



## **Adhesive Arachnoiditis (AA) Questions Answered by Dr. Forest Tennant and hosted by Dr. Bobby Koneru**

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(Opening monologue)

Welcome to a very special edition of the Monk and the Hedonist. Today we have back Dr. Forest Tennant who is really a pioneer and expert in the field of Arachnoiditis.

This is a follow-up to our previous episode for the [Monk and the Hedonist from March 18th episode #7](#). So for those of you who are just kind of coming on for the first time, it would be really great if you listen to that episode first because that gives you a really good broad overview of Arachnoiditis and some of the protocols that Dr. Tennant has developed.

For this particular episode we're just going to go over some questions that have arisen from the Arachnoiditis community based on that episode. We'll just go through them one by one and Dr. Tennant will be able to answer them. So Dr. Tennant if you're ready I'm gonna dive in...

Dr. Koneru:

The very first question, and this comes from our previous episode; in the interview you discussed your belief that the number one cause of Arachnoiditis is really degenerative disc disease (DDD) and protruding discs, along with the inflammation that can arise from them. So if that's the case, why aren't we seeing more Arachnoiditis?

Dr. Tennant:

That's a very sophisticated question and the answer is that I believe that when we say protruding disc, practically everybody that you see today has had a protruding disc. Now having said that, I actually believe that you've got to have a protruding disc plus another factor. We know a couple of the factors, and there may be more of them, but protruding discs is the thing that shows up more often.

We know that there's another group, and that's the group of people who have one of the connective tissue collagen disorders of the Ehlers-Danlos (EDS) type. Those people obviously have a collagen defect, and if they develop a protruding disc, they're really subject to going on and developing AA.

There's another group, and I didn't even want to bring it up, but since you asked I can't be sure, but I've taken a lot of viral titres in people who have AA, and have protruding discs, and you start seeing very high titres on these people. It's not just one virus, you see coxsackie (Coxsackievirus), you see Epstein-Barr, you see cytomegalic (Cytomegalovirus) disease. So one has to start asking the question, 'Did they slip the disc because they had a virus or did they slip a disc and have some inflammation?' This gave them a milieu biologically where the virus could invade.

So I've had this discussion before with a nurse practitioner who had done a lot of the tests for me and we used to have some arguments. I started off saying, "Oh viruses couldn't be a problem here," and she kept saying, "Yes they are," and I've kind of shifted over to her side.

Now obviously you might have another autoimmune disease, because let's face it, there are millions of people who have protruding discs that don't develop AA (Adhesive Arachnoiditis). But in some people that have that protruding disc, it sets up a cascade of inflammation that goes on and spreads...first to the arachnoid dural covering, then maybe into the epidural space and into the cauda equina. It takes a while but eventually that cascade can give you AA. I think the protruding disc seems to be the precursor; it's really got to be a protruding disc plus something else. Right now, some of the leading candidates are either Ehlers-Danlos, viruses, or autoimmune diseases and there may be some others.

I think that in the past, you know, we doctors took a protruding disc as being everyday life and I think today we want to look at those protruding disc patients differently.

There's something maybe going on and we've got to look at them a little differently. I think that's my message and for anybody who is out there who has a protruding disc, I think you've got to be on some kind of a program with the full knowledge that it could progress to something bad. So that's kind of where we're at, a great fertile ground for very interesting research.

Dr. Koneru:

During our last interview you also talked about the necessity of epidural corticosteroid injections (ESIs) and how corticosteroids cross the blood-brain barrier (BBB) and that you thought that injections have probably prevented Arachnoiditis more than they've caused? So what are your views on epidural injections? Because it seems like there's a lot of confusion out there as to whether or not they're harmful in the management of Arachnoiditis.

Dr. Tennant:

Epidural corticosteroids- it's a little complex. Let me first give you my views of how I think all this happened and promises that have been unfulfilled by that technique. First off, let me be real clear, if I had a protruding disc, or a back problem, I personally wouldn't take an epidural injection, so that kind of gives you my bias right out front.

So now let's go on from there, the reason I really don't like epidural injections is because they came along in the late 90s along with the long-acting corticosteroids and long-acting opioids, and pain practice changed overnight. Prior to that time, epidural injections with corticosteroids and long-acting opioids + intractable pain management -- in other words, the management of the severe Chronic Pain Patient was plodding along with new medical things being developed all the time. But it radically changed because the pitch was that these epidural injections obviate the need for physical therapy, they obviate the need for tens units, they obviate need for electromagnetic (EMG) therapies, anti-inflammatory agents, and it was sold. Indeed the early trials of giving epidural corticosteroid were wonderful. Patients felt better, they did well, and they literally founded a whole specialty called pain management. It literally, you know, birthed the basis of interventions.

Now unfortunately, like everything else, both the long-acting opioids and the epidural corticosteroid injections have run into troubles.

I know that the 'Arachnoiditis Community', if you want to call it that, is against epidural corticosteroid injections because it's caused a lot of Adhesive Arachnoiditis and so where are we at with this?

The reason I made my statement is that it's a risk vs benefit.

