

Dr. Sandeep Gupta is joined by Dr. Mary Ackerley from MyPassion4Health in Tucson, Arizona, to talk about the neuroinflammation and brain changes seen in Mold Illness/CIRS. Includes discussion on NeuroQuant, VIP, Alzheimer's disease and more.

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Moderator introduces topic and speakers.

**Dr. Gupta:**

I am really excited about this webinar because we have been working with people who have CIRS, or mold illness, for many years, both Dr. Ackerley and myself, and one of the really really huge problems that people encounter with this condition is related to the brain. And that includes things like brain fog, which means people's memory isn't working properly, people's ability to assimilate information is not working properly, they can't concentrate. It's also extremely common to get anxiety and depression and hopelessness and a variety of other conditions pertaining to the brain.

So today we're going to explore how this condition of CIRS affects the brain and how we can understand the mechanism whereby CIRS affects the brain and then also talk about what can be done about it so that we can fully regain our brain's abilities and also recover from any mood disorders or any other psychiatric symptoms a patient may be suffering from.

Anything you'd like to start off with Dr. Ackerley, about your experience with this condition?

**Dr. Ackerley:**

My experience comes from being a psychiatrist who started to see patients who said they had mold and as I've said before I simply assumed it was psychosomatic, as I was taught. There was a mold doctor practicing fairly near me and people would come to see me because they were still depressed and anxious and needed treatment and didn't want to go on medications.

At some point I began to realize that mold illness was not just psychosomatic (in the head), but that it was verifiable with labs and a reality and you could measure mold, and I became a CIRS doctor. So my experience has always been in treating people with neurological and psychiatric problems because even in the beginning I was seeing people who were afraid they were getting Alzheimer's. Over the years I've seen a broader variety of patients, but the mainstay of what I see are people whose primary complaints are "my brain doesn't work", "I'm depressed all the time", "I'm so anxious that I can't sleep", "I can't think about anything and I don't even know what to do".

Those actually encompass many of the CIRS symptoms, too. So, working with the psychiatric and neurological problems is something I have become more skilled at and knowledgeable about.

**(3:18)**

**Dr. Gupta:** <<Thanks Dr. Ackerley and introduces slideshow for presentation>>

A little bit about myself: Many of you who have had a look at the [Mold Illness Made Simple](#) course or who live in Australia will know me. I graduated here in Australia from the University of Queensland in 1999. My

original training was in intensive care in hospitals in Brisbane. Particularly I use to look after patients who had had heart surgery or cardiac surgery and were suffering from a variety of problems after cardiac surgery. I also looked after patients who something called sepsis. We may get a bit of time to talk a little bit about how the condition of sepsis has acted as a prototype condition for the discovery of CIRS or Mold Illness.

I've now been on the Sunshine Coast for around 7 years actually with my own [private holistic integrative medicine practice](#). I had a little bit of a personal journey with mold as well with a house that flooded on the Sunshine Coast. That led me to seek out Dr. Ritchie Shoemaker and become the first non-US doctor to become certified in the Shoemaker protocol. I was lucky enough to co-author the [consensus statement on CIRS](#) with Dr. Ackerley, Dr. Berndtson, Dr. Rapaport, Dr. McMahon and Dr. Shoemaker.

Dr. Ackerley would you like to introduce yourself?

**Dr. Ackerley:**

I am a classically trained psychiatrist and board certified integrative physician also. My practice is [MyPassion4Health](#). I've been a co-author on the same consensus statement and more recently have been involved with a [paper on VIP and NeuroQuant](#), showing that VIP was safe and was effective somewhat in restoring, in helping some of the atrophy that we see. I have also been involved with [Inhalational Alzheimer's](#), too, with Dr. Bredesen and wrote an article which has gotten a lot of play on [Brain on Fire](#) which is my word, basically, on the psychiatric symptoms that mold seems to cause and cause pretty quickly.

**Dr. Gupta:**

Dr. Bredesen's work really is quite fascinating, isn't it? Looking at the role of CIRS in Alzheimer's disease and how VIP, particularly, appears to have a very promising role in reversing that. That's very exciting, I think.

**Dr. Ackerley:**

Exciting and frightening when you consider how common neuroinflammation is, if it really is the predecessor, for some people at least, to Alzheimer's. I know I get an increasing number of inquiries from boomers who are, you know, getting to the age where they are thinking about Alzheimer's and really wondering "Does my brain look like Alzheimer's?", "Do I have mold? Is this something I can treat so I don't get Alzheimer's?" I think it's probably the most feared illnesses there is as you get older.

## **CIRS Introduction (7:38)**

**Dr. Gupta:**

Okay, so a little bit for those who are fairly new to this condition - for those who know quite a bit about this condition, this is going to be old hat so just bear with us - but basically mold illness is a colloquial term for what is actually known as chronic inflammatory response syndrome due to the indoor environment of water damaged buildings. Try saying that three times fast! It is abbreviated as CIRS-WDB, and commonly we just refer to it as CIRS. This condition has been discovered and named by Dr. Ritchie Shoemaker, who both Dr. Ackerley and I have trained under.

Dr. Shoemaker and his CIRS certified physicians, of which there's about 15 I believe, have co-authored dozens of peer reviewed papers which are in reasonably reputable journals as well. They are not the main journals

such as New England Journal of Medicine, but they are reasonable journals. And he has a whole collection of articles at [Surviving Mold](#).

Before we start asking Dr. Ackerley questions, I am just going to give a very brief overview to make it simpler for you. I want to introduce two terms: and they are [edema](#) and [atrophy](#). The simple thing is to change the word edema (in your mind) to swelling. Many of you may have heard of the term edema when it relates to your ankles. When you, for instance, go on a long plane flight and you're swollen in the ankles, medically we call that ankle edema. Now, the same thing happens in certain areas of your brain due to CIRS. It is particularly the front area of the brain, the forebrain parenchyma it's called, and there's a number of other areas - they become swollen due to inflammation. Now, inflammation is a silent fire that occurs in your body. The reason that we get inflammation in this condition of CIRS is because people with CIRS are not able to properly process mold toxins. Therefore, instead of creating a proper immune response, they develop a chronic inflammatory response - which means they develop a silent fire in their body. That silent fire particularly affects the brain. The brain actually goes on fire and then that was name of Dr. Ackerley's article (*Brain on Fire*), so that's what we're talking about in this condition of CIRS. We have inflammation actually physically affecting the brain, it's not just in your (well it is in your head), but there are actually measurable changes.

We also get atrophy, or shrinkage. There are various other conditions in which we use the word atrophy in medicine, but really it always means shrinkage. (Talks about diagram). There are certain areas that get shrunken in CIRS - particularly an area called the caudate nucleus gets shrunken in CIRS. That is another result of the inflammation that's occurring in the brain.

Dr. Ackerley would you like to add anything to that?

**Dr. Ackerley:**

The atrophy and the swelling combine to make what we commonly refer to as 'mold brain', which is cognitive impairment, in focus, in memory (in short-term memory), the inability to assimilate new information (which is one reason this course was developed, so that people can go at their own pace and repeat these concepts again and again until they become as familiar to the patient as they are to the doctor who is kind of rattling them off needing to get through a full hour of treatments, too). So that's where it may be very familiar to people, is in the assimilation of lots of new information quickly is very difficult with the kind of atrophy and swelling we see.

The swelling in particular affects the frontal lobes, which you can realize by their name, they are very close to the nose. Inhalation is going to occur through the nose. So, because the blood-brain barrier is most likely, I think the best word, really, is "leaky", that you can understand - it is hyper-permeable. It leads to this microvascular cerebral edema, seen usually only with [NeuroQuant](#) (not on just the normal scan read by the radiologist). It's that inflammation, or swelling of the frontal lobes, that leads to some of the executive functions being impaired. The executive in the brain focuses and organizes, and that's something that can be really difficult for people - certainly in the beginning stages of the illness. It's also the emotional regulator of the brain. You have a limbic system generating a lot of emotions and impulses and it is the executive who listens to them and says 'Stop. We can think that but not say it because it's going to have consequences down the road if you tell your boss what you really think about (or tell your wife, etc)'. It's that lack of emotional regulation which can be seen as rage or irritability that often characterizes some patients.

