

HOPE Newsletter

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Interview with Dr. Antolak

Dr. Stanley Antolak, Jr., MD, interviewed by Violet Matthews, RN

In 1998 Dr. Stanley Antolak, Jr. began to treat patients with pudendal neuralgia (PN) and since then, he has worked tirelessly to advance the awareness of PN and to provide treatment for patients with pudendal nerve entrapment (PNE). One of his patients said, "After seeing many doctors, Dr. Antolak was the first one who understood what I was going through and really seemed to care."

Recently Dr. Antolak retired but he has agreed to answer questions for the HOPE newsletter. We wish him a happy retirement and thank him for his many years of serving the pudendal neuralgia community.

Questions for Dr. Antolak

What caused you to become interested in treating patients with pudendal neuralgia?

In 1998 I began working as a staff urologist at the Mayo Clinic in Rochester, Minnesota. The department chair wanted an office urologist because of recent retirements. I saw 4-6 men daily with chronic pelvic pain (CPP), mistakenly called prostatitis. Tests for prostate fluid and semen showed no infection in over 90% of the men. I realized their complaints of perineal pain, painful ejaculation, scrotal pain, etc., were in the pudendal territory. I went to the medical library (PUB Med was not available, etc.) I found the article by Professor Robert in Nantes. That was my epiphany.

The chair of radiology was willing to treat with pudendal nerve blocks. The chair of anatomy helped with many cadaver dissections including after injections by interventional radiologists. When patients needed surgery I arranged for two operations in France by Dr. Robert. I assisted with surgery on several patients while in Nantes. One later developed a pudendal treatment program in Houston. Later, the chair of neurosurgery approved surgery on 10 patients. Before I retired from Mayo Clinic, we had treated over 850 patients and operated on 43. I sent an additional 150 (est) to France and about 75 to Houston for surgery.

I had mentoring from Dr. John Bascom, a colorectal surgeon in Eugene, OR. He was introduced to

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Dr. Stanley Antolak Jr., MD
On Speaking Tour in Shanghai

me by the Mayo chair of colorectal surgery, Dr. Heidi Nelson. Dr. Bascom had been working on PN issues since the early 1990s. In turn, he worked with JT Benson of Indianapolis. They brought Dr. Ahmad Shafik from Cairo to study the transperineal approach.

The longest absolute cure that I have seen after transgluteal surgery at Mayo is 12 years with symptom scores of zero in December 2013. The longest cure after 3 pudendal nerve steroid blocks is 14 years in June 2014. The longest cure after self care and medications is >10 years.

Do you believe there is an accurate way to determine whether a person has pudendal nerve entrapment rather than pudendal neuralgia without entrapment?

At present there is no method to determine that except surgery. MRN's etc., are NOT correlated with surgical findings to give predictive value. Thus, if the patient fails conservative care they are surgical candidates. About 30% of my patients required surgery. Anyone can see the damaged, compressed nerves in presentations such as Antolak Glasgow 2011, International Continence Society conference, or Antolak Toronto 2012, joint International Continence Society/International Urogynecological Association conference.

In your experience, what would you say is the most important diagnostic test to determine whether a person has pudendal nerve entrapment?

Pinprick testing of the six pudendal nerve branches.

What other diagnostic tests do you recommend?

I highly recommend the warm temperature detection threshold test...a sensory test. Then I recommend the pudendal nerve terminal motor latency test. Both of these are easy to perform and provide good confirmation of neuropathy that is objective.

Do you always recommend surgery if a nerve entrapment is suspected or are there other ways to treat PNE?

All of my patients have 3 to 5 months of conservative treatments prior to discussion of surgery.

How many pudendal nerve release surgeries did you perform?

About 1000.

What would you say is the success rate of PNE surgery?

At what time...1 month, 6 months 1, 3, 5 years? All nerves are not damaged equally. (Is your car in a fender bender or totaled?) In my experience about 65% are cured/near cured and the others need additional post-op

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injections, secondary neuropathies treated, or treatment of central sensitization. See my recommendations in the presentations mentioned above. I spoke to a lady today who is 11 years post op and is having the best summer since many years prior to surgery.

Patients with central sensitization have goose bumps and thickening of hair over the sacrum. I recommend clonidine for patients with central

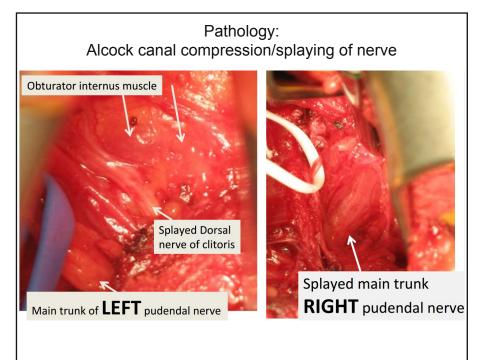
sensitization.

Can you tell during surgery if a patient was entrapped?

You can see from the attached slides that an entrapped nerve may not be round like a normal nerve but may appear flattened and splayed.

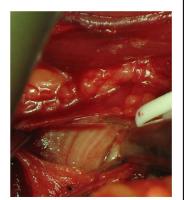
What would you say to skeptics who say there is no such thing as pudendal nerve entrapment?