Both epidural injections for delivery, anesthesia, or for inflammation is a 'risk vs benefit'. In other words, let's say that 95% of epidural corticosteroid injections go well and there are no complications, but five percent go badly. Well, if you're in that five percent, it's a terrible procedure and today you have that risk vs benefit. (And) where my gripe comes in is that these patients were not informed that they might develop chronic cauda equina syndrome, epidural fibrosis, and Adhesive Arachnoiditis (AA) with that procedure.

That procedure has probably prevented thousands of people from developing AA, but it has complications and so everybody wants a black and white answer, yes or no.

Epidural corticosteroid injections (ESIs) look to me like they're here to stay regardless of the controversies over labeling, or the lawsuits, or anything else.

But it is a risk vs benefit and I think it's terribly wrong that patients got these injections and weren't informed of the risk.

I personally wouldn't take the risk and I don't recommend it. I know a lot of physicians who would disagree with that statement because they're getting great results. I know physicians who have done thousands of epidurals and had no complications, so it looks to me like they're here to stay.

I think the Arachnoiditis community needs to understand that. It is a risk, there should be informed consent and a lot of us wouldn't take them.

Let me just give you my first real gripe- prior to the long-acting opioids, and the epidural corticosteroid injections, we had a pain process that was plodding along. One of the questions coming up is, well what about doctors who won't use corticosteroids? It's amazing doctors, after the late 90s, were told to give a bolus of methylprednisolone in the epidural space, but are scared to give two milligrams of methylprednisolone two days a week, and what it did--it wiped out the treatment realm.

Now let me just say, my gripe about medical practice today is we went too fast with our technology. We gave up the treatment loop. You go into a general practitioner's room today in any town in America and ask a general practitioner or a nurse practitioner if you have a treatment room. Now, the old treatment room had some hot packs, we had some braces, we had some kind of electromagnetic device, we gave some shots, those are gone. Because today the standard is you walk into a general practitioner's office, you have a bad back, you have a work injury, you're set for an epidural corticosteroid injection as first line treatment. We gave up the World Health Organization's (WHO) three-step analgesic ladder which said try non-medical options first. Try exercise, try diet, try stretching, try a local corticosteroid injection, not an epidural injection.

I know it's not what people want to hear. They want to hear, "Let's stop them." It causes problems, you can't do that. It's a risk/benefit ratio and you do have to face the fact that there are physicians out there who had great success with those injections. They've lobbied to keep them alive. They're doing them daily and they've had great results. Where I'm at is-- the least we can do is inform people that there is a risk.

I know that that's a little complex and it sounds like I'm on a soapbox and I'm as unhappy about these things as other people, maybe for different reasons, but I think it changed medicine and it went too fast.

Dr. Koneru: Yeah, it is a complicated question with a complicated answer, indeed. My father was an anesthesiologist and probably did thousands of these throughout his career and yet he developed Arachnoiditis by getting one on his own back (ESI), so it's a really complicated answer. So I appreciate that.

As we're talking about steroids and how necessary they are in the management of Arachnoiditis

because they cross the blood-brain barrier (BBB), yet so many Arachnoiditis patients are having difficulty with their physicians having reluctance to prescribe corticosteroids. If you can take a moment to specifically talk to a physician who might encounter a patient who has Arachnoiditis, what would you tell them?

Dr. Tennant:

I would tell them first off, only do things you're comfortable with. If you start something new, try a little bit before you try a lot. Now my generation of physicians is comfortable with corticosteroids, why? We grew up in the days before we had biologics.

The advent of biologics for rheumatoid arthritis, lupus, scleroderma, and the other collagen or autoimmune diseases, what it did; it really eliminated training in medical school and in residency to use corticosteroids. Now when I was a resident, my head of medicine carried in his hip pocket a syringe with lidocaine and a couple of cc's of a corticosteroid, and every other room, we gave corticoids to somebody. Nowadays, you would never see that. And a lot of us again we're military trained, Army or the Navy, and so we used corticosteroids liberally and knew how to use them.

Today's doctors it's like putting your toe in the water; they weren't taught to use them, they're afraid of them, and they should be afraid of them. So when a doctor tells me they're afraid of them, they don't want to use them, I understand fully. It's new for them. However, here is my advice for the doctor who is worried about it and hasn't either taken the training or doesn't know and hasn't got the time to go read about it and study it, or go to a seminar on it; start easy and start safe. How about one injection once a month? Have the patient come into your office and put a cc of dexamethasone or methylprednisolone in the syringe and give it to them. You know that's going to be safe and it's not going to hurt anybody.

Here's the other thing for patients, one of the better things that FDA has done in recent years is to allow the adrenal cortex, adrenal whole gland supplements to be on the commercial market. They're quite safe and they were taken off for it for a while, but they can at least help substitute. They're safe and that gets your foot in the water.

So when doctors don't want to do it, I fully understand. The other thing that they don't understand is you're trying to have a doctor who wasn't trained to use these things because of the advent of biologics and the potent anti-inflammatories and other procedures, and before that doctor or nurse practitioner can bring themselves up to speed, they're going to have to walk before they run. So you want to approach it from that basis.