**Dr. Gupta:**

So if someone is suffering with this condition and they find that they're a bit more emotional than normal and they are saying things to their partner, for instance, that they usually wouldn't say and they are snapping at little things. It sounds like you are saying that there is actually a real physical cause for this.

**Dr. Ackerley:**

Yes, and it is important to remember that. Because there's going to be a lot of conflict usually in CIRS, in a couple, in terms of executing a plan to get out of water damage, and remembering that each side's responses in this planning are not entirely rational is important to just have a lot more tolerance, and even some laughter once in awhile at what's going on. I know sometimes I will just burst out laughing at some of the arguments I see going on because I've seen them so many times – and it's the same thing said back and forth and it's not going anywhere, it's not soluble, and it's usually regretted at some point afterwards. So I'll just sort of laugh and go "let's keep going..."

**Dr. Gupta:**

Okay, great, so do you think sometimes one strategy can be for a patient with this condition to just be able to name when they think they are becoming more emotional or not acting in a characteristic way. To say "here's my brain on fire again" or "here's my mold brain again"?

**Dr. Ackerley:**

Absolutely. "Hey, I'm sorry", when you calm down, "Hey, I'm sorry I really didn't mean this." "Let's take a time out." That sort of thing. "Let's go do something we like and not think about this for the rest of the night."

## **Brain related symptoms of CIRS (15:42)**

**Dr. Gupta:**

Yeah, I think that's very helpful.

So, I think it's worth noting that on this slide around 13 to 19 of the main 36 symptoms which make up the cluster table, which is part of the way that we diagnose CIRS, are neurological or brain-related. Therefore, the brain is a very, very major component of this illness. Maybe, roughly, we could say half of the symptoms pertain to the brain.

Anything you'd like to add to that Dr. Ackerley?

**Dr. Ackerley:**

No. Just to emphasize that if you just look at this based on physiological symptoms – you know, you have the psychiatric – the mood swings. I'd like to point out anxiety is not there, but in my experience and in many physicians' experience, anxiety is one of the most prominent symptoms. Dr. Shoemaker said once upon asking him he just didn't know how to measure it since it is so subjective. In my opinion anxiety should be part of this, too. As well as mood-swings, there's all the focus, decreased word finding, concentration problems, ability to assimilate new information, those are the cognitive issues.

Then there are the more neurological issues. Light sensitivity tends to be a real symptom of

neuroinflammation. And it's important to know that you see more in kids sometimes, that sensitivity to sounds, sensitivity to light, sensitivity to smell. Smell gets labelled as multiple chemical sensitivity, for other people sounds and lights are worse. It's neuroinflammation. It's a hallmark and is a way to identify "Oh, there's something going on", "Bright lights really bother me now" or "I just can't stand loud music" or "The kids chattering or playing really gets on my nerves."

Vision is actually a neurological function. That's the blurred vision – and visual contrast when you fail it, is a measure really more of neurological function. Which I think has been covered here. Vertigo is another neurological symptom and the thermal regulation that is often seen. Again, that is the [hypothalamic and pituitary axis](#). The increased urination and appetite swings, that's the HPA.

Probably if you're good, you can make the case that the brain is involved in everything – pain and headaches too. The point of all this is that the brain starts to get affected, and my guess is that for many people it's what is first affected. I think we're going to talk about that later when we talk about what happens to some people when they walk into water-damaged buildings and how they can use that to turn around and walk out.

## Measuring brain changes

### NeuroQuant (18:43)

#### **Dr. Gupta:**

In this slide, we have a NeuroQuant result. NeuroQuant is a FDA approved computer program which interprets the brain volumes of 11 different brain areas from a MRI brain scan and it provides a table of numbers which most of the Shoemaker certified physicians interpret through a spreadsheet and come up with a score for CIRS due to water-damaged buildings. There are also some scoring indices which may indicate that tick-borne diseases may be playing a factor as well.

One of the big things, for instance, on this particular NeuroQuant, I'm sure Dr. Ackerley will notice. The [caudate](#) is severely shrunken. It's at an average of about .16, would you put that in the severe range, Dr. Ackerley?

#### **Dr. Ackerley:**

Depending on the age, but yeah. It would certainly...

#### **Dr. Gupta:**

Fairly severe. What sort of symptoms would someone expect? I think we're seeing a swollen forebrain and cortical grey here as well, which is classic of mold brain.

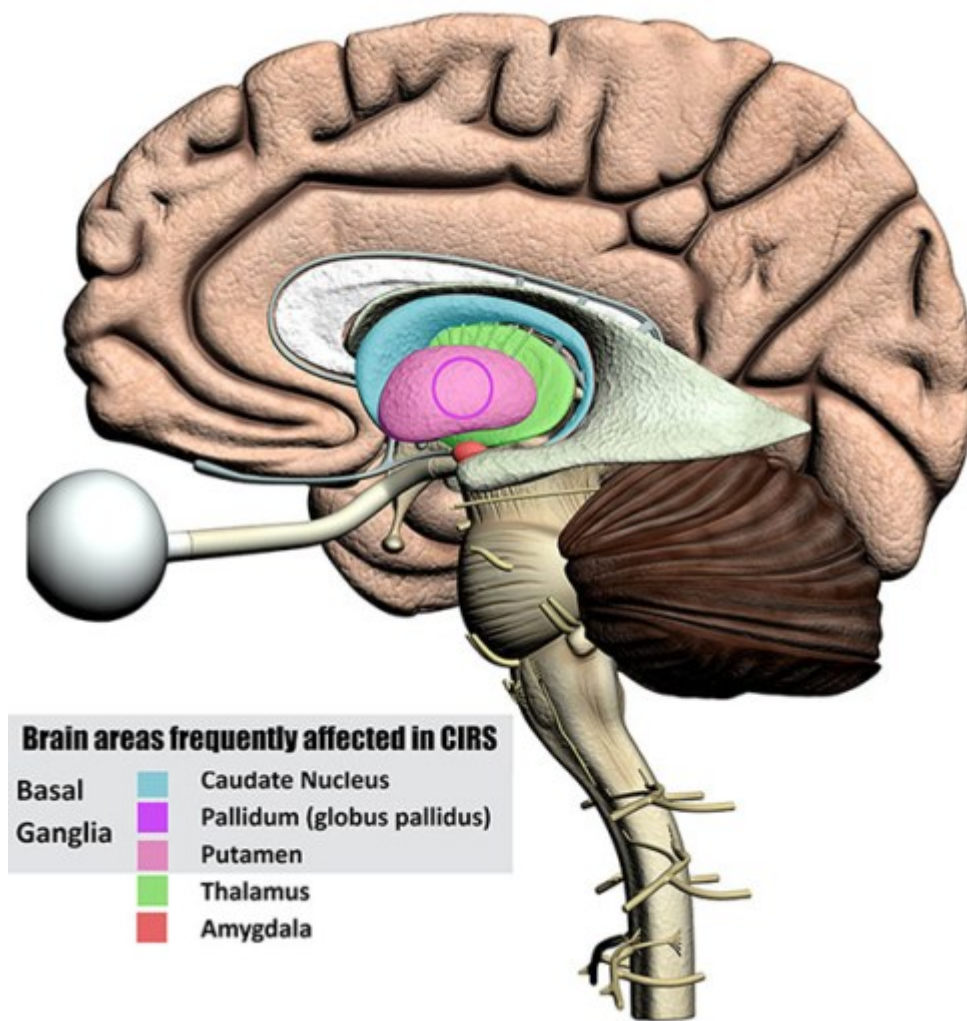
#### **Dr. Ackerley:**

Absolutely, and also the [cerebellum](#) is a little bit on the larger side, something that interests me. The hippocampus is a nice size, that's not atrophied. So, the caudate is the most [dopamine](#) rich part of the brain and dopamine, as most people know, is our passion neurohormone or neurotransmitter. It has to do with pleasure and reward, and so obviously if that starts getting smaller there's going to be less ability for a person to experience pleasure in their life, and reward. One of the things most associated with caudate atrophy will be

lack of motivation. Motivation is passion and passion is pleasure and you have to get excited about things to want to do things and what you see (and what most people experience) is the life just becomes somewhat grey - or a lot grey. It's being run really more by what we call the amygdala, which deals with fear and survival and things you *have* to do (you *have* to pay your taxes, you *have* to pick up your kids, you have to do this). It doesn't have a lot to do with getting up in the morning and thinking "wow, I can't wait to write that book" or "I can't wait to go paint this painting". Most people just laugh at that thought because that was a long time ago. So, you know, showing any restoration there is going to change the psychological experience of most people.

