



**Newsletter:** Meeting Date: 28 March 2017, Edition 9

**Moderator: Speakers:** Edward L. Davis, M.D. – Lisa Regan

**Topic:** “Percutaneous Tibial Nerve Stimulation (PTNS)” Dr. Davis  
“IC/BPS Diet Basics” – Lisa Regan

### **Meeting Notes**

PTNS, also called posterior tibial nerve stimulation, is a restrained form of neuro modulation to treat overactive bladder (OAB.) Symptoms of urinary urgency, frequency, and urge incontinence also occurs with interstitial cystitis (IC/BPS.)

The medications for OAB symptoms generally produce comparable improvement and side-effects; dryness of mouth and constipation are two common complaints. No wonder nearly 80% patients stop use in less than a year.

The American Urological Association (AUA) & U.K., National Institute of Clinical Excellence (NICE) recognized the positive symptom relief.

At present it is under review for fecal incontinence and the efficacy in the reduction IC/BPS symptoms of which OAB is one.

### **Technique**

This is where PTNS is emerging as an effective alternative of treatment. The procedure is as follows: Seated comfortably with one leg elevated. A fine needle electrode is inserted into the lower, inner aspect of the leg. The goal is to send stimulation through the tibial nerve, so it is important that the needle electrode near (but not on) the tibial nerve. The needle electrode connected to external pulse generator and delivers pulse to sacral plexus via the tibial nerve; the sacral nerve regulates the bladder and pelvic floor function.

- Treatment procedure requires once-a-week treatments for 12 weeks,
- 30 minutes per session.
- Many patients begin to see improvement by the 6<sup>th</sup> treatment.

### **Conclusion**

PTNS is a low-risk procedure; the most common side effect with PTNS are temporary and minor discomfort, resulting from the placement of the needle electrode – include minor bleeding, mild pain and skin inflammation.

Limited studies show 60-80% OAB symptom relief and with the stopping oral OAB the chronic side-effects stop.

For further information: [www.ncbi.nlm.nih.gov/pmc/articles/PMC3438389/](http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3438389/)

**Next Meeting**

**May 23, 2016**

**Time: 6:30-8:30 P.M.**

**Speaker:**  
Edward L. Davis, M.D and  
Everyone Who Wants to  
Speak

**Topic:**  
Share Questions &  
Challenges

**Location:**  
Foothill Presbyterian Hospital  
(In Doctor's Dining Room)  
**6:30 – 8:30 P.M.**

**Group Contact:**  
[icaction.com](http://icaction.com) – visit often for  
updated meeting  
information

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Cystitis Support Group  
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## Discussion on Diet

For those of you who don't know me already, my name is Lisa. I was diagnosed with IC in 2000. I worked with Dr. Davis and Jo in the IC clinic and research office from 2001- May 2015 as a patient advocate and research coordinator. I am now helping out with the support group and taking a much needed break from work.

I still remember the day I walked into Dr. Davis office as a patient and explained all of my symptoms and he said to me, "I think I know what's wrong with you." I broke down into tears. You see it had taken me years to get to his office. Many probably unnecessary antibiotics from other doctors and possibly unnecessary surgeries and I had a diagnosis... NOW what? I'm pretty sure at this point I went through the stages of grief.

I was happy, mad, and scared all at the same time. I finally got to the point of acceptance and that lead me to want to learn all I could about my diagnosis. There wasn't as much information available then compared to now. I did my own research and brought things to the support group meeting and said "what about this? Have you heard about this?" I learned a lot. I read a lot. I figured out which things worked for me and which were not so good for me. That led me to the IC diet. For me the IC diet is one of the ways that I can control my IC.

I learned a lot about the frustrating & not easy to get a handle on IC diet. I learned there are some foods I to this day still cannot eat. Hello pineapple and strawberries. I love both of those food but they don't like me so much so I have learned that the few minutes of eating them and the enjoyment I receive is NOT worth the 3-5 days of misery they cause me so I had to say goodbye.

Let me back up a little for those of you who are new to the IC diet. The IC diet is a suggestion; a list of foods that MAY bother you. The one thing I know from years of talking with IC patients is no two paths of navigating the IC diet seem to be the same. So yes, look at those lists; see what bothers other IC patients use it as guidance, but you are going to have to find your own path.