The other thing that's a little sophisticated is-- for years prednisone has been the popular drug for physicians. Unfortunately, prednisone doesn't work in Adhesive Arachnoiditis (AA) all the time. Apparently it doesn't quite get through the blood-brain barrier (BBB) or the spinal cord -barrier (SCB) as well as methylprednisolone or dexamethasone. You have something like 12 or

13 commercial corticosteroid products, but those two seem to be the ones that will get past the blood-brain barrier (BBB) and seem to be the best.

My final word on this: we talk about the term low-dose naltrexone (LDN), let's also talk about the term low-dose ketorolac and low-dose corticosteroids.

Corticosteroids in AA are probably going to have to be used in a lot of people for years, maybe a lifetime. Therefore, you don't want to use them daily unless you just have too. You want to use them intermittently at a low dose. You don't get the complications if you're taking, let's say half a milligram of dexamethasone twice a week, or let's say two or four milligrams of methylprednisolone two or three times a week. But above all, you want to skip days with corticosteroids unless somebody's just gotta have them. If you've got to take them daily there's going to be complications, no question about it. You're going to get pituitary suppression, osteoporosis, the moon face, you're going to get it all.

So with long-term lifetime management today of this disease we've got to be thinking in terms of low dose, low intermittent doses over a long period. That's where we're at this stage. We might get a break. I happen to know that there are some scientists who are interested in developing biologics for this kind of disease. Let's pray and hope it comes through. We might have stem cell therapy that comes through, we may have polypeptide therapy, we've got a lot of people trying new things and I'm delighted to see it, we need it, but in the meantime we're going to have to rely on corticosteroids. Again, I hate to apologize for all you young folks, but in my generation, we had to use rheumatoid arthritis-gold, we didn't have prednisone. We had to use plain cortisone. And so in some ways we have to go back to those old days in this disease. To us, it's a new disease, but it can be done and will have to be done. But again for doctors out there and patients, start with maybe a one time a month shot.

Work with your doctors, bring some information. You've got to remember today's doctor may have to see a lot of patients and doesn't have a lot of time. Continuing education for physicians has fallen through the roof. I mean with Covid, and everything else, you just don't have the seminars or the monthly talks for doctors. I talk to doctors all the time that they haven't been able to go to a continuing education forum for two years, so we're all in this together.

Dr. Koneru:

Thank you, that was a great explanation. You know for patients who may have some kind of medical contraindication to steroids, (and you I know you've hit on this a little bit), but are there any other viable alternatives that you know are reasonably effective?

Dr. Tennant:

Yes, I'm not saying everybody is going to have to have corticosteroids. But I will say this; based on my experience, (and I hope it changes), but based on where I'm at today there's been three compounds that an AA patient better have. Two of the three probably; one's low-dose naltrexone the other is ketorolac, another is a corticosteroid.

When you get past those three, I'm not sure what your success is gonna be. Some people do well with a diclofenac, indomethacin, nandrolone, or a lot of the non-prescription agents like PEA (palmitoylethanolamine), or what have you. However, the three agents that really have stuck, if you will, really seem to get us somewhere is either low-dose naltrexone (LDN) or one of the corticosteroids.

Now, if you're not going to take a corticosteroid, you better certainly try to take some ketorolac because that's the one anti-inflammatory that gets in the spinal fluid. And it's potent enough to penetrate into the spinal fluid and somehow attach along your cauda equina nerve roots and get you some relief.

I like to see people take two out of those three compounds as a good start, and so that's kind of where I'm at. When I hear somebody say they can't take a corticosteroid, I think what they're really saying is they've been given too many, too often, of the wrong kind. And practically anybody can tolerate a once in month shot of a corticosteroid, you just can't take it very often. You've got some people with severe osteoporosis, or you've got some other kind of contraindication, so you don't have to take them on a regular basis. I know it sounds funny, but even a once a month corticosteroid injection will help.

Dr. Koneru:

That's great; that's very practical advice. Another topic that came up from our last conversation was hormonal supplements such as DHEA and progesterone; the question is, "do we need to have those hormone levels tested regularly?", because that seemed to have caused some confusion.

Dr. Tennant:

This is an excellent question. Let me put it this way, we're talking here about health plan coverage and finances. We're not talking about clinical optimism. Optimally a person with AA should be having a hormone panel every quarter. I mean you ought to check your cortisol, your pregnenolone, your testosterone, probably estrogen and progesterone, and DHEA. About a little panel of around a half a dozen hormones, if you could financially attain them.

Today's laboratory costs have come way down, but it's still a lot. A lot of your insurance plans aren't going to cover those compounds and they're probably too expensive to pay yourself. So in patients who can't get the hormone tests, you're not going to hurt yourself by going down to the health food store and getting some DHEA or pregnenolone; those two are non-prescription and have been proven to be very safe, even at very high doses and you can start those two and get some effects.

If you can, get tested, that's great, do it, then you can monitor or titrate your therapy to where

you get normal blood levels.

Let me just say this, when you do start something like a hormone from the health food store, or on the internet, get whatever you want, one brand is about as good as the other as far as I can tell.

Most patients on DHEA find that it's quite effective at a dose of around 200 milligrams a day, but some do well at 50, somewhere between 50 and 200 milligrams a day you're not going to hurt yourself. Pregnenolone has about the same doses, and you can take them alternate days, you don't have to take hormones every day of the week.