We should also point out the [basal ganglia](#). Deficits in the basal ganglia are associated with [Parkinson's](#), which is a disorder of decreased dopamine. Slowed movement is probably one of the first things we notice in Parkinson's - and tremor. Tremor can be seen fairly frequently in mold. It's one of the things that brings people in, too. "I have a tremor, I'm really worried."

(22:50)



Drawing of the brain showing basal ganglia. Image Bigstock.com

**Dr. Gupta:**

Right, thank you very much for that explanation. It's a very interesting test – NeuroQuant. It will be interesting to see how the research on NeuroQuant develops over these next few years.

**Dr. Ackerley:**

NeuroQuant is being used in other fields. It was [originally developed](#) for Alzheimer's and everyone who gets a NeuroQuant there is a sheet that comes along with it, "age-related atrophy" that shows "no you don't have Alzheimer's" (just about everybody, there were a couple where I did see that Alzheimer's was an issue). It's also being used in other fields a lot because the ability to measure the brain accurately (much more accurately than humans can do) is a very important concept in psychiatry and neurology in trying to figure out "What is manic-depressive illness?", "What is Parkinson's?" etc.

**Dr. Gupta:**

I think one thing that is worth addressing very quickly... a lot of people, Dr. Ackerley, who I speak to, when they see their NeuroQuant, it creates a fair bit of anxiety in them – in that the image of having a shrunken and swollen brain feels very scary to them and they wonder whether their brain is actually beyond repair. Would you mind just speaking about that really quickly – as to whether the changes in the brain are permanent or whether they may be totally reversed?

**Dr. Ackerley:**

No. The swelling is something that seems to reverse faster in my experience when we do repetitive NeuroQuants. In the papers that have come out, that's something you see decrease faster. I like to compare it to a computer. The hardware is still all there, it's just a little soggy, and we're going to try and dry it out. That's a lot easier than replacing hardware that's not there. You know, there's still a motherboard there.

Atrophy is a little different. VIP does seem to help restore growth in the grey matter but grey matter atrophy is, you know, a pressing concern in most of neurology as being associated with neurodegenerative diseases. So, that is a little bit more concerning to me than swelling.

People, often, when you say the brain is swollen will go "Yes, I know it. I feel it. I can feel my head. It is like it just wants to pop out and I feel pressure – and especially pressure in the back of the head and the headaches there." And it's actually confirming to people. This is not in mind, you know, this is in my brain. But it is a distinction between what is in your mind and what is in your brain, so there's a confirming part of seeing this, too. And it's always relieving when you hear "No, you don't have Alzheimer's." In fact you have usually the opposite pattern of Alzheimer's.

**Dr. Gupta:**

Great, that's very helpful. I also want to just very quickly mention the condition that we call multinuclear atrophy. Some people have a NeuroQuant which has three or more areas which are atrophied or shrunken and we often call that multi-nuclear atrophy. Would you be able to just briefly talk about what that diagnosis means, or what that term means, and is there any differences in terms of whether people's brain can recover if they have multi-nuclear atrophy?



**Dr. Ackerley:**

I'm going to say we don't know the answer to the second part because multinuclear atrophy is also associated with aging and we're going to see more as people get older. It's not necessarily Alzheimer's, either. It does just seem to be a factor in growing older. So, the recovery we did see in the hippocampus - is one of the places, that's the one that's most associated with Alzheimer's - when that is two standard deviations below the cut offs of the means for the age and the ventricles are two standard deviations above, that's something where we're thinking about Alzheimer's and is pretty characteristic of Alzheimer's. That one you can get better, and everyone is looking for actual reversal of Alzheimer's. That would be probably one of the most sought after things for many people - is again, "If I die of cancer, if I die of a heart-attack, I go. But if I'm sitting in a nursing home for years with my kids, you know, taking care of me or having my diapers changed, please." I'll hear many different variations on that, you know "I don't want that to happen."

**Dr. Gupta:**

Okay, great, and just very quickly on the subject of Lyme, actually this patient {{referring to slide}} it's interesting to note, their right thalamus is actually getting right up there. Which is the main, I believe that's the main area we look at for (acute) Lyme on the NeuroQuant. So, if someone does come up and there is some concern about the possibility of them having a Lyme-like illness, which is what we call it in Australia, how would you suggest that they proceed?

**Dr. Ackerley:**

I think right now, the criteria is that right thalamus is .61 or greater. I actually saw one the other day in a person who had three bands positive on their IGM Western Blot and I said "I think those ticks did have Lyme that bit you." That was like "Wow, I can feel comfortable." It is not a criteria for *chronic* Lyme. This was all done with *acute* Lyme (these numbers). So, I can't really tell people does this mean you have chronic Lyme. What I can say is "Your thalamus is really pretty normal sized here and it looked like you have acute Lyme."

**Dr. Gupta:**

Okay, so NeuroQuant may not be that helpful in distinguishing chronic Lyme from mold. Is that what you're saying?

**Dr. Ackerley:**

It's helpful to me, because I get to see a lot of people who have been treated for Lyme for several years, they're not getting better, they hear about mold and they come for a consult and I'll point out in a brain like this "Wow, you have some marked swelling here on the right frontal lobe and you have some real atrophy of the caudate and the cortical grey swollen too. We see this in mold. That's a fingerprint - you already have 6 out of 8 here for CIRS and I think it's certainly worth exploring the possibility that mold is either your main problem or keeping you from making progress in your Lyme treatment."

## **Blood Biomarkers (29:29)**

**Dr. Gupta:**



Okay, great, so looking at the biomarkers. These are markers that we commonly check in CIRS patients, or patients who we are assessing. It's a bit of an alphabet soup when you first get exposed to these terms – such as [TGF-beta 1](#), [MMP-9](#) and [C4a](#) – but you've just got to hang in there and learn to navigate the alphabet soup.

Basically what these markers are, we call these proteins which fuel the fire of inflammation in the body, in our course. What happens is that these proteins increase inflammation. And (backing up a moment) we get increased inflammation due to toxins in water-damaged buildings, which then causes interstitial edema and can also cause “leaky brain” and that can eventually lead to atrophy. The atrophy is, as Dr. Ackerley said, a more severe manifestation of inflammation in the brain.

Dr. Ackerley, anything you want to mention about these markers specifically and how they actually affect the brain and how they contribute to the brain inflammation that we see in CIRS?

**Dr. Ackerley:**

There are several things. TGF- $\beta$ 1, by the way, is associated with Alzheimer's, when they do spinal taps. We know it is certainly playing a role in atrophy in the brain. MMP-9 seems to cause more 'leakiness' of the blood-brain barrier and is associated with headaches in the brain. There's probably a lot more associations, they're just not well researched in neurological and psychiatric literature as say other markers of inflammation.

C4a is very exciting to me. I think people have heard me talk about it before. In psychiatry we have symptoms that we call schizophrenia or we call it bipolar. We think we're separating people out by the symptoms. Then when we go to look at their brains and their physiology, they look wildly different and our diagnostic categories don't seem to make much sense. So, it's very exciting, that finally they studied about 60,000 people and found a genetic marker for schizophrenia. It's a big deal that this is the first thing in schizophrenia they've found at the genetic level. I was reading this in the New York Times last year thinking “Wow, we finally got something in psychiatry that looks like science” and they're calling it C4 (it is complement 4) and I'm thinking “Wait, complement 4, C4, is it our C4a?” It is. This is the association finally found in schizophrenia. It is a cytokine that we routinely measure in CIRS every day. It's an indicator that the innate immune system has been activated and about how much activation is going on.

What C4 does in the brain, is something called pruning. There was a slide a while back that was a brain basically covered in shrubs and you could see there was a little bit of pruning – and little bit of pruning is necessary in any garden for things to grow. It's the same with the brain. A little bit of pruning is associated with the 'cleaning up' we do when we sleep, for instance, so we can start with a fresh slate the next day. However, you don't want the slate too fresh. When the gardener basically cuts away far more than they're supposed to and takes the trunk down just to the woody branches saying “Oh well, you know it's all going to grow back next spring”, that's what's associated with schizophrenia. Is C4a actively prunes and over-prunes the brain and there's some speculation that this is what's happening in schizophrenia – the gardener has overdone it and lost vital connections. The slate has become too fresh.

