



Newsletter: Meeting Date: 27 September 2016, Edition 6

Moderator: Edward L. Davis, M.D. + Group Discussion

**Topic: "Share Questions, Challenges, What You Have Learned &/or
What You Think Doctors Should Know"**

Meeting Notes

Dr. Davis began the discussion reporting the changes in how he practices urology since City of Hope (COH) acquired CVUMG on January 01, 2015. IC/BPS has become 70% of his patient care. This significant focus on IC has resulted in his clearer understanding of the many elements that make up taking control of the symptoms of bladder pain. "When finally we put the puzzle together - the result for the patient is becoming really better."

"The ability to have IC at the center of care has made me aware of the elements that are required to stay on the course of treatment when your body feels it's falling apart. There is always something else going on medically - you are not just a bladder with legs. The discipline to stay on the treatment plan means the need for focused effort."

Know your goal, stay focused, be patient and work with tools we have available.

Dietary chemistry is very important. You can't just step over it. Learning your individual sensitivities is difficult and time consuming but worth it as it helps your bladder not be negatively impacted by what is contained in urine through dietary consumption. But it is not diet alone. Other factors that impact the bladder often include both pelvic floor spasms and large bowel inflammation/IBS. Other reactions to inflammation can be migraine, TMJ, or Fibromyalgia. Each of these conditions need to be recognized and treated for IC treatment to be successful.

The biggest elephant in the room is *stress* and not many doctors want to recognize this fact and deal with it. All the Elmiron® in the world isn't going to result in the stress reduction needed for your body to heal. I have recognized that people already live with stress when BPS/IC brings them to a physician and this can negatively affect the bladder through the nervous system.

Support discussion turned to open forum - drug free stress relief methods.

How do you cope? Methods shared by the group: Comfort food, have a manicure – go wild and add a pedicure, massage, see a chick flick, see a therapist, get your mind off the hurt.

Personal stories from attendees about ways they deal with pain/ stress relief:
(excerpts from multiple members each experience shared begins with *)

* I am the patient that Dr. Davis was referring to who came back from the depths of misery generated stress. I have had two failed back surgeries added to my IC. I complained, cried, and acted in ways I probably shouldn't have. I dumped on Dr. D., dumped on my husband, Escape came when I do mindless reading- like a steamy novel.

I have found you have to care about yourself - when you get down to it no one cares a crap about you – you have to care for yourself. I have learned there is *always* someone worse off. I changed my perspective.

Next Meeting

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November 22, 2016

Topic: "Continuing Education in Bladder pain Control - IC and the Pelvic Floor Connection-It's Not Just Your Bladder"

Speaker:

Nicole Cozean, PT, DPT, WCS
MS Cozean serves on the Board of Directors of the Interstitial Cystitis Association (ICA)

Location:

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

Notes From:

September 27 Meeting

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Dr. Davis shared - New procedure IC Pain control: Triamcinolone bladder injections for Hunner's Lesions under anesthesia
Call office 626.914.3921

Group Contact:

icaction.com – visit often for updated meeting information

Citrus Valley Interstitial Cystitis Support Group
IC Action

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Members shared experience continues:

*I also found exercise helps I joined water aerobics, Tai Chi, yoga. I noticed I started to feel better with a change in mind set, and connected with my body. After each session I began to feel better and better.

*Another member agreed – do mild exercise – listening to soft music helps relax – watch a good movie – it is important to talk to your doctor and review if any medication changes would help – Stress can be worse than coffee in its effect on the bladder.

*How to deal with Holiday stress: I have found it is very important to carve out time for yourself – Had to learn not to feel guilty when I know the best thing is to take a break. “*Retail Therapy*” Shopping takes mind off pain- Stop self-perpetuating cycle of doing too much – Learn it is O.K. to say NO - if you can't make or prepare for holiday gathering. Best gift to yourself and your family is to take time for self so health doesn't spiral out of control and you are unable to do anything.

Dr. Davis Spoke about distraction from symptoms and lessening flare impact key.

*Janet said that her method – keeping busy lessens the stress caused by pain.

* Has found professional therapist helpful – able to talk to someone who is not a family member or friend has helped learn better communication and improved quality of life. Remembering the term healthy boundaries makes sense when the holiday demands grow. Remember the word *nap* is helpful

*I have found walking helps. I take short multiple walks a day I feel healthier and may have helped IC. I underestimated the power of exercise – I have learned can do things when I'm in pain. I was sitting and doing nothing and was still in pain- moving helps

As you can tell we had a lively discussion with many shared stories. The consensus of group was - what works for one may not work for all when it comes to stress management -We all have to find our own path- for some keeping busy is better than laying down with ice, heat, book etc. Like with diet learn what works for you. We hope, as one member shared as we walked to our cars, that you are inspired to do something just for you- to take time for yourself.

Final Thought: Sadly we recognize the death of group member, Jane B., 52, story in Support Book “Peeing as Fast as I Can.” Prescription pain medication appears to have been given to her by a friend. Intense pain and anxiety relief can seem a pill away. The problem is the mixing of opioids and anti-anxiety drugs combined can have be a deadly risk.

Always make sure you are aware of what medications you are taking and even if a doctor prescribed the medicines for you years ago they may not mix with your current medications. Always be sure all your doctors know the medications that you are currently taking. We all get into pain and get desperate but do not take multiple medications without knowing if they mix. It can mean life or death

We would like to remind you about our next meeting:

Nicole Cozean PT, DPT, WCS has been asked to address our group again this year because her presentation in May 2016 was phenomenal. We highly encourage your attendance to the November 22, 2016 meeting. The information shared is very educational and diverse, and in Dr. Davis' opinion well worth your attention.

Nicole is a physical therapist who specializes in treating interstitial cystitis pelvic pain condition, and pelvic floor dysfunction. She earned her advanced board certification as a Women's Clinical Specialist (WCS), making her one of the select few holding the credential.

Seeking to help patients beyond the walls of her clinic, Nicole founded PelvicSanity to provide practical, positive information for patients with pelvic pain conditions like IC. Her book on interstitial cystitis, “The Interstitial Cystitis Solution” publication date is October 2016.

Nicole is also the Medical Director of the Non-profit East Africa Partnership and was the 2012 Chapman University Alumnae of the Year. She was recently selected to serve on the Board Directors of the Interstitial Cystitis Association.