The lists are good starting point but they don't tell the whole story. You are going to have to put some effort into learning what works for you. Start a diet log. (go to [www.icaction.com](http://www.icaction.com) to download diet log) Start an elimination diet. What's that? You need to figure out what that is for you. Some people start a log so they see where their symptoms are right now. That gives them a starting point then they either start taking foods away one at a time and see if symptoms get better or what I did was I took out all the foods the lists suggested might be bad for me like: acidic foods – tomatoes, strawberries pineapple coffee etc. , heavily processed foods – nothing from a package or box no processed meats- no fast food- if I didn't make it I didn't eat if for a while- I became a label reader and once you do you realize all the junk in our foods., NO Preservatives this is a biggie for me- no MSG or any on the LIST on icaction.com on the "What is IC page- MSG Myths". Common Food allergies – dairy, gluten, soy, sugar, corn, poultry including eggs for some may need to be avoided. Now to add to the many irritating foods there is a now list of inflammatory foods. There is a great diet suggestion list on the IC network. I strongly suggest you do your own research look up IC diet, acidic foods, processed foods, common allergic foods, food preservatives, hidden MSG and inflammatory foods are a good places to start.

Remember these lists are suggestions of foods that COULD irritate your body in some manner. Don't stress out about the diet that won't help at all. If it seems like too much to start an elimination diet take one step and then see where you are symptom wise then reevaluate and see if there is another level that you can go to. Less preservatives, eliminate another food etc. One step at a time...

I know it seems like there is nothing left to eat but for me safe foods are: brown rice, sweet potatoes, broccoli, spinach, green beans, cooked onion, (yes a food raw vs cooked may make a difference to your body) eggs, white fish, and beans. While preparing for this talk I learned that there is a new list of recommendations on the American diet wonder how much you should be getting of a nutrient look it up (2015-2020 Dietary Recommendations –look it up very interesting). Again put in the effort and work to learn what you should be eating. Your list of safe foods will vary from mine. I am very diet sensitive. Keep track see if your symptoms change, this doesn't just mean your bladder, do you get less headaches, is your energy better are your bowels moving better? We are not a bladder on legs eating better can affect your whole body. It is time to learn how foods affect you. Listen to your body. If you get better WAIT give yourself a couple of weeks to let the inflammation go down. I know it's hard. But it is so worth it. When you are ready start slowly adding foods back in one at a time. Wait a few days after each addition. There are foods I feel seconds after I eat them and there are foods or combinations of foods that it may take 3-5 days to show up. This is so frustrating.

I have never met an IC patient who is not diet sensitive in some way. They will say "Oh I can eat whatever." Then you ask and they know they can't eat Chinese food or they know that if they drink coffee at night they will be up all night. That is diet sensitive. You can do this - you can figure out what foods are friendly and which ones not so much and which ones you will have to say goodbye to. If you have a favorite food don't give up you may find a version of it that is not so irritating like. I can occasionally eat the tomatoes that are in the store on the vine or grape tomatoes but canned tomatoes or ketchup not so much.

Over the years I met so many patients that the diet made a huge difference for them. Keep track, keep a list, a log. When you do get better I know you won't want to hear this but you will have a flare someday. If you keep a list of how you were eating and felt better it will help you when you are in a flare and in pain. You will get to the point where you start eating foods that you learned weren't so good for you. You will find yourself experimenting with what I call my safe box. You will find if you step out occasionally you may get away with it sometimes and sometimes you won't. You may find you can put one toe out of your box you are ok but if you jump out with whole hearted abandon you are in a flare.

The magic is learning what to do when you are in a flare go back to safe foods only, ice pack or heat whichever you have found works for you maybe ice to pelvic are heat to back, meds what helped in the past – Pyridium , Prelief, the dreaded baking soda rescue? Resting with your feet up or walking ...what works for you? You will figure it out keep a list of these things too; it's hard to remember when you are in pain what helps. The lists help. The other thing I want to say is don't give up. There are always new developments in the IC world. We are all still learning. Go back to your doctor if you haven't been in while don't blame everything on IC most of us have other issues that we need to keep on top of too. Most of all be good to yourself. Having IC isn't easy, the diet isn't easy, and having a chronic no cure disease isn't easy; but you can do this and this support group is one of the ways I keep myself on track so I hope to see you at a meeting someday.

Please feel free to email me at [infoicaction@gmail.com](mailto:infoicaction@gmail.com)

I would be happy to answer any questions you have keep in mind I'm a patient just like you not a doctor.

#### Conclusion:

While the IC diet may seem impossible to navigate, you can find your own path that leads to feeling better if you put in the time and effort – it is very much worth it!!! Take one step today to learn which foods help your body to function at its' best.