One of the issues that I really want to emphasize to everybody is that you've got to be on what I call an "anabolic program" and I'm hoping every listener here remembers that term "anabolic program". That's where the hormones come in, now, anabolic is Latin or Greek, "bolic" means growth and "ana" means before growth and catabolic, broken down, is "cata" means deterioration. So that together with "bolic" catabolic means a declining growth. If you're not careful with a disease like Arachnoiditis, you go into a catabolic state, meaning your tissue is fundamentally declining all the time. For those of you who have Ehlers-Danlos Syndrome you're genetically programmed to deteriorate collagen and your tissues so you've got to be on something to rebuild it. You've got to do that daily with your diet, exercise, and your supplements. If you can get the hormone levels checked, do it.

Let me just say a couple other things about hormones. The thyroid in some patients are going to have the autoimmune manifestations of Arachnoiditis and have Hashimoto's disease. You may need to be taking thyroid, others of you are going to have intractable pain syndrome. If you take a prolactin level, that's almost diagnostic of intractable pain syndrome. Prolactin goes up. So you can use blood testing for hormones, but don't let the fact that you can't get it due to financial reasons, (or a doctor won't order everything, or for some other reason),--don't let that hold you back. You can get started with some of these over-the-counter supplements and do it safely and cheaply.

Dr. Koneru:

Doctor, what about patients who, as this is more specific to men, but as men age they may develop BPH? Their prostate may be getting enlarged, or they may have risk factors for even prostate cancer, so when you're taking things like DHEA, does that increase your testosterone levels and do you still consider DHEA to be safe in that patient population?

Dr. Tennant:

Yes I do, as long as you keep the dose down under around 200 or 300 milligrams a day. Let me tell you the problem with DHEA, it doesn't convert enough to testosterone or to estradiol, only a fraction of it does convert, and so our problem has been that we can't take enough DHEA as a

substitute for testosterone and estradiol.

Let me just say something before I forget it. I remember the days when most general practitioners in America would have any number of women in their community who were postmenopausal who came into their office once a month for an estrogen shot. I truly believe we had less pain problems in those days because I think the estradiol is very protective. When you study the metabolism of estrogen on the spinal cord it's profound and so is testosterone.

I think that everybody with AA is going to have to kind of pick their therapy that's going to work pretty well, but the old-fashioned estrogen and testosterone shots are quite good. The fear of BPH and cancer with these hormones I think is way overstated because we're not getting into the high dosages. For example, they've scared every woman in the country who has taken Premarin, but they have to remember that those premarin studies were done and people didn't take estrogen blood levels. Researchers gave it every day; they gave it to high-risk patients and they've scared everybody from taking estrogen supplements or a shot of estrogen and I think that's very unfortunate.

Just remember this about hormone use for therapy, again it goes right back to what we said about corticosteroids which are also cortisone, also a hormone, low dose intermittent, not daily, not high dose, you take them low dose intermittently and that way you avoid the complications.

Dr. Koneru:

Excellent. The next question has to do with surgery. So many patients with Arachnoiditis suffer from conditions that may require surgery and some of our patients are being advised that they have to have surgery done. The general consensus in a lot of these AA groups, however, is that you cannot have surgery without fear that your Arachnoiditis is going to progress. Is that a realistic fear?

Dr. Tennant:

The answer is 'yes', but there's another part to that. And that is sometimes you just have to take the surgery. I have sent many patients to the neurosurgeon and the patient didn't want to go because they were afraid of this. But I could take one look at their x-rays and do their physical exam and see; but may not like the risk of the surgery. Indeed, you've got that risk, but on the other hand if you don't get the surgery you are going to have problems.

The idea that we're going to be able to eliminate all neurosurgery, or all orthopedic surgery, is a misplaced fear. There comes a time when you just have to go do it and for example, I've gotten awfully good at looking at a lateral view of an MRI, and if that disc is just cutting off the spinal cord, you've got to go have surgery. I mean if that spine is just too unstable, or that tarlov cyst is just getting too big, you just have to have the surgery.

I've gotta give from my point of view- compared to where we were three and five years ago- I'm

so pleased and proud of the medical profession. I see surgery and the surgeons now taking on the whole mantle of Arachnoiditis and they didn't even used to discuss it. And it has a risk, but if you've got to have neurosurgery, you're going to have to have it. Getting a second opinion is always a good idea, but nevertheless, we're not going to be able to avoid all surgery even in patients who may already have Arachnoiditis.

Dr. Koneru:

Historically we know that myelograms were a major issue and risk factor for Arachnoiditis so a question that came in is, "What's your advice on having a CT myelogram now if you have Arachnoiditis, or suspect that you have it?"

Dr. Tennant:

I'm very partial to the contrast MRI either with the dye or with the new Tesla devices. These are great advances and you can really see what's going on. If we didn't have the contrast MRI, I wouldn't be standing here. That's given us the ability to see into that spinal canal and know what's going on and the ability to do this research. I don't like myelograms in the sense that you've got to inject dye, perhaps into the spinal canal, but again, there may be conditions in which you're gonna have to do it. I confess that I'm not an expert in myelograms and exactly why you would do a myelogram compared to an MRI; so I'm afraid I'm going to have to refer you to your radiologist as to whether the myelograms got to be the technique to be used. I have seen myelograms that have been excellently done, but no, you don't like to see anything injected into the spinal fluid, but sometimes again, that's something that may have to be done.

