

“A HEADACHE IN THE PELVIS”

AN INTRODUCTION TO A NEW PELVIC PAIN THERAPY PROGRAM FOR IC, PROSTATITIS, VULVODYNIA AND OTHER PELVIC PAIN CONDITIONS

FEATURING: DR. RODNEY ANDERSON, PROFESSOR OF UROLOGY, STANFORD UNIVERSITY
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Introduction - Welcome to the ICN Guest Lecture Series. My name is Jill Osborne and I am the founder of the Interstitial Cystitis Network. It is my pleasure to be your host and moderator tonight. One of our goals for this lecture series is to bring the nations best resources directly into the homes and offices of IC patients in need. With the assistance of our sponsors, Farr Laboratories (makers of *CystaQ*) and Akpharma (makers of *Prelief*), we have welcomed many of the brightest researchers and physicians in the IC world, in part to our sponsors. Tonight, it my pleasure to welcome Dr. Rodney Anderson, Professor of Urology, Stanford University School of Medicine

Dr. Anderson received his medical education and degree from The George Washington University School of Medicine in Washington DC. He performed an internship in internal medicine and then embarked upon a general surgery residency at The University of Utah Medical Center in Salt Lake City. He then entered the United States Air Force and performed as a flight surgeon and general surgeon for two years. His urology specialty training began at Stanford University Medical Center and, during this four-year period, he engaged in basic laboratory research for one year as a National Institutes of Health research fellow. Upon finishing his residency he was awarded the American Urologic Association Wyland Leadbetter Research Scholarship and studied prostatitis with Dr. Thomas A. Stamey, the chairman of urology at Stanford.

Dr. Anderson is currently professor of urology and practices at Stanford University Medical Center as a partner in the female urology and neurourology Center. His interest and expertise focuses on urinary incontinence disorders and chronic pelvic pain syndromes. He conducts a regular weekly clinic devoted to managing pelvic pain problems such as chronic prostatitis, interstitial cystitis, orchalgia, prostatodynia, and vulvodynia. He is actively engaged in clinical research trials of new drugs and medical devices to alleviate problems of urinary incontinence, urinary obstruction with benign prostate hyperplasia (BPH), and pelvic pain syndromes. He also directs a clinic devoted to the problem of female sexual dysfunction

Tonight, Dr. Anderson comes to the ICN to discuss his groundbreaking book "A Headache In the Pelvis", co-authored with David Wise, Ph.D. This book has received rave reviews from the medical community. It is the first of its type to document a successful and management pelvic pain reduction program. Martin Schwartz, PhD, NYU School of Medicine said '*A Headache in the Pelvis is a book which casts an entirely new light upon the serious problem of chronic pelvic pain, and introduces a treatment that offers hope and relief to the many who suffer from it. It is surely must reading for all who must deal with this debilitating problem, as well as all who attempt to treat it.*' Erik Peper, Ph.D., Professor, Cal State Univ San Francisco said "*This is the book to read before you contemplate surgery, drugs or resign yourself to continue to suffer with chronic pelvic pain. Return to health is possible. By transcending the simplistic mechanical solutions, Drs. Wise and Anderson have developed an innovative clinical protocol that works.*" It is a hallmark work for the IC, prostatitis and chronic pelvic pain communities. Welcome Dr. Anderson!

Dr. Anderson- Thank you. It's a pleasure to join this network.

Let's begin with an important topic, the name of IC. Several years ago, when the first meeting on prostatitis was held in Washington DC, a decision was made to rename prostatitis as a "*chronic pelvic pain syndrome*." Similarly, earlier this spring, an international team of doctors discussing new diagnostic criteria for IC also came to the same conclusion. They also suggested that IC be renamed as a chronic pelvic pain syndrome. Why now?? Why this new name??

Dr. Anderson - I was attending that meeting and I think the good thing that came out of it was that we stopped trying to slice and dice all the pain syndromes in the pelvis and that we acknowledge that we don't have specific origins or causes and we don't have very good biologic markers. So, this allows us to start fresh and look at it as a total pain syndrome. I think that the trend will be that we will say cpps/ic/prostatitis... in other words, you will have various subcategories of CPPS which simply means that it's more focused in or around one of the pelvic organs...

Jill O. - Moderator - What are the names of the some of the other conditions that you believe are also CPPS disorders??

Dr. Anderson - In men: non-bacterial prostatitis, isolated orchalgia, proctalgia. In women, it can be vulvodynia, urethral syndrome. In both sexes, it can be interstitial cystitis, levator ani syndrome (very tight muscles around the rectum). There are also some cases of pudendal nerve entrapment, which means that the nerve is being squeezed between ligaments and is usually very painful with prolonged sitting and usually relieved by standing.