To me, it's incredibly exciting, is that there's an immunological basis linked to the inflammation that we see every day and that is incredibly common. I am going to make a point at the end of this at how common this inflammation is that has been linked to schizophrenia and it's the first thing in psychiatry, really, that starts to approach science – on the level of what we see in, say, cancer or cardiology.

**Dr. Gupta:**

Okay, great. So it's a little bit of a scary analogy to think that a gardener may have come with the shears to your brain. The good news is that the bushes can to some degree grow back if the gardener calms down a bit!

**Dr. Ackerley:**

Absolutely. I make that point is I wouldn't be doing this if I didn't see people getting better. You know why? In neurology it's very hard to see people get better from neurodegenerative diseases. Psychiatry, they get better but they are being treated for the rest of their lives with medications and they don't really recover. I just thought that when I found treating inflammation for psychiatric illnesses and people actually began to return to wholeness, I thought "Wow, this is the best thing I've seen in this field." So that's why I'm here doing it and that's why I want other people and other psychiatrists and neurologists to know about it. It's optimistic.

**Dr. Gupta:**

Absolutely. Dr. Ackerley, just so people have an idea of what levels of these markers might be associated with brain changes, would you say just as a rough indication: maybe TGF- $\beta$ 1 levels that are above 10,000 and C4a levels above 10,000 and maybe MMP-9 levels above around 500 are more likely to cause significant brain symptoms, or would you use different figures?

**Dr. Ackerley:**

I see people with significant symptoms lower than that but, yes, that would be significant and certainly very easy to make a diagnosis with those levels. I do see that people whose numbers are pretty low still have significant symptoms and sometimes I'm going a little bit on faith that the numbers are low, but they are significantly impaired. I think there are other things related to people's vulnerabilities, too, which make lower numbers just as dangerous as higher numbers in some people.

**Dr. Gupta:**

Okay, that's actually interesting because sometimes what I had been telling people - or my understanding had been - so, for instance, if someone has had chronic Lyme disease and they've got a TGF- $\beta$ 1 of only 3,000 and a C4a of only about 3,000 and maybe the MMP-9 is only about 380, I would say to them "Look I do think you have CIRS going on but if you're really, really unwell, these numbers may not explain the severity of your symptoms and therefore you could have some ongoing infections." Do you agree with that thought process, or not so much?

**Dr. Ackerley:**

I say something similar, I'm a little puzzled because I do think you have CIRS, but something I've seen a fair amount, really, with people with lower levels is that when you start binders those numbers start coming up. It's almost like the body has turned off the mechanisms until you start trying to pull it out of the cell membranes. It goes back in the bloodstream, it starts going up. Then they start going up and I'll usually get a little bit of relief with that and say "Yeah, I think I'm on the right track here. I think the intuition and the diagnosis of the symptoms were right." So, I'm actually a little happy they went up but eventually we want them to go back down again.

**Dr. Gupta:**

That's really interesting. I think that TGF- $\beta$ 1 and C4a can also be suppressed by MARCoNS, so that could possibly be another reason that someone could be a bit lower than their symptoms suggest?

**Dr. Ackerley:**

Yes, and I think one of the other CIRS doctors recently mentioned that she had found some research that there are certain SNPs associated with making TGF- $\beta$ 1. She had a patient who was homozygous and had really low TGF- $\beta$ 1 levels even though they had CIRS. So, there's more to all of this than we really know now and may ever know – it's just a very big field and a lot of things. That's why making the diagnosis is really based on the exposure to water-damaged buildings, the labs and the symptoms – all of them – and the decline in health that's puzzling, too. So, there's an art to diagnosing this, a lot of judgement calls we're making a lot of the time.

## **Treatment**

### **Binding toxins (39:00)**

**Dr. Gupta:**

Okay, great, thank you. Starting to talk about treatment, now, and how people can start to feel a little bit better from certain symptoms, such as the brain fog and anxiety. One of the first steps after removing one's self from exposure to a WDB, is taking binders. These are a certain class of medications or supplements which actually bind onto biotoxins from a WDB.

The main one is [cholestyramine](#), most of you would know, which is often abbreviated as CSM. Dr. Ackerley, could you talk a little bit about CSM? On the right of this diagram we also have [charcoal](#) and [Welchol](#) pictured. Maybe just talking a little bit about how these medications and/or supplements can make people get some improvement with their brain symptoms?

**Dr. Ackerley:**

You know, unfortunately the only way we really have to get the [mycotoxins](#) out of the body and get the inflammation down is using a binder. People are sometimes surprised that I don't have a magic pill or IV that's going to do this and it's over with. It's a long-term effort, especially since the fat cells and the membranes have been storing these toxins and if exposure has been going on a long time, the fat cells have essentially been protecting the person by packing them in there instead of the brain or the heart or other places where they do more damage.

So, as we bind to the bile with cholestyramine and prevent its [enterohepatic reabsorption](#) – which is a really important thing to understand – we start to rid the body of some toxins, which enables the cells to release more toxins and that's why detoxification takes time. So, of all of these, cholestyramine is the strongest binder and if people essentially have pretty good guts and don't have a lot of GI symptoms, that's always my first choice. Unfortunately, people with guts that really work well are somewhat rare. That would just be regular old Questran – I don't like Prevalite, I don't like aspartame, I don't think we need to add any more toxins into a body. I like compounded cholestyramine for a number of people because I think the constipation issues can be less. There are no additives. Usually I'll use the stuff that has nothing in it but cholestyramine and I see less problems with constipation, certainly a lot less problems with rash and allergic reactions. People seem to

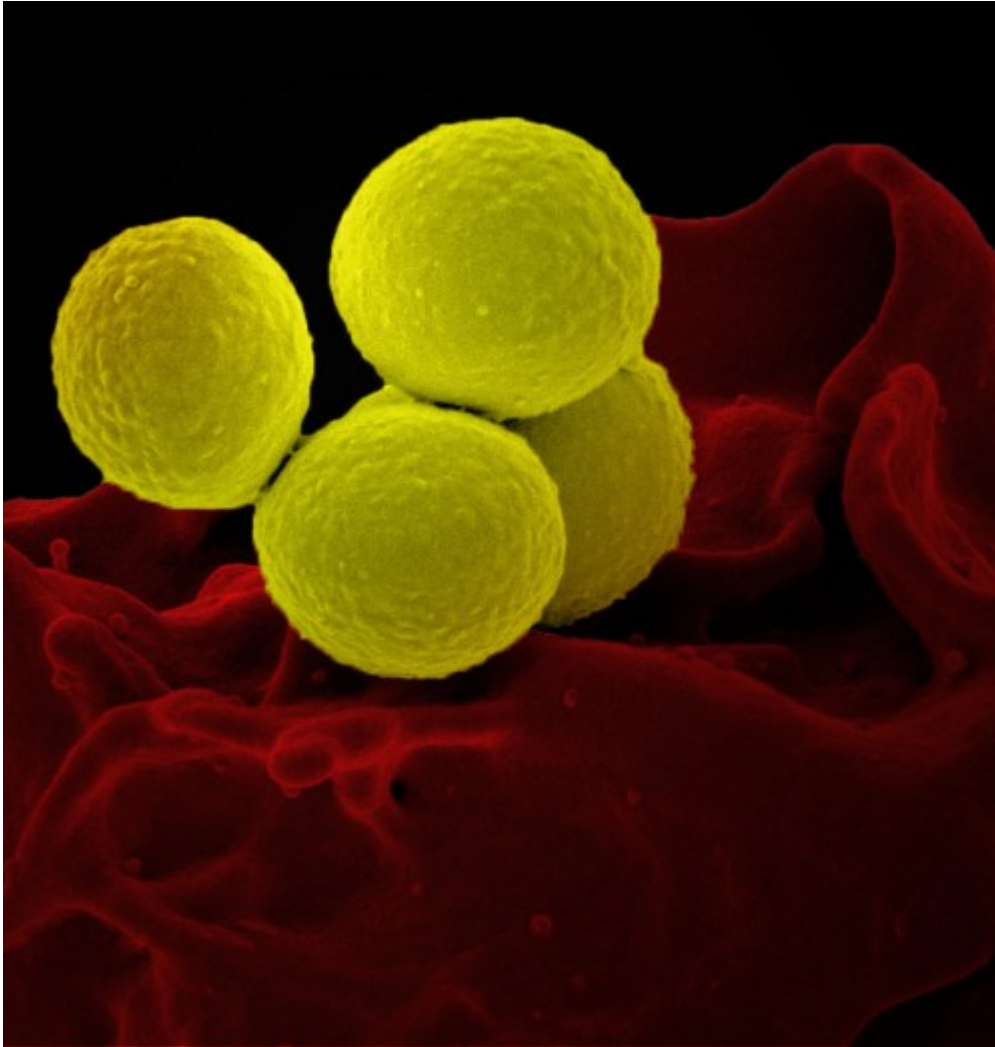
tolerate it better and if I have a sense that people are sensitive and react to other medications I'm going to go with compounded cholestyramine, which in the long run can be cheaper if it is efficient (rather) than trying other things that don't work.