Dr. Koneru:

Next Question, can the inflammation that you see in Arachnoiditis travel up the spine to affect other areas such as the thoracic, the cervical spines, the arm, or even the brain?

Dr. Tennant:

You know of all the questions you ask, this is one I didn't really want. There are people who swear that they have had lumbosacral Arachnoiditis and the next thing you know they've got it in their neck, and you know something? It does appear that way on MRIs. Now how did it get there and can it travel?

Arachnoiditis itself is a mass of adhesions and nerve roots embedded in a ball so that it doesn't travel, but I will have to say it does raise a question; 'Is it possible?' And looking at these slipped discs is it possible that inflammation is like an ember from a fire. And can a piece of inflammation float through the bloodstream, or limb, from the spinal fluid and land somewhere and sort of start inflammation? I'm asking that question and I don't know the answer.

Is it possible that people with Adhesive Arachnoiditis develop an autoimmune disorder that could start in the lumbar section and then it goes to the neck?

The other thing that I think happens that makes people think it's migrated is that they have Ehlers-Danlos Syndrome, or one of the syndromes and they just simply have had the arachnoid dural lining break down in a second area.

So whether it actually spreads or not, I don't know, but we do have people today who may start off with cervical Arachnoiditis and then it can go and start into having lumbosacral Adhesive Arachnoiditis.

So we do see that but the cause of it is not certain. I don't know if it can migrate because the only way it can migrate would be to have inflammatory particles, if you will, break off and float up the spinal fluid. You have to have that, but I don't know if that's biologically been documented or could happen.

Dr. Koneru:

The next question has to do with pain pumps and spinal cord stimulators, in lieu of pain medication. What are your thoughts on spinal cord stimulators and pumps and can you talk a little bit about the potential pros and cons of them?

Dr. Tennant:

Spinal cord stimulators and pumps are a necessity in some cases. I send people to get them every once in a while and there have been wonderful technological advances.

Having said that, most of the people who are being asked to get these things have not gotten themselves on a good three-component medical program.

One has to remember that a spinal cord stimulator is an adjunct, or should be an adjunct, to a program that's in place that doesn't work totally. Stimulators and pumps were never intended, and aren't intended, to be a substitute for a solid ambulatory program.

Let me put it this way, you got to have, in my opinion, a program, a protocol, to deal with Adhesive Arachnoiditis. Arachnoiditis is not a forgiving disease. If you leave out an element, you're going to pay for it. You have to be on the right diet and the right supplements. You've got to be on spinal fluid exercises, and other oxygen giving exercises, stretching exercises, you're going to have to be on something that's a medication to suppress inflammation. You've got to be on medications to build tissue. You've got to be on one to have pain control, because once you get that stimulator and the intrathecal pump, one or the other, it's not a substitute for those other things. It's to be in addition to a basic program that is not working, so I send people and they get the stimulators all the time. But there are people who are not making it with a basic program

because even if you have the stimulator or the intrathecal pump, you're still going to have to be on anti-inflammatory agents. You're still going to have to be on hormones.

Pumps and stimulators are not a substitute, so that's why I harp on the fact that you've got to be on a comprehensive program for Adhesive Arachnoiditis. You can't leave out an element and you can't expect-my gripe is-people think, well if I just get a stimulator, or I get stem therapy, or a polypeptide therapy, or I try this new thing I heard about, I won't have to take all these medicines, I won't have to do these exercises, I don't have to follow the diet- and it won't work because they're not. I think that's where people are going wrong, and if a physician does say you should do that-and I don't think the physicians do that-I think they go to a pain specialist. And the pain specialist says 'look I can offer this, I can't offer you the medical component.'

Now let me just say another thing about this Adhesive Arachnoiditis and incidentally Bobby (Dr. Koneru), I'm so glad you're starting to take patients. I'm hearing from doctors all over the country who are starting to take patients. This thing (Arachnoiditis) is now common enough that every community is going to have to have doctors to treat this problem.

Adhesive Arachnoiditis is a medical problem, it has gone into like rheumatoid arthritis. We're going to have to treat it medically, in every community. And so once your medical treatment doesn't do well, 'we better call in the stimulators, call in the intrathecal pumps'-be honest about it; I spend more time trying to tell patients and doctors to use the stimulator and the pumps than I do telling them not to use it. Because there's a terrible cost involved and insurance companies don't want to pay for it. They're very expensive and so therefore everybody's got to realize -- don't think of these new high-powered technical devices as being a substitute for a solid diet, physical measures, and medical approach to treating this disease.

You can't leave out anything with this disease; it'll get you. Leave out your diet, you leave out your hormones, you leave out your corticosteroids, you leave out your anti-inflammatories, this disease is going to bite you. It will progress, it does not go away on its own. I want people to really realize stimulators and infusion pumps are in people who fail our medical treatments.

Dr. Koneru:

Thank you for explaining that so well. I think really the take-home point is the pain management part of this is just one part, one component of the entire comprehensive protocol that you're talking about, which includes lifestyle management, exercise and diet, and modulation of neuroinflammation, and regeneration of your spinal cord. So there's so many different components that all have to be addressed outside of just the pain.