Jill O. - Moderator - What are the common symptoms of someone with CPPS? Where does the pain occur?

Dr. Anderson - In men, pain occurs in the rectum & perineum, pain while sitting, above the pubic bone (suprapubic) pain, pain in the penis (tip or urethra), etc. Men will also have pain, discomfort, burning during urination, urgency, and nocturia. The most common symptom in IC for men is the suprapubic pain. Women can have vaginal/vulvar pain, rectal pain, suprapubic, sitting and clitoral pain. Pain may be higher during the menstrual cycle and during stress. In both men and women, pain can be intermittent or constant. Once again, most of the men have a lot of complaints with long term sitting whereas many women will report pain after (or during) sexual intercourse. Once again, most of the men have a lot of complaints with long term sitting whereas many women will report pain after (or during) sexual intercourse.

Jill O. - Moderator - Your book is the first book to ever mention clitoral pain. We call this one of the secrets of IC because patients often don't tell their providers that they are having this painful arousal feeling, so thank you for legitimizing that for us. I'm not sure patients understand that pain in another part of the pelvis can cause bladder symptoms. When a patient has pelvic pain, can it change the way that we urinate??

Dr. Anderson - This is an important point. There are 27 muscles in and around the bladder. Pelvis and mechanical back injury, which includes slipped disks, can often cause a lot of pelvic organ pain and dysfunction. In the bladder, it often can cause frequency, urgency, pressure, pain, decrease in stream, incomplete emptying, etc. The whole gamut of bladder symptoms can be caused by a problem outside of the bladder itself.

Jill O. - Moderator - Can pelvic pain impact our ability to have sex? If so, how??

Dr. Anderson - Yes... The concept of good sex is good relaxation. Pain causes upregulation or tension.... and interference with relaxed sensory pathways. It also inhibits a mans ability to get good erections. Usually, men can also have painful ejaculation because the tone of the prostate and pelvic muscles is abnormally high. One of the concepts of our books is that pelvic pain syndrome is neurologically induced problem, possibly leading to the inflammation in the bladder wall and surface or distortion of the GAG layer. We are measuring elevated proteins, neuropeptides in the urine, but the outcome of all of this still leads to pelvic muscular tension. It's not the patient tensing their muscles... as much as it is an unconscious tension going on... and it comes from the autonomic nervous system. The classic dysfunction in women is vulvodynia where they have pain with touching tissues and inflammation in the vaginal tissues, which is very similar to IC and that is the most inhibiting sexual dysfunction in women.

Jill O. - Moderator - What has lead you to believe that pelvic floor tension and tightness was a primary source of pain in the pelvis???

Dr. Anderson - I want to credit my partner Dr. David Wise who brought this phenomenon associated with CPPS to my attention and wanted to study it with me. When we started actually looking for trigger points in the pelvis I was amazed at how many of these were occurring outside of the bladder and prostate and were definitely contributing to the whole syndrome. I also want to give credit to Dr. Jerome Weiss... who also pioneered a lot of this work with Rhonda Kotarinos and Howard Glazer, in NY. They really are the ones that developed the concept of the pelvic tension myalgia and the association it has with IC and prostatitis.

Jill O. - Moderator - What did you usually find when you examined your pain patients?? It seems that IC and prostatitis have more bladder symptoms than muscle symptoms. Could the patient sense that they had muscle tension too??

Dr. Anderson - In women, we found that they have weakness in their pelvic muscles... which is a paradox. You would think that they would have a lot of high electrical energy but instead they have weak muscles and a poor ability to sustain a kegel contraction. As we treated women with physiotherapy, they could then begin to approach a more normal level of muscle function. Men tend to have very high tone levels in and around their levator muscles. This same phenomenon has been studied in people with migraine headaches where they find these high-tension trigger points and EMG in the shoulder and upper neck muscles, which is why we called our book "A Headache in the Pelvis."

Our basic premise is that a lot of these painful syndromes represent neurobehavioral disorders so that somehow the patients stress levels, their anxieties, stimulate the autonomic nervous system and enhance this tension myalgia. It could be either emotional or physical stress.... such as a bladder infection, childbirth, hemorrhoids, uncomfortable sex, hernias. All types of events that can trigger this upregulation of the nervous system, upregulation meaning a hypersensitivity of the nervous system in the pelvis. Sometimes we call this neuroma plasticity... that the nerves can be modulated both up and down... depending upon stimulation or relaxation. That's why, when we get frightened, or we are trying to run away from something, we get all this great muscle activity and stimulation going on.