Welchol is a great choice. Especially when people work because it's much easier to take these pills and you can take them with food and you can travel more easily with it. It's just weaker than cholestyramine. It doesn't bind as much.

On the other hand, when people are consistent with the treatment, we're going to get great responses. So if people are doing cholestyramine like once every other day it's not very efficacious. And that's because you have to block the enterohepatic reabsorption where 90% of the substances in the bile are essentially reabsorbed back into the body before they are finally excreted. And in that reabsorption, all we've done now, is take toxins that may have been safely hidden away, brought them through the body, and are now pumping them back into the body so the rest of the immune system can start reacting. It's not a great idea and maybe one reason people seem to get worse is they are being inconsistent. So, I'd rather do like half a scoop of cholestyramine twice a day than a full packet once every other day. That's really an important point to remember. So, Welchol is a great choice.

And then there are people who are just so sensitive or constipation is such an issue that we start with charcoal. And I always tell people, yes, I have seen people get better with charcoal over the years. I think is effective. It doesn't work the same as cholestyramine or Welchol. It's not as strong, but in animal literature there's a lot of literature that it does bind directly to the mycotoxins and appears to escort them out and people get better. Charcoal can be taken after meals, it helps with gas and bloating. It's used by every ambulance in the US for poisoning and toxicity. For some people, it works very, very well.

So, the choice of binder depends an awful lot on the individual. You have better responses, I think, if you sort of gauge how a person is going to respond and start with the one they can best handle.



Methicillin-Resistant Staphylococcus aureus (MRSA). Image by NIAID / flickr.com

## **MARCoNS (44:30)**

### ***Dr. Gupta:***

Great, thank you for that Dr. Ackerley. So, the use of binders is a very, very important step in the CIRS treatment protocol and it can make people's brains feel a lot better. It's important also not to withhold this even if you're not totally out of a water-damaged building. That's an important little bit of mythology we are wanting to bust as well. That you don't have to be totally, I mean of course it's better, it is preferable to be out of a water-damaged building, but you don't have to wait for that step to have occurred for you to start taking cholestyramine or another binder. You can still get some benefits from doing so. So that's an important point.

Now, a little bit about MARCoNS, which stands for multiply antibiotic resistant coagulase negative staphylococci. We all know staph is an incredibly common bug and it's associated with skin infections and

bone and joint infections and things like that. However, in CIRS there's a different type of staph that we look at called MARCoNS which gets in the nasal cavities [PMID [9839561](#), [12836500](#), [27902368](#)]. There's a number of things we use for that. We know that MARCoNS can have a direct effect on the brain so I was just wondering if you could talk a little bit about how treating MARCoNS can also help people feel better in terms of their brain symptoms, Dr. Ackerley.

**Dr. Ackerley:**

We hypothesize, and there is some evidence now with Joe Musto's lab, that the biofilms which are holding the MARCoNS - the MARCoNS themselves are making a toxin that's really quite toxic - neurotoxic. And again, given the proximity of the colonization of the nasopharynx, the jawbones, and the nose itself, the sinuses with the brain, it's not too surprising to hear that MARCoNS probably does affect the brain. And the impact of a neurotoxic substance coming from those may be why people routinely say, when finally get rid of MARCoNS, "Wow! That's made a big difference", "I am a lot less anxious", "That really feels good", "I just feel so much better." I've seen that enough over the years, consistently, to know that that's not a step I really want to ever skip and it's worth persisting - going to the dentist, looking for cavitations, going through different sprays, knowing that we will eventually (with dental treatment as well as nasal treatments) get rid of MARCoNS. It's worth it - especially if you're again thinking "What is the effect of neurotoxins on my brain as I'm getting older?", etc.

I think Bredesen has said there is definitely an association between poor dental health and Alzheimer's.

### **Full Shoemaker protocol and VIP [Vasoactive Intestinal Peptide] (47:25)**

**Dr. Gupta:**

Yes, great, so treating MARCoNS is a really, really important other step of the CIRS treatment protocol. And here is the full CIRS treatment protocol, which was also call the [Shoemaker protocol](#). We've talked about removal from water-damaged buildings, we've talked about binding toxins with binders, and we've talked about eliminating MARCoNS. There are a whole bunch of other steps in the middle there in light blue which we call hormonal and immune correction. We're not going to talk too much about them today - that includes things like DDAVP nasal spray and using either Actos or high-dose fish oil along with a low-amylose diet. And Losartan is a medication that's used to reduce TGF- $\beta$ 1 levels.

The cherry on top of the CIRS treatment protocol is VIP nasal spray [[2013 study](#)]. I think the research that Dr. Shoemaker presented in Irvine last year [[now published](#)] was very exciting, actually, in terms of amount of reversal of brain shrinkage that one could achieve with VIP nasal spray. It seems that really this is an extremely important step for reversing some of the brain changes of CIRS. Would you like to talk a little bit about that, Dr. Ackerley, and how you think this is beneficial in terms of people's brain and neurological symptoms?

**Dr. Ackerley:**

Absolutely. I try and get people to understand VIP usually comes at the end of treatment. Sometimes there are exceptions, but that it is worth hanging on for because when you start it, for many people, they will say that is the most significant thing they've done. They are starting to again feel normal. One is its effect on the lungs and the ability to relax smooth muscle, to take a deep breath again, to get more oxygen back in the body, it can

help POTS in that way. Those are all very, very big deals. The research on the brain that I get very excited about, it's being linked to dissolving plaque, it's linked to helping memory, it's being researched for Alzheimer's and I've had a number of patients over the years who say their first spray of VIP they got the euphoria but it stayed – and they've been depressed for a long time. They finally started to feel again, pleasure, euphoria, and that does happen and the depression hasn't come back. I'm not saying that happens for everybody. It's unique, but it's happened for enough people that yeah, that one's worth it.

For others, it's a slower haul. They may get more of a [dysphoria](#) in the beginning. I've worked with a number of people where we just started a very low dose- like a 1/10th dose- and work with getting a person to be able to increase the ability to tolerate the detoxification. We think VIP is what's helping release or move some of that extra fluid from the brain back into the CSF and out of the body. So, it's helping the edema, and sometimes that can be irritating before the brain starts working again. But, it's worth sticking with.

For others, it's a combination of having more energy and improved cognitive function as well as perhaps even tolerating some exposure a little bit better, that makes it where you can begin to think "Maybe I'm going to return to full health."

So, lots of things about VIP, and I think there's a lot more exciting news to eventually come from studying what VIP is doing in the brain at the genomic level as well as the neuropsychiatric level.

**Dr. Gupta:**

Great, so it sounds like there is a lot of potential for improvement through the Shoemaker protocol. It does look like people can get really good improvement with their brain symptoms through all of these steps of the Shoemaker protocol and that's really encouraging for people, because it can be quite scary. I think it's worth noting that at the start of having CIRS, just the amount of memory loss and impairment to clear thinking that occurs, but perhaps just knowing that there's a stepwise treatment protocol and that the brain changes can be reversed is somewhat calming for people, I guess, Dr. Ackerley, wouldn't you say?