They have no experience whereas I have data...evidence based diagnostic and treatment results.



Left: Nerve is flattened under obturator fascia. Nerve not round, it is splayed. Fascicles are apparent.





You went to France and trained under Dr. Bensignor and Prof. Robert on techniques for performing pudendal nerve blocks and the transgluteal approach to pudendal neuralgia. You later began to perform a modified TG approach. Could you explain the difference between your early and later approaches, why you modified the approach, and your thoughts on the difference in results between the original TG approach and your modified approach?

I stopped cutting away the sacrotuberous ligament. I open that structure in its mid-line, like unzipping something. The operation is more tedious but prevents a "loose pelvis" which I saw in one lady using the Nantes technique. I see no difference in the PN results.

What is your recommendation for patients who have undergone PNE surgery who are still experiencing severe pain 1-2 years post-op?

- 1. Stop exercising, bicycling and sitting.
- 2. Be reexamined for other neuropathies that can be causing problems such as middle cluneal, perineal branch of the posterior femoral cutaneous nerve; have treatment for central sensitization.
- 3. Take your medicines. Try topical compound creams.
- 4. Try a series of nerve blocks using ketamine and benadryl which are beneficial and prolong the effects of the block.
- 5. Epidural ketamine and bupivacaine.
- 6. Sacral nerve stimulation. I recommend treating the pudendal neuropathy first. I do not recommend neurostimulation until several years post-op because healing from PNE surgery can take several years.

Now that you have retired, will you continue to be active in the PNE community or are you retiring completely?

I teach when requested...today at a Gyn office in St. Paul; in June at a university urology department. As long as patients need help I will encourage the medical profession to open its eyes and mind.

I have about 23,000+ symptom scores in the data base of the Pudendal Neuralgia Foundation. I need to provide the evidence to the medical world of the long term success of each treatment modality.

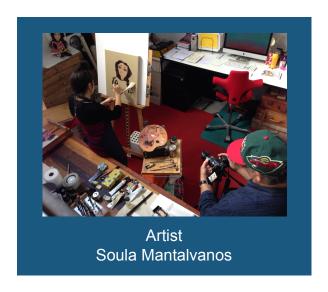
Do you have any additional comments you would like to add?

The role of support organizations is MOST important. I am arranging care for a lady MD who has seen 60 doctors...this is another confirmation of the American medical profession's need for upgrading awareness and skill in the area of chronic pelvic pain (CPP).

Report of Documentary on Chronic Pelvic Pain By Catherine A., Director of HOPE

Soula Mantalvanos is a 44 year old Australian Artist living in Victoria Australia. In 2007 she had a workplace accident that left her injured and searching for answers.

To quote Soula's own words, "I always had an abundance of energy, ideas flowed endlessly through my head and I executed all of them. I had no limits, I had no pain and I had no health issues."



All of that changed when the fit ball Soula was sitting on burst and caused her to hit the concrete floor with such force that she has been left with severe, chronic pelvic pain ever since.

To make matters worse, no one could explain her chronic pain. She consulted physiotherapists, two GPs, a rectal surgeon, orthopedic surgeons and chiropractors. When none could give her a diagnosis, a series of diagnostic injections indicated she had probable neuropathic pain.

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Four and a half years after her injury, Soula met Anne-Florence Plante (Pelvic floor Physiotherapist at The Royal Hospital for Women in Melbourne.) She listened, she understood, she explained Soula's experiences of pain and most of all she diagnosed her with Pudendal Neuralgia (PN).

Social media became Soula's connection to the community and

to the world. Today she still suffers the pain of Pudendal Neuralgia but has improved greatly since her accident in 2007.

She dedicates her time to her art and is an avid advocate for injured workers.

Recently Soula met film maker, Peter Lamont who filmed this documentary. The film itself does not focus on pudendal neuralgia as such but it does give an insight into Soula and her family's experience with chronic pelvic pain.

Pudendal HOPE is in no way affiliated with this documentary or with Peter Lamont but thanks Soula for her contribution in raising awareness and education on this condition.

You can view Soula's documentary "The Hurting Strings" here. https://www.reelhouse.org/artly/the-hurting-strings

HOPE 2013 Financial Report

(as reported to the government)

HOPE 2013 EXPENSES

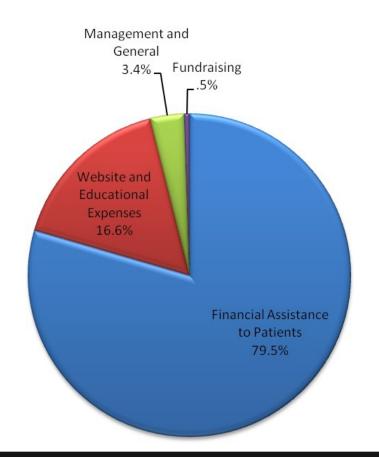
Program Expenses

Financial Assistance to Patients 79.5% Website and Educational Expenses 16.6%

Supporting Services

Management and General 3.4% Fundraising 0.5%

Total Expenses 100.0%



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