Dr. Tennant:

Absolutely, well said; absolutely, and I think that's just a message from the pulpit that you won't

see me give up.

Dr. Koneru:

As I started to also see Arachnoiditis patients, there are some common overlaps from my primary specialty, which is treating cancer patients. You know, one of the questions of course that comes up in both of these populations is, 'Can I be cured of this diagnosis?'

So when it comes to Arachnoiditis, can it be stopped and reversed if caught early enough? What about those patients that have severe Arachnoiditis? Do they have any hope in successfully treating their symptoms or stopping the progression?

Dr. Tennant:

The answer is 'yes' to both questions. If we can catch the disease early enough and we can catch it at the inflammation, at the cauda equina stage, or the protruding disc stage.

I've got patients that are totally off all medications and for all practical purposes have cured themselves. So that's one of our messages, 'get started early!' If that MRI comes back and it doesn't show adhesions, it doesn't show nerve clumping, but it may show a little something that indicates inflammation, you get a CRP and ESR and you get started on anti-inflammatory treatment, the answer is yes.

We've got a lot of people now who are into treatment and they are either almost curing themselves or bringing their symptoms down to where they don't have to go on to opioids, or into the catastrophic areas. Unfortunately, we have a lot of people who nobody knew when they developed the disease,...5, 10, 20 years ago..and they were put on high-dose opioids, they've been put on stimulators, they've been put on all kinds of things. In other words, they and their families and their doctors did the best they knew how, but unfortunately they're catastrophic. Some are bed-bound, wheelchair-bound, now do we have any hope for them?

The answer is 'yes!' I'm hearing from people all the time that are trying new things, and let me emphasize something; keep trying new things, just be on the basics, but keep trying new things.

For example, I've got a wonderful letter about a physician who has terrible Arachnoiditis and she is out of bed walking around by taking boron. I've got another patient who had been bed bound for years who's out of bed now and took one of the intrathecal polypeptides or stem cell type therapy. We're starting to see occasional people with new things, but I don't care at what stage you are, you're bed bound, you're in a wheelchair, you're on high dose opioids, stay with it, stay with whatever is working for you. Try to get a balanced program and try new things.

I don't buy this argument that somebody has just got to give up and can't get better. Okay, so you're in a wheelchair, or you're bed bound, a lot of people still have a good life and the good Lord hasn't taken you yet so he wants you here for some reason! So develop some kind of a life

and get some kind of good pain treatment, keep studying, keep finding out what we can do. I don't like this idea that we give up, hopefully there's something we could do.

One of my pet peeves is when I hear from a patient who says I've been to my doctors, been to my pain specialist, I've been to my endocrinologist and they say there's nothing that can be done. I totally disagree with that, we can do something for everybody. I think we should do something for everybody and, like I say, all of us are not to leave this earth in good condition. We all got to go, and so you have to kind of be a little philosophical about it, a little spiritual about it, and that is that. This is your disease, you do the best that you can, but let's keep working to help everybody. I don't buy the idea of giving up.

Dr. Koneru:

Dr. Tennant, that's such a powerful message and I think someone who has seen as many patients with Arachnoiditis as you and still saying that patients have hope and that many of these patients can be reversed, if caught early, and even successfully treated even if they have severe diseases.

I think that's very encouraging and that should bring hope to a lot of these patients.

What about patients who are having a hard time getting their physicians to take their Arachnoiditis symptoms and concerns seriously? What would you say to these patients as to how they can approach their doctor? Is there any literature that you would recommend that they take with them?

Dr. Tennant: The answer to that is 'yes'. Now in my career, for example, I was one of the founding members of the Lupus Society and nobody believed in Lupus. Then along came Fibromyalgia, and nobody believed in Fibromyalgia. I could probably come up with a half a dozen other diseases that nobody believes in. For example, dementia.

A new condition always goes through a cycle of a few innovative patients families, and physicians (who) identify something, then the medical profession, (kind of instinctively, and I know better than anybody else), denies that the disease exists, because doctors are busy, they're terribly busy.

They're taught to do certain things and they teach themselves to do certain things, so then there's sort of a denial phase. And then there's sort of the acceptance phase -- 'I'll accept it, but do I have to treat it?'

The fourth phase is, 'I've got to recognize it, I've got to accept it, and I've got to treat it'.

But we're not in the fourth phase yet. We're moving everybody down the spectrum and so just keep,...putting it very bluntly,... keep hammering away.

We've got to bring everybody to the carpet here and just keep taking their physicians information from the websites: brochures, articles, whatever you can find and keep laying it on the doctor's desk.

I don't think there's a doctor alive who today doesn't kind of instinctively appreciate it when the patient does bring stuff to them. Because, I want to emphasize something, if I had the health system, I don't want to say it's degenerated, but it's been cut up. When I was a young doctor, if there was an article published in the Journal of the American Medical Association, everybody in the world knew about it. We knew it and read it and everybody accepted it. Today there are hundreds of journals, associations. Many universities don't even do postgraduate education for practicing doctors. The federal government has essentially banned pharmaceutical companies and medical device companies from putting on continuing education. Hospitals feel it's a loss leader, they don't want to do continuing education. So the doctor's are out there on their own, and he's a small businessman, usually who has got to get his information from somewhere. So I think deep down, I don't know many doctors who aren't pretty appreciative when patients bring in brochures, and particularly if their family comes in with them and says, doctor my family has this, can you help us?. They may give you a little guff at first, they may resist it at first, but don't give up. We've all got to be advocates on this and bring everybody knowledge about this disease.