## **Other modalities (52:17)**

**Dr. Ackerley:**

It is, and then learning to identify re-exposure by some of the very quick reoccurrence of these symptoms. I've talked before about how people can walk into water-damaged buildings and really very quickly start to feel suicidal (and they were feeling fine beforehand). And learning to walk out and have it stopped. And every time I tell it to a new patient it's like "Yeah, right", you know. And as they get better, and then suicidal thoughts re-occur, they will begin to realize "Wow, these things I consider meaningful, the fact that I want to hurt myself in some way, it's coming from a chemistry, it's coming from inflammation, it's mold". I call it "Black mold, black thoughts". That's what happens. And it can reverse as quickly as turning around and getting out of the building. Maybe wiping off your nose, taking a swig of cholestyramine, going home and showering. Things like that. Nobody believes it until it happens to them and they go "Oh my god".

That's a lightbulb for a lot of people, that thoughts and feelings that they consider real are based on "Black mold, black thoughts". So, that's a big deal and that's where *Brain on Fire* has been helpful to a lot people, to just realize this isn't you, you don't have to act on this stuff, and you can get better. Like turning around and just looking up at the shower and realizing "Oh my god, there's black mold right on top of me as I'm sitting



here thinking about ways to kill myself”. And that’s being frank.

So, that’s important to know that that can reverse and stay reversed and can then be used as a warning sign. For some people it’s not as dramatic, it’s irritability, anger. Things are happy, you are getting along with your spouse and you walk into a building and all of a sudden everything rotten they’ve done is just right there at the tip of your tongue – think about it for a second. Realize, wow we’re at each other’s throats. What happened? Walk out and you can find the pleasure back in life again. These things are real and I suspect they happen to a lot more people than people who are treating for CIRS. That the irritability and arguments we see going on may be due as much to presence of environmental inflammagens as they are to the reality that there’s an endless war of the sexes, etc. So, I think that’s optimistic to know this.

Other things we certainly can do... Certainly diet, I like anything that’s basically going to be low-carb/paleo (below 50 grams of carbs, when I’m asked), anti-inflammatory. I don’t like gluten or dairy for most people. I try to work with people where they are but just realize that in my experience and most people’s experience those are two of the most common allergens and inflammagens. They are making things worse in the brain.

The anti-inflammatory diet, if you are going to go on some sort of treatment for Alzheimer’s or pre-Alzheimer’s, it’s going to be a very low-carb diet and lots of aerobic exercise (are the mainstays for the [Bredesen Protocol](#)) and it’s the same thing for CIRS I believe. Getting rid of the inflammatory components of your diet, it can’t be overstated how important that is. And important for your lifelong brain health, so it’s a big deal.

Fish oil. I really like fish oil. There is so much research on fish oil in psychiatry and how incredibly useful it is for inflammation. Inflammation, by the way, turns out to be a very strong factor (if not maybe the only factor) in every psychiatric illness that is studied. So, when we’re asking what causes this stuff, inflammation plays a major role. You would hear more about it if the drug companies had better anti-inflammatory medicines for the brain. In fact, they’ve kind of given up developing new anti-depressants because they know that anything they do is only going to get about 50% of people better if it’s along the neurotransmitter route. Things you can do without drug companies really are fish oil, curcumin, [NAC](#). All of them very well researched, at this point, in psychiatry and in neurology as the supplements most linked with helping inflammation.

Magnesium. Hopefully that is on everybody’s list and is getting measured and treated because it is such a common nutrient deficiency. Treating that helps anxiety pretty quickly, as well as blood pressure.

Probiotics and vitamin D. To me that’s kind of normal. You know? There are very few people who don’t need those.

Other things that I think are important are: counseling and therapy can always be useful as long as the person you’re working with accepts that you’re not psychosomatic and that mold illness, or Lyme, or that neuroinflammation is real. If they are kind of undermining everything that is said and nodding and winking – move on. You can definitely find people. I certainly know people, and do others, who are psychologists, have had mold themselves, and are very happy to work with other mold patients. And very helpful in many aspects of all of this.

Relaxation, yoga and [eudaimonic happiness](#). These things have all been shown to decrease inflammation at the genetic level. Turning off the inflammation at the epigenetic level is going to work far better than just working SNP by SNP to try and correct each SNP. If you can turn off the whole epigenetics with inflammation you’re going to get a lot more done.

I do mention limbic retraining a lot more these days to people. It's called [dynamic neural retraining system](#) (DNRS). It's a course that's easily available on DVD and it is for training the amygdala and limbic over-responsiveness that many people start to develop somewhere along the line. Either in this illness or for other reasons, they're in what we call sympathetic-overdrive and everything has become a fight or flight situation. Relaxation, which is where healing takes place with [vagal tone](#), is very hard to achieve.

I think it can be summed up as "When your mind is not your best friend you're really in trouble". The mind is a very powerful part of healing. When it can be your best friend and coach you and encourage you it's terrific, but when it's gone into hyper-fear mode and it's seeing fearful situations in everything new it's in overdrive and it's really your worst enemy at that point. I had one CIRS physician say, "I think it's better than cholestyramine". For some people it's going to be the only way really we even get them to cholestyramine is to start turning off the fear response to everything new. This does seem to really work. I've seen it work now dramatically with a couple of people who really stick to it and well worth investigating if you can turn around and say "You know, my mind really is my worst enemy, and if there's something I can do about it, terrific".

One other point I want to make as we close, is that I am very passionate about getting other psychiatrists, psychologists, neurologists, family practitioners, to recognize how important inflammation is in what they are labeling depression and anxiety. Depression and anxiety is about 25% of the population that is said to have mental illness (a word I hate) and that's about the same percentage we say is influenced by mold – an interesting coincidence. We don't have really effective treatments for depression. By 2030 WHO says it's going to be leading cause of disability *worldwide*. Obviously, if antidepressants did what their name said, it would not be the leading cause of disability, but psychiatry has made no progress in the last 30 years in actually reducing the amount of psychiatric illness in the world, while we've made big strides in infectious diseases, cardiovascular, cancer, things like that. So, learning about the causes of inflammation and learning that mold is a very common cause of neuroinflammation is really important to me. Anyone else you can educate about it or just learn yourself to treat your own depression and anxiety is a big deal. And Alzheimer's, that is becoming an epidemic. People will use the word epidemic as more and more boomers are reaching social security and that's a pretty fearful thing. If there's something you can do to prevent by fixing the roof, fix the roof. It's worth it.

## **Q & A (1:02:07)**

### **Moderator:**

Do you have time for some questions Dr. Ackerley?

### **Dr. Dr. Ackerley:**

Yes, of course. Yes.

### **Moderator:**

There's some good questions, as always, from this community. This one is from Dana. "Wondering how we can distinguish from autoimmune encephalitis and mold illness?"

### **Dr. Dr. Ackerley:**

That's a really good question. Autoimmune encephalitis is pretty rare and actually somewhat hard to diagnose, even if you might suspect it. I know it's gotten a lot of play in books, but it's much, much rarer than mold illness. As you know, mold is also what can certainly contribute to turning on the whole autoimmune response. In terms of symptoms, I don't really know. Laboratory testing is where you have to go for that and also oddness of symptoms. Hallucinations are relatively rare in mold illness. They do occur, but if someone is having unusual musical auditory hallucinations in the absence of other things, I'd be thinking perhaps more autoimmune – or hallucinations just really coming up out of nowhere. But again, it's going to be called schizophrenia or bipolar pretty fast. You are looking for things like sed rate. There are things you can look for in autoimmune so even knowing about either one of them would be welcome in psychiatry or in an emergency room.

**Moderator:**

Okay, here's another question. "If one finds patterns of mold and Lyme in a NeuroQuant when, specifically, is Lyme treated in the protocol? After avoidance, after binders, after MARCoNS or after VIP or somewhere in the middle?"

**Dr. Ackerley:**

That's a really good question and probably depends on the physician and the patient. I think acute Lyme, if you find it, should be treated right away. If you have a chance to prevent it from developing into chronic Lyme, by all means treat it right away. If we're talking chronic post-Lyme, I often recommend patients get out of exposure and start treating for mold and see if in the protocol are they getting any better; are things developing? For so many people they start to get a lot better and the idea of post-Lyme fades in the background. It doesn't happen for everybody. At some point it becomes obvious the joint pain is not going away and we're going to treat Lyme or test for it more robustly than the usual screening tests we use.