Jill O. - Moderator - And, yet, once the event has occurred, we would think that the initial injury or muscle tension would resolve. In the book, you talk about how that pelvic floor tension can become long term, almost a life-long habit. That over time, those muscles develop a predisposition to tension?

Dr. Anderson - Once a physical or stressful event has occurred and triggered these responses, it becomes a sort of cyclic.. process. It feeds on itself and that's why it seems to go away and then suddenly be triggered back to a flare. That initial event sets up a foundation of hypersensitivity. The muscles then become extremely vulnerable to stress, both physical and emotional and that creates a long-term cycle of muscle tension that can last, for some, years. It becomes this chronic pain disorder.

Jill O. - Moderator - What happens when muscles become tight? How does that impact the rest of the pelvis?? How does that impact the bladder??

Dr. Anderson - I think a good analogy is that if you clench your fist for a long period of time, how does your hand feel after you stop? It hurts. There are changes in blood flow. We believe that this is why some people get congested veins in the pelvis with these problems. If you look at certain types of CT scans you can see a lot of big congested veins around the prostate. There are some theories about IC that you get poor blood flow into the bladder. They all fit together. We have to think about the nerves, the muscles and the blood vessels and not just the organs. *(Note: One of the reasons why bladder removal doesn't remove the pain of IC is that leaves behind a lot of the nerves and muscles that have been part of the process and part of the problem.)*

Jill O. - Moderator - How can a patient know if they have tight muscles in their pelvis??

Dr. Anderson - Well, it's tough. I think that's where a good physician or physiotherapist needs to help. It's not only a matter of tight muscles but also of flexibility. You have to have the ability to contract and relax the muscles voluntarily so a lot of therapists will teach you how to do that. But, you usually have to start by eliminating the trigger points that occur in the muscle. That's where we have to break that cycle.. by stretching those muscles, lengthening those muscles, and working out those trigger points... these hyperirritable fibers. But, you still need to work on the bladder with IC. We still have to keep treating the surface inflammation in the bladder but you need to combine it with good relaxation and treatment of the muscles around the bladder that are contributing to this thing.

Jill O. - Moderator - How big is a trigger point?? Do you find them all over the pelvis? Can a patient have a trigger point by their urethra??

Dr. Anderson - Usually, you can identify them about being about 1/2" in diameter. You can stick a needle in those spots and get this very excitable electrical signal. You can also stick a need into that same muscle outside of the trigger point and it will be perfectly normal. So, a trigger point is a small bundle of issue that is hyperexcited and causes referred pain. You can view several videos of this testing at the website for Headache in the Pelvis at: <http://www.pelvicpainhelp.com>.

Trigger points are typically most common in the levator muscles up in the front of the pelvis, but some patients also have trigger points down around the rectum in the back part of the pelvis... and in and around the obdurate muscle and in and around the pudendal nerve. I don't see them that often by the urethra. In IC, the urethra can be tender from the inner mucosa. There can be trigger points around the bladder neck (on each side of it) but we don't often see them around the urethral opening.

Jill O. - Moderator - One other key focus of your work is understanding, compassionately, the fear and anxiety that pain can cause. When a patient experiences severe, constant pain, they become scared. It's normal to be scared and anxious, right??

Dr. Anderson - Yes, it is. What Dr. Wise, as a psychologist promotes, is learning to accept your pain, this fear, and to learn how to mentally relax through it rather than allowing that fear to cause more muscle tension. This is what he calls paradoxical relaxation. His method of learning how to do this EVERY DAY almost on an automatic basis constitutes one of the fundamental aspects of our treatment program. Patients have to learn to recognize when their anxiety level is contributing or causing pelvic tension, because so much of this is subconscious.

Jill O. - Moderator - So, basically, what you're saying is that pelvic pain patients can become stuck in a cycle of elevated muscle tension. That they experience pain, it frightens them and they have anxious thoughts (i.e. I'll be in pain for the rest of my life). They then subconsciously tighten those muscles, which causes even more pain?

Dr. Anderson - We actually teach this method by first treating the face, TMJ, neck and shoulders. As a surgeon, I have a problem with neck muscle tension. Once the patient learns how to do that there... it just translates into the pelvis very logically and easily. And because you learn how to relax your mind... and by doing this several times a day has been one of the most helpful things for our patients.

Jill O. - Moderator - Why are the pelvic floor muscles so vulnerable??