I'll just say one other thing; this disease, I hate to say, it's a fascinating disease, and it's very interesting, but I'm talking to doctors now or scientists.

It's very interesting to me about how the inflammation occurs and the nerve roots get clumped and how we entrap nerves and how we're going to untrap them and get people doing things. I find it very scientifically very interesting, and the worst thing that can happen to the patient is to have the doctor say you have an interesting case, because you have a case that (still) needs treatment,...but yeah, I think you get what I mean,...but don't give up on it.

I will give you a practical message; every patient with AA needs to find out what their primary care doctor will prescribe, okay? If that doctor will prescribe some tramadol, if he'll prescribe some estradiol, and he'll prescribe some ketorolac, or whatever, you gotta find out what he will do and then fill in the 80 to 90 percent of your program.

An effective program is done without a doctor's prescription.  
Remember that!

Don't be paralyzed because you got a doctor who won't quite do what you think is on the protocol. You can get started with your diets, your exercises, your spinal fluid exercises, your non-prescription supplements. 80 to 90 percent of a good program is not based on your doctor's prescription, it's what you can do with your family. You may have to study some once you get a disease, like hey, you've got to go back to school, you got to start reading and studying, talking

to people, joining groups.

You've got to start studying and start doing stuff on your own, you can't be waiting for your doctor to save you!

You've got to do it and that's one of my messages today, "Don't expect your doctor to guide you on this, you need to guide yourself!"

Medicine has changed, your doctor's probably too busy and has a lot of technical things he's got to do. So remember, you've got the disease, not your doctor.

Dr. Koneru:

One of the great things about technology compared to 20-30 years ago is the fact that there are so many more resources out there that patients can access information.

Now they can be a part of online communities such as these Facebook communities, so at least there are ways now in which AA patients can connect with each other and get good information and I've always been impressed with how educated, self-educated, a lot of these AA patients have become.

Dr. Tennant:

I think it's just great and that's your savior. Understanding the disease, understanding the anatomy of your spinal canal on your nerve roots.

You got to learn a new vocabulary, and you've got to learn agents. In fact, one of my soap boxes today is I want everybody to know what, if you're taking something by shot or by mouth; what is its purpose? Not just the name of it, not its dose, what's the purpose of this thing you're taking now? Why are you taking vitamin C? I recommend vitamin C for everybody, every day, but I want to know why you're taking it, to build tissue?

Do you know why you are taking ketorolac? You're taking a ketorolac like drug to suppress spinal canal inflammation.

You want to know why you're taking drugs, what's its purpose? And again, this is kind of new for people who have a terrible disease, but that's what you have to do today. I don't see a way out except for patients who get very educated about their diabetes, heart failure, EDS (Ehlers-Danlos), and particularly AA. You've got to go back to school and learn about it. I don't think you have a choice. You cannot depend on some big university center, or some high-powered specialist to take care of you. It's going to have to be in your community, and you're going to have to learn enough to kind of take care of yourself.

Dr. Koneru:

Another question; 'What do you feel about stem cell therapy and do you believe it's a viable option for those who can afford it?'

Dr. Tennant:

I'm all for people trying stem cell therapies. Let me see if I can put this together in perspective; it's a little bit like the spinal cord stimulators. You first need to be on a basic good program, okay?

Now once you're on a good program, you've got pain medications, you've got tissue growing agents, you've got your suppressing inflammation, you're doing your spinal fluid exercises every day, you've got some kind of electromagnetic device you're using etc. You put a good program in place, then search out stem cell therapy. Polypeptides are kind of being used right now, there's some amniotic fluid things being used, there's nothing wrong with trying these experimental things.

There's going to be, in my opinion, some kind of a stem cell type therapy, if you will, that's going to work pretty well. I know of some different techniques being used at this time, there's nothing that's been consistent yet. I hate to see people spend a lot of money for something that's too darn experimental.

Put a good program in place. Don't buy any line that this stem cell treatment, or anything else, is going to solve your problem. Get a program in place to try it. You've got nothing to lose.

Most stem cell therapies are past the point of being toxic, or having a lot of side effects, so they're worth trying. If people don't try, we'll never figure out which ones are best, so yeah, I support it, but I only support it after you've been on a good basic program.

The stem cell therapy is not going to be curative. What it'll do, and let me give you another therapy that I kind of like these days, and that's infusions, stem cell therapy and let me talk about infusions in the same breath. These things may bring you into a remission, or close to a remission, give you a lot of comfort for a few months and then you've got to repeat the test or repeat the therapy. Nothing wrong with that, and so that's one of the things you can do. I'm convinced that these stem cell therapies are going to have that same kind of treatment effect. For example, a lot of people today with AA, they will get one of the infusions. The infusions that have been used are lidocaine, vitamin C, ketamine...I may have left one out, or two,..but nothing wrong with trying these things either and some people will find that you're gonna get some good relief that'll stay there for a few months or a few weeks. Again you can give them a try but don't

let these things be a substitute for the basic protocol.