So, I think that's pretty individual, but getting out of mold exposure for those undergoing Lyme treatment is a big deal. It's going to make things much easier.

**Moderator:**

Okay. "Could Dr. Ackerley please comment on the increased size of the cerebellum and any effects this may have on the ability of the brain to cope with the CIRS protocol?"

**Dr. Ackerley:**

What I see, and what I've talked about, is that more commonly that large cerebellum (which is at the back of the brain), is going to, we presume, decrease the ability of the CFS to flow easily out of the brain, does contribute to making VIP in particular harder to tolerate and may actually even make binders harder to tolerate, again, because we're going to be pulling toxins. So, when I have hypermobile people and I get NeuroQuant's pretty early in treatment and I see the cerebellum is really big we'll talk about it. I actually love craniosacral treatment and lymphatic drainage as a treatment which is (a)not going to hurt anybody because it's pretty pleasurable and for many people becomes almost lifesaving because it helps vagal tone tremendously (that's documented). If you find someone who is pretty good at it, especially D.O.s who are really good, it starts to readjust the face.

I wish I had it with me, someone just showed me, with a large cerebellum, someone actually in treatment for Lyme far longer than they should have been who started to get better when mold was mentioned, who found a D.O. She showed me her face from last year, it was kind of swollen. She's been getting treatment for three months and her face now looks like she had a face lift. There's no swelling. The cheeks look good. It's like "wow!" That's just from craniosacral and D.O. and she's getting a lot of relief from headaches and brain fog from that.

I like to mention that's a way, that there seems to be treatments that help increase that drainage. That can be done independent of the protocol. For patients who are really having a hard time getting detoxification started, I like what I call manual drainage. Which is going to be craniosacral, lymphatic, colonics. Things like that that just open the lymphatics, open detoxification of the gut and can help the patient begin to tolerate some detoxification. If everything is clogged and you start now demanding the body detoxify more it doesn't work very well.

### **CBD Oil (1:07:30)**

#### ***Gutpa:***

I believe you mentioned CBD oil at the Irvine conference, Dr. Ackerley. Is that something you still feel is a useful strategy for people with cerebellum swelling?

#### ***Dr. Ackerley:***

Yes, and for others too, but certainly for large cerebellums. It has, evidently, a lot of cannabinoid receptors and I rarely see bad reactions to it. People sometimes say it's not doing much but others say just a few drops, and these are the people who say a few drops of anything makes things worse, are like "Wow, I'm sleeping better", "Wow, my pain is better" and not really negative stuff – anxiety. So, I think it's absolutely helpful and it's fairly easy in a number of states – it's legal in every state but in some states it's even easier to get. It's certainly worth trying.

### **Q&A - Pyroluria/KPU (1:08:20)**

#### ***Dr. Gupta:***

Actually I have a very quick one, if you don't mind me jumping in, which I think is a very important to mention. [Pyrrole disorder](#). How important do you think is for people to look into and be diagnosed for pyrrole disorder if they're suffering from anxiety and depression and mold illness?

#### ***Dr. Ackerley:***

I test everybody for zinc and sometimes copper but always for magnesium and zinc. I make an estimate when people's zinc is below 1000 – I get them at 700/800 red blood cell zinc – we're probably looking at KPU. Especially when I start giving zinc and it's not going anywhere. So, I think it's obviously important. It's a long term, it's not a fast thing to correct and again I think Klinghardt who knows the most about it probably has said it's a product of chronic Lyme, a product of chronic mold, chronic infections. But I'm always using treatments for KPU if I think it's present.

**Dr. Gupta:**

Okay, so just for those of you who are not familiar with what KPU or krytopyrrole is, it's a condition described by Abraham Hoffer in the 1960's. There's a certain substance which we call urinary pyrrole which is created in the blood of people who are unwell and we don't know why people create this substance but it's created in the process of red blood cell production. Importantly, it causes people to excrete more zinc and vitamin B6 in the urine and there's also some other nutrients such as biotin. As a result what tends to happen is that people get an excess of copper. That tends to increase adrenaline and noradrenaline which can increase anxiety and the low zinc and vitamin B6 can lower serotonin. So, in my practice I've found that to be an extremely important cause of anxiety and depression problems so I thought that was an important point to mention as a part of this call.

**Dr. Ackerley:**

If you're going to bring up Abraham Hoffer, I'll make one point too. He was actually the first person to popularize histamine, along with KPU, as a major cause of psychiatric illness. Unfortunately, he was pretty well laughed at including by someone like me, who was trained in institution, that loved to make fun of the histamine theories. Well, it has actually turned out that histamine is a major player in neuropsychiatric symptoms - certainly anxiety, bipolar, schizophrenia, depression, as well as brain fog, as well as probably contributing to all the neurodegenerative sorts of things we see. So, the relationship of histamine and CIRS appears to be there. Water-damaged buildings certainly do seem to destabilize mast cells with the innate immune system. Turning off exposure probably helps what we are calling mast cell now. I will say that I've begun more and more to appreciate that histamine is a major player in what we call reactivity. In this protocol there are people that react to everything. And if VIP is not working, you know, things are not working, is that starting to look at mast cells in treatment can be quite successful. I like working with allergists locally who also look at that. I'm very lucky in Tucson we have a geneticist who is really good and taught me a lot about Ehlers-Danlos type 3, which is certainly more common in the people I see and more common in the CIRS population. And someone who also works with mast cell syndrome, not the disorder, which is different. It's learning those things and learning about POTS that I can start to get a bit deeper into this whole protocol of what people need to do to calm down what we're simply calling anxiety and depression. But the histamine is a very big player in neuropsychiatric symptoms. Based on research, not just based on me saying so, but based on actual research it does bad things to the whole microglial system.

**LDN (1:12:40)**

**Moderator:**

There's a few people asking about low-dose naltrexone (LDN) and the CIRS protocol.

**Dr. Ackerley:**

It's certainly fine. I use it whenever anybody asks me or when they actually have an autoimmune illness or when I see that maybe the depression which is sort of low-grade might be helped with it. It helps insomnia. It helps pain. It certainly helps autoimmune issues. I have a couple of patients diagnosed with MS who use low dose naltrexone and they could tell majorly when they started that it was helping their symptoms. So, there's really very little drawback associated with trying it. You can also take it in the morning if it's keeping you up. The whole idea of only taking it at night seems to have been debunked. It's absolutely worth trying. It's

inexpensive and has a low amount of side effects.

**Dr. Gupta:**

More questions Caleb or do you want us to start talking about the course?



Vasoactive Intestinal Peptide (VIP) spray. Image by Caleb Rudd.

## **VIP correcting neurological issues (1:13:50)**

**Moderator:**

Yes, maybe one or two more questions. Does VIP correct the neuropsychological issues unique to CIRS or do the sleep issues, anxiety, depression, etc. require independent treatment?

**Dr. Ackerley:**

You know, that's one of those questions that's probably best answered on a case by case basis. Sleep is incredibly important and that's something I will work on in the protocol independent of where people are. If they're really not sleeping, there are hormonal things we can do or sometimes medications that will make a big difference in sleep. Getting sleep is really important.

What were the other ones beside sleep? The neuropsychiatric stuff? You know, there's a whole group of people who are kind of depressed and anxious when you ask them but they're kind of quiet about it. They're not

making a big deal about it. You go along in the protocol and suddenly you notice one day they're coming in, they're kind of smiling, they crack a joke, and it's like "hello, are you feeling better?" So, yeah, I haven't really labeled them depressed or anxious but they had those symptoms, will acknowledge them and they're getting better without really treatment or focusing on them. And that happens for a lot of people.

If the depression or anxiety is the overriding symptom, depending on the severity of the depression, I am still going to offer anti-depressants. They do work for in people and it's worth trying - especially in someone who is seriously depressed and we're talking about hospitalization (which I've had happen for a couple of people at points).

Benzodiazepines, I don't like the dependency aspects and there are supplements that can really help increase GABA but I'm not shy about using them in people who are having severe anxiety. Again, which is interfering with treatment which is interfering with sleep and it seems that getting that rest or getting GABA better under control is really helpful. I think there's a real role. I don't have people having really bad reactions to benzodiazepines. When they need them, they work. As opposed to anti-depressants and other psych meds which tend to make things worse a lot.

