testing, Treatment, and Patient Evaluation

This is made up of abnormal fibrous, it's been changed by its interaction with the spike protein and it doesn't break down with the normal enzymatic processes.

So we don't see d dimmer and the timer is often normal. – we do a thorough history and testing to understand the underlying issues in the long haul patients biologic terrain.

We can't help but compare in our own minds other chronic illnesses that we've seen repeatedly with long haul. There are many similarities. Now this is what we have seen.

We're not talking about research here, there isn't enough yet. We're talking about our observations at this point in time. It appears that the amount of nervous system involvement in long covid mimics more the chronic or post treatment tick borne disease patterns that we've seen over many, many years rather than the standard post viral fatigue.

But we've also seen over many years. So there's a different flavor between chronic fatigue and chronic tick borne diseases. We see more neurological issues, peripheral neuropathy and G. I. Issues and those with tick borne than typical post viral chronic fatigue. That was pre pandemic.

Now, in long haul, we do see these neurological issues that we don't normally see post viral chronic fatigue that was pre pandemic. We also started to see the contribution of post vaccine in 2021.

In some people we start to see people who are developing symptoms. We know the vaccine has been lifesaving for some people. We want to be clear here. Okay, there are a subset of people who likely because of the protein bodies. Response the spike protein develop symptoms that are similar to long covid. Again, the research is still out on this.

It's not out yet. It's still in the workings? – Well, the big question is if the spike protein is in fact the trigger for

can induce micro clots in certain people.

You know, there's currently no definitive research implicating the spike from the vaccines in forming clots. But Dr. Pretorius and Dr. Kell have received a grant from the South African Medical Research Council to study these issues.

There there are many safety concerns about the vaccines. And just raising these are uncomfortable. As Dr. Hammerstrom protein chemist from Linkoping University puts it, we don't want to be over alarmist, but at the same time, if there is a medical issue, at least in certain people, we have to address that and only by the research that's ongoing.

That allows us to figure out perhaps there are a subset of people who we should be more careful with vaccine use. – Son, why are we positioned to understand and treat long haul?

Why do we do this Summit?

## Why the Summit Matters for Healing

We treat chronic inflammatory illnesses and we have for decades over the years that we've treated chronic illnesses, we've always seen the need of of being on the cutting edge of new treatments.

Okay. Ones that are being presented by by well qualified researchers and scientists. Doctors. These chronic illnesses are not a one size fits all these illnesses are reflection of individual biochemical responses, triggering genes. Therefore there isn't typically one treatment.

There isn't typically one cause it's a layering of treatment that's tailored to each patient and that is why we need to listen to the well qualified researchers and doctors who have ideas on treatment because though they may not apply to all patients, they will apply the different subsets. So we need to identify which patients apply to which therapies and in which order the therapies and treatments should be used in.

– Yeah, this is the style of medicine that we practice and it's a bit different. One of the great arguments of conventional or academic medicine is that anecdotal medicine or a collection of anecdotes is not data.

And that is true. And we love when we get a good study that can show us the way unfortunately there are almost no studies on therapies for long covid yet. And so I don't subscribe to the idea that people should suffer until we have the appropriate studies, especially 2.5 years into this. So that's why we're doing this summit.

You know, we want everyone to have a chance to listen to the ideas that out there and understand that what works for one person very well may not work for you.

So just speaking, but listen, listen carefully and see what resonates with you. Okay? And hopefully by presenting a wide range of possible causes and possible therapies, you'll find something oh, that will move the needle and return you towards health.

You know, remember that as Dr. Parpia was saying, once you're in this area of chronic illness, you're gonna often need multiple steps, multiple therapies, multiple practitioners sometimes.

## Long Covid as Multiple Overlapping Conditions

But trust yourself, trust your intuition and be kind to yourself. And I just hope that you find this information informative and give you the information that you need to move forward in your healing journey.

So just best wishes to you all. – Thank you. I just want to add one more thing and that we're calling it long Covid right? It's been given one name, but I would say that this is many different diseases, many different inflammatory

So yes, we're calling it the long haul summit. But when we're treating our patients were not thinking, oh we're just treating long haul, what we're doing is treating your immune system for treating you retreating the infections that have that have arisen as a, factor of the inflammation. We're treating your biologic terrain.

It's not just long haul that you have, but it's a series of different, different diseases or different infections, different reasons that are causing you to have inflammation. So really this Summit isn't only about long haul is about the multitude of issues that encompass it are different for each person.

So thank you. Thank you again, I'm just so happy you've joined us for the Summit. And I also hope that you learn a lot and such an honor to do this