Dr. Koneru:

Thank you and our very last question has to do with AA and how it impacts CSF (cerebral spinal fluid) flow. It seems like there's been a lot of confusion within the AA groups regarding this specifically because some of their physicians don't agree that there could be CSF flow blockage from AA.

Can you talk about that a little bit more, and also talk about how some medications like acetazolamide can help with that?

Dr. Tennant:

First off, we're not 100% certain how this works. Let me start with a couple of basics. The spinal fluid is made in the midbrain and you totally turn over the spinal fluid in your whole body every four to six hours. So you make new spinal fluid every four to six hours and the spinal fluid itself is in a very small pipe. You want to think of the spinal canal as a pipe, and it's kind of amazing. The spinal fluid is made in the brain and it goes straight down the spinal column, turns around, comes back up and there's no pump as far as we can see. Maybe the heart beating forces it to move, but there have been studies, particularly in the neck, to where the gradient across this very small pipe with an Arachnoiditis mass does interfere with the flow. And so you get patients with Arachnoiditis who have blurred vision, tinnitus (ringing in the ears), headaches, dizziness, and things like that and people think they have a spinal fluid leak. Most of the time they don't.

There is no question that in the lower lumbar spinal cord area when you develop Adhesive Arachnoiditis, you fundamentally put a mass inside this pipe. Because that's what Adhesive Arachnoiditis is; it's a clump of nerves made of adhesions, scarring, inflammation, and nerve roots. It's a ball. It's a mass, and it does interfere with spinal fluid flow.

Why acetazolamide works, again, that's really a little bit uncertain. It's thought that it lowers spinal fluid pressure and some people can take a small dose, 125 to 150 milligrams of acetazolamide and feel a lot better. So we assume it's dropping pressure a little bit and that's just like in the eye, but you do get some kind of interference with the flow.

I can't tell you whether the symptoms are caused by slowing down of the fluid flow, or making it pulsate, or do something abnormal, we don't know, but when you do get these symptoms trying Palmitoylethanolamide (PEA) has recently been shown to at least regulate some fluid in the eye. So that and acetazolamide are worth trying but we really don't quite know what's going on with spinal fluid. It's really an area that very few people have done research on.

I'm sure that I'm like most physicians, I've never thought about spinal fluid flow until three or four years ago and so I'm just learning about it. I think all the other physicians are too so we got a lot of questions, so if somebody disagrees with me, I may disagree with me too. I'm not just certain, but we do know that spinal fluid flow is important.

Spinal fluid has some functions that just can't be overlooked. First off, it carries your nutrients right from your diet into the spinal fluid and bathes it. I mean it carries in vitamins, minerals, and enzymes just like blood does. It also flushes the system, and so between nutrition and flushing, the good lord has us turn over and make new spinal fluid every four to six hours. It has got some functions that the body considers absolutely essential.

Now that I've said that, I think there are too many people think they have leaks when they don't, and you can try some acetazolamide, but I don't have a good answer for a lot of the people I see that that thinks they have symptoms related to spinal fluid flow.

But I really don't know the cause. I'm trying to investigate and learn what I can and I take anybody's knowledge. So anybody who's got some good theories, let's hear them! We need some of your engineers, medical engineers, and some of your basic scientists to try to give some answers on this because as clinicians, I'm not quite sure how we study this, but it is a problem.

Dr. Koneru:

Dr. Tennant, thank you so much for your time and answering some of these complicated questions. I'm sure that the Arachnoiditis groups and Facebook groups are going to really appreciate this follow-up episode!

Before we get off, I also want to thank Lori Verton. She's the President of the Arachnoiditis and Chronic Meningitis Collaborative Research Network (ACMCRN). Lori was the one that really kind of encouraged us to do this follow-up episode, and she put these questions together, so thank you, Lori.

If you enjoyed this episode, please subscribe to our podcast and our YouTube channel where we'll continue to bring you information like this. Dr. Tennant, is there another way patients can find you, or get information from you, if they're not already doing that?

Dr. Tennant:

Our reward is if you go out there and keep telling your local doctors to get with it, that'll be the reward. We do have a website, and we do put up a bulletin about once a week to try to get people updated. One of the things I'm trying to do is something new and that is trying to give people with this disease an update each week to remind them how to take care of themselves,

bring them anything new to try to give them a boost in spirit, so that's all. They can make donations, if they wish. I'm pleased to say that raising a little money for this good cause has not been all that difficult. So, we do have a website, we do put out a bulletin to which I'd recommend everybody who has this condition, or any physician, nurse practitioner, or naturopath who wants to try to treat it. We try to keep everybody apprised of what's going on. I for one plan on continuing this effort until I'm pretty confident that we've got physicians and practitioners in every community in the modern world willing and able to see these patients.

Dr. Koneru:

Thank you again Dr. Tennant! Thanks for being a beacon of hope for so many patients who have this condition and we appreciate your time.

Dr. Tennant:

Thank you, my pleasure and good luck.

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Link to the follow up interview with Dr.

Tennant: <https://youtu.be/f5M79HfT3LY>