So, again, it's individual depending on the severity, depending on how well people tolerate things as they're able to get better. The whole Ehlers-Danlos, POTS, sympathetic overdrive, those are the people who may benefit the most from anything we can do to calm down the pulse rate and calm down sympathetic activation.

**Dr. Gupta:**

Have you used Epsom salt baths as just a little additional thing people can do?

**Dr. Ackerley:**

Always recommend it. There's no contraindication. Even people who feel that they have SNPs that don't tolerate sulphur often do fine. There's magnesium and sulphur, they are both needed and taking a warm bath before bed instead of watching a computer, TV, or fighting with somebody is really a good idea. So, yeah, that's like automatic. Absolutely go for the Epsom salts. Dead sea salts have a few more trace minerals in them. You know? Don't hold back.

## **Mold Illness Made Simple Course (1:17:10)**

**Dr. Gupta:**

So, Caleb, can we go directly into the course. We're probably taking up a lot of Dr. Ackerley's time here. So, I just want to close by just explaining a little bit about my course. This is a tiny bit commercial but I really, really do believe this helps people and I believe it's very important because I think it's vital to understand the illness that you're suffering from and to gain clarity and confidence.

This condition is extremely complex, or it can be made extremely complex, and I created an 8 week online course to help people, as much as anything, feel less anxiety around the condition and less despair around whether they could better. I see that in a lot of patients - you probably do as well Dr. Ackerley.

**Dr. Ackerley:**



Yes, so much so that let me finish the commercial for you. I recommended to our local Tucson group that start using it. In fact, the leaders bought your course and they are studying one module a month. And I'm finding it helpful that I'm getting questions that are little more fact-based from some people. There's sometimes a tendency of people to have problems figuring out who that they are reading knows what their talking about and who doesn't know what they're talking about. Your course is just really helpful in "Hey, here's what we know. This is the facts of the protocol. This is what the protocol is. This is why we're doing it. This is what we expect." Just even the simple question that is coming around a lot recently "I can't take cholestyramine until I get out of a water-damaged building?" Well, if that were part of the protocol, we wouldn't be treating 50 percent of the people for the first year or maybe two because it's that hard to get out of water exposure for some people. So, no. Totally false. And one of those things that really would hinder people who believe that from getting better. So, having some factual based resources is real important. The group here is doing it, they like it, people are wanting to attend more and to listen to it. So, that's my recommendation.

**Dr. Gupta:**

Thank you Dr. Ackerley. And I think there is a little bit of a risk just using the online support groups, such as on Facebook, even though there are some excellent people like Caleb on there who are giving good information. Of course there are all sorts of people who are chiming in there and the quality of information is variable. In this course, I believe the quality of information is excellent and you can rely upon the information. We talk about how to screen and diagnose CIRS. We talk about the Shoemaker protocol in depth - what the steps are, what are the medications, how to tell if a building is a water-damaged building. And these are big questions because remediation is a big deal and the decision making around that can actually be very expensive if you make mistakes in that area. Therefore, I believe that's probably one of the most important areas. Also to make sure you get a good remediator if you're doing to remediate because not every remediator is going to be at the standard that you require to recover from CIRS. If you just get that one point out of it, I guarantee that the course is worth it. Just for that one little thing.

Delving into each biomarker. We talk about C4a, we talk about TGF- $\beta$ 1, we talk about MMP-9. We talk about the normal ranges, which laboratory should you use, what they do in the body. Again, we help you through this process of deciphering the alphabet soup.

Where to send patients if you yourself do not have a Shoemaker certified physician, we help you to navigate which ones have a special expertise area. So, Dr. Ackerley is a psychiatrist, Dr. McMahon is a pediatrician. Dr. Natasha Thomas is an internal medicine physician. We are getting a growing number of specialists who have special interest areas. We have certain Shoemaker certified physicians who have an interest in Lyme disease. In the course we go into that a little bit more than what you'll find on the website of [SurvivingMold.com](http://SurvivingMold.com). We talk a little bit about building remediation, including the do it yourself remediation and the science on that.

We talk about other sources of biotoxin exposure such as Lyme, babesia, ciguatera and algae. We talk about the Lyme controversy. I'm not going to lie and say that's a simple thing to navigate - it's not. It's quite complicated and confusing. I believe the course makes it as simple as possible to really understand why there's such a big difference between the ILADS and IDSA perspectives and how to understand the difference on Lyme disease.

So, there's a website at [MoldIllnessMadeSimple.com](http://MoldIllnessMadeSimple.com) which you can check it out. Once you sign up you get access to all the materials which includes 18 video lectures and slides, a workbook for each chapter, weekly quizzes, exclusive webinar archives. So, for instance, the previous webinars such as the ones we did with Dr.

Sonia Rappaport and Dr. Samantha Clark, and so on. They're all on there and you can access them. We also have a private Facebook group where people ask questions. I go on there regularly. Caleb's on there regularly. Other people who are very, very experienced in this area are on there answering questions. There's also a degree of peer support on there which is rather nice actually.

So, you can see some examples of PowerPoint slides. For instance, the concept of cytokines is quite of confusing and it's quite hard to get your head around but we make it as simple as possible by explaining that they are chemical messengers, or proteins, used by immune cells to communicate with each other. So, as you can see, we make these basic concepts understandable and if you can get the key basic concepts, you can understand this illness.

We do have a discount code for people who have come along to this webinar. It's BRAINONFIRE which is named after Dr. Ackerley's article. The course is \$149.25 for the next 48 hours. I really do believe it's worth it. It's a very complicated illness. If you can understand it and you can gain a level of confidence over it and understand the steps you are going to need to take, it's much more likely you're going to hang in there and not drop out of the process and get yourself well. That's my passion, it really is. I really don't like seeing people who get overwhelmed and depressed and get stuck through this illness. I've recovered from it myself – I'm not sure if you're aware Dr. Ackerley that I actually had it myself and recovered.

**Dr. Ackerley:**

That's a great example. Yes, people recover every from it and get on with their lives and don't identify as mold survivors, particularly, but just try and help others identify it and recover, too. It's quite possible. I was going to say, if people learn this in depth I'm hoping they might even get interested in research themselves at some point. You know, real research and going into careers or getting involved professionally because it's that kind of awareness coming from the ground up which is happening that's beginning to turn the academic establishment to have to pay attention to this very common and sometimes very devastating illness. So, that would be my wish.

**Dr. Gupta:**

That's right. And I want to just close by saying a few things from the heart, that if you can get through this illness and get to the other side, there are really good things on the other side. I believe this can be an amazing growth journey for you personally as individuals. I know that sounds difficult to stomach if you're right in the middle of this at the moment but I definitely believe that and I believe there are really good things on the other side in terms of you being able to then jump into another life purpose – or your own deeper level of life purpose – if you like. I've seen that happen in a number of individuals and I believe it can happen for you.

Dr. Ackerley, anything you'd like to close with?

**Dr. Ackerley:**

No, just thank you. I've seen the same thing. I have a few patients who've become real advocates, at different levels, more pediatric/adolescent – getting doctors and professionals to pay attention to the fact that not every adolescent who's suicidal just needs more antidepressants. You know, they may have mold, they may have Lyme, or may have Babesia or Bartonella. The more awareness that is brought that these things are real and

really do cause illness first seen in adolescence usually in the neuropsychiatric realm and not in the rest of the physical realm is going to help save a few more lives from endless bouts of depression and maybe actually committing suicide. That's an enormous, big deal, if you can do that for others.

***Moderator:***

Thank you Dr. Gupta and Dr. Ackerley for your time today and thank you to everyone who joined us. A replay will be available and that will be going out through the mailing list and Facebook groups. Thank you again.

***Dr. Gupta:***

Great, and I also just want to very quickly express my gratitude for Dr. Ackerley's contribution to this field. Including her research she's done on VIP and NeuroQuant and MARCoNS. I think it's making a real difference for this whole field to move forward and for us to help patients. Thank you for being on today, I really appreciate it.

***Dr. Ackerley:***

Okay, thank you and happy Memorial Day for everyone in the US.

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