Dr. Anderson - You know... we think of various areas of our body that are vulnerable to stress and anxiety such as the brain with headaches, the stomach with ulcers, the bowel with colitis. The sexual and excretion organs are particularly vulnerable because we grew up focused on them. Usually we're trying to protect those areas. So, Dr. Wise believes that it becomes a subconscious pattern of protecting the bladder. Think about what a man does when he is hit in the testicles. He bends over rapidly, the muscles contract and pull up and he's in great pain. That is the bodies' protective response at work. So, in IC, it might not be that dramatic but it appears that we may also have a similar protection mechanism going on.

Jill O. - Moderator - What's the recommended sequence of events for therapy?

Dr. Anderson - Firstly, a good urologic and gynecologic exam to make sure that nothing else is going on. #2. Identification of the trigger points, #3 Treat the trigger points with myofascial release/soft tissue mobilization. Simultaneously... we begin teaching paradoxical relaxation. This is not a quick fix. This is a slow fix. We often tell patients that they need to expect three months of time to make significant impact on their symptoms especially when they've had this problem for years.

----- Audience Question & Answer Session Begins -----

Audience Member - What should I do if I'm having a sharp, painful pelvic flare?

Dr. Anderson - If that person has been undergoing internal massage therapy then they could have a revisit with their therapist. The relaxation exercises that we teach are probably the most beneficial. Each individual has to find whether cold therapy or heat therapy helps him or her through the flares. Those kinds of physical modulations can be pretty good crutches. You can also do a pushing exercise, like you are trying to have a bowel movement. that also can help to relax them. *(Rhonda Kotarinos, in a past lecture, talked about just squatting down... and how that seems to put the muscles into their proper positions.)*

Audience Member - My bladder has stopped functioning four times in the last year, to where I have to be catheterized. Now I'm even able to do it myself at home if need be. Why is this happening?

Dr. Anderson - The main reason that bladders become sluggish with IC is that the pain fibers go into the spinal cord and inhibit the function. It's the same reason that women sometimes can't void after childbirth, flaring hemorrhoids, after herpes, after colitis. When that happens, usually getting into a hot bath and letting the urine go is helpful. Working VERY HARD on the relaxation and trying to eliminate the stimulus of the pain. A lot of men have bladder elimination problems as well with IC and prostatitis..

Audience Member - I've got a few: in the mornings, I have problems urinating. I can't get my flow started and it's extremely painful. Is that PFD?

Dr. Anderson - Same answer as above. The opening of the bladder neck is autonomic in function. So.. it's overstimulated.. You have too much stimulation of those muscles. Again.. it's about relaxation.

Audience Member - How does the menstrual cycle impact the pelvic pain muscles and how can we get relief?

Dr. Anderson - My own theory goes back to the fact that you have a lot more congestion to the veins during the cycle plus some hormonal effects that we don't understand. The relief has got to be a physical thing, unless they find that any medications might be helpful.

Audience Member - Jill, could you ask him if there are any new treatments on the horizon

Dr. Anderson - It's common knowledge that we're excited about RTX, BOTOX and the BCG trials but that's all relative to the bladder wall and the bladder surface. I think that there is more interest in neuromodulation and that might be using electrical stimulation. These are the ideas that are going to be developed with the NIH project coming soon! My approach or belief is that if you are having success with bladder therapies... it still is important to explore pelvic muscles issues as well. I feel that they go hand in hand..

Audience Member - I am 24 yrs old and have had IC for 3 yrs. I have done different treatments that have helped, but none of them have helped with the sex. I know they say that there are other ways to have sex besides penetration, but that just doesn't do it. It has really hurt me emotionally. Luckily my boyfriend has been understanding. Any ideas? Where are they in research on fixing this problem?

Dr. Anderson - This sounds like a lot of the nerve receptors of the vaginal area are effected including the muscles of the pelvis and I would recommend some biofeedback learning how to relax and contract those muscles because Howard Glazer showed that that was very successful in women who had painful intercourse.

----- Audience Question & Answer Session Ends -----

Related Links:

Headache in the Pelvis - <http://ic-network.com/cgi-bin/ustorekeeper.pl?command=goto&pid=HIP>

Pelvic Pain Institute - <http://www.pelvicpainhelp.com>

Stanford University Urology Clinic - <http://www.stanfordhospital.com/clinicsmedServices/clinics/urology/>

Dr. Andersons Contact Information

Department of Urology, S-287
Stanford University Medical Center
300 Pasteur Drive
Stanford, CA 94305-5118
Phone: (650) 723-3391
Fax: (650) 498-6278

"A Headache in Pelvis" is available for sale in the ICN Shop!. Purchases can be made on-line via our website or by phone to our mail order center at: (707)433-0413

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